THE PRIMARY CARER'S EXPERIENCE OF CARING FOR A PERSON WITH A MENTAL DISORDER IN THE WESTERN AUSTRALIAN COMMUNITY: A GROUNDED THEORY STUDY

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This thesis is presented as part of the requirements for the award of the Degree of Doctor of Philosophy of the Curtin University of Technology Perth, Western Australia

November 2002
DECLARATION

I declare that this thesis is my own work and no part of it has been submitted for a degree at this, or any other university.

Signed:............................

Date:..............................
ACKNOWLEDGEMENTS

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1. My principal supervisor, Adjunct Professor Vera Irurita. Her level of knowledge, guidance, and support during all phases of this research was outstanding. I am privileged to have her as my supervisor, mentor, and friend.

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ABSTRACT

One in five Australians has a mental disorder and it is estimated that one in four families have a member who has a mental disorder. Since the 1960s there has been an 80 percent decrease in Australian institution-based mental health care. The majority of people who have a mental disorder are now treated in their local community and many of them live with their families.

The change in the delivery of mental health care has seen the family emerge as one of the most important supports to their ill family member. While the changes in the delivery of mental health care have been based on human rights concerns, changes in mental health legislature, and economic factors, the multi-dimensional experience of being a primary carer of a person with a mental disorder remains relatively unexplored. The need for empirical evidence on the primary carer’s experience is noted in both the scientific literature and from carers themselves and the principal aim of conducting this research was to address the identified need.

This qualitative study, using grounded theory methodology, presents the findings of interviews with 27 primary carers and memos documented throughout the study. In addition, existing literature of relevance to the findings of this study is presented.

A substantive theory of seeking balance to overcome being consumed is presented in this thesis. Using the grounded theory method the constant comparative analysis of data revealed that the basic social psychological problem shared by all participants was the experience of "being consumed". The problem of being consumed consisted of two stages: "disruption of established lifestyle" and a "sustained threat to self-equilibrium". Six conditions were identified as influencing participants’ experience of being consumed.

In order to address the problem of being consumed, participants engaged in a basic social psychological process of "seeking balance". When participants were engaged in this process they moved from a state of being consumed to one whereby they established and consolidated a balanced life perspective that incorporated their caregiving role. The process of seeking balance consisted of three phases: "utilising personal strategies to reduce the problem of being consumed", "restoring self-identity", and "reaching out to make a difference". In addition, data analysis identified the presence of a three phase sub-process
entitled “trying to make sense of what was happening”. Phases one of the core and sub-processes occurred primarily in the period prior to the time when a psychiatric diagnosis was made on the affected family member. Participants became engaged in the remaining two phases of the core and sub-processes when they became aware that their affected family member had a mental disorder. At the time of being interviewed for this study some participants were not yet engaged in the final phase of the process of seeking balance. Participants’ experience of seeking balance was not related to the length of their caregiving experience but rather to their experience of seeking balance and the conditions influencing that process. Four conditions were identified as influencing participants’ experience of seeking balance.

This thesis presents the substantive theory of seeking balance to overcome being consumed. While the findings support existing scientific literature, the substantive theory also presents a new insight on caring from the primary carer’s perspective. In particular, the findings challenge health professionals to actively pursue strategies to reduce carers’ experience of being consumed. The findings of this study have implications for service provision and clinical practice, policy and planning, research, education, the general population, mental health consumers, and carers.
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PART ONE

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CHAPTER 1

INTRODUCTION AND BACKGROUND TO THE STUDY

1.1: Introduction

Caregiving to a person who has a mental disorder is both an emotional and a challenging experience. This thesis is concerned with exploring the primary carer's experience of caring for a person who has a mental disorder in the context of the Western Australian community. Globally, the trend is to provide mental health care in the least restrictive environment and, preferably, in the ill person's home supported by their family. Community mental health care is viewed as a dramatic step forward in the treatment of people who have a mental disorder (Mohr, 2000).

Families have always been involved in caring for their ill family members. However, historically these families have not been treated well by society, or by health professionals (Doornbos, 1996). Many families have been implicitly or explicitly blamed for causing their family member's illness. A plethora of literature over many decades has stereotyped these families by describing such things as "double-bind communication" (Jones, 1977), "the dysfunctional family" (Leff, 1979), the "schizophrenogenic mother" (Fromm-Reichmann, 1959 a & b), and high levels of expressed emotion and the use of critical comments in these families (Miklowitz, Goldstein & Falloon, 1983). Furthermore, according to Chafetz and Barnes (1989) the stigma directed by society towards people who have a mental disorder has often spilled over onto the family, leaving family members experiencing stigma by association.

Changes affecting the human and legal rights of people who have a mental disorder have resulted in the family emerging as one of the most significant supports to their ill family member (Peternelj-Taylor & Hartley, 1993). In most countries, the family is now viewed by mental health policy makers as a major member of the stakeholder group (ie. consumers, health professionals, policy makers, advocate groups, and carers) working together to make community mental health care more effective and efficient (Health Department of Western Australia Policy Document on Carer/Consumer Participation, 1999;
Mental Health Promotion & Prevention National Action Plan, 1999). According to the Australian Second National Mental Health Plan (1998), a stakeholder group needs to be in a position to influence decisions on all aspects of mental health services and be adequately resourced and assisted to do so. The Australian National Mental Health Report (1997) "advocates consumer and carer participation to empower and inform consumers, carers, and the community, to destigmatise mental illness and ultimately improve mental health outcomes for consumers" (p. 88). However, for these policies to become a reality and for modern mental health care to be grounded in local communities, the stigma directed towards people who have a mental disorder and their family needs to be resolved at a societal level (Sartorius, 1998). This chapter will explore factors shaping the recognition of the family as a major support and provider of care. In addition, the chapter will detail the need, significance, purpose, objectives, and limitations of the study, as well as the assumptions made by the researcher prior to commencement of the study.

1.2: The use of the term “mental disorder” throughout this study

Throughout this study, the term “mental disorder” rather than the more familiar term “mental illness” has been used. When conducting research it is important to be precise so that others can replicate what has been measured and examined. In this case, a disease and an illness are not the same thing even though they are related. The term mental disorder relates to the underlying pathology or symptoms that make up the disease as measured on Axis I of the 1994 Diagnostic and Statistical Manual Fourth Edition (DSM IV) produced by the American Psychiatric Association. The impact of the family member’s mental disorder (Axis I, DSM IV) on the primary carer is the focus of this study. The illness or the consequences of the disorder on the person who has the mental disorder in terms of impairment, disability, functioning in one’s social roles (DSM IV, Axis IV and V) is not the focus of this study and, therefore, these consequences are discussed only when they have relevance to the primary carer’s experience.

1.3: Definition and classification of mental disorders

Health is a primary objective and value of any society. Moreover, definitions of health and illness are bound to culture as evidenced by Campinha-Bacote’s (1994) claim that an individual’s deviation from their defined role in their culture casts them as engaging in maladaptive behaviour or as being ill.
According to Conrad and Schneider (1992) the objectives, values, and behavioural standards by which health is defined can be used politically, socially, and economically to control powerful corporations, for instance, safety and/or pollution controls to prevent contamination of waterways, rivers, and oceans. This pollution would be detrimental not only to the environment but also the health of the resident population. In addition, these authors claimed a society's commitment to health also ensured the treatment and control of people who displayed behaviours outside the society's given norm, for example, people who have a mental disorder and are displaying at-risk behaviours in the community. In response to the need to care for people who have a mental disorder, the discipline of psychiatry emerged and, along with it, descriptions and classifications of mental disorders. According to Hirst and Wolley (1982); psychiatrists became the discipliners of society as well as the definers of normality. Likewise, Dain (1994) highlighted the power given to psychiatrists to treat and control people who displayed "undesirable behaviours". The power given to psychiatrists was further supported by laws, allowing for involuntary detention and compulsory treatment of people who have a mental disorder.

Keltner, Schwecke, and Bostrom (1991) defined a mental disorder as "a condition that substantially impairs the person's thoughts, perception of reality, emotional process, judgement, or behaviour" (p. 51). The American Psychiatric Association (DSM IV) (cited in Townsend, 2000) states that a mental disorder is:

...a clinically significant behavioral [sic] or psychological syndrome or pattern that occurs in a person and that is associated with present distress [a painful symptom] or disability [impairment in one or more important areas of functioning], a significantly increased risk of suffering death, pain, disability, or an important loss of freedom... and is not merely an expectable response to a particular event. (p. 17)

The DSM IV is a five axial diagnostic system. Globally, the DSM IV and the International Classification of Disorders Version 10 (ICD 10) are the two official tools used to diagnose mental disorders and health professionals often use these two systems simultaneously. The systems provide uniform, universal approaches by which to diagnose mental disorders.

The DSM IV provides a comprehensive and systematic framework (American Psychiatric Association, 1994) that facilitates the assessment and diagnosis of mental disorders (defined on Axis I of the DSM IV) as well as any other general medical condition the person may have, for example, diabetes (Axis III of the DSM IV). The DSM IV also assesses whether or not the person has a personality disorder (defined on Axis II) or if they
are experiencing psychosocial and/or environmental problems (Axis IV of the DSM IV). Finally, the DSM IV assesses the person's level of functioning over the previous year (Axis V of the DSM IV). Throughout this study the DSM IV criteria for the diagnosis of mental disorders has been utilised whenever a description of a particular mental disorder is presented.

Health professionals claim that the accurate diagnosis of a mental disorder allows an ill person to receive prompt and effective treatment. However, many people who have a mental disorder report feeling different and claim a loss of their identity as a result of their psychiatric diagnosis. The stigma people experience as a result of their psychiatric diagnosis further impacts on their level of well being (SANE, 2002).

1.4: The social construct of stigma

Cohen (1972) stated that throughout history, those designated as scholars and experts by a society have erected moral barricades around groups of people that have been stigmatised. The author claimed any society is subject to periods of moral panic, and a condition, behaviour, or a group of people may be labelled as a threat to a particular society. The internalising and development of stereotypes towards the images we fear, as well as the images we glorify, is a developmental process that begins in childhood (Sibley, 1995). Sibley claimed that this developmental process facilitates our ability to come to terms with the world we live in, by splitting the world into a binary opposition of good and bad objects for the individual. Once an object is stereotyped as bad, the individual simplifies, distorts, and distances oneself from that object; however, this serves only to further perpetuate the fear of the object to the person.

Stereotypes are said to allow us to make sense of the world and also to provide us with a stable, secure, and confident view of the world. As Zygmunt Bauman (cited in Sibley, 1995) asserted "the human attitude is an intricate mixture of interest and fear, reverence and adherence, impulsion and repulsion" (p. 14). Stereotypes are described as distortions of the real world because they are simplifications and they deny differences between people. However, according to Bauman, because there is little chance of further interaction with the object the bad or negative image is rarely challenged. Understanding the development of bad or negative stereotypes is important to our comprehension regarding social exclusion of individuals or groups of people, for example, people who have a mental disorder. As Young (1990) contended:
When the dominant culture defines some groups as different, as the other, the members of these groups are imprisoned in their bodies. Dominant discourse defines them in terms of bodily characteristics and constructs those bodies as ugly, dirty, defiled, impure, contaminated or sick. (p. 126)

In western cultures in the nineteenth and twentieth centuries physical characteristics and visual images of imperfection were important when defining the moral standards and acceptable boundaries of society. Until today, this association has endured (Sibley, 1995). It has formed the basis by which an individual, or group of people, are stereotyped and, more importantly, whether or not they are rejected by society. If rejected, Sibley claimed, the individual or group of people is afforded values that further exclude or dehumanise them. Dehumanising and exclusion values include the colour of one’s skin, social class, or the assigning of animal characteristics to the stereotyped individual or group of people. In addition, this process allowed the stereotyped group to be exploited and legitimised their exclusion from society.

1.5: The impact of stigma on a person

Goffman (1968) defined stigma as an “attribute that is deeply discrediting” (p. 13). Stigma is a socially discrediting, enduring perception that brings disrepute to a person’s character. According to Bruton (1997), a stigmatised person is prevented from being fully accepted by society, suffering negative perceptions that devalue them as a person. This concept is clearly portrayed by Jones in the following extract (cited in Human Rights and Equal Opportunity Commission, 2000):

a black woman...asked her white female colleague what she saw when she looked in the mirror. "I see a woman", the colleague said. She asked a white male colleague and he said, "I see a human being". But the black woman said she saw a "black woman" when she looked in the mirror. (p. 40)

As the above example demonstrated stigma is present in many forms. It is also reflected in attitudes and language (Kaminiski & Harty, 1999). Page (1984) stated that stigmatisation was frequently used to label people as "homosexual", "juvenile delinquent", "prostitute", "drug addict" or "mentally ill" and these labels shadowed all other characteristics of the individual and masked the real identity of the person. According to Goffman (1963) stigma is an undesirable attribute that disqualified one from social acceptance and motivated the individual to hide the attribute where possible. Conditions likely to have stigma attached to them are usually chronic, irreversible, or relapsing.
McKeon (1998) added that stigma was sustained through cultural beliefs, negative media coverage that sensationalised and perpetuated the assigned stigma, and a lack of supportive government policies, health education, research, and community based campaigns.

1.6: Stigma and people who have a mental disorder

The stigma directed towards people who have a mental disorder has resulted in them being labelled and stereotyped for centuries (Link, Phelan, Bresnahan, Stueve & Pescolido, 1999). This group of people often experiences discrimination that can compound the distress they already experience as a result of their illness (Johnstone, 2001; Human Rights and Equal Opportunity Commission, 1993) and the stigma and marginalisation experienced is often further increased by the use of psychiatric diagnoses or labels. Many people who have a mental disorder felt that people in society only noticed their psychiatric label (Human Rights and Equal Opportunity Commission, 1993; SANE, 2002). Szasz (1973) went even further and suggested that although words such as hysteria or schizophrenia may have some descriptive value, generally psychiatric terms do not describe "identifiable disease entities" (p. 58), but instead degrade and demean the person to whom they are attached. Hence, Herrick, Pearcey, and Ross (1997) asserted that people who have a mental disorder are often labelled by a society as inferior and, therefore, devalued as human beings because they are seen to be different. These authors claimed that the consequence of labelling was the promotion of generalisations towards specific groups, which is experienced when they are called names such as idiots, loonies, or morons. When a person is devalued or dehumanised, powerlessness results and this leaves the person feeling out of control. These feelings may further aggravate an already difficult situation and in extreme circumstances, it may push people to contemplate suicide.

People who have a physical illness evoke community concern and sympathy and their needs are readily recognised. However, people who have a mental disorder are not so fortunate and generally society demonstrates intolerance towards them (Australian National Mental Health Strategy, 1999). Fann (1999) claimed that an individual's beliefs, personality characteristics, and situational circumstances are important determinants in the formation of attitudes towards this group of people. Moreover, many of the symptoms and behaviours displayed by people who have a mental disorder are perceived as violations of rules or norms of society and the public has a desire to sustain social distance from them. There is a significant association between the beliefs that this group will always be violent and Link,
Phelan, Bresnahan, Stueve, and Pescocolido (1999) claimed that if the symptoms of mental disorders continued to be aligned to fears of violence, then this consumer group would be rejected and this would have a negative effect on them. This fear of rejection is present whether the person is a current consumer or an ex-consumer of mental health care and it affects their ability to seek and obtain treatment. It also affects the person’s recovery, their support system, and their acceptance in the community. Moreover, people who have a mental disorder may be reluctant to seek professional help for fear of stigmatisation.

There is little doubt that stigma can be created. In Australia, the success of anti-smoking and drink driving campaigns are testaments to this (Australian National Mental Health Strategy, 1999). However, the Australian National Mental Health Strategy (1999) asserted that stigma can be decreased. An illustration of this is the campaign to reduce public fear and stigma directed towards people with autoimmune deficiency syndrome (AIDS). However, observation suggests that it is easier to reduce stigma directed towards a behaviour, such as smoking than towards people, for example, people who have a mental disorder (Australian National Mental Health Strategy, 1999). Research conducted by McKeown and Clancy (1995) identified three main factors that contributed towards the stigma experienced by people who have a mental disorder: the media, a lack of education about mental disorders, and fear.

Stereotypes of insanity are central to the stigma and discrimination that surround people who have a mental disorder, undermining their recovery and integration into society. Szasz (1973) pointed out that in the relatively short 300 year history of the speciality of psychiatry, the condition known as mental disorders had been labelled and relabelled as madness, lunacy, insanity, and emotional illness, to name a few. Similarly, the places that have been used to confine people who have a mental disorder have been labelled as madhouse, lunatic asylum, insane asylum, and mental hospital. Bhugra (1989) indicated that these stereotypes spill over into common attitudes carried by the general population who view mental disorders as shameful, frightening, imaginary, and incurable. Marrone and Golowka (1999) contended that until a change in public attitude occurs, the human rights of people who have a mental disorder remain compromised.

1.7: Human rights of people who have a mental disorder

People who have a mental disorder are vulnerable (Johnstone, 2001) and Hawley (1997) claimed that these people are possibly the most politically powerless group within
society. By the very nature of their illness, many people who have a mental disorder find the concept of autonomy difficult to achieve. As early as 1977, Annas, Glantz, and Katz claimed that the human rights of people who have a mental disorder have been violated for centuries. In addition, the authors suggested that many of these people were deprived of basic legal protection, and were used in the performance of unethical and/or illegal human experimentation as, in the past, institutionalised patients were frequently used as research subjects. According to Annas et al (1977), this exploitation of institutionalised patients occurred as a result of patients’ accessibility and convenience rather than their applicability to the research. These patients were used because they generally had a uniform diet, schedule of sleeping hours, and daily routine. Furthermore, because of their mental state, many of these patients were unlikely to withhold consent to participate.

In order to clarify what we understand by human rights, for the purpose of this study, one needs to look for guidelines as a working basis. Therefore, the 1948 United Nations Declaration of Human Rights, which together with two covenants on human rights make up the International Bill of Human Rights (Williams, 1981), will be used. According to Orb (1993):

Even though this declaration is only a statement and not a philosophical justification of what a human right is, it has the value that is accepted globally. This notion embraces the idea of universality and acceptance of the rights even in spite of cultural differences. (p. 41)

In 1991, during the first part of its 46th session, the United Nations General Assembly adopted the resolution of the rights of people who have a mental disorder which are detailed in the document: The protection of persons with mental illness and the improvement of mental health care. The document outlined 25 principles related to the rights and care of people who have a mental disorder (WHO collaborating Centre for Mental Health and Substance Abuse, 1999). These principles were statements that addressed the fundamental freedoms and rights of people who have a mental disorder, governed the principles of treatment, ensured access to information, and monitored the standard and delivery of care in the hospital and community settings (see Appendix A).

Australia was a signatory to the United Nations Document, and in 1991 Australian Health Ministers produced the Mental Health Statement of Rights and Responsibilities. In this document, the Chairperson Raphael claimed that for years the Commonwealth of Australia had been concerned about the needs of people who have a mental disorder.
Raphael highlighted that social justice, equity, and access had not always been available to this consumer group. The Mental Health Statement of Rights and Responsibilities provided a framework to redress these principles, in an attempt to facilitate a more compassionate society.

The Mental Health Statement of Rights and Responsibilities (1991) provided direction and guidelines for consumers, carers, service providers, and the community regarding the rights of people who have a mental disorder. It ensured that these people are aware of their rights and responsibilities. These rights covered issues such as: the right to privacy and dignity, the right to family and friends, and the right for culture and gender to be taken into account with regards to the provision of care. The rights and responsibilities also extended to such factors as the right to information regarding the disorder and treatment and the right to question or complain about care. However, due to the severity of some types of mental disorders, some people may be detained at a mental health facility against their will as an involuntary patient. Therefore, laws enacted to protect these patients' rights stress that these people should be detained in the least restrictive environment for as short a time as is appropriate to their illness. The law indicated that these people have the right to an explanation of their condition and the reason for their admission to the health care system. They also have the right for advocacy representation. Moreover, these people have the right to have their involuntary status reviewed regularly by a Review Board (Mental Health Statement of Rights and Responsibilities, 1991).

The Mental Health Statement of Rights and Responsibilities aimed to provide a framework to assist in the implementation of the planned strategies surrounding modern mental health care. At a state level, legislation that supported the movement to community based care was introduced in Western Australia in the form of the Western Australian Mental Health Act in 1996. This Act provided the legal framework for a modern system of community based mental health care in Western Australia which allowed people who have a mental disorder to be treated and to live in their local community, preferably with their families.

1.8: Families of people who have a mental disorder

Family involvement is said to be an important factor in the quality of life of people who have a mental disorder. Skelton (1994) argued "the present policy of treating mentally ill people in the community could not exist without family carers who bear the main burden
of care. ... Carers are the glue that holds the system together" (p. 2). Home caregivers play an increasingly important role in the provision of health services to ill family members (Boland & Sim, 1996). The process of moving large numbers of people who have a mental disorder from isolated stand-alone psychiatric hospitals to the community was called deinstitutionalisation (Jones, 1996). Many people who were once housed in stand-alone institutions now live at home and it is estimated that one in four families has a member who has a mental disorder (Heffern, 1993).

During the last century families were shunned by health professionals and were viewed as not being important to their relative's recovery. Patients were often encouraged to distance themselves from their families following their discharge from hospital (Doornbos, 1996). In fact, families were often blamed for contributing to their relative's illness: interpersonal theorists proposed that schizophrenic processes began in infancy as a result of inadequate or impaired parenting (Sullivan, 1953); psychoanalytic theorists proposed that psychotic behaviour began because of a disturbed mother-infant relationship during the first year of life (Erikson, 1963); and family theorists viewed the identified patient as a symptom of a dysfunctional family (Bowen, 1978). The blame directed at family members and, in particular at mothers, left many family members feeling guilty for causing the family member's illness. Some families dealt with this guilt and/or shame by trying to hide the illness from their friends and neighbours and this was particularly true if the ill family member was female, did not live at home, or was not displaying severe positive symptoms, for example, hallucinations or delusions (Fung & Fry, 1999). However, many families also experienced the effects of stigma by association because they had a family member who had a mental disorder.

Deinstitutionalisation, along with changes in legal rights of patients, shifted care to the community (Saunders, 1997). Since several types of mental disorders have been reconceptualised as a neurophysiological disease with an associated chronic disability (Tuck, DuMont, Evans, & Shupe, 1997), the family is now viewed as a friend rather than a foe to the ill family member. Similarly, community mental health care has shifted many of the responsibilities for the management of the consumer's health care needs and costs from the health care system to the home care system (Smitka, 1998). According to Camann (1996) "community care became by default family care with little understanding of the implications for families" (p. 481). Families must now be responsible for many of the physical,
emotional, and social tasks associated with caring for a family member with a mental disorder at home (Reinhard, 1994).

Caring for a person in their home environment sets the stage for purposeful and meaningful involvement in life (Roberts & Fitzgerald, 1991). However, caring for a person who has a mental disorder also entails being confronted with and managing behaviours that most other families rarely encounter (Reinhard, 1994). Moreover, families who are thrust into the role of caregiving display a range of responses and emotions such as fear, anger, self-blame, or guilt (Paternelj-Taylor & Hartley, 1993).

In 1963 Grad and Sainsbury described the strain on families posed by this caregiving role (Saunders, 1997) and it is now generally acknowledged that mental disorders create burdens for family caregivers (Rose, 1996). Marsh (1992) claimed that all aspects of family functioning, family relationships, and family roles were altered, sometimes permanently, through this burden. According to Jones (1996):

Studies of mental illness in the family now span well over 30 years. No longer is the focus on the etiologic [sic] hypotheses concerning patterns of social interaction and communication within the family that promote illness; rather the focus is on the family as the bearer of burden. (p. 77)

Hoenig and Hamilton (1966) first described the objective and subjective components of the burden of care experienced by carers. The subjective dimension is the carer's perception of, and attitude towards, the experience, while the objective component relates to the social and economic cost to the carer. Despite decades of research, some authors still consider that the burden of care is not well understood and remains a problem for families (Maurin & Barmann Boyd, 1990; Rose, 1997). This situation may be accounted for by the fact that only a few of the studies pertaining to the families of people who have a mental disorder have focused on exploring family health or family strengths whereby family caregivers were recognised as experts in managing their relatives' care (Yamashita, 1998). Moreover, Yamashita (1998) pointed out that a large portion of the caregiving literature is atheoretical.

Several authors have examined the role and participation of carers in the treatment and care of people who have a mental disorder on a long-term basis. It is usually one family member who assumes the role of carer and this person is most often a woman (Jeon & Madjar, 1998) and Jablensky, McGrath, Herrman, Castle, Gureje, Morgan, and Korten's (1999) study found that 42 percent of their carers were mothers. Others considered that
providing care on a long-term basis impacted on the carer's domestic, social, occupational, and leisure routine. In addition, financial security and stability, relationships, mental health, coping and adjustment, and achievement of personal goals are affected by caring (Bernheim & Lehman, 1985; Jeon & Madjar, 1998; Zirul, Lieberman, & Rapp, 1989).

King, Collins, and Liken (1995) identified four main themes of why families make a commitment to care for a family member. The themes were that: 1) families are obligated to care, 2) families are owners of their difficulties, 3) families should protect vulnerable members, and 4) families are self-reliant units. One or more of these themes may account for a family's ongoing provision of care even when the personal cost of this care has been documented as being considerable. However, by failing to understand the family's experience of caregiving and by reinforcing societal expectations that families will take on this role, abnormal levels of stress can be placed on the family (Jeon & Madjar, 1998).

Caregiving has many dimensions (Bernheim & Lehman, 1985; Browning & Schwirian, 1994; Nankervis, Bloch, Murphy, & Herrman, 1997) and poses demands that may last for many years. Meeting these caregiving demands may result in family members experiencing increased levels of burden. There are many factors attached to the level of burden experience; it may be influenced by the caregiver's age (Cook, Lefley, Pickett, & Cohler, 1994), whether the patient lives with the caregiver (Jones, Roth, & Jones, 1995), the developmental stage of the family (Rose, 1997), ethnicity (Horwitz & Reinhard, 1995), and the socioeconomic status of the family (Biegel, Milligan, Putnam, & Song, 1994). Although this burden may not be obvious to those outside the family, it has an influence on the level of support and ongoing commitment the family will make to care for their family member. More recent studies (Kavanagh, 1995; Falloon, Magliano, Graham-Hole, & Woodroffe, 1996) suggested that families also experience positive outcomes from caregiving. Some families expressed positive attitudes towards their caregiving role, and generally viewed their family member as making a valuable contribution to family life. These positive contributions identified by carers include such things as providing comfort, helping with household chores, and providing the carer with a meaning and purpose to life.

Camann (1996), reported that families are often asked to provide care with limited support and resources from the health care system. In addition, caregivers are left to construct their own meaning concerning their relative's mental disorder, and its causes and consequences (Jeon & Madjar, 1998). They often receive little information from health professionals and may not be included in the decision-making processes. According to Jeon
and Madjar, caregivers receive little financial support, incentive, acknowledgment, or assistance for the role they undertake. Consequently, every member of the family is affected by the caregiving experience and, while community programs focus on the well being of the consumer, in general they are not presently designed to support and meet the needs of the family. Collaboration between health professionals and carers, although advocated in principle, may in reality only be operationalised in varying degrees. Inadequacies in support services for families and consumers have been noted by Backlar (1997) who claimed that while there is a large amount of research on family caregiving and family burden (Zarit, 1989; Parker, 1990), there remains little understanding of the relationship between caregivers, the cared for, and formal services.

The families of people who have a mental disorder value the service provided by health professionals but are often less satisfied with the extent to which their own needs are valued (Solomon, Draine, Mannion, & Meisel, 1998). Health professionals may not always be aware of the needs of the ill family member or their family. There is often a vast difference between the therapeutic goals of clinicians and the outcomes evidenced by the daily lives of the family (Backlar, 1997). Carers generally seek more involvement and information from health professionals about management plans, their family member’s illness, or support systems available to them. However, as carers are often unable to express their needs, health professionals need to consciously address these day-to-day concerns (Chafetz & Barnes, 1989). Historically, collaboration between carers, consumers, and health professionals has been characterised by tension and conflict (Pickens, 1998). The Human Rights and Equal Opportunity Commission (1993) highlighted the need for respite, accessible support, and acute care services for carers who maintain their family member in the home. Therefore, health professionals must provide more support and prepare families for their caring role (Peternelj-Taylor & Hartley, 1993). This increased level of support was deemed necessary to ensure that the family remained committed to community mental health care (Human Rights and Equal Opportunity Commission (1993).

Finally, while there is extensive research on family caregiving, the experience of caregiving from the carer’s perspective remains relatively unexplored (Dean et al, 1993; Falloon et al, 1996). The majority of studies on caregiving have used quantitative methodology and the need for further exploration and documentation regarding all aspects of the caring experience is required to fully document the “lived experience”. In 1958 Ludwig Wigenstein (cited in Backlar, 1997) stated that “one cannot guess how a word functions.
One has to look at its use and learn from that. But the difficulty is to remove the prejudices which stands in the way of doing this” (p. 456). This statement by Wiggenstein appears particularly pertinent in the context of this study. Unless people inquire from, rather than presume, caregivers' experiences of caregiving, they may never fully understand the reality of that experience.

1.9: Need for the study

Currently, the global burden of disease associated with mental disorders is increasing (Kleinman and Cohen, 1997). The process of deinstitutionalisation has seen the focus of mental health care move from the hospital to the community setting. Many authors have viewed the move as necessary not only for the well being of the mental health consumer but also from a financial perspective (Mechanic & Rochefort, 1996; Moller & Murphy, 1997).

The family has emerged as pivotal to the success of community mental health care and much of the care once provided to consumers by health professionals is now undertaken at a family level (Smitka, 1998). While families have always cared for their sick members, the level of involvement in the care of their family member has increased dramatically over the last few decades. Under the Australian National Mental Health Strategy the family and, in particular, the person who takes on the primary caregiving role is viewed as one of the major stakeholders in the success of community mental health care. The "partnerships model", that is, consumers, carers, and health professionals working together to improve the care and the quality of life of people who have a mental disorder is now a major focus of the Australian National Mental Health Strategy (Australian National Mental Health Policy, 1992, Australian National Mental Health Plan, 1992; Second Australian National Mental Health Plan, 1998).

While there is an abundance of literature on the caregiving experience of families (Bernheim & Lehman, 1985; Browning & Schirwin, 1994; Falloon, Boyd and McGill, 1984; Nankervis, Bloch, Murphy & Herman, 1997; Parker, 1990; Twigg, 1992; Zarit, 1989; Zirul, Lieberman & Rapp, 1989), the assessment of stress, coping, and the burden of caring on carers remains at a relatively early stage of development (Falloon et al, 1996). In Australia, only a few in-depth qualitative reviews of carers' experiences of caregiving have been completed (Sane, 2002).

With the implementation and on-going evaluation of the Australian National Mental Health Strategy and, more recently, the implementation in Western Australia of the 1996
Western Australian Mental Health Act, the findings of this study will provide a valuable insight into the unique experience of the primary carer.

1.10: Significance of the study

There is a large body of research on caregiving. Despite the contribution made by the existing literature to the knowledge of the experience of caregiving, these studies have not provided an understanding of the multi-dimensional experience of caring (Tuck, duMont, Evans & Shupe, 1997). This grounded theory study, undertaken in the Western Australian community and set within the framework of current scientific literature, presents a substantive theory on the primary carers' experience. Therefore, the findings should contribute to knowledge and be relevant to health care providers, policy makers, carers, and consumers throughout the world. In light of mental health reform both nationally and at a state level, the findings of this study also provide valuable information on caregiving within the Australian context.

Community mental health care offers a more creative, flexible approach to the treatment of mental disorders in society (Second Australian National Mental Health Plan, 1998). With the second stage of the Australian National Mental Health Strategy currently being implemented, consumer, professional, and carer collaborative strategies that facilitate increased communication, decision-making ability, and the provision of support need to be identified and implemented. However, in order for health professionals to engage in this process, they require an accurate understanding of the primary carers' experience of meeting their commitment to care for an ill family member. This fact was highlighted in a recent Australian policy document on education and training for health professionals. The document stated that for health professionals to be able to provide the optimum level of care to consumers and carers they needed "to learn about and value the lived experience of consumers and carers" (Deakin Health Services Australia, 1999, p. 1).

The substantive theory developed from this study details the primary carer's experience of caring for a person with a mental disorder and the findings provide stakeholders with a comprehensive framework for further research studies, policy development and movement towards best practice standards of mental health care. According to Orb, Davies, Wynaden, and Davey (2001), best practice "is the ongoing commitment to continual evaluation of current practice and the development of new practice initiatives" (p. 11). Best practice is not measured simply in cost terms but includes quality,
timeliness of delivery, and the outcomes achieved, particularly consumer satisfaction. An increased understanding and awareness of the carers' experiences will aid the movement towards best practice by helping carers to more clearly define their experience. The findings of this study may be used in carers' interactions with other carers, mental health care providers, and policy makers. In addition, the substantive theory provides health professionals with a framework that may be used for the further development of a comprehensive community mental health service. The findings are significant and should aid health professionals to initiate, support, and further expand mental health care policies that focus on the well being of the consumer, the family, and the primary carer as recommended by Camann (1996).

In conclusion, the findings of this study will facilitate the development of more effective collaboration between carers, consumers, and health professionals. It will provide a framework for the development of collaborative models of caring as suggested by Reinhard (1994) that respect each person's knowledge while recognising the strengths, resources, and expertise each individual can offer.

1.11: Purpose of the study

The purpose of this study was to use grounded theory methodology to develop a substantive theory on the primary carer's experience of caring for a person with a mental disorder in the Western Australian community. This substantive theory should make a significant contribution to the knowledge and understanding of the primary carer's experience of caregiving within the Australian context.

1.12: Objectives of the study

In order to achieve the above purpose the objectives of this study were, in the context of the Western Australian community and from the primary carer's perspective, to:

1. Explore and describe the experience, social processes, and interactions involved in caring for a person with a mental disorder;

2. Identify factors that facilitate or inhibit the experience of caregiving, and

3. Generate a substantive theory, which explains the phenomenon of caregiving to a person with a mental disorder, and place it in the context of the relevant theoretical literature.
1.13: Assumptions underlying the study

There were several assumptions underlying this study. These were:

1. Carers are subjected to considerable, even severe, emotional and material hardship as a result of their caregiving role;

2. Carers' perceptions and constructions of the social reality of caregiving have a strong influence on how they experience the phenomenon;

3. A better understanding of the experience of caregiving has the potential to enhance both consumer and carer outcomes;

4. There is a need for health professionals to collaborate with carers to document the "lived experience" of caring. This enhanced understanding of the "lived experience" will facilitate better collaboration between health professionals, service providers, and carers; and

5. Carers assume a heavy burden and endure this burden quietly while incurring increased social, psychological, physical, and economic costs to themselves.

1.14: Limitations of the study

While the experiences of caregiving are universal, this study was restricted to the primary carer's experience of caring for a person with a mental disorder in the Western Australian community. Therefore, this could be viewed as a limitation of the study. All participants were Caucasian and a self-selected motivated group of carers and this may be viewed as another limitation of the study. However, the theoretical sampling strategies employed in this study ensured that all aspects and variations of carers' experiences in this context were represented.

1.15: Summary

Modern mental health care is based on a significantly different health care philosophy than that which sustained the large stand-alone mental institutions found in most countries up until the middle of the twentieth century. Prior to deinstitutionalisation, the health care philosophy perpetuated the belief that people who had a mental disorder were dangerous and, therefore, needed to be isolated from society. The families of these people were often blamed either implicitly or explicitly by the experts for causing the illness in the family member.
Modern mental health care has seen the family rediscovered as one of the most significant supports for people who have a mental disorder. However, stigma has been identified as one of the major threats to the ongoing expansion of community based mental health care. The stigma that is either directed towards or perceived by the affected family member and/or their family determines not only the person's willingness to seek and continue to receive care, but also their family's continued commitment to support and willingness to care for their family member.

The findings of this study present a substantive theory on caregiving in the Western Australian community that is set within the context of the current scientific literature on caring. In the context of mental health reforms locally, nationally, and internationally, the findings will provide valuable insights into the experience of being a primary carer of a person with a mental disorder.

1.16: Organisation of the thesis

Part one of this thesis is comprised of three chapters. This chapter contains the introduction and background to the study and the research purpose, objectives, and justification for the study. Chapter two presents a description of the setting in which the study was completed, an overview of the Australian mental health care system, and information about the consumers being cared from by participants in this study. Chapter three covers the methodology used in this study. The chapter details an overview of grounded theory methodology including grounded theory's links with the philosophical perspective of "symbolic interactionism". The chapter concludes with a description of the application of the grounded theory research method as used in this study and a brief overview of the research findings.

Part two of the thesis (chapters four and five) details the basic social psychological problem experienced by participants and chapter four describes the two-stage problem of being consumed, while chapter five focuses on the conditions that influenced participants' experience of being consumed. Part three of the thesis (chapters six and seven) presents the basic social psychological process of seeking balance which participants engaged in to manage their experience of being consumed (chapter six) and the conditions influencing that experience (chapter seven). The fourth and final part of this thesis (chapters eight and nine) presents the substantive theory of seeking balance to overcome being consumed and discussion of literature pertaining to the substantive theory. In chapter eight, comparisons of
the theory are made to other pertinent theories, research findings, and related literature. Chapter nine, the final chapter of this thesis presents the implications of the research findings and the concluding statement of the thesis.
CHAPTER 2
THE CONTEXT OF THE STUDY

2.1 Introduction

This study uses grounded theory methodology and, therefore, it is important for the researcher to provide the reader with an understanding of the context in which the study was completed. This chapter details background information on the changing focus on mental health care and the Australian mental health care system. A description of the city where this study was completed is also included. In addition, information is presented on psychiatric diagnoses of the people being cared for by participants in this study. A case study from a mental health consumer's perspective is also presented to provide readers with an insight into what it is like to live with a mental illness.

2.2: The changing focus of mental health care

In Australia, one person in five will at some stage in their life experience the burden of a major mental disorder (Australian Bureau of Statistics, 1997; National Mental Health Report, 1997). Historically, people who have a mental disorder were isolated from society in large stand-alone mental institutions on the outskirts of cities. These institutions, located in most countries, provided custodial care and isolated ill people from their community (Zelestis, 1989). The health care philosophy that sustained these large mental institutions also perpetuated the image that these people were dangerous and, therefore, they were unable to live in society (Kelly & Stephens, 1999).

Caring for and supporting people who have a mental disorder in the least restrictive environment, and preferably with their family, is now a focus of the Australian National Mental Health Strategy. Current mental health policy supports the continuing process of deinstitutionalisation, that is, the movement from institutional to community care along with the integration of psychiatric care into the mainstream general health care system (Australian National Mental Health Policy, 1992).

Johnson (1997) defined deinstitutionalisation as "the discharge of large numbers of psychiatric clients from inpatient treatment centres to the community" (p. 1044). The process of deinstitutionalisation began in Australia in the 1960s, and since that time there has been an 80 percent decrease in Australian institution-based care (National Mental Health Workforce Education and Training Consultancy Report, 1994). In Australia, the
process of deinstitutionalisation followed similar movements in other parts of the world, such as, the United States of America (Wilding, 2000). Deinstitutionalisation developed in three ways: the reduction in stand-alone in-patient psychiatric beds, the expanded provision of community based care, and the integration or mainstreaming of mental health care services with other components of health care (Australian Health Ministers, 1998). The major push behind the move from hospital to community care was based on human rights concerns, changes in legislature, and the perceived reduced costs involved in providing mental health care in the community setting. Reducing the harmful effects of institutionalisation, for example, the loss of independence, along with the stigma directed towards people who have a mental disorder were examples of what the process of deinstitutionalisation hoped to change (Wilding, 2000).

Deinstitutionalisation was not simply concerned with a reduction of in-patient psychiatric beds; it also sought to improve patterns of shelter, care, quality of life, and treatment for people who have a mental disorder. The philosophy behind deinstitutionalisation also aimed to change the general population’s beliefs and attitudes about mental disorders. Nevertheless, while much of the reasoning behind deinstitutionalisation was based on better treatment methods, reducing the cost of the burden of treating mental disorders, was also behind the move to community based care (Green, 1995). Mechanic and Rochefort (1996) claimed that, globally, national health systems faced common pressures related to mental health care and the process of deinstitutionalisation reflected important changes in many countries’ social welfare policies, as well as their financing and provision of mental health care.

Murray and Lopez (1996) estimated that psychiatric disability accounted for up to 10.5 percent of the global disease burden. However, these authors also claimed that by the year 2020 schizophrenia, depression, and alcohol and drug related problems alone would account for 15 percent of the global burden of disease. In addition, people who have a mental disorder showed the lowest percentage of recovery to full-time working and social capacity.

Globally, as a result of deinstitutionalisation, the provision of mental health care in the least restrictive environment has continued to expand (Mechanic, 1987). Modern community mental health care, supported by legislature, aims to maintain the consumer in their community by providing treatment, rehabilitation, and support services at a local level. However, throughout the world since deinstitutionalisation began, the main problems facing people who have a mental disorder have been the provision of adequate housing,
along with basic medical care, employment, and the opportunities to fully participate in community life (Mechanic, 1987). These problems have been enough for many people to consider that the objectives of deinstitutionalisation have failed, not because it was not a good idea, but because in most countries it was poorly planned (Martin, 1990; Mechanic & Rochefort, 1990; Talbott, 1991). These authors suggested that governmental planning lacked the development of appropriate social support strategies, accommodation, the provision of employment opportunities, and adequate family education and preparation. Furthermore, Mossman (1997) suggested the large number of homeless people who have a mental disorder was an example of this poor planning and the process of deinstitutionalisation had failed to integrate them back into the community.

While much of the philosophy guiding the process of deinstitutionalisation sought to change the knowledge level and attitudes of the general population regarding the nature of mental disorders, in reality little was achieved in dispelling the stigma attached to mental disorders. Several authors have suggested that reducing stigma was the most crucial issue to the success of community mental health care (Heginbotham, 1998; Sartorius, 1998). Heginbotham (1998) claimed that stigma should have been addressed before the movement of people from hospitals into the community began. This author suggested that ironically, because people who have a mental disorder are now more visible in the community, deinstitutionalisation might have, in fact, increased the social stigma directed towards them (Heginbotham, 1998). This is further exacerbated by the fact that the general public remains ignorant about mental disorders due to the lack of effective educational programs. According to Morrall and Hazelton (2000), numerous reports from pressure groups, as well as the media, have further increased the visibility of people who have a mental disorder. In addition, these authors concluded that in Australia the media currently supports the notion that community mental health care provides inadequate care and supervision of those who may pose a threat to society.

Normalisation has been one of the guiding principles behind deinstitutionalisation, with its two key concepts: the integration of mental health care with general health care and an increased independence and achievement for people who have a mental disorder. However, the level to which these two concepts have been successful has been dependent upon the values held by a particular community (Heaney & Burke, 1995). In addition, Heaney and Burke indicated that community mental health care facilitated the rehabilitation process and fostered the hope of normalisation, along with an increased community acceptance of people who have a mental disorder. However, they claimed that
confusion and different philosophical backgrounds amongst policy makers and providers has, in reality, impacted on the operationalisation of these two key concepts. Encouraging independence in people who have a mental disorder may involve health professionals and society practising some degree of risk-taking behaviours. For example, the earlier discharge of a person from hospital may conflict with ideologies of care that emphasise paternalistic, protective, safekeeping goals. Moreover, providing an independent life may be difficult for the varied and changing capabilities of some people who have a mental disorder. While many people who have a mental disorder are now cared for in the community, a large proportion of these people are still not fully integrated into life within their community. Mechanic (1995) claimed that in order to improve the daily lives of these people, a society must create a supportive environment where they can learn new coping strategies. Similarly, policy makers must be more receptive to approaches to care that concentrate on psychosocial as well as medical interventions. Furthermore, there is a need for new kinds of partnerships between health professionals, consumers, and carers to ensure that consumers are allies in their own treatment (Mechanic, 1998).

2.3: The Australian mental health care system

In Australia until the 1990s, mental health care was grossly under funded. This is evident from the findings in the report titled Human rights and mental illness: Report of the national inquiry into the human rights of people living with mental illness, also known as the Burdekin Report (Human Rights and Equal Opportunity Commission, 1993). The Burdekin Report was critical of Australia's neglect and history of confinement of people with mental disorders. The Burdekin Report also criticised the treatment of carers by the mental health care system. According to Coffey (1994), the Burdekin Report directed criticism at all levels of psychiatric care in Australia (administrative, legislative, and service), criticising the lack of a national policy, and was “in short, a catalogue of the failures of our psychiatric system” (p. 33).

The Burdekin Report identified that an inadequate level of funding was being directed to the promotion and treatment of mental health in the Australian community. Commissioner Burdekin cited many incidents of human rights violations, for example, the inadequacy of the law to accurately address and encompass people who have a mental disorder. This occurred primarily because the police were regularly involved in transporting people who have a mental disorder to hospital and, therefore, these people were treated in the same way as criminals. Minority groups such as migrants, Aboriginal
and Torres Strait Islanders, and the homeless were also mentioned in the report as people who were disadvantaged. In addition, Commissioner Burdekin considered that the move from institutional to community based mental health care had not delivered a successful integration of these people into the community as anticipated by the ideologies of the community mental health care movement.

Whilst the Burdekin Report was being completed, an historic meeting of all Australian Health Ministers was also taking place. The 1992 meeting endorsed what became known as the Australian National Mental Health Strategy. According to McDermott and Carter (1995) the Australian National Mental Health Strategy had three main aims: to promote the mental health of the Australian community, to reduce the impact of mental disorders on Australian society, and to affirm the human rights of people who have a mental disorder. The Australian National Mental Health Strategy set clear directions for the future development of mental health care in Australia. The Strategy outlined a reform process for improving the mental health care, which was originally articulated in four documents:

1. **Australian National Mental Health Policy** (1992)
   This policy, endorsed by Australian Health Ministers in April 1992, outlined significant changes in the approach to mental health care. The policy promoted the move from institutional to community care, which was operationalised through the processes of deinstitutionalisation, and supported the concepts of normalisation.

2. **Australian National Mental Health Plan** (1992)


The agreement outlined the role that the Commonwealth, States, and Territories would undertake to achieve mental health care reform. It also outlined the conditions for the transfer of federal funding to achieve this reform (Evaluation of The Australian National Mental Health Strategy: Final Report, 1997). In addition, the Evaluation of The Australian National Mental Health Strategy Final Report (1997) outlined twelve key areas for reform set out in the National Mental Health Strategy. The objectives and strategies to achieve the reforms were also detailed (see Table 1).

An *Evaluation of the Australian National Mental Health Strategy Final Report* (1997) indicated that the reforms outlined in 1992 were ambitious by international standards and may not be achievable within the planned timeframe. In 1998, the Australian National Mental Health Strategy was extended for a further five years (1998-2003) and was accompanied by the Second National Health Plan (1998) which provided guidelines for further development of the National Mental Health Strategy (National Mental Health Report, 1997). The evaluation of the first part of the Australian National Mental Health Strategy highlighted that international experience, in Canada, the United States of America and Europe, had shown that more than good intentions were necessary to make the strategy work and that the Australian National Mental Health Strategy's success was dependent on a change in community attitudes towards people who have a mental disorder. Moreover, the evaluation reasserted the earlier findings of the Burdekin report that people who have a mental disorder remained disadvantaged due to the stigma directed towards them. In addition, the evaluation reported that the stigma present in the community directed towards people who have a mental disorder was a major threat to the acceptance and implementation of further mental health reform in Australia.

2.4: Setting for the study

This grounded theory study was conducted in Perth, Western Australia. Western Australia, the largest State in Australia, spans over 2.5 million square kilometres. Bordered largely by desert to the east, Western Australia is bound by 12,500 kilometres of the world's pristine coastline to the west. Perth, the capital city of the State, is home to 1.38 million people (Mighty media, 1999). Participants in this study lived in suburbs throughout the Perth metropolitan area. The family member being cared for was either linked to a public or private health service or a psychiatrist in their local community region. Some of
| **Table 1: The 12 key objectives of the Australian National Mental Health Strategy** |
|---|---|
| **1. Consumer rights** | Reforms to safeguard the rights and civil liberties of people who have a mental illness. |
| **2. Mainstreaming of health services** | This reform aimed at providing comprehensive mental health services in local communities along with other mainstream health services, for example, maternity, and child health services. |
| **3. Linking mental health services with other sectors** | Access to housing, accommodation and support, as well as income support and the opportunity for employment opportunities, were identified as being vital to the success of any community mental health care program. |
| **4. Service mix** | The provision of a comprehensive mental health service system that was adequately resourced and accessible to respond to the needs of the community. These services include acute inpatient care, rehabilitation services, and outpatient treatment. |
| **5. Promotion and prevention** | The need to educate the community regarding mental illness, as well as increasing promotion and preventative mental health care interventions. |
| **6. Primary care services** | The establishment of adequate primary care services in local communities. |
| **7. Carers and non-government organisations** | Adequate funding directed to key non-government organisations that support mentally ill people and their carers in the community. |
| **8. Mental health workforce** | The provision of a highly educated workforce of mental health professionals able to deliver care in both rural and urban regions of Australia. |
| **9. Legislation** | Consistency in mental health legislation throughout the country was a goal of reform in order to facilitate ease of treatment across State/Territory boundaries. |
| **10. Research and evaluation** | Research and evaluation of current care practices be undertaken routinely. |
| **11. Standards** | National standards of mental health care be established. |
| **12. Monitoring and accountability** | Greater accountability and visibility of reporting progress in implementing new approaches to care in Australia. To develop nationally agreed measures of performance and to report these annually and publicly. |
these health services were designated under the 1996 Western Australian Mental Health Act as "Authorised Hospitals" and, therefore, admitted and treated some clients under an involuntary status.

The 1996 Western Australian Mental Health Act was implemented in 1997. It brought about the most significant mental health changes in Western Australia in 35 years and imposed safeguards to ensure the rights of people who have a mental disorder (Rolfe, 1998). Under the new Act, involuntary patients are treated in either an "Authorised Hospital" or while residing in the community on a Community Treatment Order (CTO), thus preventing unnecessary hospitalisations. The new Act established an independent Mental Health Review Board to review the treatment of all involuntary patients shortly after admission and every six months thereafter.

2.5: The experience of being a consumer

For those people reading this thesis who are not familiar with mental disorders, the following personal account of what it is like to have schizophrenia has been included to allow the reader insight into the experience of living with a mental illness. The following account “Waking from a schizophrenic’s nightmare” by Lori Schiller was taken from schizophrenia.com, a newsletter that is freely available on the internet. Permission to include this segment in this thesis was obtained from the editor of schizophrenia.com.

Waking from a schizophrenic’s nightmare
By Lori Schiller (1996)

I remember little of what happened in my life in the past eight years ...... I suppose it’s a lot like an alcoholic’s blackout. Life seems dark, scary and fragmented. I battled strange, ominous voices [auditory hallucinations] and sights [visual hallucinations] in a forever tormented, day-to-day nightmare. I couldn’t get relief from my psychotic world. I wanted to die desperately in an effort to free myself from this world. The first time I heard those derogatory voices was as a teenager. I didn’t know what was happening to me. I felt like I was possessed, and my mind was infected by demonic spirits.

I was afraid to tell anyone about the voices for fear of being carried off by “white coats”. Imagine being a 15 year-old kid hearing the words over and over again: “You must die. You will die”. And imagine the naïve little squirt keeping the echoing vicious voices inside of herself for many years without sharing the
pain and fright of them with anyone. Eventually, I entered the “revolving door” into the so-called mental health care system. The doctors, so dapper and professional in their psychiatric style and attire, told my parents that I was a paranoid schizophrenic who had little chance of getting better. .... I can imagine how crushed my parents were, with their ignorance about mental illness and suffering along with me. But they did not give up hope. Never.

.... My imagination became infested with all kinds of “me-murders”. Some of my favorites [sic] to relish were standing on a bridge, pouring a can of gasoline over my head, lighting a match, and as I went up in flames, jumping onto the highway to my end. How about death by jumping inside a ferocious animal’s cage at the Bronx Zoo? Or maybe hoarding pills grinding them up in a blender as ingredients in a chocolate milk shake, and drinking it down with a straw.

As frightening as these potential suicidal scenarios seem, they all held for me real endings of tranquility [sic] and peace. I’d pray for this, and then visualize [sic] myself in a coffin, rotting like an old potato, with worms coming out of my nostrils, and all kinds of creepy things eating away at me like a Thanksgiving banquet. I had many terrorizing [sic] experiences while in hospital that were so frightening at times I became physically sick to my stomach. My behaviour left me acting out, necessitating medications and restraint. I would be in my room and afraid to leave because there were creatures sitting on my bed and coming through my windows. I couldn’t leave and I couldn’t stay, so I’d “freak out” and smash my fist into a wall or window safety screen to curse out those faces. .... I used to dread every morning for what was going to transpire on what day. Every night when I went to bed, I was petrified that the foreboding voices would leave me sleepless.

If it weren’t for the newer medication, clozapine, ... I would never have survived this continuously exhausting illness. I felt as though I was weakening; the voices were going to conquer. With the assistance of that new medication and the comfort and support from my psychiatrist and others, I have been able to make distances down my path to recovery.

I am now involved in working part time in a gift shop and part time as a counselor [sic] in a halfway house. I am currently working on a book about “my story” in the form of expansion of this article. I co-lead a class once a month with two nurses about schizophrenia; my part of the class is about managing the illness. I am a spokesperson for the Mental Illness Foundation in New York City. The bottom line, I believe, is that I’m on my way to being a “cured” schizophrenic. With hope, motivation and courage, and proper care, there can be recovery for the mentally ill.

2.6: Description of the psychiatric diagnoses of consumers being cared for by participants in this study

A brief description of each of the mental disorders of the consumers being cared for in this study is now presented. A more detailed description of each disorder is given in Appendix B. Permission to include the more detailed description of the
DSM IV criteria in this thesis was obtained from the American Psychiatric Association in October 2000 (See Appendix C).

2.6.1: Schizophrenia

Schizophrenia is a major group of mental disorders. It is estimated that one percent of the population is, has been, or will be affected by the disorder (See Appendix B for more information on diagnostic criteria). The onset is usually during adolescence or early adulthood. For many it is a progressive and disabling disorder, although recovery is possible. Torrey (1998) equated schizophrenia to leprosy as a stigmatising disease. Schizophrenia is identified in all societies. However, there were different incidence rates when statistics on the disorder were compared cross-culturally (Townsend, 2000). Six types of schizophrenia are outlined in the DSM IV: paranoid type, disorganised type, catatonic type, undifferentiated type, schizoaffective disorder, and schizophreniform disorder.

Three major categories of symptoms are present in people with schizophrenia: positive symptoms, negative symptoms, and disorganised symptoms. Positive symptoms include: delusions, unusual thoughts and/or suspiciousness, and auditory and/or, less commonly, visual hallucinations. Distorted perceptions such as bodily sensations, smells or background noises, lights, and distractions are also commonly experienced. People with schizophrenia also display negative symptoms such as a lack of motivation, lack of pleasure and interest in life, a flattened or blunted affect and limited speech. The third group of symptoms include disorganised speech, confused thinking, and disorganised behaviour such as ritualistic movements or rhythmic gestures (Weiden, Scheifler, McEvoy, Frances & Ross, 1999).

2.6.2: Mood Disorders

The DSM IV described the essential feature of mood disorders as a disturbance of mood, characterised by a full or partial manic or depressive syndrome that is not attributed to another mental disorder (See Appendix B for specific diagnostic criteria). Mood disorders are sub-categories under depressive disorders and bipolar disorders (Townsend, 2000). Depressive disorders are characterised by depressed mood or loss of interest or pleasure in usual activities. Evidence of impaired social and occupational functioning that has existed for at least two weeks
with no history of manic behaviour must be present. In addition, the symptoms must not be attributed to a medical condition or substance use.

Bipolar disorders are characterised by mood swings from depression to mania with intervening periods of normal mood. Psychotic features, including delusions and hallucinations, may be present. During mania, the person's mood is elevated, expansive and irritable causing severe impairment of occupational functioning. Personal relationships and social interactions are also impaired by the manic symptoms. Depression occurring as part of a bipolar disorder is identical to that described in major depressive disorders, with one exception: the person has a history of one or more episodes of manic behaviour (Townsend, 2000).

2.6.3: Anxiety Disorders

The term refers to a group of psychiatric disorders characterised by the emotion of intense terror. This feeling prevails over a substantial period of time and is accompanied by feelings of catastrophe. Failure to achieve the relief from the feelings of anxiety increases the severity of the symptoms (See Appendix B for specific criteria). Anxiety disorder includes panic, phobia, generalised anxiety, obsessive-compulsive disorder, and stress disorders. All the disorders are characterised by a single symptom or a group of symptoms, the person perceives the symptom(s) as intensely uncomfortable, without treatment the condition endures, the disorder is not attributed to an organic cause, and the person perceives reality accurately (Johnson, 1997).

One participant in this study was caring for a relative with obsessive-compulsive disorder. Obsessive-compulsive disorder may begin in childhood but more often begins during adolescence and adulthood. The recurrent obsessions and compulsions are severe enough to be time consuming or to have caused marked distress of significant impairment in functioning (Townsend, 2000). Obsessions are unwanted, intrusive, persistent thoughts, impulses or images that cause distress. Compulsions are unwanted repetitive behavioural patterns or mental acts that are carried out to reduce anxiety, not to provide pleasure or gratification. The individual recognises that the behaviour is unreasonable but is compelled to continue the act in order to receive relief from the feelings of anxiety.
2.6.4: Borderline personality disorder

Personality disorders develop when the person's personality traits become inflexible and maladaptive, causing significant functional impairment or subjective distress for the individual (See Appendix B for specific criteria). These disorders are coded on Axis II of DSM IV and as such are classified differently to psychiatric disorders (Axis I). Personality disorders develop in response to a number of psychological and physiological influences, for example, heredity, temperament, experiential learning, and social interaction. There are three clusters of personality disorders described in the DSM IV and these are cluster A: behaviours described as odd or eccentric; Cluster B: behaviours described as dramatic, emotional, or erratic; and Cluster C: behaviours described as anxious or fearful. Although not classified under Axis I of DSM IV many people with personality disorders are treated within psychiatric services. Several participants in this study were caring for a person with a Cluster B type personality disorder known as a borderline personality disorder. Each of these people had extensive contact with and treatment from psychiatric services.

Borderline personality disorder refers to a group of disorders where people have symptoms that appear to fall on the border of other diagnostic categories. They display a stable course of unstable behaviour. They are always in crisis, their affect is intense, and their behaviour is very changeable. They often exhibit a single, dominant affective tone, such as, depression. These people often have problems in forming relationships; they use manipulation and self-destructive behaviours to deal with anxiety or to elicit a response from significant others. They have poor impulse control and acting out behaviours may occur in response to real or perceived feelings of abandonment (Johnson, 1997).

2.6.5: Disorders first diagnosed in infancy, childhood, or adolescence

One participant in this study cared for a 16-year-old adolescent with a diagnosis of borderline personality disorder, depression, and attention deficit/hyperactivity disorder (See Appendix B for specific criteria). The DSM IV asserts that it is difficult to determine if children's behaviours are indications that they are experiencing emotional problems. An emotional problem is present if the behavioural manifestation is not age appropriate, deviates from cultural norms, and creates deficits or impairment in adaptive functioning. The essential feature of attention deficit/hyperactivity disorder is a persistent pattern of inattention and/or
hyperactivity-impulsivity that was more frequent and severe than that observed in individuals at a comparable stage of development (DSM IV, 1994). The disorder is often undiagnosed until the child starts school (Townsend, 2000). There are three main subtypes of this disorder: combined type, predominantly inattentive type, and predominantly hyperactive-impulsive type.

2.6.6: Dementia

Dementia refers to a severe loss of thinking abilities, especially memory. It occurs most often in people over 85 years of age (See Appendix B for specific criteria). Dementia is a disease that damages brain tissue leading to disturbed brain functioning (Kahn, Gwyther, Frances, Silver, Alexopoulos, & Ross, 1998). The most common type of dementia is Alzheimer's disease. Alzheimer's disease causes gradual death of brain tissue due to biochemical problems inside individual brain cells. Many people with dementia suffer emotional distress and behavioural changes that are best described as agitation (Kahn, et al., 1998). This agitation is displayed in several ways, for example, aggression, and is one of the main reasons why people with dementia are sometimes hospitalised within the psychiatric health care system.

2.7: Summary

This chapter has provided contextual information about the Australian health care system, the setting for this study, and the psychiatric disorders of the family members being cared for by participants. A case study on the personal experience of living with a mental illness was also included. Chapter three outlines the methodology used in the study and details the grounded theory method. This chapter will now be presented.
CHAPTER 3

METHODOLOGY: THE GROUNDED THEORY METHOD

3.1: Introduction

This chapter describes the methods used to investigate the primary carer's experience of caring for a person with a mental disorder in the Western Australian community. The rationale for using qualitative methodology, and more importantly the choice of grounded theory methodology, is presented. The origin of grounded theory is detailed, as well as a description of the grounded theory method. Discussion on the continuing debate regarding grounded theory methodology is also presented in this chapter. Glaser and Strauss' method, first described in 1967 (Glaser & Strauss, 1967) and aspects of both authors' subsequent diverged methods were followed for this study and their methodological steps are outlined.

The chapter also covers ethical considerations, a description of the participants as well as data collection and storage methods. In addition, the procedures undertaken to ensure the trustworthiness, credibility, and transferability of the findings are presented. Finally, the chapter concludes with an overview of the study's major findings.

3.2: Qualitative Research

Qualitative research is not new to the social or behavioural sciences with nursing's interest in this research methodology dating back to the 1960s (Burns & Grove, 1999). Qualitative research embodies numerous methodological approaches that focus on describing the in-depth experiences of people's lives and the social contexts that strengthen, support, or diminish those experiences (Leininger, 1985; Munhall, 1989). Qualitative research provides the researcher with multiple choices and means to explore the depth, richness, and complexity inherent in the phenomena being studied (Carr, 1994). Each methodological approach has a different philosophical stance that guides the questions asked and the procedure used for data collection and analysis. According to Morse (1999a):

they offer alternatives in analytic approaches; cater to different disciplinary perspectives, assumptions, and agendas; provide a means to explore various levels of analysis, from micro-analytic to complex behaviors; [sic] and permit the development of the necessary level of conceptualization [sic] of results. (p. 393)

Although the terminology and the procedures used are determined by the philosophical orientation of the identified approach, for example, phenomenology, grounded
theory, or ethnography, there are two major commonalities of all qualitative methodologies (Munhall & Boyd, 1993). Firstly, all approaches acknowledge that reality changes over time and is based on the individual's perception making reality different for each person. Secondly, an individual's knowledge only has meaning within a given situation or context, and, as each individual's perception differs, many distinct meanings are possible.

Qualitative research is popular in nursing mainly because it focuses on understanding the whole experience, a concept that is central to the philosophy of nursing (Burns & Grove, 1999). The outcomes of qualitative research demonstrate new understandings of a phenomenon, which, when applied more broadly, provide new guides for nursing practice and further theory development. Qualitative research, like quantitative research, follows a predetermined methodological process. Initially, the researcher identifies a problem, provides justification for the merit of the study, determines the study design and selects the subjects (called participants in qualitative research) and/or other data sources, gathers data, analyses, and interprets data, and provides a written report of the results.

The most common data collection methods used in qualitative methodologies include observation, interviewing, and the examination of written text (Silverman, 1993). Initially, participants are obtained using a purposeful sampling technique. This sampling technique is where the researcher recruits participants who are viewed as being typical in relation to the phenomenon under study. In addition, participants who are in some way different are also sought in order to obtain diverse perspectives regarding the phenomenon under study. Sample sizes vary and the decision to stop seeking new participants occurs when the researcher ceases to obtain any new information and all categories appear to be complete. This process is known as theoretical saturation (Sandelowski, 1995).

Data analysis occurs at three levels: description, conceptualisation, and interpretation. In grounded theory this process (known as constant comparative method of analysis) occurs continuously throughout the research process and directs further data collection and/or theoretical sampling techniques (Strauss & Corbin, 1990). Researchers, using qualitative research methods, ensure the trustworthiness, credibility, and transferability of findings by providing detailed descriptions of the methodology used during the research in the written report. Audit trails and memos that clearly demonstrate the validity of decisions made by the researcher during data collection, analysis, and interpretation also add to the trustworthiness, credibility and transferability of data (Miles and Huberman, 1994).

Denzin and Lincoln (1994) claimed that qualitative researchers are more likely to "confront the constraints of the everyday social world. They see this world in action and
embed their findings in it" (p. 5). Grounded theory methodology was chosen for this study because it was viewed as the most appropriate methodology, for ontological and epistemological reasons, for exploring the phenomenon under study.

3.3: The Grounded Theory Method

Sociologists Barney Glaser and Anselm Strauss (1916-1996) developed grounded theory methodology in 1967 at the University of California, San Francisco. Their original grounded theory research was a study on dying and resulted in two texts, *Awareness of dying* (Glaser & Strauss, 1965) and *Time for dying* (Glaser & Strauss, 1968). The research also led to the publication of a book outlining the methodology used in the study, "*The discovery of grounded theory*" (Glaser & Strauss, 1967). At that time, Glaser and Strauss' (1967) work was viewed as revolutionary because:

- it challenged (a) arbitrary divisions between theory and research, (b) views of qualitative research as primarily a precursor to more "rigorous" quantitative methods, (c) claims that the quest for rigor [sic] made qualitative research illegitimate, (d) beliefs that qualitative methods are impressionistic and unsystematic, (e) separation of data collection and analysis, and (f) assumptions that qualitative research could produce only descriptive case studies rather than theory development. (Charmaz, 2000, p. 511)

Symbolic interactionism, a distinct theoretical perspective in social psychology that focuses on the meaning of events to people in their natural setting, underpins grounded theory methodology (Chenitz & Swanson, 1986). However, Sir Frances Bacon (1561-1626) is also regarded as contributing to the philosophy guiding the development of grounded theory (Warhaft, 1965). Bacon, who was a major stakeholder in the initiation of the scientific revolution, wrote "It is plain that the more you recede from your grounds, the weaker do you conclude: and as in nature, the more you remove yourself from particulars, the greater the peril of error you do incur" (cited in Kitchin, 1973, p. 215). Grounded theory has sometimes been criticised because of its philosophical links to "Baconian" inductivism. However, according to Haig (1995), "grounded theory methodology embodies a conception of scientific inquiry that is far removed from such a naive account" (p. 2).

The discipline of symbolic interactionism arose out of the Chicago School of Sociology between 1920 and 1950 where George Herbert Mead (1863-1931) used this approach to study human behaviour (Robrecht, 1995). Herbert Blumer (1900-1987), another sociologist, articulated three basic premises based on Mead's understanding of social
psychology relating to the symbolic interactionist approach (Becker, 1993). According to Blumer (1969):

human beings act towards things on the basis of the meaning that the things have for them; the meaning of such things is derived from, or arises out of the social interaction that one has with one's fellows; and meanings are handled in, and modified through, an interpretive process and by the person dealing with the things he encounters. (p. 2)

Blumer's beliefs about symbolic interactionism were supported by Denzin's (1989) work that also outlined three fundamental assumptions linked to symbolic interactionism: 1) individuals define their own situation, 2) individuals are capable of self-reflection, while at the same time directing their behaviour and that of others, and 3) in directing their own behaviour, individuals can interact with others and adjust their behaviour as necessary. In addition, Denzin (1989a) linked symbolic interaction to qualitative research and suggested that researchers must enter the participant's world of social interaction to "fully" allow them to understand the participant's perspective of the situation under study. Streubert and Carpenter (1995) further supported this notion claiming that through social interaction individuals can "learn about" and "define" their experiences (p. 260).

Grounded theory is derived from the study of the phenomenon it represents (Glaser & Strauss, 1967). Two types of theories, substantive and formal, can be produced using grounded theory methodology (Backman & Kyngas, 1999). Substantive theories concentrate on a specific social process and are developed for a narrower empirical area of study. Substantive theories can be used to generate or re-formulate existing formal theories (Blaikie, 1993). Substantive theories are relevant to the people concerned and are readily modifiable (Glaser, 1978). In contrast, formal theories are more general and deal with a conceptual area of inquiry (Strauss & Corbin, 1990; Morse & Johnson, 1991) that can be related to a range of substantive areas (Blaikie, 1993). Both substantive and formal theories are mid-range theories, and while narrower in scope than grand theories, provide valuable insights of reality and are useful in linking theory with practice (Fawcett, 1995).

Glaser and Strauss (1967) alleged that theories are deduced from logical assumptions or generated through observation. Their basic position regarding grounded theory is that it is a "way of arriving at theory suited to its supposed uses" (p. 3). Grounded theory is an inductive approach that derives its name from the practice of generating theory from observational research that is "grounded" in data (Bachuk, 1997). The goal of grounded theory is the construction of theory that gives understanding to the phenomena being studied. The finished theory should be "inductively derived from data, subjected to theoretical
elaboration and judged as adequate to its domain with respect to a number of evaluative criteria" (Haig, 1995, p. 1). According to Charmaz (2000) "the power of grounded theory lies in its tools for understanding empirical worlds" (p. 510). The methodology enables the researcher to generate explanatory theory about social and psychological phenomena rather than generating results to support or test existing theories (Glaser & Strauss, 1967). The resulting theory is an explanation of categories, their properties, and the relationships between them (Calloway & Knap, 1995) and it is a powerful way of interpreting reality (Strauss & Corbin, 1990). Theories based on data can't be refuted or replaced by another theory and since it is linked to data it is destined to withstand inevitable modification and reformulation (Glaser & Strauss, 1967). Chenitz and Swanson (1986) stated that:

The objective of grounded theory is the development of theory that explains basic patterns common in social life. Grounded theory represents an advance in technology for handling qualitative data gathered in the natural, everyday world. It describes a method to study fundamental patterns known as basic social-psychological processes which account for variation in interaction around a phenomenon or problem. (p. 3)

Since the original publication by Glaser and Strauss (1967) other publications by Glaser and Strauss writing alone, or with others, have emerged. In addition, several other authors have given their views on grounded theory methodology, for example, Chenitz and Swanson (1986), Denzin and Lincoln (1994) and Streubert and Carpenter (1999). These publications reflect differences in how Glaser and Strauss view grounded theory (Babchuk, 1996; Strauss & Corbin, 1990). As a result, Glaser (1992) argued that two distinct methodologies have evolved based on Glaser and Strauss' (1967) work and that each has their own underlying epistemology and methodological approaches (Babchuk, 1995). Essentially, the difference in the approaches lies in the methods of coding which is the heart of grounded theory analysis. Glaser (1978) described 18 "Coding Families" which assist researchers to analyse data using the grounded theory method. One of the coding families termed "the six C's", comprise the conceptual codes of: "Causes, Contexts, Contingencies, Consequences, Covariances and Conditions" (p. 74). Strauss and Corbin (1990), in "Basics of Qualitative Research", outlined the "paradigm model" as their framework for data analysis. The paradigm model linked by Strauss and Corbin to "the six C's", was challenged by Glaser who stated that it promoted the "forcing" rather than "emergence" of the theory (p. 118). In counteracting this claim, Strauss asserted that unless the model was used, the grounded theory research would lack density and precision (Glaser, 1992). Strauss also placed emphasis on replicability, generalisability, precision, significance, and verification of data (Babchuck, 1995). In contrast, Glaser viewed grounded theory as a method that was inherently flexible.
and primarily guided by informants and their socially constructed realities. He stated that the informants' world would emerge from the analysis along with the research problem and that forcing this process would result in researchers focusing only on their favourite codes while ignoring other equally important ones (Glaser, 1978).

As with any research technique, grounded theory has strengths and weaknesses. The main criticism of grounded theory is that the epistemological assumptions are not clearly explained (Charmaz, 1990). Weaknesses in the use of grounded theory have mainly been attributed to the researcher not fully understanding grounded theory methodology, not using the constant comparative method of data analysis throughout the study, and threats to the researcher's theoretical sensitivity, for example, due to over familiarity with the study area (Backman & Kyngas, 1999; Skodol Wilson & Hutchinson, 1996).

3.4: Application of the Grounded Theory Method for this Study

While the researcher was aware of the continuing debate concerning grounded theory methodology, this study is predominantly guided by the original method described by Glaser and Strauss (1967), and further expanded by Glaser (1978) and Strauss (1987). Having first discovered grounded theory through the writing of Glaser and Strauss (1967), the researcher believed it was appropriate to continue to use this approach in the pursuit of producing a substantive theory of the primary carer's experience of caring for a person with a mental disorder in the Western Australian community. The method allowed the development of a substantive theory on caregiving developed from the primary carer's perspective, which had meaning and relevance for them. A description of the application of Glaser and Strauss' method to this study will now be presented. The application is based on the researcher's interpretation of Glaser and Strauss' (Glaser & Strauss, 1967; Glaser, 1978, Strauss, 1987) original descriptions of conducting grounded theory research but the application also includes aspects of both authors' divergent methods. Strauss (1987) and Morse and Richards (2002) support the application of grounded theory methodology used in this study. These authors urge researchers to discover the differences between Glaser and Strauss' approaches but to avoid using the abyss that there is only one way to achieve a grounded theory. According to Morse and Richards to use only one method "prevents researchers from modifying recommended procedures or developing new ways of combining them" (p. 58).

Grounded theory methodology provides a sound procedural method to study the research problem and, therefore, triangulation with the use of quantitative methodology was not employed in this study. Morse (1999b) also supported this notion and made:
a plea for methodological pluralism - not the ad hoc mixing and matching or the blind methodological muddling of strategies or methods but consideration for the multiple ways in which one problem or one context might be explored - and the awareness and respect for the alternative ways in which research could possibly proceed. I argue that different research methods answer different research questions and use different research perspectives and different types of data according to the question asked. (p. 393)

Grounded theory is based in the symbolic interactionist school of thought and the researcher agreed with Sheldon (1998) who claimed that grounded theory provided a unique way of studying human behaviour and interaction. Grounded theory methodology places emphasis on social processes, the perceptions, thoughts, intentions, and actions of individuals, as well as how individuals define their situation (Denzin, 1989; Lal, 1995). Therefore, grounded theory had the potential to discover new perspectives on the primary carer's experience of caring for a person with a mental disorder in the Western Australian community. Specifically, grounded theory methodology allowed the researcher to develop a substantive theory to explain the unique world of the primary carer of a person with a mental disorder.

3.4.1: Data Collection

Data collection methods for this study included: semi-structured interviews with carers, using theoretical and purposeful sampling techniques, field observations and documentation, memos and reflective journaling, and the review of relevant literature and reports. In addition, demographic data were collected from each carer who participated in the study. This information was obtained on nine variables. Three of the variables identified information about the carer, that is, their age, gender, and length of time the person had been a carer. The remaining six variables obtained information regarding the person being cared for, that is, their age, gender, psychiatric diagnosis, how many times they had been hospitalised, if they were currently on a Community Treatment Order (CTO), and whether they lived with the carer.

3.4.1.1: Selection of participants

Morse (1989) stated that the ultimate quality of the research is profoundly affected by the selection of the sample of participants. Initially, a purposeful sampling technique was used with participants who had experience in caring for a person with a mental disorder in the Western Australian community. Informants do not have to be experts in the usual sense
but rather someone who has undergone or is currently undergoing the experience being studied and are able to reflect on their experiences and provide detailed descriptions of the phenomenon. When categories began to emerge, through analysis of data, informants who were seen to have had expanded or specific experiences and knowledge were sought, for example, prominent carer advocates and multiple carers. In addition, participants who were viewed as fulfilling the criteria of atypical carers, for instance, carers who also had a mental disorder were interviewed. The process ensured that the whole range of experiences was captured during the initial data collection phase (Morse, 1989).

Theoretical sensitivity, prompted by self-reflection and memoing and the constant comparative method of analysis of the completed interviews, indicated when theoretical sampling techniques needed to be implemented. Strauss and Corbin (1990) define theoretical sampling as, "sampling on the basis of concepts that have proven theoretical relevance to the evolving theory" (p. 176). Furthermore, Charmaz (2000) claimed that theoretical sampling helps the researcher to "define the properties of our categories; to identify the contexts in which they are relevant; to specify the conditions under which they arise, are maintained, and vary; and to discover their consequences" (p. 519). Therefore, Strauss and Corbin (1990) stressed that theoretical sampling directs the researcher to seek out participants who can provide "depth" (p. 178), "variation" (p. 178), as well as "density" (p. 178) of experience of the phenomenon under study to allow for expanded theory development. For instance, there were several experienced and articulate carers in the Western Australian community and these people were actively sought to be included in this study. Talking to these carers enabled the researcher to share, clarify, confirm, and expand on the experiences gained through the interviews with other participants. This process further added to the trustworthiness, credibility, and transferability of the findings.

Glaser and Strauss (1967) claimed that theoretical sampling generated by constant comparative method allowed the researcher to "develop a theory that accounts for much of the relevant behavior [sic]" (p. 30) displayed by participants. The researcher's job is to "generate general categories and their properties, for general and specific situations and problems" (p. 30).

According to Glaser and Strauss (1967) the basic question facing the researcher when using theoretical sampling is "What group or subgroups does one turn to next in data collection? And for what theoretical purpose?" (p. 47). If data are collected using theoretical sampling concurrently with the constant comparative analysis "then integration of theory is more likely to emerge by itself" (p. 109). This process allows the questions that guide future
data collection to fill the gaps and to fully extend the theory. The final sample size was
determined by theoretical saturation or the failure to obtain any new data (see sub-section
3.4.2.6 on theoretical saturation), at that time a sense of closure was experienced (Streubert &
Carpenter, 1999).

The study used the following selection criteria and participants:
1. Were eighteen years of age or older;
2. Did not have a mental or physical condition that affected their ability to understand the
researcher or to express their perceptions concerning their experience of care giving;
3. Spoke English and could be interviewed without the aid of an interpreter;
4. Lived in the Perth metropolitan area;
5. Were carers for people diagnosed with mental disorders, behavioural problems associated
with dementia, childhood mental health disorders, or people diagnosed with a borderline
personality disorder who had been treated under the psychiatric health care system, and
6. Gave informed consent.

One participant in this study had a mental disorder and another participant was 85
years of age. However, the ability to fully participate in the interview was not impaired by
either the participant's illness or age. In addition, one family member was present when his
spouse (participant) was interviewed. The carer was happy for her husband to be there during
the interview and both made substantial contributions to the success of the interview.

3.4.1.1.1: Characteristics of the participants

Twenty-seven carers participated in this study and their ages ranged from 31 to 85
years with a mean age of 52 years (SD = 11.8). Twenty-two participants were female and five
were male and most (n=20) were caring for a son or daughter. Four other participants cared
for their spouse and of the remaining three participants, one cared for a mother, another cared
for a sister, and the last cared for a sister-in-law. Five of the 27 carers were multiple carers,
caring for more than one ill family member and these participants have been referred to
throughout this thesis as multiple carers. In addition, four of the 27 participants were brought
up in a family where one of their parents had a mental disorder. Two of these four
participants still cared for their parent or for another ill family member and throughout this
thesis these two participants have been referred to as a child/adult carer. The length of time
participants had been caring ranged from one to 33 years with the mean of nine years (SD =
8.0). Of the people being cared for by participants in this study, 14 affected family members
lived at home, 16 lived in a flat or hostel while the remaining two lived away from home but spent some time living at home each week.

3.4.1.1.2: Description of family members being cared for by participants

The age of family members being cared for by participants in this study ranged from 16 years to 65 years with a mean age of 37 years (SD = 17.6). Twenty-two consumers were female and ten were male. Seven family members were on a Community Treatment Order and had been cared for at home during an acute phase of the illness. Eleven family members had a psychiatric diagnosis of bipolar disorder; thirteen had a diagnosis of schizophrenia, six were diagnosed with depression, one had an obsessive-compulsive disorder and another had agitation and behavioural problems associated with dementia. Although these were their primary psychiatric diagnoses, many of the family members had multiple psychiatric diagnoses. For example, one family member had psychiatric diagnoses of depression, borderline personality disorder, and attention deficit hyperactivity disorder.

3.4.1.1.3: Recruitment of participants

Initially, a letter (Appendix D) and information sheet (Appendix E) outlining the proposed study was sent to the Chairpersons of three community organisations that provide support for carers of people with mental disorders in Western Australia. A description of each of the three organisations is provided (see Appendix F). The letter requested that the Chairperson advise their group members that the study was being conducted. Two of the three organisations contacted placed the information sheet in the monthly newsletter to members. Two days after the newsletter was distributed a number of carers responded to the request to participate in the study.

When the study was underway for approximately two months it became apparent from data analysis that broader recruitment of participants was indicated to accurately represent all experiences of caring. Similarly, Maurin and Barman Boyd (1990) found that participants obtained only from self-help groups were not representative of all carers of people who have a mental disorder. They reported that carers who attend self-help groups were generally white, married, better educated, financially secure, and more supportive of their affected family member than the general population of carers. In addition, these carers tended to be middle-aged women caring for severely impaired, male family members.

In responding to the results of data analysis, field notes, and memos, the media relations coordinator at Curtin University of Technology was contacted for advice regarding
the best avenues to reach the broader Western Australian population of carers. The media relations coordinator suggested that an interview with Curtin University of Technology's community radio station 6NR be completed, and following this interview, the station routinely advised their listeners that the study was being conducted. Listeners who were interested in the study were asked to leave a telephone message expressing an interest in the study on an answering machine in the researcher's locked office at Curtin University of Technology. Again, the response rate from potential participants was good, and many of the carers recruited from this avenue had no connections with self-help groups. In addition, the media relations coordinator at the University provided information regarding the study along with the contact procedure to local Western Australian community newspapers as part of a community service initiative. Several participants were recruited through that avenue.

3.4.1.2: Research Interviews

Participants in this study were interviewed between September 1999 and December 2000. The interviews ranged in length from one to three hours with a mean interview time of 1 hour and fifteen minutes (SD = .56). All interviews were conducted in a private, mutually agreed on location with adequate lighting and hearing distance. The extraneous occurrences outlined in the literature that can adversely affect the interview procedure, for example, equipment failures or telephones ringing (Easton, McComish, & Greenberg, 2000) were safeguarded against by the choice of interview environment and the use of high quality recording equipment.

Twenty participants in this study were interviewed at their home at a pre-arranged time that was convenient to them. Most participants lived within a half to one and a half hours drive from the researcher's home. The interviews were conducted in either the participant's lounge room or kitchen. Five participants were interviewed at the researcher's office at Curtin University of Technology as the person they cared for lived at home and, therefore, privacy during the interview could not be assured. Another two participants were interviewed at their workplace for their convenience.

According to Johnson (1997) interviewing "is a specific type of guided and limited intercommunication with an identified purpose" (p. 72). The purpose is to obtain a deep mutual understanding between the participant and researcher of the subject being researched (Burns & Grove, 1999). Although the focus of the interview was not set, it was based on the guidelines outlined by Swanson (1986) and there were several semi-structured questions (see Appendix G). Each interview began with the open-ended question "Can you start by telling
me about the person you care for". After introducing the topic the researcher felt comfortable enough to sit back and actively listen to what the participant was saying. As theoretical sampling techniques were implemented the open-ended questions became more focused. These more focused open-ended questions were in accordance with the findings to that time and the ongoing use of the constant comparative method in data analysis. This process is supported by Glaser (1992) who stated that the researcher "never, never [underlined in original work] asks the questions directly in interviews as this would preconceive the emergence of data" (p. 25). However, in order to obtain the maximum amount of non-forced data the research questions have to "relate directly to what the interview is about, empirically" (p. 25).

The researcher conveyed a professional, engaging communication style, during the interviews, through the use of active listening techniques based on Egan's (1990) model. This model identifies the importance of five proponents of active listening: sitting squarely towards participants, using an open posture, leaning forward, maintaining eye contact with participants (culturally determined), and being relaxed. When participants felt calm and safe they were likely to be more communicative and time was spent making sure that the environment was conducive to participants feeling safe and trusting of the researcher. Barry (1996) supported this approach claiming that participants find it difficult to share their experiences if they feel frightened or embarrassed.

Each interview was audiotape recorded. Each participant was provided with a pen and piece of paper on which to write any ideas that they would like to come back to during the interview. This procedure was employed to enable the participant and the researcher to return to any issue identified during the interview process without interfering with the flow of the interview. Permission was sought from participants before completing each interview to contact them again in the future to clarify or follow up on any information given during the initial interview if needed (Swanson, 1986). More than one interview was conducted with eleven participants in this study. These participants were re-interviewed to clarify or expand on data obtained during the initial interview.

3.4.1.3: Field notes

Glaser and Strauss (1967) noted the importance of fieldwork and the resulting documentation, claiming it provided "real life character" (p. 226). The "first hand immersion in a sphere of life and action - a social world - different from one's own yields important dividends" (p. 226). Furthermore the researcher who has observed closely in this social world
has been sufficiently immersed to know it while remaining detached enough to think "theoretically" about what was observed (p. 226). This detachment allowed the researcher to be protected against "going native" but allowed him/her to pass as a "native" to a large extent (p. 226). In this study, the researcher was an experienced hospital-based mental health nurse and therefore, did not have contact with any carers on a long-term basis. This mix of expertise but lack of experience in the area under study facilitated balance in the role as a researcher.

During and following the interview process, information pertaining to relevant observations made during the interview was documented by the researcher. The focus of these observations included the environmental setting of the interview and the verbal and non-verbal communication used during the interview, for example, the level of eye contact or the participant's tone of voice. In addition, if family members were home the interactional process observed between the carers and their family member(s) was noted. Field notes added important contextual content to the study and the researcher's audiotape-recorder was left on during the journey home as the full impact of the interview began to emerge. The following is an example of a memo made after an interview with one participant:

Participant provided a different perspective of caring from those obtained from other participants so far. There was a difference regarding the participant's philosophy on caring. The participant is also the first carer not recruited from a carer group. The sample group needs to be broadened to include more participants who do not have contact with carer groups to determine if they have similar experiences to this participant (Field note 18, 9th December, 1999).

3.4.1.4: Documents and literature as data

Strauss and Corbin (1990) distinguished between two types of literature, technical and non-technical, and both are seen to play an important and varied role in grounded theory research. The initial literature review for this study was undertaken when the research proposal was being written in order to determine the scope, range, intent, and type of research that had been conducted in the area under study (Chenitz, 1986). Grounded theory methodology enables the researcher to identify categories and their relationships rather than testing relationships among variables (Strauss & Corbin, 1990). Therefore, apart from the literature obtained to prepare the research proposal and the researcher's previous knowledge in the subject area, no other search for relevant literature occurred during initial data collection and analysis. As coding, conceptualising of categories, and the write up the theory
began, additional literature reviews pertinent to emerging findings were undertaken on an ongoing basis.

3.4.2: Data analysis: The constant comparative method

Glaser and Strauss (1967) first described the constant comparative method of analysis used in grounded theory. According to Haig (1995) the constant comparative method is an amalgam of systematic coding, data analysis and theoretical sampling procedures which enables the researcher to make interpretive sense of much of the diverse patterning in the data by developing theoretical ideas at a higher level of abstraction than the initial data descriptions. (p. 5)

When using the constant comparative method, data collection, coding, and analysis occurs concurrently throughout the research (Streubert & Carpenter, 1999), using a four stage process:
1. Comparing incidents applicable to each category;
2. Integrating categories and their properties;
3. Delimiting the theory, and

Two steps are basic to the constant comparative method of coding. Firstly, phenomena must be continually compared for similarities and differences and when concepts emerge this process must be repeated (Strauss & Corbin, 1990). The second step undertaken by the researcher is to continually decide which category or property of category the phenomena being analysed belongs to, and then name this category. These two steps ensure the generation of categories and their properties from the data (Glaser, 1992). Furthermore, they highlight the need for any expansion of the theoretical sample to further clarify, define, or consolidate categories and properties identified through open coding. Chenitz and Swanson (1986) claimed that by using this method of analysis it is possible for the researcher to "progressively focus the research as data becomes clearer" (p. 18). The result is a "theory which describes the core category that characterizes [sic] the behaviors [sic] of the group" (p. 18).

3.4.2.1: Bracketing researcher bias

A hallmark of qualitative research is the researcher's emphasis on open mindedness and curiosity (Chenail, 2000). However, Sword (1999) indicated that some qualitative researchers "do not acknowledge how, among other things, their own background, gender,
social class, ethnicity, values, and beliefs affect the emergent construction of reality" (p. 270). This is further supported by Rose and Webb (1998) who claimed that "not only the research process" but also the researcher’s effect on the research process and "vice versa" is relevant (p. 559).

Throughout this study, the researcher reflected on how her personality and knowledge of the subject area may bias or impact or compound research outcomes. The ten tips outlined by Ahern (1999) to enhance reflexivity and the researcher’s ability to bracket was useful in this process. This work gave structure to self-evaluation and journaling that covered:
1. Interest and personal issues that led to completing this research were documented.
2. Value system and areas of subjectivity that could influence the researcher’s ability to conduct the research;
3. Areas of conflict that may influence the researcher’s ability to complete the research;
4. Problems with gatekeepers and how these were managed;
5. Feelings that might compromise the researcher’s neutrality;
6. Ability to recognise if there is anything new or surprising in data collection. If not, is this a concern or does it indicate saturation;
7. Problems and blocks that occurred during the research and the questions asked to identify what was happening;
8. Reflection on the procedure of writing up the findings when data analysis was completed;
9. Ability to identify if the substantive literature review was supportive of the results of the study or whether it is just expressing the same cultural background as the researcher; and
10. Ability to deal with any bias, for example, a script may need to be reanalysed if it was identified that bias had occurred during the analysis (Ahern, 1999).

In practice, the above framework was used throughout all aspects of this study. It allowed the researcher to reflect on what had been achieved, it was useful in developing the researcher’s theoretical sensitivity, and as a framework to solve problems encountered during the study.

3.4.2.2: Theoretical sensitivity

All of the above points outlined by Ahern (1999) were useful in developing the researcher’s theoretical sensitivity as they facilitated a structured framework for the researcher to assess and manage any problems encountered during the research process. Throughout this study the above points were reflected on to determine how they impacted on data analysis. According to Glaser and Strauss (1967), theoretical sensitivity is developed in
the researcher over a period of time and they claimed that it had two major characteristics: "first, it involves his personal temperamental bent. Second, it involves the sociologist's ability to have theoretical insight into his area of research, combined with an ability to make something of his insights" (p. 46). Strauss and Corbin (1990) elaborated further that theoretical sensitivity refers to "the attribute of having insight, the ability to give meaning to the data, the capacity to understand, and capability to separate the pertinent from that which isn't" (p. 42).

Glaser and Strauss (1967) implied that the virtual process of completing a grounded theory study increased the researcher's theoretical sensitivity. However, this process may be hampered if the researcher focused on a preconceived theory and could no longer "see around" (p. 46) a "pet" theory (p. 46) thus becoming insensitive or defensive of questions that cast doubt on their preconceived theory. Strauss and Corbin (1990) further supported this notion claiming "we have to challenge our assumptions, delve beneath our experience, and look beyond the literature if we are to uncover phenomena and arrive at new theoretical formulations" (p. 76). In this study, theoretical sensitivity was increased through increased self-awareness as well as acknowledging prior knowledge accumulated over many years as a mental health nurse. In addition, time was spent reflecting on the researcher's assumptions about caring and about mental disorders. Assumptions are statements considered to be true even though they have not been scientifically tested. According to Burns and Grove (1999), "assumptions are often embedded (unrecognised) in thinking and behaviour, and uncovering these assumptions requires introspection" (p. 38).

The ability of the researcher to recognise any assumptions or preconceived ideas regarding the study object is a strength and leads to a more rigorous study development. Firstly, the researcher's awareness of the "partnerships model" promoted under the Australian National Mental Health Strategy was documented. Secondly, the researcher's knowledge in the area was detailed. For example, the researcher had recently read an article that identified four themes as to why families take on the role of caring (King, Collins, & Liken, 1995). A plethora of literature over many years has documented the negative effects or burden of caring for a person with a mental disorder. In writing the research proposal the researcher was familiarised with some of that literature. The literature highlighted that providing care on a long-term basis may impact on the carers' domestic, social, and leisure routine. It can also affect their financial security and stability, relationships, mental health coping and adjustment, and achievement of personal goals (Bernheim & Lehman, 1985; Zirul, Lieberman & Rapp, 1989). In noting these preconceived ideas the researcher also observed
that the majority of studies undertaken on caring in the mental health area used quantitative methodologies and therefore these studies, which formed the basis of many of the researcher's preconceived ideas, had not fully explored the multi-dimensional experience from the carer's perspective. By using qualitative methodology the researcher anticipated that a more expansive view of caring than that currently portrayed in the literature would emerge. The final literature search was not undertaken until after data collection and analysis was well established and then the literature relevant to the emergent findings was sought.

Thirdly, the researcher's exposure to community mental health nursing was limited, having worked in the acute hospital psychiatric setting and educational sector. However, the researcher had sufficient exposure to the mental health care system to facilitate acceptance and understanding of the culture and language of the community setting. Prior to commencing the first interview with a participant the researcher made the following memo in a journal:

Today I am reflecting on what I believe it must be like to be a carer. I have had limited contact with carers and families on an ongoing basis as a mental health nurse. Working in the acute hospital setting and then the education sector my contact with carers has been in times of stress when a family member is hospitalised. Although each contact was over several days no in-depth, long-term relationship was ever established. That must be one of the rewards of being a community nurse. In the acute hospital setting you provide support and information but you never really get to know carers well.

Since I began to plan this study I have thought about what it must be like to be a carer. I have read quite a lot of literature over the years highlighting issues, such as, the burden of care, which is frequently mentioned. What does this burden really mean? I presume it has some influence on finances, some effect on the carer's health and leisure time. They may be unable to work because of the responsibilities of caring. Many people being cared for must live at home and this must have a disruptive influence on family life. I feel that carers must get tired with all the worry and responsibility associated with the role.

The National Mental Health Strategy, the 1996 Western Australian Mental Health Act, and the operationalisation of a "partnership model" must have made a difference to the carer. They must now have more help and find it easier to communicate with health professionals. The consumer is now living with their family in the community rather than being institutionalised. However, it must also be frightening for carers if their family member is really unwell. They might be aggressive.

I hope that I find very positive aspects of caring. I also hope that the new partnership in care model implemented as part of the National Mental Health Strategy is working to the benefit of carers. I am concerned that economic issues may cause cuts in services and carers may be more vulnerable in their role today than they have been previously. Moving people out of institutions is great but support and collaborative
care must also be channelled to this area for this process to be a success. (Memo 1, August 10th, 1999)

Finally, during the course of this study, the researcher’s assumptions and preconceived ideas were challenged and debated with colleagues at university as PhD qualitative analyses seminars were conducted every month. During presentations to the group, the assumptions, along with the findings of data analysis, were scrutinised by supervisors and colleagues (at no time during these discussions was participants’ confidentiality compromised). Their feedback helped to clarify the overall methodological process and to avoid the imposition of researcher biases on the data. The meetings also facilitated theoretical sensitivity and opened data to new insights of meanings. In addition, the regular meetings with supervisors provided further mentorship and guidance in this area.

3.4.2.3: Data preparation and computer management procedures

The researcher transcribed verbatim each audiotaped interview. This was done to increase the researcher’s sensitivity to the data, and to add to the trustworthiness, or credibility of the findings. Easton, et.al (2000) highlight several pitfalls that may occur during transcription, for example, a word may be misunderstood and consequently change the meaning of the entire sentence. The researcher completed the following process with all interviews:

1. Listened to the audiotape;
2. Transcribed the audiotape;
3. Read the transcribed manuscript while again listening to the tape, making corrections as necessary (editing), and
4. Qualitative notes, for example, level of eye contact, tone of voice, or anxiety were noted next to transcribed text.

When the interview was transcribed it was then imported into QRS.NUD.IST (Richards & Richards, 1997). QRS.NUD.IST stands for qualitative solutions and research: non-numerical unstructured data indexing searching and theorising. It is designed to handle non-numerical and unstructured data obtained using qualitative research. QRS.NUD.IST allowed the researcher to manage, explore, and search documents; link ideas, and generate reports from data. The transcription was completed allowing a wide right-hand margin to be present when printed from QRS.NUD.IST with each line numbered. These print-outs were then used to code for categories that would reflect what was happening in the data. An example follows:
R: THANK YOU VERY MUCH FOR AGREEING TO DO THIS INTERVIEW. IF YOU COULD START BY TELLING ME ABOUT THE PERSON YOU CARE FOR?

P14: My husband

R: YES

P14: He suffers with manic depression and we are on a disability pension because of it. I am on a disability wife’s pension. Yes and we have got four kids. He and I tend to share the running of the house quite a lot which is very helpful especially as we have got twins. Our twins are two and a half year old.

There is considerable debate amongst qualitative researchers regarding the use of computer software packages (Richards, 1998) and in this study QRS.NUD.IST was used to manage data. It was used for preparing interviews for coding and the management and linking of data from participants for comparing categories identified during the open coding process. It was also used for retrieving coded sections across all data for constant comparative analysis.

3.4.2.4 Open coding

Open coding is the initial step of grounded theory analysis of the transcribed data that leads to the discovery of categories and their properties (Glaser, 1992). Once an interview was transcribed each line was analysed by the researcher for as many codes as might fit the data (Glaser, 1978). This coding helps to build ideas inductively and keeps a focus on the data (Charmaz, 2000). Furthermore, Charmaz claimed, "it helps us to remain attuned to our subjects' views of their realities, rather than assume that we share the same views and worlds" (p. 515). Beginning with no pre-identified categories, the open coding method breaks down the data into codes representing meanings of phenomena.

Code words were written on the transcribed interview on the wide margins provided on the print out from QRS.NUD.IST. This process, called code mapping, was completed with all transcribed interviews. In addition, during the coding process memos assigned to these codes were written in a separate code-book. The memo identified if the code was being used for the first time or if it had occurred previously in the data linked to another participant.

Using open coding, several hundred codes were generated during data analysis for this study. These codes were mainly descriptive in character (Glaser, 1978) and referred to as in-vivo or substantive codes (Hutchinson, 1986). For example, "just a nobody" or "just a mum" were two codes that emerged from data in this study. These codes were then compared
and contrasted for similarities and differences in other parts of the interview and with interviews conducted with other participants (constant comparative method). According to Glaser (1992), this stage of data analysis should be used to identify the category or property of a category to which data being analysed belonged. Data were broken down into phenomena and these phenomena were closely examined for differences and similarities. Using the constant comparative method comparisons of phenomena to phenomena, phenomena to concept and the formulation of categories and their properties were completed (Glaser, 1992; Strauss & Corbin, 1990).

Some of the initial codes were subsumed into a larger category, which resulted in 114 categories eventually being identified from all of the interviews completed for this study. For example, in this study the codes "just a nobody" and "just a mum" were subsumed into the broader category "lowered self-esteem". When a category was used for the first time a definition of the category was given on a new page in the coding book.

3.4.2.5: Theoretical coding

Theoretical coding, the next stage in analysis, was commencled concurrently as open coding of data continued. While open coding splits data into concepts and categories, theoretical coding (also sometimes referred to as axial coding) brings those data back together and makes new connections between categories and sub-categories (Pandit, 1996). This stage of the coding process conceptualised how substantive codes (and categories) relate to each as hypotheses to be integrated into a theory (Irurita, 1996a). According to Glaser and Strauss (1967) "in the beginning, one's hypotheses may seem unrelated, but as categories and properties emerge, develop in abstraction, and become related, their accumulating inter-relations form an integrated central theoretical framework - the core of the emerging theory." (p. 40).

Glaser (1978) described a number of families of theoretical codes that guide data analysis and theory development. These families of theoretical codes are made up of, for example, the Six Cs- causes, contexts, contingencies, consequences, covariances and conditions; process - stage, staging, phases and progressions; The Degree Family - limit, range, intensity, extent, amount, level and the like, and The Dimension Family - dimensions, elements, divisions, properties of, aspects, section; as well as other families not used in this study. These families of theoretical codes directed the types of questions asked of data during analysis for this study, for example, what caused this behaviour? Were there stages in the process? These questions directed further data collection strategies and hypothesis testing.
Theoretical sampling was then employed to verify the evolving theory. Theoretical sampling was the process of explaining elements of the emerging theory to participants and encouraging their evaluation. Through this process categories were elevated to a more abstract level and the relationships between categories were integrated.

Through data analysis a major category “being consumed” emerged, representing the basic social psychological problem experienced by primary carers of a person with a mental disorder in the Western Australian community. Through coding and further analysis a basic social psychological process also emerged as the analysis became more conceptual. The core category “being consumed” was broad in scope and able to provide explanation for the links to other categories that emerged (Strauss, 1987). The process detailed how participants managed the basic social problem encountered in this study.

3.4.2.6: Selective coding and theoretical saturation

Once the core category “being consumed” emerged, the analysis shifted to the identification of the relationship of this category to all other categories. Selective coding was then used to systematically link all other categories to the core category. This process may uncover and clarify additional categories and may also lead to further data collection through theoretical sampling techniques (Hueser, 1999). The core category “being consumed” arose from the data and the data determined its properties and relationship to other categories. According to Strauss (1987) six criteria are used in the process:

1. The core category must be central to and related to as many other categories and their properties as possible.
2. The core category occurs frequently in the data. By occurring frequently it becomes a stable pattern and therefore frequently related to other categories.
3. The core category relates easily to other categories and the connections are frequent and can be clearly identified.
4. A core category in a substantive theory has implications for the development of a more formal theory;
5. As the details of the core category are analytically expanded the theory moves forward in development.
6. The core category allows the researcher to build maximum variations from the analysis of data and to identify, for example, dimensions, properties, conditions, consequences, and strategies which relate to different sub patterns of the phenomenon referenced by the core category (p. 36).
Validation of this process was continually carried out by reviewing the data and through the further exploration of concepts with participants (theoretical sampling). During this stage of analysis, data were perceived theoretically instead of descriptively and the analysis involved a two-stage process: sorting and saturation. Firstly, the intent of sorting, according to Glaser (1978), is to "weave the fractured story back together again" (p. 72). "Weaving" is sorting theoretical memos and the coding families. Secondly, the process of reaching saturation occurs when delimiting features of the constant comparative method begin. This involves two stages: the theory "solidifies in the sense that major modifications become fewer and fewer" (Glaser & Strauss, 1967 p.110), and later modifications to clarify and elaborate on details of "properties into the major outline of inter-related categories and - most important - reduction" (p. 110).

Theoretical saturation according to Morse (1995) is "data adequacy" (p. 147). Glaser and Strauss (1967) viewed saturation as occurring when no additional data were collected that enabled the researcher to develop properties of the category (p. 61). They stated, "the criteria for determining saturation, then, are a combination of the empirical limits of the data, the integration and density of the theory, and the analyst's theoretical sensitivity" (p. 62). In this study, sampling was continued until saturation, or the failure to obtain new information for all identified categories, occurred. The importance of achieving saturation was also described by Strauss and Corbin (1990) who claimed that the researcher must continue to sample until there was no new data, category development was dense and the relationship between categories were well established. These authors suggested that if saturation was not achieved the theory generated would be conceptually inadequate.

3.4.2.7: Theoretical memos

Strauss and Corbin (1990) describe several types of notes that are documented during the course of completing grounded theory research. These notes may be written or visual representations of emerging concepts. They provide directions regarding sampling, leads to follow up on, possible comparisons as well as descriptions as to how the researcher arrived at categories and conceptual labels. According to Strauss and Corbin (1990) "memos provide the written form of our abstract thinking. Diagrams, on the other hand, are the graphic representation of visual images of the relationships between concepts" (p. 198).

Memos and diagrams continued to be developed throughout the research process and grew in complexity during data analysis. This was a vital step in the analytical process, as stated by Strauss and Corbin (1990). Each memo was dated and included references to
documents, code number of the participant, observations, date, and any other identification that enabled the researcher to easily retrieve the memo at a later date. During this study a total of 156 memos were made. Many of these memos were made during the stage of open coding as Strauss (1987) recommended that the researcher should "always interrupt coding or data recording for writing a memo, when an idea occurs, so that the idea is not lost" (p. 127). The following memo demonstrated the importance of documenting these ideas:

Interview with P14 was very interesting. Her husband [the affected family member] was present throughout the interview. I was a little apprehensive about this to begin with but the participants did not seem to be deterred by it at all. She said what she wanted to say and her husband's contribution to the interview was valuable. The participant showed strength, integrity, and personal attributes of respect and trust in her husband's ability to participate and contribute during the interview process. They were there for each other and provided valuable support. There was a sense of calmness in the house that I have experienced during interviews with other participants. They [participants] appear to have great inner strength, compassion and acceptance about what they have been through. This may be important to the overall process of caring. (Field note 30, 10th May, 2000)

Diagrams were also used extensively in this study to aid data analysis. Figures 1, 2 and 3 (drawn on 6th July, 2000) are presented as examples of the diagrams used during data analysis to facilitate the emergence of the basic social and psychological problem and process from the data. The use of diagrams was a crucial step in the analytical conceptual process that enabled the researcher to move from the descriptive to analytical level of analysis using Glaser's (1978) coding families, including Causes, Contexts, Contingencies, Consequences, Covariances and Conditions. The basic social psychological problem of being consumed was emerging and the coding families were able to identify the links to other categories, for example, "outside advice", "relationship with friends", "stigma", and "relationship with neighbours". The game board of the well-known monopoly game, of gaining wealth through purchasing property, was used in one diagram and the colours represented the different coding families and their established links to each other. At this stage of data analysis the application of aspects of the monopoly game appeared to be useful in conceptualising the developing theory.

The analogy of the monopoly game board was developed, as the experience of being consumed appeared to have several conceptual similarities to the well-known game. Three
EXPERIENCE OF CARING

- Personality before illness
- Onset of illness
- Seeking help
- GO BACK SIX SPACES
- Impact on family
- Initial contact with health professionals
- START

- Caregiver's management strategies
- Contact with the Health Care System and HP
- Community support
- COMMUNITY CHEST

- Caregiver's personal issues
- The dimensions of caring
- Family strategies
- Family life
- Friends and neighbors
- Impact on society

- Relationships
- Family life
- Strategies
- Caregiver's
- Support
- Keeping
- Monitoring

- HPV attitudes
- Communication with caregiver
- H/P dynamics
- Relationships
- C/C
FIGURE 2: USING DIAGRAMS IN DATA ANALYSIS
examples of these similarities will now be presented. Firstly, the carer's experience of being consumed (the basic social psychological problem) was influenced by their interactions with health professionals. Whether or not these interactions were beneficial, for the carer, was based on an element of chance, for instance, the level of established rapport between the carer and the health professional. Secondly, the consistency of health professionals created a situation whereby carers had to interact and establish rapport with new health professionals on many occasions during the caregiving experience. As a result, existing collaborative arrangement between health professionals and the carers often changed. For example, in some situations, carers returned to a stage similar to when they first began to care for their affected family member until rapport and trust was again established between themselves and the new health professional. Thirdly, caring was, in some aspects, similar to buying hotels in the game of monopoly. The more skilled and knowledgeable the carer became the more mastery and control they achieved over their caregiving role. Diagrams were found to be particularly useful during data analysis as they facilitated a plethora of theoretical memos as the diagrams were further analysed and developed in line with the data.

3.4.2.8: Comparison with Existing Theories

The final stage of data analysis consisted of comparing the findings of this study with related or relevant existing theories already reported in scientific literature. When using grounded theory this comparison with existing literature is done at the end rather than the beginning of the research process (Glaser, 1978). This approach minimises the risk of the imposition of preconceived ideas on data analysis. Comparing the substantive theory developed in this study involved critically reviewing theories identified in the literature as potentially having relevance to the newly developed theory. Those that were found to be related to some of the theoretical constructs identified in this study were considered in depth. This aspect of the study is fully described in chapter eight.

3.4.3: Writing the grounded theory

When saturation was reached and the basic social psychological problem and process were identified, the process of documenting the framework of the primary carer's experience of caring began. Data that had been broken down during open coding and developed through theoretical and selective coding, along with the many theoretical memos, were now documented as the emerging substantive theory.
In writing this thesis a high proportion of direct quotes from participant interviews have been included thus providing "thick descriptions". Inclusion of this data assisted the researcher to descriptively explain variations of concepts (Morse, 1991, p. 139). Although some readers of this thesis may find some of the language offensive, the main advantage of using undiluted quotes is that they provide participants with a voice, which has not been altered by researcher bias. Therefore, the words used by participants have not been changed in any way. Denzin (1994) supported this, asserting that "the intent is to create the conditions that will allow the reader, through the writer, to converse with (and observe) those who have been studied" (p. 506). In documenting the information obtained from participants in this study the following procedure was followed:

- For each quote by a participant documented in this study the participant’s code number is recorded, for example, P1.
- For each field note the number and date is recorded, for example, Field note 1, 20th September 1999.
- For each memo the number and date is recorded, for example, M1, 10th August, 1999.
- Major conceptual terms used in the substantive theory were placed in italics.
- Square brackets [ ] were used in direct quotes when additional information was added by the researcher.
- Pseudonyms and asterisks * were used in the quotes used from participants to protect the identity of the participants, people identified by participants during the interview, and the names of hospitals or health services.

3.4.4: Definition of terms

To avoid ambiguity and enhance conceptual clarity, definitions are provided for the terms "carer", "consumer or affected family member", "mental disorder", "mental illness", "participant", and "health professionals".

**Carer:**  A person who has made a commitment to care for a person with a mental disorder.

**Health professional**  Any member of the multi-disciplinary health care team. However, the majority of health professionals referred to in this study were doctors, nurses, social workers, and psychologists. The generic term "health professional" is used except when the participant has specifically used a term to denote a specific discipline, such as "social worker" or "nurse".
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental disorder</td>
<td>A term used to describe the full range of recognised, medically diagnosable disorders that result in significant impairment of an individual's cognitive, affective, or relational abilities. Using the American Psychiatric Association’s Diagnostic and Statistical manual of Mental Disorders - fourth edition (DSM IV) terminology, it encompasses all disorders on Axis I of that classification system.</td>
</tr>
<tr>
<td>Mental illness</td>
<td>The illness or the consequences of a mental disorder on the person who has the disorder in terms of impairment, disability, functioning in one’s social roles (DSM IV, Axis IV and V)</td>
</tr>
<tr>
<td>Participant</td>
<td>In qualitative research the terms &quot;informant&quot; or &quot;participant&quot; are used. In this study the term &quot;participant&quot; is employed. It refers to all of the people who agreed to help the researcher by sharing their experiences of being a primary carer for a person with a mental disorder in the Western Australian community.</td>
</tr>
<tr>
<td>Mental health consumer/ affected family member</td>
<td>A person with a mental disorder who is being cared for by a person participating in this study.</td>
</tr>
</tbody>
</table>

### 3.4.5: Trustworthiness, credibility, and transferability of findings

Establishing trustworthiness, credibility, and transferability of data is an essential step in qualitative research (Rose & Webb, 1998). Particular requirements of grounded theory methodology which relate to trustworthiness, credibility, and transferability of findings are that: the theory fits the substantive area where it will be applied; it is understood by those who can use it, and in general, it is applicable to different situations and provides those who use it with some control over changes in daily situations (Glaser & Strauss, 1967). The sampling strategies used in this study ensured that the experience described by participants was the experience of the population of carers in this study area and that the data were saturated, comprehensive, complete, and accounted for negative cases. The credibility of the findings of the study was supported by accounts of similar experiences by the majority of participants. Recurrent patterning of responses from participants also added to the trustworthiness of the findings and these similar patterns of experiences became more evident as the stages and phases of the substantive theory emerged (Muhlbaier, 2000). The credibility and trustworthiness of the findings of this study also add to the transferability of the findings and the substantive theory developed in this study may be applied to carers in other geographical areas and to carers of people with other enduring illnesses. Glaser (1978) supported this concept when he transferred the theory about becoming a nurse to becoming a
teacher (cited in Morse, 1999a). According to Morse (1999a), qualitative findings can be
generalised and the knowledge gained is:

... not limited to demographic variables; it is the fit of the topic or the comparability of
the problem that is of concern. Recall it is the knowledge that is generalised.

Once qualitative researchers recognize [sic] that qualitative findings are
generalizable, [sic] qualitative research will be considered appropriately and more
useful, more powerful, and more significant. (p. 6)

In this study, the trustworthiness, credibility, and transferability of data were
primarily assured by following the detailed methodological process of grounded theory
method (constant comparative analysis method). Using the grounded theory method, raw
data were reduced to concepts and assigned to relevant categories that were conceptually
linked. According to Glaser and Strauss (1967) this process involved "(1) comparing
incidents applicable to each category, (2) integrating categories and their properties, (3)
delimiting the theory, and (4) writing the theory" (p. 105). Using grounded theory
methodology, data analysis began at a descriptive level whereby individual participants
experience of caring for a person with a mental disorder in the Western Australian
community was coded and categorised. Coding then progressed to a conceptual level,
whereby comparisons were made between patterns of social responses to the phenomenon.
Data analysis included the use of theoretical memos about data driven ideas and questions
regarding codes, hypotheses, categories and the evolving grounded theory. From this process,
the basic social psychological problem experienced by participants and their response to that
problem were identified. Using Glaser and Strauss' (1967) grounded theory method, the
coding process completed in this study was not linear, in that although analysis progressed
through three coding stages, coding methods continued to overlap and early coding practices
continued to be used throughout the process.

Further support of the trustworthiness, credibility, and transferability of the data was
provided by memos and reflective notes. These notes were seen to contribute to the rigour of
the study as they complimented data obtained from participants during interviews. Rose and
Webb (1998) agreed with this approach, claiming that these notes "contain immediate and
later perceptions and thoughts about the informants" (p. 560). Another aspect related to
establishing the trustworthiness, credibility, and transferability of data was the development
of an audit trail. According to Rodgers and Cowles (1993), the "qualitative research audit
trail, as conceptualized [sic] by Halpern (1983), and later described by Lincoln and Guba
(1985), is an essential component of any rigorous qualitative study" (p. 219). Furthermore,
Glaser and Strauss (1967) outlined the importance of the conveyance of the "credibility" of
findings in a way that "sensible judgement" could be made about them (p. 228). There is considerable discussion regarding what constitutes an audit trail in the qualitative research literature with some authors stating that too rigorous demands on the researcher to document audit trails may impinge on the creative process fundamental to qualitative research (Sandelowski, 1993). Rodgers and Cowles (1993) claimed that there is confusion regarding what researchers need to demonstrate in an audit trail. They describe four types of documentation that should be presented as part of all qualitative research and these were followed in this study:

1. Contextual documentation, field notes (were used);
2. Methodological documentation, such as, changes to interview questions based on data analysis and clear descriptions of the methods used, for example, theoretical sampling decisions;
3. Analytical documentation, for instance, the identification of conceptual links in the emerging data, and
4. Personal response documents of ongoing reflexive self-awareness notes by the researcher throughout the process of analysis.

Another way that the trustworthiness, credibility, and transferability of the findings were ensured was to review the findings with participants as well as other people who had experience in the phenomenon under study (part of the theoretical sampling procedures used in this study). Therefore, eleven of the twenty-seven participants in this study were re-interviewed to help to clarify and/or further explore concepts identified in their original interviews. Their confirmation that the conceptual theory reflected their experiences fortified the trustworthiness, credibility, and transferability of data. The inclusion of participants who had typical, expanded, and atypical experiences strengthened the data. It ensured that a wide perspective of experiences of the phenomenon was explored. Using theoretical sampling to broaden the sample population where indicated by the constant comparative analysis further ensured trustworthiness. This allowed the validation and expansion of key concepts identified by the initial sample group. In addition, the findings of the study were presented to eighteen carers (six of whom participated in the study) at a carer support group meeting in May 2002. These carers affirmed that the substantive theory presented to them was an accurate representation of their caregiving experience.

As mentioned earlier, during the time the study was in progress, the researcher met once a month with other students undertaking studies using the grounded theory method. The discussion and feedback from these forums provided support for the trustworthiness,
credibility and transferability of findings. In addition, the researcher completed all transcriptions of interviews to further reduce the chance of misinterpretations and mistakes being made (Easton, et. al., 2000) and direct quotes from participants have been included to allow the reader to "personally" observe what has been studied. These steps further enhanced the trustworthiness, credibility, and transferability of the findings of the study.

Finally, the substantive theory of seeking balance to overcome being consumed was compared to the existing literature on caregiving. This literature is presented throughout this thesis and adds to the credibility, trustworthiness, and transferability of the data and validation of the findings of this study.

In summary, detailed descriptions of the research process, the identification of an audit trail, linkages between data and observational notes, and comparisons with existing literature on caregiving facilitate the trustworthiness, credibility, and transferability of the findings nationally and internationally. The findings also provide the basis for further development and refinement of theory through studies in different contexts.

3.5 Ethical considerations

Ethics and ethical principles apply to all of our interactions with each other, animals, and the environment. Ethical principles guide acceptable standards of conduct when performing research (National Health and Medical Research Council, 1996). Modern codes of ethical practice arose from the ten principles outlined in the Nuremberg Code accepted by the United Nations in 1946 on "Permissible Medical Experiments". These principles were developed as a result of the atrocities and disregard for human rights and dignity by Nazi researchers during the Second World War (The Nuremberg Code, 1947). Their experiments on humans in concentration camps involved brutality, torture, led to disabling injury or death, and were performed with total disregard of international conventions, customs of war, or principles of criminal law present at the time (The Nuremberg Code, 1947).

Ethical issues are present in any kind of research (Orb, Eisenhauer & Wynaden, 2001). The Charter of the Declaration Helsinki (1964) adopted by the World Medical Organisation established further important safeguards for conducting research on humans. It was revised in 1975 and the Declaration focused on five main components: explanation to participants of the research procedure, providing an understanding of the benefits, a description of risks, disclosure of any alternative treatments including the risks and benefits of those treatments, and the freedom of the participant to withdraw consent without explanation at any time (Shephard, 1976). In addition, governments proposed that
independent review committees be established at institutions to approve proposed experimentation on humans and animals.

In Australia, the National Health and Medical Research Council Act (1992) established the National Health and Medical Research Council (NHMRC) as a statutory entity, setting out its functions, obligations, and powers. Under the Act, the NHMRC requires all institutions or organisations that receive NHMRC funding to establish a Human Research Ethics Committee and to present all research involving humans, whether related to health or not and whether funded by the NHMRC or not, to ethical review by that committee. These guidelines, which closely follow the Declaration of Helsinki, not only protect the human rights and dignity of those who willingly agree to participate, but they also provide a reference point for all research involving humans (NHMRC Statement on Human Experimentation, 1996).

Permission to conduct this study was obtained from Curtin University of Technology's Research Ethics Committee (See Appendix H) after evidence was provided that the study met the research guidelines set down by the NHMRC of Australia in the Statement on Human Experimentation (1996). The major aspects of these guidelines are now presented.

3.5.1: Informed Consent

The voluntary informed consent of research participants is essential. According to Polit and Hungler (1997) "informed consent means that participants have adequate information regarding the research; are capable of comprehending the information; and have the power of free choice, enabling them to consent voluntarily to participate in the research or decline participation" (p. 134). Burns and Grove (1999) described a four stage process to obtain informed consent: disclosure of essential study information, comprehension of this information by the subject, competence of the subject to give consent, and voluntary informed consent of the participant.

3.5.1.1: The need to be informed

Disclosure of essential information at the participant's level of comprehension is necessary in any kind of research. The participant should be informed about the purpose of the research, about any risks or discomfort that he/she may experience, as well as the benefits of the research being undertaken (Munhall, 1988). The disclosure must also include what researchers intend to do with the findings of a study.
Information regarding the objectives of this study and the sample population of potential participants was presented to the Western Australian community in a radio interview conducted with a local radio station, through local community newspapers and through newsletters to members of different carer support groups. Therefore, initial contact with all potential participants was made when telephone messages expressing an interest in the study were left by potential participants on an answering machine in the researcher’s locked office at Curtin University of Technology.

During the initial contact with all of the potential participants, the purpose and focus of the study were outlined. The initial phone contact usually took about half an hour and provided a picture of the "potential story" that the participant would provide. This was useful in managing several ethical dilemmas that were presented during the first contact with potential participants. Munhall (1988) stated "the therapeutic imperative of nursing (advocacy) takes precedence over the research imperative (advancing knowledge) if conflict occurs" (p. 151). During the initial contact a number of potential participants shared with the researcher experiences of severe personal trauma that had occurred during the process of caring and on two occasions, the potential participants had lived through the suicide of the family member. Due to these experiences, the need for advocacy outweighed the need to advance knowledge, as it was paramount that the potential participants were not placed at risk of harm, that is, personal distress, by their participation in the study. Therefore, the potential risk of harm (the possibility of personal distress) was discussed at length with each individual. However, three people still wanted to participate, and so they were asked to reflect on their decision for a week and then they were again contacted. During this time, two individuals decided that they would not participate. However, another participant, while acknowledging her vulnerability, felt that she wanted, and needed, to participate. According to Rolby (1995), social responsibility calls for the attention to diversity and, therefore, researchers must consider the selection of voices that need to be heard. Therefore, this participant was included in the study, but a meticulous procedure (detailed in 3.5.1.4) to obtain continued informed consent from her throughout the interview was completed to ensure that no harm resulted.
3.5.1.2: Comprehension by the participant of the information given concerning the study

For informed consent to be obtained, participants must fully comprehend the information that has been provided, and all researchers must allow time to answer questions to in order to facilitate this process. According to Streubert and Carpenter (1999), it is essential that researchers and participants discuss and clarify their understanding of the research to be conducted. In addition, Alty and Rodham (1998) consider that this process is essential as even under the best research circumstances it is difficult to determine if the researcher and the participant have a common understanding of the topic being researched.

Several participants had read the information sheet regarding this study as it was published in the self-help group newsletters. Therefore, it was the conduit for contacting the researcher to express interest in the study. Prior to any interview being conducted, the information sheet was sent to those participants who had not previously read one. When participants were met for the first time at the interview, another copy of the information sheet was given to them. The participant was then encouraged to re-read the sheet and the researcher’s willingness to answer any questions was reinforced. Particular emphasis was placed on answering questions regarding the methodology. The participant’s right to decline to answer questions and to withdraw their consent at any time without penalty was also discussed. No coercion was used at any time to encourage any participant to be involved in the study. When participants stated that they were happy that they were informed of the study, they were asked to sign the consent form prior to the interview commencing (see Appendix I). The process was also beneficial in developing rapport with the participant as well as making them feel empowered regarding their role in the interview process. Batchelor and Briggs (1994) suggested that the participant is the least powerful person in the research process and that many of them participate only to help others. In addition, Batchelor and Briggs reported that people continue to participate, even when they experience stress, because they felt morally bound to do so.

3.5.1.3: Participants’ level of competence to give informed consent

It is generally accepted that individuals who have diminished autonomy due to legal or mental incompetence, terminal illness, or those confined in institutions may not be legally competent to consent to participate in research (Burns & Grove, 1999). All participants in this study were over the age of 18 years and did not have a mental or physical condition that affected their ability to understand the researcher or to express their perceptions concerning
their experience of care giving. As mentioned earlier, one participant was a mental health consumer but the mental disorder did not interfere with the participant's ability to participate. In addition, all participants were required to speak English at a level that enabled them to be interviewed without interpreters. Although one participant was 85 years of age, she met all of the criteria necessary to participate in the study.

3.5.1.4: Voluntary informed consent

Voluntary informed consent means that the individual has decided to participate in the research on his/her own volition. It was essential that this decision be made without coercion or undue influence by researchers (Orb et al., 2001). Voluntary informed consent can only be obtained when the participant has been given essential information regarding the study and has demonstrated an ability to comprehend this information, thus ensuring his/her competence to give consent. What researchers intend to do with the findings of the study needs to be clearly explained to the participant prior to obtaining informed consent (Munhall, 1988). The original consent form was kept in a locked cupboard in the researcher’s office at Curtin University of Technology. All of the 11 follow-up interviews conducted with participants occurred only after consent was renegotiated with each participant.

Although voluntary informed written consent was obtained from all participants there is a broader concept of informed consent posed by the use of qualitative research methodologies. According to Ramos (1989), the emergent designs of qualitative research and data collection methods make the direction that research will take to a large extent unknown. Therefore, the use of an ongoing process of consensual decision-making in this study was paramount. This allowed participants to be kept informed about their vulnerability to potential dangers of emotional distress. It was particularly pertinent with one participant who was assessed as having the potential to be put at risk of emotional distress during the interview process while relating traumatic caring experiences (see section 3.5.4). Prior to commencing the interview with this participant, a more formal process of obtaining consent throughout the interview was obtained. Her right to control whether the interviewed continued was reinforced and her consent was renegotiated several times during the interview. Although this individual cried and experienced temporary discomfort during the interview process, she gave consent to continue. The service of two psychiatrists was available if support or counselling to participants was required.
3.5.2: Withdrawal from the study

All research participants had the right to withdraw their consent (either verbal and/or written) at any time. When the decision to withdraw consent is made, the participant should not be coerced or put under any influence by researchers to continue. In addition, participants do not have to provide any reasons as to why they have decided to withdraw and the withdrawal of consent incurs no consequences for the participant. If requested, any audiotaped recordings, written material, and field notes pertaining to the participant would be destroyed. No participants withdrew from this study, or requested that any information given to the researcher be erased or destroyed.

3.5.3: Privacy, confidentiality, and anonymity

Anonymity and confidentiality are an integral part of the research process. Anonymity occurs when participants’ data is not linked to their identity. However, in qualitative research methodologies it is difficult to achieve this because the researcher knows the identities of participants (Streubert & Carpenter, 1999). Therefore, the researcher must ensure that their identity remains confidential. In this study a code number and pseudonyms were used for each participant, affected family member, and other significant people mentioned by participants. Any reference to a health service, doctor, or a family member or significant other that may reveal the identity of participants was omitted.

Confidentiality in research means that private information identifying the participant will not be reported unless the participant has agreed to the release of this information (Kvale, 1996). Confidentiality is linked closely to the concept of beneficence, or that the risk of harm to the participant should be the least possible. Moreover, Levine (1986) stated that confidentiality is based on the premise that:

(1) individuals can share personal information to the extent they wish and are entitled to have secrets; (2) one can choose with whom to share personal information; (3) those accepting information in confidence have an obligation to maintain confidentiality; and (4) professionals, such as researchers, have a duty to maintain confidentiality that goes beyond ordinary loyalty. (p. 164)

The small population from which the sample is drawn as well as the rich descriptions provided in qualitative research pose additional problems in maintaining confidentiality. Therefore, researchers have the responsibility to present the research finding in such a way that no one can identify the source (Ramos, 1989). Every attempt to address these aspects was made in this study. A code number was assigned to each participant and the codebook
and audiotapes were kept in separate locked cupboards. All participants were told that the researcher was the only people who could connect them with any data.

3.5.4: Minimising risk of harm

Based on the ethical principle of beneficence, the right to protection from harm is afforded research participants. Interviews can, at times, be expected to create some temporary discomfort and in some circumstances unusual levels of temporary discomfort for participants. While this may be anticipated it is not expected that they will be placed at risk of experiencing any permanent damage. However, some research has the potential to permanently damage subjects emotionally and socially, for example, examining sexual identity or abuse issues. Moreover, conducting research that places participants at risk of permanent damage is highly questionable regardless of the benefits that may be gained as these studies violate the fifth principle of the Nuremberg Code (Burns & Grove, 1999). Minimising the risk of harm in this study was addressed from two perspective's: the participant's and the researchers.

3.5.4.1: Minimising risk of harm to participants

Due to the nature of the topic being researched, it was anticipated that some participants might experience some temporary discomfort while relating their experiences of caring for a close friend or family member with a mental disorder. In addition, from the initial telephone contact it was also anticipated that one participant in particular could experience unusual levels of temporary discomfort when the interview involved reliving traumatic events. As an experienced mental health nurse the researcher felt confident in identifying and managing any temporary level of discomfort the participant may display. As previously stated, arrangements were made with two psychiatrists to allow the researcher to refer participants for counselling and support if needed. At the end of each interview time was spent with the participant and the conversation was normalised to the social level. In most cases this was done over a cup of tea or coffee. This process ensured that the participant had not experienced any unusual levels of distress. Approximately three days following the interview participants were telephoned and again thanked for their participation. This action facilitated further assessment of any distress that the participant may have incurred. In addition, the information sheet given to the participant had the researcher's name as well as that of the principal supervisor if the participant required any assistance following the interview. One participant did display unusual levels of discomfort during the interview
process. However, the participant indicated that the interview should continue. As the
decision making process concerning the participant's control of the interview had already
been established, the participant was followed up using the same procedure as other
participants. A duty of care to participants would have stopped the interview if the researcher
considered that the need for advocacy was greater than the need to advance understanding
and knowledge.

Although several participants in this study experienced some temporary discomfort
during the interview, none experienced any harm. All participants who were interviewed
were able to complete their interview without distress. For several participants the interview
provided benefits and they expressed that it had allowed closure and provided relief for them.
One participant wrote to the researcher following the interview stating that the interview had
been emotionally beneficial (permission was obtained from participant to include the letter in
thesis). She commented on the empathetic ability to "walk in her shoes" during the interview
and for the sensitivity displayed during the interview. In closing, the participant wrote "Thank
you - for your lovely manner and kindness and for helping me, to very gently attain a sense of
closure". In addition, two participants requested that they be given the audiotape at the end of
the study. These two requests resulted from the positive outcomes of being interviewed. Both
participants stated that the interview had really helped them in addressing issues related to
their caregiving experience and they wanted the audiotape for future reference. These
positive outcomes support the concept of reciprocity described by Kvale (1996) who claimed
that participants should receive as much from participation as they give. Listening to
participants' experiences makes the interview a unique experience for both the participant and
researcher.

3.5.4.2: Minimising risk of harm to the researcher

When participants are recruited from the general community and are therefore not
known to the researcher it is also important to minimise the risk of harm to the researcher
(Paterson, Gregory & Thorne, 1999). This was achieved by the development of strict
protocols for conducting qualitative research interviews. The initial contact with the potential
participant, via the telephone, was valuable as a screening mechanism as it allowed the
researcher to assess the level of exposure to harm. This was particularly important as many
interviews were conducted in participants' homes. During the initial telephone contact with
each participant, several questions were asked of the potential participant that could only be
answered by a person familiar with the role of providing care to a person with a mental
disorder. On one occasion the researcher was uncomfortable (a gut feeling that something was not right) in conversation with a potential participant. The person was thanked for making contact with the researcher but was not interviewed for this study.

Before an interview was completed the address and telephone number for the place each interview was being conducted was given to the researcher’s husband. When the interview was completed the researcher’s husband was telephoned. On returning home the paper with the address and telephone number of the house where the interview was conducted was destroyed. At no time was the researcher’s husband given the name of the participant, only the address and telephone number was supplied. As a further safeguard a conversation was held with the participant, at the door of their house, prior to entering the house.

Although a mental health nurse with 20 years exposure to the impact of mental illness, the intensity of hearing a “lived experience” of a carer is very different from perceiving that experience as an outsider. While it was essential to reflect on the interviews, on several occasions during this study the researcher experienced distress as a result of the interview experience. The use of this extract from an interview in the methodology section is to demonstrate this point.

One participant recounted this experience:

I remember * [my husband] calling me aside and saying “I think you are going to have to face up to this. May [daughter] is always going to be with us. She is always going to be abnormal and we just have to deal with it. We have to put up with it, she is our daughter and we love her”. I said “I think I will go off my brain if she stays with us and there is absolutely no hope. The difference would be if she didn’t mind being different, but she does. She takes it out on us and I don’t believe that we can live the rest of our lives like this”. It was like living on a razor’s edge. I never knew when the exacerbation would take place; I never knew when I come home if I would find her hanging. Or would she be behind the door springing me with a knife? I just didn’t know, but I hoped we didn’t have to live that way. And I don’t know what it was but a couple of nights later I went up to our bathroom. There is only a bathroom; our house is a bit odd there is a bath in the bathroom upstairs. I didn’t realise that she was in there, and I just opened the door and she was having a bath and I said “Oh sorry love”. Then I saw where she had cut her arm, Dianne so badly [participant cried] and I said, “May what have you done to yourself?” She said, “I tried to cut my arm off. I just want to die, I just want to die” [participant cries]. My husband had to go up and see our general practitioner [family doctor] and he sent her somewhere [to a hospital] to see if it could be stitched. It had been done sometime before. It was healing and it was awful. Dianne how could she feel so miserable that she could do that to herself? I didn’t want her to live [participant cries] it was so horrible. I was overcome by my own thoughts. She must have heard that you could gas yourself in a car and she gassed herself in our car about a week later. We did not make her go back to the flat when I saw that arm. She was always talking about suicide. She longed for it and said "kill me, kill me". It was terrible living with it, it really was. Nobody knows what it is like living with it. It is terrible. (P15)
Prior to the interview commencing time was spent with the participant discussing how she would maintain this control over the interview process if she experienced emotional distress. It was agreed that if the participant wanted to stop the interview at any time she would raise her hand in the air and this would suffice to inform that the interview should stop. While a system had been established for dealing with emotional distress, the researcher was not fully prepared for the impact on herself of the experience portrayed by the participant. The researcher wrote the following memo shortly after the interview was completed:

I am constantly thinking of what happened in the interview just completed. It really has had an impact on me. I never expected it to affect me in this way. I feel emotionally dull and I am distressed by what I have just heard. I also feel privileged that the participant felt able to share those experiences with me. What must it be like for her? She lives with it everyday. I am sure as this experience fully impacts on me I will learn a great deal from it and some of this learning will be about myself. (Field note 40, June 10th 2000)

As researchers, we are privileged to listen to participants’ experiences, which may include tragedy. The experiences told convey both strength and courage by participants who have maintained their dignity and integrity through difficult circumstances. While, as researchers, we listen to these experiences we can never guarantee that we will not experience distress. The distress was a component of conducting qualitative research. The distress allowed the researcher to more fully comprehend the dimensions of the experience that was being researched. Moreover, analysis of the processes and interactions may not have been as sharp if the distress had not been experienced. In other words, the researcher believed that the distress experienced facilitated personal growth and a widening of perception of the primary carer’s experiences of caring and increased the researcher’s theoretical sensitivity.

3.5.5: Data storage, access, and disposal

All interviews, field notes, and reflective notes were coded to prevent the identification of any participant. The codebook containing participants’ names was kept in a locked cupboard separate from the transcribed interviews and audiotapes. All the audiotaped interviews, with the exception of the two given to participants, were destroyed when the study was completed. Transcribed data will be stored in a locked cupboard in the researcher's office for a period of five years following the completion of the study. After five years data will be destroyed. Any written publications resulting from this research will maintain the confidentiality of participants. Extracts from the interview transcripts may be published but no identification to the source will be made.
3.6: Overview of major findings

The emerging data identified the core category of *being consumed* as the basic social and psychological problem experienced by the primary carer of a person with a mental disorder in the Western Australian community. The problem had two stages: *disturbance of established lifestyle* and *sustained threat to self-equilibrium*. A major component of *being consumed* was the things that the carer had taken for granted in life, for example, their family, level of support, ability to work, self-governance and autonomy, and financial security were threatened by their experience of *being consumed*.

The analysis of data also identified that participants engaged in the basic social psychological process of *seeking balance* in order to manage their experience of *being consumed*. *Seeking balance* was a three-phase process that facilitated participants’ movement towards a more balanced, harmonious, and calm life whereby their caregiving commitment was proportionate to other areas of their lives. Data analysis revealed that the process of *seeking balance* also included a three-phase sub-process. The basic social, and psychological problem and process will be presented in chapters four, five, six and seven.

3.7: Summary

This chapter details the use of the grounded theory method of qualitative research first described by Glaser and Strauss (1967). The data were obtained from: interviews with participants who had direct experience with the phenomena under study, contextual documentation such as field notes made by the researcher along with background information, methodological documentation regarding decisions that were made during the research process, analytical documentation of decisions made arising from data analysis and the constant comparative method, and personal response documentation such as that noted in section 3.5.4.2 of this chapter (Minimising risk of harm to the researcher). Once the substantive theory emerged a comprehensive literature review was conducted and literature pertinent to the findings of this study was added to the thesis.

Purposeful and theoretical sampling techniques were used in conjunction with the constant comparative method of analysis. This process led to the emergence of the basic social psychological problem of *being consumed* and the basic social process of *seeking balance* from the data. The basic social psychological problem of *being consumed* will now be presented in chapter four of this thesis.
PART TWO

CHAPTER 4
THE BASIC SOCIAL PSYCHOLOGICAL PROBLEM: BEING CONSUMED

CHAPTER 5
CONDITIONS INFLUENCING PARTICIPANTS' EXPERIENCE OF BEING CONSUMED
CHAPTER 4

BASIC SOCIAL PSYCHOLOGICAL PROBLEM: BEING CONSUMED

4.1: An Overview

Using grounded theory methodology the analysis of data leads the researcher to "generate a theory that accounts for a pattern of behaviour which is relevant and problematic for those involved" (Glaser, 1978, p. 93). As such, the researcher looks for two central points in the research: the identification of the basic social psychological problem and the search for and possible identification of the basic social psychological process. Glaser (1978) claimed that this search allowed the researcher to identify:

... what - in their view - is the main concern or problem for the people in the setting, for what sums up in a pattern of behaviour the substance of what is going on in the data, for what is the essence of relevance reflected in the data ... (p. 94)

In this study it was identified from the data that the basic social psychological problem was being consumed. Although not articulated as such by participants, the data indicated that being consumed was a problem shared by primary carers of people with mental disorders in the Western Australian community. The Australian Concise Oxford Dictionary (Turner, 1984) provided several definitions for the word "consumed". These definitions included "to destroy ... to use up ... to waste (time, trouble, etc) ... to be entirely preoccupied" (p. 219). The Merriam-Webster Online Dictionary (2001) added two additional meanings "to engross ... to squander" (no pagination). The Macquarie Dictionary (Delbridge, Bernard, Blair, Butler, Peters & Yallop, 1997) expanded further with the definition "to expend by use ... to devour ... to spend ... to absorb ... to suffer destruction" (p. 470).

Participants' experiences of being consumed were as variant as the above definitions. However, for most participants being consumed included a bewildering sense of preoccupation, absorption, and engrossment with what was happening to both themselves and to their family member. They experienced threats to their integrity, identity, self-esteem, and self-equilibrium. They felt consumed by the impact of their experience on their life goals and dreams. A major component of being consumed that emerged from the data was categorised as being overwhelmed. When participants became overwhelmed they felt overpowered by the situation in which they found themselves. They felt crushed by the enormous load they were carrying. Participants felt that their own psychological and physical well being was endangered, as the following participant described: "Things got so bad with John [son] that I
thought I am going to jump in front of the next train. I really thought that it was the only solution" (P3). When participants felt overwhelmed they questioned their ability to continue to be there for their family member. Several participants articulated this as "How can I go on?" (P15, 20, 22). The basic psychological problem, being consumed, was comprised of two stages: "disruption of established lifestyle" and a "sustained threat to self-equilibrium" (See Figure 4). The conditions which influenced/varied the problem will be discussed in Chapter 5.

Stage one, disruption of established lifestyle, commenced when participants became aware of a change in the affected family member’s behaviour and an increasing level of disturbance occurring to their family’s established pattern of life. Their recognition that something was wrong led to participants’ preoccupation with not knowing what was wrong. This preoccupation began to absorb their time. Some participants believed that they could have caused the affected family member’s abnormal behaviours while others thought the affected family member could have a mental disorder. Participants also experienced feelings of being overwhelmed as a result of what was happening, to both themselves and to the affected family member. Participants remained in stage one until their family member was formally diagnosed with a mental disorder. At that time participants entered stage two of the basic social psychological problem. This stage was called "sustained threat to self-equilibrium".

Upon entering the second stage, participants were aware that their family member had a mental disorder. In addition, they had recently made a commitment to care for the affected family member, possibly on a long-term basis. During this stage, participants’ experience of being consumed arose from the day-to-day caregiving commitment. In addition they became consumed by their feelings of grief and loss. They also experienced a personal cost of caring for the affected family member. Finally, at times participants again experienced feelings of being overwhelmed. Each of the two stages of the basic social psychological problem, being consumed, will now be presented. In presenting this substantive theory many direct quotations of participants’ data have been included. As previously mentioned pseudonyms were used in all extracts of participants’ interviews.
FIGURE 4: THE BASIC SOCIAL PSYCHOLOGICAL PROBLEM: BEING CONSUMED

- **Stage One**
  - Disruption of established lifestyle
  - Aspects
    1. Recognition that something was wrong
    2. Preoccupation with not knowing what was wrong
    3. Being overwhelmed

- **Stage Two**
  - Sustained threat to self-equilibrium
  - Aspects
    1. The day-to-day caregiving commitment
    2. Grief and loss
    3. The personal cost of caring
    4. Being overwhelmed
4.2: STAGE ONE: DISRUPTION OF ESTABLISHED LIFESTYLE

4.2.1 Introduction

The problems and events that created participants' initial feelings of being consumed were related to the period of time prior to when their family member was officially diagnosed by a psychiatrist as having a mental disorder. The first stage of the basic social psychological problem, being consumed, was conceptualised as the disruption of established lifestyle.

The Macquarie Dictionary (Delbridge, et al, 1997) defined "disruption" as "to interrupt continuity of ... to cause disorder to" (p. 620). The Australian Concise Oxford Dictionary added two additional meanings: "to shatter ... to split" (Turner, 1984, p. 298). In addition, Turner (1984) defined "lifestyle" as "the individual's way of life" (p. 620). The Merriam-Webster Online Dictionary (2001) added "lifestyle" was "a typical way of life for an individual, group or culture" (no pagination). The Macquarie Dictionary (Delbridge, et al, 1997) further elaborated that it was the "mode of life chosen by person or group" (p. 1241).

The above definitions of "disruption" and "lifestyle" summarised what was conceptualised from the data. Participants found their lifestyle and established pattern of family life was shattered from the time the affected family member's abnormal behaviour began to become pronounced. Data analysis indicated that disruption of established lifestyle consisted of three aspects: "the recognition that something was wrong", "preoccupation with not knowing what was wrong", and "being overwhelmed". Initially participants recognised that something was wrong with the affected family member due to a change in their behaviour. Participants became preoccupied with the fact that while they recognised that something was wrong they did not know what was wrong. The preoccupation consumed participants time, taking over their daily routine and impacting on their ability to accomplish their life goals. It also disrupted established communication patterns and relationships, particularly those associated with family life. Furthermore, the consequential results of the crisis situations precipitated by the affected family member's abnormal behaviours carried through to other members of the family. It consumed participants' time and they were unable to meet their planned life obligations, which resulted in participants experiencing feelings of isolation from friends and other family members. Participants' feeling of being overwhelmed challenged their ability to offer continued support to their family member. The duration of stage one was different for each participant in this study. For some participants, the stage
began when their family member was very young, while for others the abnormal behaviours presented for the first time during adulthood. However, for the majority of participants the disruption of established lifestyle began when their family member was an adolescent. Each of the three aspects of disruption of established lifestyle will now be presented.

4.2.2: Recognition that something was wrong

The disruption of established lifestyle began as a result of participants’ recognition that something was wrong with the affected family member. Participants noticed little things that were a cause for concern to them: “I had a few concerns ... John [son] was always in the back of my mind as a concern. ... I was scared, I didn’t know what was happening” (P3). This description given by one participant mirrored the experiences of many participants. All participants reflected on events that triggered for them the recognition that something was wrong with the affected family member. These events typically fell into two categories: the warning signs displayed by the affected family member and the increasing disturbance to the family’s established pattern of life.

4.2.2.1: The warning signs displayed by the affected family member.

Some participants first noticed warning signs when the affected family member was very young. One participant noticed that her daughter would not feed properly and did not like to be held: “Jan [daughter] cried continuously. She did not like to be held and I could not breast-feed her. She was very tactile. She became a very [emphasis by participant] aggressive toddler” (P22, multiple carer). Similarly, another participant noticed that her daughter never really cried and that she appeared to have an abnormal calmness about her from the time she was very young:

Just little things I noticed, for example, Carol [daughter] never really cried as a baby. ... I had taken my son to pre-school and she did a somersault off the television onto her hand and cut it. She got a nappy, bandaged it and sat there calmly until I got home [Carol was then around four years old]. (P18)

Likewise, the following participant noticed her daughter’s abnormal rocking movements from an early age. The participant became concerned about this behaviour as her daughter would sit on her bed for hours and move her head rhythmically:

One of the first things that I saw that made me wonder if May [daughter] from a psychological perspective was alright was that from an early age when she would lie
on her bed and move her head rhythmically on the pillow. She could do it for hours. I tried a lot of things to stop her doing it. She told me that it relaxed her. But it made me wonder if this head banging stimulated some endorphin release. (P15)

For the following participant, the recognition that something was wrong with her daughter began when her daughter was around three years of age. Her daughter was now 17 and the participant reported that the behaviour was still present:

Well when April [daughter] was born she was an extremely happy baby, very easy. Not easy in terms of placid, very lively but really happy. When she was about three and a half she hit the terrible two’s and I can remember saying “late but with vengeance”. She hasn’t come out of it yet. It is like the terrible two’s gone wild. So that would have really been the onset at that age. (P20)

Health professionals originally diagnosed many of the early warning signs as medical conditions. However, as one participant explained, she knew that her son was not deaf despite the initial medical diagnosis. She knew that something else was wrong with him:

It really goes back to Peter’s [son] first admission to Irrabena [this was an assessment centre for children with learning disabilities] when he was three and a half. They [health professionals] thought he was deaf because he just didn’t answer and he didn’t talk. But I knew he wasn’t deaf, it was as though he didn’t want to hear. (P11, multiple carer)

However, for the majority of participants the recognition that something was wrong first surfaced when the affected family member was between 13-20 years of age. Participants’ recognition centred around three areas: poor school attendance and physical problems; behaviours that could be interpreted as obstinate, rebellious, or destructive; and bizarre out-of-character behaviours.

Poor school attendance and physical problems were important indicators for several participants that something was wrong with the affected family member. These participants noticed the affected family member started to refuse to go to school: "Peter [son] was doing all of these peculiar things, he wasn’t sleeping, he wasn’t going to school" (P11, multiple carer); "Michael started not going to school, he was unhygienic and you could not talk to him" (P17); "Jan missed a lot of school" (P22, multiple carer). Other participants noticed that the affected family member also complained of frequent physical symptoms, for example, headaches or sleep disturbances: "When June [daughter] was about 15 years of age she started getting headaches which we thought were odd. ... Gradually things got worse and she didn’t go to school" (P16).
Obstinate, rebellious, destructive, and out-of-character behaviours also triggered the recognition that something was wrong with the affected family member. The following participant became aware of this when her son's boss contacted her and told her that her son had been acting out-of-character and refusing to do things that had been requested of him at work:

Josh [son] was 16 years of age because he had just begun the apprenticeship. I had a phone call from his boss. He said, "Whatever is wrong with Josh?" and I said, "tell me, what is the matter?" Well he said "I asked him to shift some sand from point A to B and I said I would come back in half an hour to see how he was going". When I came back he was sitting down doing nothing. I said "Josh I asked you to do job A to B" and he said "No, No. Why do I have to do that, it does not matter". He said, "I asked him to hose down one of the trucks and make it clean. He didn't do it and he said, "Oh there was no point cleaning. It is only going to get dirty again". (P13, multiple carer)

Another participant described how she first became aware of her son's obsessive-compulsive behaviours. She had just finished decorating his bedroom and was shocked to find a few days later her son had pulled all the paper from the walls and the ceiling fan from the power socket. When she questioned him about his actions he appeared unable to trust reality:

John [son] had a very quiet wallpaper in his room. He had pulled every single piece of wall-paper, shreds of it off the wall, except in the corners and difficult bits. I burst into tears because it had taken so long to do it. I was still doing work around the house. It had cost a lot of money. I told him that I would give him a bucket and a scraper and he would have to finish the job. ... I said, "Why did you do this?" He said, "I wanted to see what was underneath it. Then I saw there was this great hole in the ceiling [participant talks loudly]. I said, "What is the ceiling fan doing on the floor?" He said, "Well I was afraid that it might come out of the ceiling and I could not sleep. I was afraid it would hit me on the head and kill me". He could have killed himself by electrocution. (P3)

Another presentation of warning signs during adolescence was identified when the family member displayed bizarre and out-of-character behaviours. One participant told that "Sky [sister-in-law] has always been weird [strange] but she then became paranoid and there was antisocial behaviour" (P8). Another participant was concerned when her daughter started to experience auditory hallucinations: "Zoe couldn't sleep at night and she said to me one night that she could hear screaming in one ear and birds singing in the other" (P6). The following participant had already recognised a change in her son's behaviour but when he
started to sleep outside under the stars she knew that there was really something wrong with him:

I just didn’t know Michael [son]. This went on for a couple of years and we had terrible arguments. He used to go round and round in circles without getting anywhere. There was no logic to his arguments and I didn’t know why. Then he started sleeping with his doona [bed cover] outside under the stars. I knew then that something was wrong. (P17)

Participants also developed the recognition that something was wrong when they became embroiled in their family members’ bizarre and out-of-character behaviour. The following participant’s daughter began hallucinating and thought that her mother was evil:

Carol [daughter] started hearing voices and she would sit in her room. She thought that I was evil and that I was saying things to her. I would say "but I am not" and she would say "but I can hear you". And she would accuse me of all these things. (P18)

Other warning signs evoked personal hurt and feelings of guilt for participants. One participant’s daughter claimed she had been sexually abused by her father: “Everything was tipped out all over Hannah’s [daughter] bed and she kept accusing her father of sexual abuse and her friends’ fathers of sexual abuse” (P11, multiple carer). For another participant the recognition that her daughter’s changed behaviours were a result of early childhood sexual abuse stirred up feelings of guilt and self-blame, which were very consuming: "It all stemmed from the sexual abuse when Pauline [daughter] was a little girl. I felt so guilty, I did not know anything about it" (P2). Another participant gave a similar account of early sexual abuse being responsible for the change in her daughter’s behaviour:

When Robyn [daughter] was in boarding school she was sexually abused. At 13 years of age she was sexually abused, I was devastated. ...We sent her to * [another high school] to normalise things but she did not fit in there. It was a very rebellious time and she did not fit in. All this was building the traumas that she is now dealing with. (P12)

Several participants who were caring for their spouse noticed the warning signs after their spouse was ill or, for example, involved in a motor vehicle accident. One participant noticed a change in his wife’s enthusiasm for life following her involvement in a motor vehicle accident. Prior to the accident she was working in a high profile job and appeared to be satisfied with her life:

I would come home and see that Rose [wife] was basically just sitting around, just lying around all day. It was difficult after living with this person who was quite satisfied with life, we both were. She changed quite quickly in that respect. ... I
noticed she wasn't getting up in the morning. She was sleeping in quite late. ... she would sleep in every morning, the problems was that she was having nightmares. (P7)

Another participant noticed similar signs after her husband had a brain tumour removed. Following surgery her husband's outlook on life changed:

About four years ago Barry [husband] had a tumour removed. He had a Magnetic Resonance Imaging [MRI] done and it was picked up. The surgery was successful. He lost his hearing in one ear and it was quiet frustrating. ... I could see there was a change in him, he was low, quiet and withdrawn. He just seemed so closed and withdrawn. His mood would get so low. (P24)

It has previously been identified in the scientific literature that the onset of the first episode of a mental disorder may be gradual and preceded by low-grade signs and symptoms. These documented signs and symptoms are consistent with the early warning signs described by participants in this study and are known as the "prodrome" (Beiser, Erickson, Fleming & Iacono, 1993; Vaglum, 1996; Yung, McGorry, McFarlane, Jackson, Patton & Rakkar, 1996). According to Yung et al (1996), the "prodrome", a term derived from medicine, refers to early signs and symptoms of a disease that are present before the obvious characteristic features manifest. However, these authors claim that it remains, prospectively, very difficult to predict the development of mental disorders as many individuals with prodromal signs and symptoms do not go on to develop the disorder. However, retrospective studies on individuals presenting with prodromal signs and symptoms have shown a range of phenomena, with researchers noting the prodromal stage ranging from a few days to many years (Hafner, Riecher-Rossler, Hambrecht, Maurer, Meissner, Schmidtke, Fatkenheuer, Loffler & van der Heiden, 1992; Hafner, Maurer, Loffler, Fatkenheuer, van der Heiden, Riecher-Rossler, Behrens and Gattaz, 1994). Patients in Beiser et al's (1993) study on assessing the onset of psychiatric illness reported a prodrome that ranged from zero to twenty years and a median of 37.9 weeks. According to Yung et al (1996), the symptoms most commonly identified in retrospective studies of prodromes were "in descending order of frequency, reduced concentration and attention, reduced drive and motivation, anergia, depressed mood, sleep disturbance, anxiety, social withdrawal, suspiciousness, deterioration in role function and irritability" (p. 287).

In summary, all participants in this study could reflect on warning signs that led to their recognition that something was wrong with the affected family member and this recognition began stage one of being consumed, called disruption of established lifestyle. For
some participants these signs began when the affected family member was very young while for others they noticed the warning signs in affected their family member following an accident or surgery. However, the majority of participants developed the recognition that something was wrong with their family member during the adolescent period.

4.2.2.2: Increasing disturbance in the family's established pattern of life

In addition to the individual warning signs displayed by the family member, participants also developed the recognition that something was wrong when they noticed an increasing disturbance in the family's established pattern of life. The disturbances in family life could be linked directly to the affected family member's abnormal behaviours, or the impact of those behaviours on other family members.

Clausen and Yarrow (1955 a & b), in their classic two-year study on mental illness and the family, first identified the stress experienced by families when one family member has a mental disorder. Similarly, Marsh (1992) in her study of families and mental illness asserted that severe mental disorders were "a catastrophic stressor for all families and families differ in their ability to cope with that stressor" (p. 152). Recent studies demonstrated that similar levels of family distress were reported across all psychiatric diagnoses (Friedmann, McDermut, Solomon, Ryan, Keitner & Miller, 1997; Jenkins & Schumacher, 1999; Toseland, Rossiter, Peak & Smith, 1990). Friedmann, et al (1997) in their study of family functioning and mental illness elaborated further stating that:

Regardless of specific diagnosis, having a family member in an acute phase of a psychiatric illness was a risk factor for poor family functioning across many areas, including problem solving, communication, affect expression and responsiveness, role allocation, and general functioning. (p. 357)

Furthermore, these authors claimed:

Despite the fact that some psychiatric disorders have more severe and pervasive symptoms than others (schizophrenia versus adjustment disorders) the specific nature of the patient's mental illness did not appear to have specific implications for family functioning. Rather, the evidence from this study supports the hypothesis that having a family member in an acute phase of any psychiatric illness is a general stressor for the family, and that it can often exceed the family's adaptive resources. (p. 364)

In this study the areas of disturbance of family life were identified as increasing: family conflict, family dysfunction, family isolation, and disturbances in other vulnerable family members.
4.2.2.1: Increasing family conflict

Participants in this study became aware of increasing family conflict in several ways. Sometimes it was because of heightened marital conflict between themselves and their spouse:

When Melinda’s [wife] behaviour started we almost got a divorce. The whole world was skewed in her direction. I have a friend and I told him about it and he said “Yes I have noticed that.” He noticed the difference in Melinda. She was angry at herself somehow, the screaming and the yelling was terrible. You could not please her and she accused me of not loving her, of being non-compliant and I said, "non-compliant with what?" She threw back at me that my perception of reality was skewed and everyone in the household knew that it was her reality that was skewed. (P23)

Frequently, the conflict occurred between family members over the affected family member’s behaviour: “One boy [affected family member’s sibling] couldn’t understand it at all. He said ‘a stiff kick in the backside would make her better’” (P2); “I used to try to talk to Craig [husband] but we didn’t always agree on much over Jill [daughter] and how we were handling it [the warning signs]” (P10). Conflict also emerged between participants and their partners in new relationships:

My former partner [not son’s father], he hated Josh [son who was unwell]. He had no time for him at all. He kept saying "Oh he is a good for nothing lazy little cow, there is nothing wrong with him, I don’t want you to waste your time on him". (P13, multiple carer)

Several participants spoke of how they spent a lot of time mediating between members of the family who did not want the affected family member to continue to live in the family home. Due to the increasing level of family conflict several participants described feeling isolated from other family members: “You know I felt like I was the only one that wanted him to stay in the home” (P9). Similarly, Parker (1993) in her study of the family as a caregiver reported conflict between family members due to differing perceptions regarding the cause of the affected family member’s behaviour. The author found that some family members believed there was nothing wrong with the affected family member that discipline wouldn’t cure, while others believed the affected family member’s abnormal behaviour was, in fact, caused by an illness.
4.2.2.2.2: Increasing family dysfunction

A second area of disturbance in the family’s established pattern of life was an increasing level of dysfunction in the family. Sometimes the disturbance resulted from an increasing level of dysfunction in the affected family member. This was especially consuming for participants when the affected family member was their spouse: "It happened fairly suddenly, Larry [husband] did the finances and I found out the car had not been insured for a year. He did not want to insure it. We had been driving around for a year with no insurance" (P25). Other participants in this study became aware of increasing family dysfunction through changes to the basic foundations of the family’s routines and communication patterns. One participant’s son started to sleep during the day and then he stayed awake all night:

I work shiftwork and when I had to get up at five [in the morning] it was a problem. Michael [son] did not sleep at night and the TV would be on. He would be walking around. I wasn’t getting any sleep and I was like a zombie [unable to function]. Then when I went to work he would sleep all day and at night he would be rearing to go again. (P17)

Another participant suggested that the increasing family dysfunction resulted in a change in the established routine of the family. Family members no longer ate together and there was increased avoidance of the abusive affected family member:

Rachel [daughter] became extremely abusive and to get her out of bed was a major problem. Then to get her to speak to anyone civilly was even a worse problem. It came to the point where all of us would run and hide. You would go and grab a bowl of cereal and you would gulp [eat quickly] it down standing in the kitchen. You would shove [put] the dish in the dishwasher and then you would run [leave the kitchen]. We [husband and wife] realised that we were walking at midnight with the dogs. We then knew the kids were safe in bed and asleep. We would walk just to have a safe place to talk. If we tried to talk at home Rachel would hear us and attack us. (P21, multiple carer).

I asked the participant whether her daughter attacked her physically during this time and she said:

Yes, on occasions. We have got holes in doors. The damage to the house was probably more than the physical damage to any of us. We were a very dysfunctional family and we could not even sit at the table together. When Rachel walked in the door we would know what type of evening we would have. When you said, "Oh hello Rachel how are you?", if she said, "Oh fuck off you old bitch", you would know that this was not going to be a good evening. We would retreat and go quiet. (P21, multiple carer)
The following participant gave a similar account of the disruption to family life caused by the affected family member’s hostile behaviour:

April [daughter] was like another person because she was increasingly acting as if she was angry as her neutral stance. Like everything is fine, there is not a crisis and everything is happy. Then you say to her “April would you like a cup of hot chocolate?” You get as far as “April would you like a cup” and she turns around “What do you want?” Yelling at you in this horrible voice, so nasty and horrible [participant very distressed while recounting this incident]. It was like she was unable to speak. Every word that came out of her mouth day and night, all day long, was just screeching. I just lived like that. I tried to pull my head in like a turtle. (P20)

Similarly, Rolland (1994) described that the impact of increasing family dysfunction on the basic foundations of the family reporting that it was particularly disturbing to the family unit when the affected family member was a parent:

When a parent develops a chronic condition during the highly cohesive child-rearing phase of development, the family’s ability to stay on course is severely taxed. In essence for more serious conditions, the impact of the illness is like the addition of a new infant member, one with special needs that will compete with those of the real children for potentially scarce family resources. (p. 112)

4.2.2.2.3: Increasing dysfunction in other vulnerable family members

Several participants in this study reported a change in the behaviour of other family members as a result of the increase disturbance to the family’s established pattern of life. Some participants reported that some family members turned to alcohol as a way of managing what was happening: “Ron [husband] didn’t realise that he was unconsciously turning to alcohol because of all of the stress Zoe [daughter] was causing” (P6). Other participants began to notice changes in the behaviour of other family members: “I thought Natalie [sibling of daughter who was unwell] was riding with it very well. But she became very resentful of the time that it took [to manage daughter who was unwell]. She felt as though she wasn’t getting her proper attention” (P15); “Karen [daughter of father who was unwell] said ‘you are too busy for me’. She went through a bit of a hard stage, she started to be withdrawn as well” (P24).

During this time several participants discovered there was a history of a mental disorder in their spouse’s family of origin. The growing awareness helped them to piece together an explanation for some of the "abnormal" behaviours they had previously noticed in
their spouse, but had never fully understood. Consequently, the degree of disturbance to the family's established pattern of life caused by the family member also triggered other vulnerable family members to display behaviours that increased participants' experience of being consumed. It also resulted in participants being left without vital support from their spouse during this stressful time as these participants explained: "My husband [who was later diagnosed with a mental disorder] was there at the time [when son was unwell] but he was more concerned about how he felt rather than how our son [who was the family member who was unwell] felt" (P11, multiple carer); "I think my husband was suffering from it [a mental disorder]. ... I felt vulnerable, totally vulnerable and my husband didn't back me. He was not interested and I think that was because he was facing his own demons [husband had a family history of a mental disorder, was displaying similar behaviours but was not diagnosed with a mental disorder]" (P18).

Stuart and Laraia (1998) also identified an increasing dysfunction in other vulnerable family members. These authors claimed that all theoretical models of mental disorders acknowledge the concept of the interactive family system. These authors explained that the stress-coping model assumes that symptoms arise at the interface of biological vulnerability and environmental stressors and, therefore, the affected family member's symptoms can trigger responses in other vulnerable family members.

4.2.2.4: Increasing family isolation

Finally, participants reported that they experienced increasing isolation from friends and from other members of the family. This was manifested in various ways. Some participants found that they were alone and no one offered them help: "Certainly no one helped me during that time" (P18); "My sister-in-law knew [what was happening]. I hadn't told anyone really, she knew a little bit but she never offered any help or did anything" (P18). One participant gave this description of her increasing feelings of isolation since she lost friends because her child was unwell:

I never spoke to anyone. It is very difficult for people to realise that your child does not have control over their behaviours. I lost a lot of friends and lots of family members did not come and visit. Jan [daughter] has always been violent and a lot of people can't cope with it in a child or an adult. ... You lose friends for a variety of reasons. However, there is nothing to prepare you for losing them just because your child is unwell. (P22, multiple carer)
In summary, during stage one of the basic social psychological problem, disruption of established lifestyle, participants developed the recognition that something was wrong with the affected family member in two ways. They noticed early warning signs that raised concerns for them and they began to recognise an increasing disturbance to the established pattern of family life. The recognition that something was wrong increased participants’ experience of being consumed.

4.2.3: Preoccupation with not knowing what was wrong

The second aspect of stage one, disruption of established lifestyle was conceptualised as preoccupation with not knowing what was wrong. When participants developed the recognition that something was wrong with their family member, they also became consumed by their preoccupation with not knowing what was wrong. Similarly, Stuart and Laraia (1998) claimed "parents, spouses, and other family members are typically the first to recognize [sic] that something is wrong, but are unable to determine what that 'something' is" (p. 265). In this study, participants’ preoccupation with not knowing what was wrong began to absorb their time. It also disrupted their established lifestyle as an increased amount of time was spent focussing on what was happening to the affected family member.

At some time during the first stage of the problem of being consumed, the majority of participants thought the affected family member could have a mental disorder. These participants believed this even when professionals reassured them that this was not the case. Participants believed that their response to their family member’s behaviour demonstrated the professional’s lack of knowledge, understanding, and concern about the situation: "Jan [daughter] missed a lot of school through suspension. They [the teachers] coped by ringing me, depending on the severity of the situation" (P22, multiple carer); "We were given a lot of messages from professionals that May’s problems were behavioural and that we were not reinforcing properly or disciplining properly" (P15).

Other participants recounted interactions with teachers and/or counsellors/psychologists regarding their family member’s behaviour that was causing them great concern. Several participants explained that these professionals demonstrated a lack of concern regarding the affected family member’s abnormal behaviour. One participant explained that these professionals appeared more concerned about getting her daughter to
leave school and, therefore, resolving the problem for the school than providing any help to the participant or her daughter:

The teachers didn’t really seem to bother too much about it [daughter’s behaviour]. They didn’t see very much of June [due to daughter’s school refusal] and they didn’t bother. They suggested the best thing for her was to leave school, as it was not right for her. ... Well, I think that she [the school counsellor] just didn’t know. She seemed to be more concerned with getting the whole thing out of the way. This child was being disruptive in the class and missing school. So get her out of the way. Let’s get her off to do some work experience. Let’s get her out of the school so that we don’t have to worry about her. This was the main attitude that I can remember. We [parents] just assumed it was adolescence. We thought we are going through a terrible adolescence. Everyone told us it was adolescence. You know everything we talked about seemed to be adolescence. ... Everyone, friends, people at school, the psychologist who was no help at all. Everyone told us she [daughter] is an adolescent, what do you expect. (P 16)

Another participant recalled that if her daughter did manage to go to school the participant was contacted regularly by the teachers in attempts to entice her daughter’s removal from the school. On other days her daughter did not even manage to leave the house:

Ring, ring, Mrs Jones can you come and get your April [daughter]? She is throwing up [being sick], she is disruptive in the class, she has a headache. Can you come and get your child immediately? April just came home or she did not go to school. She got as far as the mail-box and burst into tears and came back. (P20)

Participants’ preoccupation with not knowing what was wrong with their family member led them to experience feelings of self-blame. Several participants thought they were responsible for the family members’ problems. Some participants knew there was a family history of a mental illness and, therefore, felt guilty: "I recognised that it must be a family thing so I felt a lot of guilt, an enormous amount of guilt, that I caused this to happen" (P16). For other participants, most of the self-blame was attributed to parenting styles and participants spent considerable time reflecting on what they could have done wrong: "As a mum I always searched for what I did wrong. How could I have brought her up better? What could I have done differently?" (P3); "We did feel the blame of it. I searched for what I did wrong. How could I have brought her up better? What could I have done differently?" (P10); "I still think where did I go wrong" (P15); "I felt really guilty to start with“ (P2).

Other participants believed that the disturbance in the affected family member could have been triggered by their marriage breakdown and participants believed that if they had stayed married the affected family member would have been alright: "I thought if I had more
children, if I had stayed with Michael's [son] father, all of these things. If I had been a better mother! If I had not done this or that" (P17). "We [participant and daughter] went through some very bad times [daughter's sexual abuse and participant's marriage breakdown]. I should have done a lot more for her [daughter]. I should have found her support" (P7). In addition, some participants began turning on their spouse: "We blamed each other [husband and wife] for a while. You know it is something that you go through" (P6). Even when participants were told they were doing a good job they remained critical of their parenting ability:

She [school psychologists] said, "you are doing really well with April [daughter]. You are doing a fantastic job [the way you deal with her, the way you handle her". Instead of feeling pleased or proud I felt so disheartened. I realised I was looking for her to tell me what mistakes I was making so I could fix the problem. It was like tell me what I am doing wrong. I felt so disheartened. I felt why do I feel like this? I immediately recognised this emotional response. I was not at all what I expected of myself. I had tried so many different approaches. I have a very eclectic parenting style. You do things and then you evaluate them after six months and say it has not changed anything. ... Somehow when it is mental it is worse. You just rack your brain and think did I trigger that? I did the best I could do when she was a little girl. (P20)

Finally, contacts with professionals, family, and friends often increased self-blame as professionals did not believe that there was a problem with the affected family member: "I am doing something wrong because obviously they [professionals] think that it [son’s behaviour] is alright. Why aren't I coping?" (P9). Similar feelings of self-blame were reported by participants in Stueve, Vine & Streuning's (1997) study of caregivers to persons with mental illness. In addition, participants in this study described the blame directed towards them by health professionals was often more explicit: "We [parents] met this doctor. She sat us on beanbags and said 'you know what is wrong with you'. She put the blame on us" (P2); "The doctor was pretty angry with me. He blamed me for a lot of Barry's [husband] depression" (P24). Another participant gave this account of being blamed by a health professional for causing her son's problems:

Do you know who they [the professionals that participant had contact with] blamed? They blamed me. When I was feeding my third child, I went to the clinic [child care clinic]. The nurse who had been the other two children's clinic sister said, "I don't know how you are going to manage this baby with the way he [son who developed a mental disorder] is?" He was just about swinging from the rafters [very overactive]. ... Dr Black [general practitioner] left the room one day and I read, [what was written in participant's notes] "this woman is back again!" This was the hardest thing to bear. We were blamed for the actions of our child. ... He [son] was four and a half and the
doctors didn't want to know. ... The doctors blamed us and as I say the expression on Dr Black's face when Peter went there. He was swinging from everything he was uncontrollable. (P11, multiple carer)

The following participant sought help from a psychologist but felt blamed by his questions and responses to her:

He [psychologist] had all these anti-psychiatry books at his back [bookshelf in office]. Do you know the first thing he said was "why do you need a sick son?". I said, "I need a sick son like a hole in the head". In other words he was saying I was projecting my problems onto John [son]. I said, "well I am not going to get anywhere here am I?" He wasn't prepared to listen. So I walked all the way home in the pouring rain. I could not face getting on a bus and asking for a ticket. I felt so devastated. (P3)

Domenici and Griffin-Francell (1993) and Jones (1997a) reported that family members felt that they were apportioned blame by health professionals for the affected family member's abnormal behaviour. Similar to the participants in this study, one participant from Jones' study of caregiver burden stated: "They [health professionals] didn't know what was wrong and blamed it on me. I even went to a psychologist because of having to deal with this" (p. 85). According to Domenici and Griffin-Francell (1993) family members were often made to "feel patronized [sic], discarded, overlooked, or blamed for the patient's illness" (p. 31).

In summary, participants became preoccupied with not knowing what was wrong with their family member. Many believed the affected family member had a mental disorder despite assurances by health professionals that this was not the case. Other participants believed that they caused the affected family member's problems. Some participants had a family history of a mental illness and they felt guilty that they may have been responsible for the affected family member's problems. Several participants believed their parenting styles caused the problem. Furthermore, other participants recounted that the precipitant for the affected family member's abnormal behaviour may have been the separation from their spouse.

4.2.4: Being overwhelmed

The third aspect of disruption of established lifestyle was called being overwhelmed. During this first stage, participants' experienced feelings of being consumed by their recognition that something was wrong as well as their preoccupation with not knowing what was wrong. However, when participants became embroiled in a crisis situation involving
their family member, *being overwhelmed* emerged as a major component of *being consumed.* Other researchers have also identified that living with unanswered questions about the future (Rose 1998) and the unpredictability and uncontrollability of the affected family member's abnormal behaviour, particularly during periods of crisis, was very distressing for family members (Harvey, 2001; Shafran & Thordarson, 1996).

In this study, participants noticed a *disruption of established lifestyle* as a result of a change in their family member's established behaviours. The change was an escalation in the intensity, frequency, and/or bizarreness of the family member's established behaviours that had already been a cause of concern to participants. Participants experienced feelings of *being overwhelmed* because they: 1) were unprepared and unskilled to manage the evolving crisis situation; 2) did not know what was wrong with the affected family member; 3) had to make contact with emergency services, for example, the police or the Psychiatric Emergency Team (PET); 4) had to contact and communicate with specialist mental health professionals for the first time; 5) had perceptions and preconceived ideas regarding the origin and treatment of mental disorders; 6) were exposed to violence from their family member; and 7) were confused about how to access the appropriate health services.

Crisis situations that created feelings of *being overwhelmed* in participants evolved in a variety of ways. For some participants the crisis situation developed quickly over a very short period of time. The following participant explained that while she was at work her husband tried to commit suicide:

> When I left [to go to work] Barry [husband] he was having a shave and he was alright. A friend of mine was going to call over. When I got home, I found that he had rung my friend and said, "don't worry about coming over". When I got home, I knew something was wrong. He had red marks around his neck and I knew then that he must have tried to hang himself. (P24)

For other participants, the experience of *being overwhelmed* began with a sudden escalation of bizarre behaviour in the family member:

> Carol [daughter] was really off her tree [unwell]. She sat all night in her room. I watched her all night. She couldn't sleep she was so high, so manic. She was wrapping all the things in the room into little parcels with ribbons and making little messages to go with them. Sometimes she wrote, "you are a bitch or I hate you. Because you have done this to me this is what is going to happen"... I sat up all night watching her, thinking she must go to sleep sometime... It was horrible watching her do all of those things. You could see the intensity of everything she did. (P18)
An increase in self-harming behaviours also signalled an escalation in the family member's established behaviours and an evolving crisis situation which participants found overwhelming:

Pauline [daughter] would go out somewhere. Then she would come home and she would vomit everywhere. That was when I became aware of her overdosing. She had been picking up bits of glass. I found them under her bed. Then one night she cut herself. That was awful; we knew we had to get help. (P2)

For other participants, the crisis situation evolved over a number of days or weeks. In addition to bizarre and out-of-character behaviours, the family member was also observed to be losing touch with reality. The behaviours left participants with feelings of being overwhelmed about their ability to go on, as one participant outlined:

Peter [son] had gone for [attacked] another boy with an axe. He was as happy as Larry [very excited] and totally off the planet [mentally unwell]. He was high [manic] and he had not slept for five nights and days, he was still going [very active]. ... He was doing things like he would have a shower, then another and by the time he had three or four he was going in with all of his clothes on. Then he would shoot through the house. I tell you Dianne when they are psychotic; you just stand by and let them go. ... It is like living in the eye of a storm. All this is going on around you and there is nothing you can do about it. You just stand still until it stops. What else can you do? (P11, multiple carer)

Having to deal with an increasing level of violence in the affected family member was another presentation that participants found overwhelming as the crisis situation evolved:

There was this week where all sorts of things happened in this week. April [daughter] had broken my [bedroom] door down. She was also doing things like walking out of the house at ten and eleven at night. It was getting out of control. I took her to school and then came home and searched her room for the first time. I had never done that before. I found a laundry basket full of things that she had stolen and of course I took what I found of mine back. When I picked her up and she discovered what I had done she went troppo [became angry] and got really violent and threatening. I thought all right what am I going to do? I got her brother [who was at work down the street]. By the time we got back she had broken my door down which I had repaired with a steel plate around the handle. She had broken the wood and the lock and was trying to take the things back. She had my backpack and as soon as she saw her brother she bolted [ran off]. He ran after her and he had a struggle getting it [backpack] back. It was getting really violent and I ended up calling the police. (P20)

Isaac and Armat (1990) reported the distress for many family members became intolerable when they were involved in a crisis where the affected family member was violent. This aspect was further illustrated by one participant's account of being overwhelmed by the increasing aggression and out-of-character behaviour in her husband who had
Alzheimer's Disease. Her husband had never been violent and his behaviour was very distressing to the participant:

Well we [husband and participant] were staying with my son and daughter-in-law and they were really great. In fact they were more understanding of Larry [husband] than me. Sometimes I got to the end of my tether with him. You know when he was violent. They said, "can't you do this mum or can't you get out of the way? Don't talk to him like that". Sometimes when he would hit me I would say, "don't you ever do that again". It was totally out of character for him to behave like that. ... I had a screecher that I would press when I needed my son. He was only aggressive when I touched his trousers. If he came into the bedroom after me and he had in mind to hurt me then I would use the screecher [laughs]. ... In the morning it was difficult to get him to have a bath and he would get aggressive if I tried to make him. There was not anybody in the house during the day to help me. The worst time was when I had to keep taking him to the toilet. The signs were there that he was becoming aggressive. When I took him to the toilet at night. I used to dance him there because he loved dancing. However, when I got him there and I tried to unzip his pants, the look on his face would change. He would hit and I did not know where he would hit me. I was like a quivering wreck and I would say "don't you ever do that to me again". The tears would be coming down my face. I knew there was no point in me showing any emotion at all over this but I could not help it sometimes. I would end up trembling. One day I thought I couldn't take this any more. I can't cope any longer. I need help to manage this. (P25)

Often as a result of the crisis situation the affected family member was seen by specialist mental health professionals in the community or hospitalised for the first time. This experienced produced a variety of emotions in participants, ranging from relief to being overwhelmed by what was happening:

For me it was a relief that for a short time we would not have to worry about June [daughter]. She would be safe at long last. We could sleep and we did not have to worry. There was also the horrible feeling, I was overwhelmed that she was in * [a psychiatric hospital] and that she could actually have a mental illness. (P16)

Another participant gave the following account of being overwhelmed when her daughter was hospitalised. She was very distressed by what her daughter, who was very unwell, was saying about her:

The second time [daughter was hospitalised] it got worse. She believed that I had murdered a baby [a delusion] or she had murdered a baby. All these horrendous things! She didn't recognise me as a mother and even on Mother's day I went there [to the hospital] and she was abusive. She told all the patients that I was abusing her so they were abusive to me as well. They would gang up on me and tell me that I was being a terrible mother. I thought "God it is Mother's day". ... It was so distressing coming out of the mouth of someone that you love. ... It would blow you away hearing your daughter say these things. (P18)
For other participants being overwhelmed by what was happening was exacerbated by the fact they had been instrumental in initiating their family member’s first admission to hospital. One participant described that it was horrible to see her son being taken away in a police car and to know that she had initiated the process:

When I first had Michael admitted to hospital I went to the police, which was a horrible thing. He was taken away in a paddy wagon [police car]. He was sitting outside because he used to go around and sit at the side of the house. He wouldn’t talk or make eye contact and he was just totally bizarre. His eating habits, everything changed about him. ... He was sleeping outside under the stars. The first time the police came they just took him. He didn’t know they were coming. I knew and I felt dreadful. (P17)

In summary, when participants became embroiled in crisis situations involving the affected family member they became overwhelmed by what was happening to both themselves and to the affected family member. During crises, several participants were also responsible for initiating the affected family member’s admission to hospital and this was particularly distressing for them and increased their feelings of being overwhelmed by what was happening. Finally, in concluding stage one, disruption of established lifestyle, of the problem being consumed, a case study of one participant’s experience throughout this stage is presented. The case study demonstrates the three aspects of this stage and allows the reader to relate to the participants’ experience of being consumed. The array of emotions and thoughts described by this participant are representative of those experienced by other participants in this study.

4.2.5: Case study highlighting a participant’s experience of disruption of established lifestyle

The case study begins when the participant’s family member was an adolescent. At this time the participant developed the recognition that something was wrong with her son Aaron:

We had difficulties with Aaron [son] starting at 15 or 16 years of age. Social difficulties high school was a nightmare for him. He is very intelligent but couldn’t cope with the pressures. He didn’t want to study, didn’t want to learn and eventually he ran away. (P9)
As a result of her recognition that something was wrong the participant became preoccupied with not knowing what was wrong with her son. She spoke to school counsellors and school psychologists about her son’s abnormal behaviour but found this was not helpful as the professionals did not think there was anything wrong with Aaron’s behaviour:

It is just like Aaron [son] didn’t exist. Yes, he has been here I [teacher] have marked him off as attending class. I haven’t seen any work he has done. The counsellor was like “well yes he is into Dungeons and Dragons and he’s been skipping school and these sorts of things. He is not handing in assignments and homework, but that is just ‘teenage stuff’”. You accept that or you assume and hope that it is true. (P9)

Aaron’s behaviour also caused a disruption to his family’s established pattern of life. She felt consumed by the increasing level of conflict between family members and her continual role of being a peacemaker in the family:

Everybody else [other family members] was falling apart. Forget about me during that time. I think I just cried a lot when nobody was watching. It was a constant battle to keep Rhoda [daughter] and Aaron [son who was unwell] apart so they didn’t fight and argue and upset each other or hurt each other. Whenever both of them got upset and angry, Aaron would become worse. If he was stressed about something he would get full blown [really unwell] and quite aggressive and storm around and yell. That would upset Rhoda and then she would react badly and she would say “I can’t handle it” and would go into her room. The whole thing was just a big nightmare. So I spent all of my time keeping everybody apart and keeping the peace and saying “Aaron you shouldn’t say this, that wasn’t very nice. You have upset her it has hurt her feelings and I think you should just leave her alone for a while”. I would then go to Rhoda and say “I have told him to leave you alone and if he doesn’t you have just got to ignore it, he can’t help it”. (P9)

The participant’s initial exposure to a crisis situation involving Aaron developed over a period of several weeks. There was a gradual escalation in his abnormal behaviour. In particular, the participant became concerned by the fact that he was increasingly losing contact with reality. She was overwhelmed by the fact that she could do little to prevent what was happening to both herself and to her son:

There were bizarre little conversations and that sort of thing. Aaron [son] used to sit and giggle to himself. I didn’t know it at the time but he was having conversations with this voice [auditory hallucinations] and it was telling him funny stories and things. It gradually escalated to the point where he didn’t want to come back and talk to me; he would rather talk to it [the voices]. He would stand and have psychic conversations with the dog. He would say, “Yes Magic [dog], I understand. It must be terrible”. The trees were people, their brains were the roots and the top part was their body. ... if they had big roots they were brainy and if they weren’t then they had little roots. He had a whole theory on trees. (P9)
After several weeks of observing the escalating bizarre behaviour, the participant felt consumed by what was happening and began to search for professional help: "You have to be pretty desperate to pick up the phone book and go right through the phone book to find help" (P9). However, she also became aware that "I can't go on pretending there is nothing wrong when I know there is something wrong" (P9). She contacted the Psychiatric Emergency Team (PET) on a number that she found, with difficulty, in the phone book, "the entry system into psychiatric services needs to be a lot more accessible" (P9). When she made contact with staff at PET she explained what had happened to Aaron over the last few weeks. However, the staff at PET informed her she must go to her family doctor for help:

"Look there is something wrong what do I do?". They (staff at PET) said "you have got to take him to a general practitioner [family doctor]". Aaron [son] said "there is nothing wrong with me I don't need to see a doctor". All right I said, "Well I would just like him to check you out because you are a bit thin". He said, "mum I am not thin, I am perfect". All right well I said, "I would just like a doctor to reassure me that you are perfect". That didn't work either he wouldn't go. He couldn't sit still. He couldn't sit to talk to me. He was up and down, up and down. I thought there is no way that I am going to get him to sit in the waiting room, let alone see the doctor. (P9)

After continual attempts to facilitate medical treatment, the participant realised she was unable to manage the situation without professional help:

Eventually, I went to my doctor and I told him what was going on. I said, "I can't handle much more of this". He said, "he's not well, you are right. I can't tell without seeing him but you have got to get somebody [psychiatric professionals] out [to the house]". (P9)

The participant by this time was consumed by the escalating situation and the impact of what was happening on her own well being:

I wasn't sleeping and I was physically going down hill. I didn't notice that, which is a bad thing. It wasn't until my husband took me aside and said "if you don't do something about this [son's behaviour] now we are going to be visiting you in hospital". (P9)

In desperation, she called the emergency number in the phone book to try once more to access help for her son:

In the end I rang up a number in the phone book [mental health community triage in her health region] and I said, "I don't know what to do. I can't get him to go to a doctor. I don't know that he is bad enough to call you because he is not violent. However, he is bizarre, very bizarre". Anyway they ended up sending out a
community nurse. ... She came out and she said "I will just talk to him for a minute". Aaron was in the kitchen making beef mince pies with chocolate sauce. (P9)

When the nurse talked to Aaron it was clear to her he needed to go to hospital. The situation was by now so overwhelming for the participant she had to withdraw from it in order to cope. She knew Aaron was going to be taken to hospital and was distressed by her preconceptions about what that meant:

I called my husband [Aaron's step-father] and told him they were going to take Aaron [son] to hospital and that he didn’t know about it [that he was going to hospital]. I can even cry about it now [participant cried]. I said, "I am really upset about this, can you come home?". He was there in half an hour and I said "look they [police] are going to be here shortly. I can’t cope with this, I am going to be up the backyard". I bolted, I couldn’t handle it. I was sitting up under the clothes-line in the back yard howling my eyes out [crying] as they were taking him away to hospital. You have all of those misconceptions and preconceptions about what a mental hospital is and what a mental illness is. You think they are going to lock him up in a room with bars on the windows and he is going to be there forever. How could I do that to my child? (P9)

The participant experienced recurring feelings of guilt when she rang the hospital the next morning to talk to her son. He was angry and aggressive towards her because she had initiated his hospitalisation:

The next morning Aaron was quite angry. When I called [telephoned] he said to me "I don’t need to be here but they won’t let me out. How dare you do this to me. They have locked me up and there is nothing wrong with me. Why did you do this mum? Why did you do this?" I was quite evasive. I wasn’t good at facing up to things then. To be honest I didn’t know how. (P9)

After a few days in hospital Aaron was discharged and returned home. The participant was told to contact the community nurse assigned to Aaron if anything went wrong. However, the participant received no other information or education regarding what was wrong with her son, what had happened to him, or what was likely to happen to him in the future. She also felt that she had not received any support from health professionals during the time Aaron was hospitalised:

Then they just discharged him you know. I didn’t understand how things worked then [she didn’t know the system or her rights as a carer]. They said, "there was no evidence to keep him in. There was no evidence to support the fact that he was psychotic. Yes he had been psychotic when the doctor saw him at the hospital but obviously he was over it". (P9)
Aaron returned home and remained there for several weeks. Then his behaviour became so disturbing that he was re-admitted to hospital for the second time but once again was only kept in hospital for a short period of time:

The second time they admitted Aaron to hospital they put him into the locked ward. Then after a day they put him into an open ward. He was there all of six hours before he disappeared [ran away]. I was angry; I thought how stupid. He thinks he is being persecuted. He thinks these guys [health professionals] are going to get him, of course he is going to run away. How could they let him out, why haven’t they locked him away? [participant spoke loudly] I could not understand, I was furious. I know now why they don’t keep them locked away but at the time I didn’t understand. I did not have a clue. I mean you just keep them locked up there and you look after him. You treat him and he gets well. That’s what you do with every other illness. (P9)

Aaron had two further admissions to hospital before he was officially diagnosed with schizophrenia. When the diagnosis was finally made the participant knew what was wrong with her son. When the participant made a commitment to care for her son she entered the second stage (which will be described later) of the basic social psychological problem. Aaron was placed on a community treatment order (CTO) under the 1996 Western Australian Mental Health Act. He remained in the community under treatment and with his own mental health case manager [specialised community mental health professional].

The above case study was used to outline the gradual escalation in Aaron’s behaviour from his established pattern of behaviour. It also detailed the participant’s feelings of being overwhelmed as she was physically and mentally affected by the experience. In addition, it highlighted the loneliness experienced by the participant as she tried to get help to manage her son’s worsening condition. Feelings of guilt, anger, and blame weighed further on the participant’s emotional and mental well-being. This was particularly so when her son was taken to hospital for the first time by the police. Finally, although not articulated as such, it was clear that this participant was being consumed by what was occurring.

4.2.6: Summary

The first stage of the basic social psychological problem, being consumed, was called disruption of established lifestyle. It was comprised of three aspects: the recognition that something was wrong, the preoccupation with not knowing what was wrong, and being overwhelmed. When participants developed the recognition that something was wrong with the affected family member they became consumed by their preoccupation with not knowing
what was wrong. Throughout this stage participants also became embroiled in crisis situations involving their family member and when this occurred they experienced feelings of being overwhelmed. Participants entered stage two of the basic social psychological problem when a psychiatrist officially diagnosed the affected family member with having a mental disorder. The second stage, called "sustained threat to self-equilibrium", will now be presented.
4.3: STAGE TWO: SUSTAINED THREAT TO SELF-EQUILIBRIUM

4.3.1: Introduction

Participants entered the second stage entitled, *sustained threat to self-equilibrium* when their family member was formally diagnosed as having a mental disorder. Several definitions of the words "sustained", "threat", and "equilibrium" were obtained to explain the meanings of this category identified through data analysis. The Merriam-Webster Online Dictionary (2001) defined "sustained" as "to support the weight of ... to carry or withstand ... to bear up under" (no pagination). The Macquarie Dictionary provided some additional meanings " to hold up or bear up ... to bear the weight of ... to undergo the experience of ... to endure without giving away ... to keep up or keep going ... to support or aid" (Delbridge et al. 1997, p. 2133). Definitions of the word "threat" were "an indication of something impending" (The Merriam-Webster Online Dictionary 2001, no pagination), "a menace or source of danger" (Delbridge et al. 1997, p. 2204), and an "indication of something undesirable coming" (Turner, 1984, p. 1183). "Equilibrium" was defined as "a state of balance" (Turner, 1984, p. 349), a "state of intellectual or emotional balance" (The Merriam-Webster Online Dictionary 2001, no pagination), and as "equal balance between any powers" (Delbridge, et al. 1997, p.717). Data analysis revealed that the *sustained threat to self-equilibrium* experienced by participants in this study encompassed all of the above meanings of the three words "sustained", "threat", and "equilibrium". Participants' experienced a *sustained threat to self-equilibrium* for several reasons: 1) the commitment they had made to care for their family member; 2) the realisation that the commitment to care may last for many years; 3) as a result of their feelings of grief and loss; 4) the personal cost of caring for their family member; 5) the realisation that they would be involved in managing further crisis situations; 6) the need to put the affected family member's needs before their own; and 7) the disruption to achieving their own planned life goals and dreams. This stage had four aspects: "the day-to-day caregiving commitment", "grief and loss", "the personal cost of caring", and "being overwhelmed". Each of the four aspects will now be presented.

4.3.2: The day-to-day caregiving commitment

*The day-to-day caregiving commitment* posed for participants a *sustained threat to*
self-equilibrium. The experience varied between participants but mostly included providing food, support, socialisation, monitoring the mental state of the family member, and seeing that person maintained an appropriate level of self-care. The day-to-day caregiving commitment for participants was influenced by whether or not the family member lived at home. Those participants who had the affected family member living with them reported they were more involved on a daily basis with the affected family member: "Your whole life revolves around getting her out of bed, getting her breakfast and then getting her to do something. Then you have to worry about who she is worrying" (P10). Some participants described their day-to-day caregiving commitment as very ordinary in that it was focused on maintaining a home life for the affected family member: "Our caring is maintaining a home life for her. ... Our caring is very mundane doing the washing and cooking the meals. ... We are always there. She knows it, the support is always there. We are very aware of that" (P2).

Other participants had to help the affected family member meet their physical needs: "There is a physical as well as emotional component to her illness. It is hard for her to shower and her attention span is short. She will burn down the house if I leave her. I do the cooking and washing" (P23).

For other participants, visiting their family member regularly was part of the day-to-day caregiving commitment: "I visit him four times a week, top up the food in his unit and have him over here for meals. I take him out occasionally so he has a bit of a life although I don't think he worries too much about that now" (P13, multiple carer); "Since mum [mother] has been in the home [aged care] it is really just taking her to appointments, taking her home for visits, and keeping an eye on things [making sure mother's care is managed correctly]" (P1, child/adult carer). Several participants were involved in helping the affected family member run their own household: "I do the washing, ironing, and cooking for her [daughter is now married]. I help out, I do a lot for her" (P11, multiple carer). These aspects were also reflected in the findings of Domenici and Griffin-Franceceill (1993) who reported that primary carers made a large day-to-day commitment to the affected family member. This commitment included, for example, caring for the affected family member's physical needs, offering extensive financial support, and organising social and recreational activities for the affected family member. In this study participants reported that the day-to-day caregiving commitment had two prominent components: being there for the affected family member and managing accommodation and financial issues.
4.3.2.1: Being there for the affected family member

Part of the day-to-day caregiving commitment was that participants felt the need to be there for their family member. For some participants being there was based on choice while for other participants it was based on obligation. However, irrespective of the reason, being there was very consuming and impacted heavily on participants' lives: "I have to be there. If I walk away what does her [daughter] future hold?" (P12); "I just did not see that I had a choice. I had to be there for her. I could not write her off [forget about her]" (P22, multiple carer); "I feel I have to be there if she calls and needs me. I don't go out anywhere as far as visiting. ... I won't make arrangements to go out for lunch until a day before, then I ring and say 'well yes I will come'" (P2). Jeon and Madjar (1998) also found in their study of caregivers to persons with a chronic mental illness that the caregivers were unable to make any long-term plans and lived from day-to-day because of the need to care for the affected family member. As a result, carers viewed their lives with less certainty and predictability. The impact of being there was further elaborated on by Frank (1991) who declared, "caregivers are the other halves of illness experiences. The care they give begins by doing things for ill persons, but turns into sharing the life they lead (p. 6).

Several participants in this study reported that they needed to be there to provide support for the affected family member: "Just supporting him, being there for him when he needs us" (P13, multiple carer). For other participants being there was necessary because the affected family member had no one else to care for them: "Louise has never got close to anyone. So it has just been I think always being there for her" (P5). Several participants explained that they could not walk away from the affected family member: "I could not be true to myself if I turned away from her [daughter]. I have to be there" (P23); "We made the commitment that we would be there through thick and thin [good and bad times]. Whether Jill [daughter] wanted it or not we were there. I remember her saying 'I don't want you here'. I would say 'I don't care I am here and that is that'" (P10); "And of course I have to be there for her" (P18); "I have to be there for both of them" (P19, multiple carer). Another participant after viewing a video, which illuminated the perspective of the affected family member realised she had to be there to support her daughter:

I saw this video on attention deficit disorder (ADD) called "FACT City". It was like seeing ADD through a child's eyes. How they get things wrong and how people react to them with anger and put downs. All sorts of other things like the teacher or other children how they react. It is seeing it through their eyes. That was very eye opening for me to see it through her eyes it gave me an enormous amount of empathy. I have kept that in mind over the years. If this [the situation] is really bad for me what must it
be like for her [daughter has depression, a borderline personality disorder and ADHD]. So of course you have to be there for them. (P20)

The need to be there for the affected family member was also identified by participants in Brown and Stetz's (1999) study of caregivers to people with AIDS. Some participants in their study suggested this role was natural and expected because of their relationship with the ill person:

There wasn't any other thought that crossed our mind because we had made a commitment to each other 8 years ago, nothing will ever separate us, I will push you around in a wheelchair if you will push me. Well, that came 40 years sooner than we thought, and we discovered that we really meant it. (p. 188)

Another participant from the Brown and Stetz study provided a different perspective of being there based on obligation: "simply because there is no one else, there is no one else" (p. 188). Similarly, Karp and Watts-Roy (1999) reported the need to be there for the affected family member was determined by how caregivers assessed their obligations to the affected family member. One participant from their study of caregivers to the mentally ill gave this perspective:

I really don't see what I am doing as duty. ... I mean, I know that I have a duty to make it through the snow-storm to work on a bad day. I see that as duty. I see that as being a good soldier. ... I won't let you down, and that kind of thing. I don't think any of those thoughts in relation to be here for him [son]. I just feel that it is very much an unfinished job. ... Responsibility is deeper [than duty]. Duty - you know exactly the limits of it. ... Responsibility, it's your essence. I mean could you sleep? Could your soul rest? Would your dreams be troubled if you really didn't meet your responsibility? (p. 475)

Several participants in this study expressed feelings of anger and resentment that they had been placed in the position of having to be there for their family member: "Yeah, I feel resentful occasionally. I would just like some space [get away] from this. I would just like some peace" (P21, multiple carer); "I felt that I was left lumbered with him [son who was unwell]" (P3); "While you [researcher] were just talking I was thinking about another thing. You feel a lot of anger and resentment that we [parents] are in this position [of having to care for their daughter]" (P2). Similarly, Karp and Watts-Roy (1999) found some carers were angry and resentful of being placed in the caregiving position, as one participant from their study explained: "Our anger, our disappointments have been so great. I mean, she [daughter] has totally destroyed our lives for us. And these are the years that ... were supposed to be our good years" (p. 482).
Some participants in this study began to question why the experience had happened to them and to feel a degree of self-pity. However, these participants kept their feelings under control, as they were frightened to really acknowledge how they were coping:

You feel that nobody else could have it this bad. There is a degree of self-pity in that. Why me? I asked that question Why me? I couldn't ever get angry about it; I couldn't let it out. It was always under control. I always had to have a stopper in the bottle because if I let it out it would have been really frightening to acknowledge how I was coping and how I was feeling. (P9)

Many of the factors determining the decision to be there for the affected family member made by participants appeared to be based on the established normative underpinnings of social order. One such obligation was described many years ago by Smith (1976) "to feel much for others and little for ourselves ... to restrain our selfish, and to indulge our benevolent affections, constitutes the perfection of human nature" (p. 71-72). While all participants in this study made their decision for different reasons, the data indicated this commitment was the most consuming aspect of the day-to-day experience, posing the greatest sustained threat to self-equilibrium. Extracts from interviews illustrate the extent of the commitment required with the commitment not allowing participants to be weak in anyway: "If I crack [get sick]. It is huge twenty four hours a day pressure knowing that in any way if I am fragile or vulnerable both of the girls will go to pieces" (P21, multiple carer). Participants continued to be there for the affected family member at their own expense: "I would sacrifice myself for Aaron [son]. That is ridiculous because then there is nobody to help him and I have to keep remembering that. ... It can become the centre of your life" (P9); "It [caregiving] is so consuming and I feel if I don't find some kind of solution I don't know what I will do" (P12).

Winefield, Barlow, and Harvey (1998) found that a major problem for carers was the affected family member's dependency on them and the need to be constantly available for their family member. For participants in this study, the strain of being there was most obvious in the parental-family member caregiver relationship because it most often involved a long-term commitment, from the first early disruptive behaviours and diagnosis to the current status of being worried and tired. For some participants the effects of this long-term commitment were further exacerbated by their involvement in continual recurring crisis situations: "I am tired, it [the caregiving role] has gone on for years and years. With this new surprise [participant has just found out that her daughter is seven months pregnant], it is times like this when it all happens at once [one crisis after another] that it is very difficult to go on, to continue" (P22, multiple carer). Participants were also consumed by the fact that nobody
really understood the impact on them of being there for the affected family member: "Social workers say 'I know just how you feel'. I say 'You bloody don't.'" (P3). Participants reported that one consuming part of being there for the affected family member was being readily available at a moments notice whenever the family member needed support. Participants found it difficult to have a social life or to go on a holiday:

The thing that I notice more than anything is we [parents] won't go out without telling Pauline [daughter]. We won't go out for a drive, in case the phone rings. Now we have a mobile so it is better. You really hate the phone ringing. I hate it. I absolutely hate that phone ringing. If it rings at night we freeze [daughter is now married]. A lot of the time there is probably no reason for it, but it is something that has built up over a lot of years. I mean even to go on a holiday is a drama. We went to Brisbane two years ago for a nephew's wedding. We got there and had a terrific time but for a while there we didn't think we would make it. As soon as we got there the phone rang. It wasn't anything specific. Being there, that is one of the hardest things, being there. ... At home I would get a phone call probably once a week to go to Pauline either at home or in the hospital. ... We worry, we worry about two flies flying up the wall [participant laughs]. If anybody is five minutes late then we worry. I don't think we ever used to do that. I think that's sort of the single most important thing [the greatest impact on them as carers]. (P2)

Participants also explained how they needed to be there for the affected family member to protect them from people who may take advantage of them. The following participant gave this description of her need to be there to protect her daughter from people she had met who were using illicit drugs:

Carol [daughter] would not take her medication and she had some friends that would come and see her and they were taking drugs [illicit drugs]. So I was always on guard, I was always there when they came. That was a terrible time knowing what her friends were like and sussing them out [checking to see what they were like]. (P18)

Other participants needed to be there to protect the affected family member from people they met who may abuse or take advantage of them:

Another time when we got hold of [found] Sky [sister-in-law] she was actually with a religious group. We got PET to collect her from there. I cried after that because it was an enormously horrible thing to do. You know you go to a church for asylum. We had reason to believe that she was in danger of her life because you know when she is in a schizophrenic episode anything could happen. We needed to protect her. We were fairly sure there was sexual abuse with her boyfriend. (P8)

Participants viewed periods of hospitalisation as times when they needed to be there for the affected family member: "My pet issue is smoking. Carol never smoked before she went in [to hospital] and she was smoking in there. The patients give each other cigarettes. I have to watch for that, the staff don't worry, so I had to visit everyday" (P18). Another
participant spoke of protecting her daughter from people she had met in hospital that would take advantage of her and use her when she was most vulnerable:

June [daughter] met up with some of the most revolting people [in hospital]. Particularly one man, he was the most revolting person I have ever met. He was mixed up with dope [drugs]. She met him at * [hospital]. I kicked him out of the house. ... She was horrified at me doing this to him. I said "well I would not do that to your friends but I don't consider him a human. I don't like what he is doing to you. I would like to protect you from that kind of person. You have just come out of hospital and are too fragile to realise what he is like". She has since realised what he was like he was awful. ... Yes well she had very low self-esteem and anyone that was happy to attach himself to her and of course he was pleased to. It was a sexual thing and she was promiscuous. (P16)

At other times participants needed to be there to protect the family member from their delusional, psychotic behaviours as they could be harmful to the affected family member’s health:

Aaron [son] is an asthmatic. He still has this idea [delusion] that if he gets very cold and continues to expose himself to the cold his body will be beautiful and his skin will be tight and he won’t age and he won’t get wrinkles. That is something that we haven’t managed to shake. He will stand outside at three in the morning. He will run out of bed and slam all of the doors and be frantic to get outside. Then he would stand in the middle of the back yard in just his shorts doing deep breathing exercises. And then, of course, he would spend the next day coughing and wheezing [with an asthma attack]. He would say, "no it is clearing my lungs out and it is making me feel good". It is really hard to protect him from hurting himself. (P9)

For other participants it was necessary to be there to protect the affected family member from their obsessional thoughts:

John [son] rang me once at work. He said, "How big is a new born baby and is it three dimensional?". I said, "absolutely, if you have ever had to give birth to one you would see how three-dimensional it was". He said "yes, but I just got off the bus and I'm just wondering if I might have been accidentally sitting on a baby". I said, "you would have known all about it". I said, "there wouldn't have been a baby on the seat it would have been in his mother’s arms". I said, "they are very substantial and you would have felt it. It is alright calm down. I assure you there was no baby on the seat". (P3)

Another aspect of being there was to care for the affected family member’s child. Several participants in this study were caring, or about to care, for their grandchildren and this increased their experience of being consumed: "I have heard from people that it is not unusual to end up caring for your grandchild. It is common" (P6). This was an unexpected new role and, for several of the participants, it posed a sustained threat to self-equilibrium. There was not only an increased workload associated with caring for grandchildren, but participants were
also distressed by seeing the affected family member not fulfilling their role in caring for their child:

Pauline [daughter] will come down here [home] all the time. She doesn’t do any work at home, nothing at home [daughter is now married]. She comes down here and sits here all day. She will have a sleep while I look after the little one [grand daughter]. They are the things that upset me most, that she is not doing stuff [cooking, etc.] at home. She has a little girl and I have cared for her ever since she was born. It takes up a lot of my time. I don’t have time for much else. (P2)

For the following participant the circumstances surrounding the need to care for her grandchild were overwhelming for her as her daughter was using illicit drugs and her baby was regularly placed “at risk”:

Rachel [daughter] was financially broke and into marijuana and she has a baby. We had to let her come home and live with us because the baby was at risk. She relegates all responsibility to me as soon as I enter the door each night. I have to remind her that she is her mother, and that I am her mother. It means that I am leaving work later and later and getting to work earlier and earlier, just to survive. I got home at six o’clock yesterday. I had not done anything, I had just stepped in the door. She handed me the baby and two minutes later she was out the door [gone out]. The baby needed to be fed and bathed. I go into her bedroom and there are dirty nappies everywhere. They stink and they [dirty nappies] just sit there. She makes no attempt to put them out [clean up]. I have to do it or go and get her to do it. She even puts dirty nappies in the bin in the kitchen. I have to put up with it because the baby is definitely at risk. I put up with it all so the baby is safe. I find it hard it begins to consume you. I am very insistent that nobody mind this baby [grand child] except us. I will make myself available if she is desperate to go out. I do not want this baby minded by anyone who will put her at risk. When I know that she is safe I choose to go out or do something else. But if I have not got confidence in her safety I have to be there for the baby. (P21, multiple carer)

Another participant (a multiple carer) had just found out her daughter was pregnant and the baby was due in eight weeks. She was concerned by the risk of birth defects that could be present in the baby due to the prescribed medication her daughter was taking for her epilepsy and mental disorder:

Jan [daughter] is pregnant. I am trying to not think too much about it at the moment. She knows she is pregnant but that’s about all she knows [daughter has very poor life skills and level of knowledge]. The baby will be at risk as Jan is very violent. I have only known about it for two weeks. It will be born in eight weeks. I don’t know how I will cope, but I know I will have to be there. I don’t have any choice. It makes me tired thinking about it. … Because of the medication she is on the risk of birth defects is horrendous. I don’t know it is hard. I don’t know what will happen. I take one step at a time. (P22, multiple carer)
In summary, the day-to-day caregiving commitment undertaken by participants in this study included providing food, support, socialisation, and monitoring the affected family member's mental state. It also included making sure they had an appropriate level of self-care. Being there for the affected family member to protect and care for grandchildren were identified as the most consuming aspects of the day-to-day caregiving commitment.

4.3.2.2: Managing financial and accommodation issues

Another component of the day-to-day caregiving commitment posing a sustained threat to self-equilibrium for participants was the financial impact of caring for their family member. Similarly, other researchers have identified that being there for the affected family member does not come without costs for the carer. Greenberg, Greenley & Brown (1997a) and Harvey (2001) found that between one-quarter and one-half of relatives reported their finances were affected by their caregiving commitment.

In this study, many participants experienced feelings of being consumed by the financial cost associated with caring for the affected family member: "There is a huge financial burden caring for her" (P2); "With Aaron there is always something. 'I couldn't pay my rent, I had an argument with the people I was sharing with, I have got nowhere to go, I have no money and the refuges are all full'" (P9). Other participants gave accounts of the financial implications of caring for their family member. The affected family members' poor financial management meant that participants were constantly meeting their day-to-day expenses for them:

Michael [son] does not manage his money. He is always running out of money. He has to be propped up all of the time. Sometimes it gets hard when I look at other people. I suppose I am his rock if anything happens. He has been in his flat for a couple of years and he has been behind in his rent that many times. He needs financial help all of the time. ... He has a bike. He got caught at Christmas time riding without a helmet [compulsory]. He didn't pay his $30 fine. He got a reminder, so he stuck it on his front door. He put it there for everyone to see as he thought they [the police] were picking on him. I paid the bill. ... He would have been dragged off to court if I had not paid the fine. (P17).

Participants, needed to continually replace items the affected family member lost:

Materially, it [caring] is very negative. Sky [sister-in-law] lost six watches. You know stuff like that. You buy tons of sun-cream, as they are prone to sunburn because of the medication. She lost sunglasses she lost about ten pairs of those so it can be costly. (P8)
For other participants it was the affected family member’s destructive behaviour that caused a financial burden. It meant they continually had to replace items in the household that were damaged by the affected family member:

I am on a pension and it is so difficult to do anything. We just survive. I may have scored a lamp [purchased a lamp] through a garage sale and April [daughter] will destroy it. I have got a room painted and she goes and redecorates it with a black pen. I finally got the kitchen renovated and she came along and punched holes with the corkscrew all through the bench top. I mean these bench tops only cost $800 and she destroyed it in seconds. So I don’t bother anymore. (P20)

Several other participants were concerned that in the future they may not be able to continue to pay for the care the affected family member required:

We pay for the psychiatrist [private psychiatrist]. We pay $60 a month on pills. It doesn’t sound like much but it all adds up. I don’t know if my husband is going to be able to cope long-term. I mean he is working now but he’ll be fifty-seven soon and he’ll retire one of these days. What if it’s the three of us? [continue to financially support daughter]. (P6)

Participants found that when the affected family member was hospitalised, their financial burden dramatically increased due to costs associated with health care:

It cost us a lot [the period of hospitalisation] it was such an expensive thing. Even though it was on Medicare [the government health system] the extras is what costs. She [daughter] had to have clothes, she would give them away, her radio was missing someone would take it ... It was very hard to control your possessions. ... She was very bizarre [in hospital] and she would ring me up 20 times per day. I didn’t know that when you reverse a charge how much it costs [daughter was calling from the hospital and reversing the charge of the call to her mother]. It was $2 every time she reversed a call. Our phone bills were exorbitant. (P18)

The increased financial burden associated with hospitalisation was particularly difficult for some participants who were on pensions:

Well I am on a pension and the medication is a lot and finances are tight. ... Trying to juggle having a child in hospital is difficult as it always costs more. In addition, you always have to leave money for them [as they go on activities from the ward that need to be paid for]. (P22, multiple carer)

The financial burden of caring was closely linked to the accommodation needs of the affected family member. If they did not live at home, participants were regularly involved in negotiating and maintaining appropriate accommodation for them:

Aaron [son] has been through every safe haven and refuge. He usually leaves without paying his bills. He needs somewhere [to live] that understands that money is a big issue and not having money is a constant problem because they are going to spend it.
... He was staying in *hostel* and decided to go with another guy *man* to Sydney. They were gone for a few days and then they came back and said to the people at the hostel "Can we come back?". That was the third time they had done that. The hostel people said, "no you can't, you can't, you leave this time and you can't come back, we won't let you in". Aaron said, "how can they do that, I'm paying rent? Just because I ask for it back half way through the week doesn't matter. It is my money why don't they understand?". He doesn't understand. He doesn't see that people have routines and they have set ways and they have rules to live by. He does not see that sometimes he has no choice but to follow them or respect them. (P9)

The type of accommodation available for the affected family member was also a source of concern for participants. Many participants felt guilty that the affected family member did not always have the quality or stability of accommodation they would have liked for them. Two participants described how offering the affected family member accommodation in units where there was a disproportionate number of people who have a mental disorder was not really meeting the goals of normalisation outlined in the philosophy of community mental health care:

There are some units available around the metro area and they all seem to be rented by mental patients *[people with mental disorders]*. ... I don't know whether the authorities think that is a good thing or not. They are not developing social attributes that will help them mix in with the community better. (P10)

He [son who is unwell] needs to be somewhere where he can go and not feel crazy. He is petrified of being seen as crazy. He says, "I don't want to be crazy [unwell]. I want to be normal and I don't want to hang around crazy people *[people who have a mental illness]*. ... Aaron is really biased against people with mental health issues. (P9)

Similarly, participants in Rose's (1997) study reported that government-supported housing was often rejected because it was unsuitable or the condition of the apartment was poor.

In this study, trying to find the affected family member meaningful employment was another problem for participants and added to their financial burden. They found their time was not made easier by the 'red tape' they encountered when dealing with government agencies: "When they start to get better they have got no friends, no job, nothing and it is a really long hard road for them. You really need support to help them find employment" (P3).

Another participant recounted her experience when accessing support to help get her son employed:

Michael [son] sleeps all day. Being unemployed he has no discipline and time means nothing. You can do as you like. He was at Workright *[government job support agency]* and Michael is now ready to be placed [find work]. I rang her [lady at
Workright] and she said, "well Michael has to ring me". He won’t go there as he believes he does not have a mental illness. We get nowhere. (P17)

In summary, the day-to-day caregiving commitment left many participants with the experience of being consumed by what was happening to themselves and to the affected family members. Participants were particularly consumed by the need to be there to protect the affected family member and by the financial cost of caring for them.

4.3.3: Grief and loss

Participants in this study reported feelings of being consumed by the grief and loss they experienced. The grief and loss encompassed two areas, the grief for the loss of the person they once knew or expected to know, and the grief and loss associated with a 'normal' family life.

4.3.3.1: Grief for the loss of the person they once knew or expected to know

Once made aware of the affected family member’s illness, participants experienced feelings of being consumed by the grief and loss of the person they once knew or expected to know as these participants described: "John is gone, I thought, I’ve lost him. That’s it, he’s gone over the edge he’s off the planet [really unwell]. He will never be the same again" (P3); "It is very hard to come to terms with the fact that Peter [son] won’t marry, he won’t have children of his own, or a house of his own" (P11, multiple carer). One participant reflected on her comparisons of the son she used to know and the one she now had:

I went to a funeral the other week. Michael’s [son] cousins are all getting on [achieving life goals] and Michael is getting nowhere. ... He is minding my budgie [bird] at the moment. He has taken the bottom out of the cage. He has got the cage on the floor with chicken wire around it. I said "Michael what on earth have you done that for". Then I remember he is just different, he is not the same as before. You know, Dianne, he is a very gentle, kind, quiet, a very quiet person. However, when he is unwell he becomes aggressive. It has been very difficult. You grieve for the one you have lost. You have to get to know a whole new person. This son I have now I think I know him but do I really? If I don’t go along with giving him money or food, he is likely to turn on me. Sometimes it is very frightening. (P17)

Several other researchers have identified the process of grieving as a prominent feature in the lives of families of people who have a mental disorder (Eakes, 1995; Chapman, 1997; Miller, 1996; Parker, 1993). These authors claimed that families grieve the loss of the person they once knew, their ill relative’s suffering, and the death of the hopes and dreams held for the ill person. Similarly, Marsh (1992) identified that "families who are living with
mental illness are dealing not only with the actual loss but also with symbolic loss" (p. 93). A participant from Marsh’s (1992) study of families of persons with mental illness gave a description of her experience of grief and loss, similar to that previously described by P17 (above) from this study:

The problems with my daughter were like a black hole inside of me into which everything else had been drawn. My grief and pain were so intense sometime that I barely got through the day. It felt like a mourning process, as if I were dealing with the loss of the daughter I had loved for 18 years, for whom there was so much potential. (p. 10)

Likewise, a participant from Karp and Watts-Roy’s (1999) study of caregivers to the mentally ill provided this account:

I gave up the future. ... She is really lost to us as the kid that we knew and the relationship that we had. This is gone. We are grieving the final loss. And they [doctors] said to me: "she might come back". And I said: "I can’t do that. I have to grieve that she is totally gone and that she’s not coming back in any sense that we knew her". Not that we will never see her again, but that she is not coming back in any sense that we knew her. ... Anything that I get from this point forward is a gift and not a disappointment. ... Oh, I sob my guts out. But I’m not sorry for me. I mean, once in a while I say: "this sucks. This is awful. Why do I feel so terrible?" But that’s, like, really rare. I lost this kid. I lost the last piece of this kid. I sob for my loss. I don’t sob for me. Does this make sense to you? (p. 481)

The uncertainty of never knowing how the affected family member was going to behave in the future was also an upsetting part of the grieving process for other participants in this study:

Sometimes Zoe [daughter] said "goodnight" to us [family]. Other days she didn’t say "goodnight". When she didn’t it was for no reason. It’s never ever going to be the same again. It is never going to be. The uncertainty. Your average parent hasn’t got that. They raise a child and they go out into the world and they are fine. ... Even if she’s out there in the world you never know when you are going to get that phone call saying "your daughter is in hospital". (P6)

Participants spoke of the cyclical pattern of grief and loss that resulted with each relapse:

It dawns on you that your daughter has gone. This is another person. You suffer a loss. It has happened three times. It happened last time when she took her overdose. I thought I have lost that girl that I had. This is someone else. I feel all the time that I am losing a bit more. (P12)
Perera (2001), in her study of parents' response to a child's loss of mental health, also described the cyclical nature of grief and loss. Although each episode of grief and loss is resolved, it is renewed with each relapse, as Perera explained:

Though each episode of sadness may resolve over time, renewed recognition of the losses at times of relapse and at times when the child is unable to achieve a developmental milestone may trigger this grief reaction again. This is in contrast to the traditional linear, time-bound mourning described by Kubler-Ross in her seminal work on Death and Dying and suggests a cyclical model of grief. A cyclical model is based on the assumption that families undergo a series of recurring, sometimes predictable and sometimes unpredictable stresses in relation to a child's illness that forces them through a series of continual adjustment. (p. 30)

Similarly, Miller (1996) and Parker (1993) found that while the affected family member's recovery was a time for joy, their relapses were occasions when the grieving process was renewed. Participants in Parker's study of the family as a caregiver to a person with a mental illness claimed the ups and downs did not get easier with each cycle. Brown and Stetz (1999) found similar responses from caregivers of people with AIDS. These authors claimed that most participants experienced emotions of hope and the acceptance of death in a serial or cyclical manner as one participant from their study stated "every time they'd give her a new medicine we'd have a new hope" (p. 189).

For participants in this study, a component of loss was grieving the loss of the family member's established lifestyle or anticipated life goals that were beginning to come to fruition when the affected family member became unwell: "Michael [son] was going to be a lawyer" (P17); "She [wife] had a very high level job before she became depressed" (P7); "John [son] had graduated in physics and maths. ... He decided to do astrophysics honours. ... After about six weeks at university he really began to fall apart" (P3); "Josh [son] had been awarded an apprenticeship. He was a very bright boy. Motor mechanics, cars were his real love" (P13, multiple carer); "I sent her [daughter] to a very high powered high school. She was very academic and there was a lot of pressure to do well. She did physics, chemistry, applicable maths, French, Art, and English in year eleven and twelve [final years of high school]" (P6); "Melinda [wife] was doing her degree at university, we both were" (P23).

Another aspect of grieving was the loss of the participants anticipated relationship with the affected family member, as this participant described: "The thing I miss most is, you see lots of mums and daughters meet each other for a cup of tea in Perth. They go shopping [together], I don't have that" (P2).
In summary, when they became aware the affected family member had a mental
disorder participants grieved for the loss of the person they once knew or expected to know.
Participants had established life goals and dreams for the affected family member and these
goals and dreams were shattered when a diagnosis of mental disorder was made on the family
member.

4.3.3.2: Grief for the loss of "normal" family life

Another loss identified by participants was the loss of a "normal" family life. This
grief and loss was experienced in two areas: impact on all members of the family and the
family's interactions in the broader community.

4.3.3.2.1: Impact on all members of the family

Most participants were consumed by what was happening to both themselves, the
affected family member, and to other members of their family. The majority of participants,
recounted experiences regarding how the affected family member’s abnormal behaviour
impacted on other members of their family. They described that every member of the family
was affected by what had happened. Similarly, Kinsella, Anderson and Anderson (1996)
stated that:

Mental illness is, by its very nature, a familial experience. A single family member
may exhibit symptoms, receive a diagnosis, and undergo treatment, but because of the
interdependence that exists within a family system each and every family member is
affected in some specific way. (p. 24)

In this study participants reported that other members of their family developed
interpersonal or emotional problems: "The impact is enormous, absolutely enormous. It is
equal to having someone in the family with paraplegia. It is equal in that it is so stressful. It
changed all of our lives, everyone in the family is affected" (P6); "June’s behaviour has had
an effect on other members of the family" (P16); "Other family members have been badly
affected" (P11, multiple carer); "They are gorgeous kids [children] and they love each other.
The boys have been badly affected by it [daughter’s illness]" (P18); "It [sons' illnesses] had
a dreadful impact on our other two sons" (P13, multiple carer); "They [children] found it very
hard. It really affected them. My sons moved out when they got married but the damage to
my daughter is there. She was very protective of me" (P23). Another participant spoke of the
impact of his wife’s behaviour on their two children:
My daughter is 18 years old and my son is 16 years old. They went through some very bad times. It might have been something as simple as "keep your room tidy". Rose [wife] would just scream at the top of her voice. That has happened a couple of times probably to all of us. It is pretty hard to take, to see your mum like that. My daughter won't forget what it was like. There are stages, I know I have seen letters in her [daughter's] room where she was writing to her friends and talking about suicide herself. My wife said to her once, when she was screaming at her, something about cutting her throat. That sort of stuff is very difficult for anyone and again I didn't really get her [daughter] any support. (P7)

A participant from Marsh and Dickens' study of family members of persons with mental illness (cited in Marsh et al, 1996) provided a similar account of the personal impact of living with a sister who had a mental disorder. The participant displayed a competent public persona that masked an inner state of anguish and turmoil:

I learned from a very young age that I should act mature and self-reliant and not cause any waves. I did not want to hurt my parents after observing how much my sister [affected family member] had hurt them. I kept my difficulties to myself and kept up a good front in part because I didn’t want my parents to be disappointed. I finally sought counselling at the age of 30. (p. 5)

In this study, participants reflected on how the amount of time they had spent caring for their sick family member had impacted on "normal" family life, particularly the time they spent with their other children: "Pauline has taken our time and our thoughts. We have neglected other members of the family" (P2). Another participant discussed how caring for her two affected sons had impacted on her relationship with her other two sons. She had missed many of their achievements because of the time taken to care for her two sons who were mentally ill. Her other two sons resented the lack of time she had spent with them:

Our third son was apprentice of the year. Three weeks after the presentation I found a letter in his bedroom about the presentation evening inviting him and his parents. When he came home I said "what is this Mike? You didn’t even tell me that you had won the award and there was an evening where we could have gone". He said "why would I tell you. You are too wrapped up with Josh [son who had a mental disorder]. Oh, Josh is sick we have to go to the hospital. Oh don't bother me now". ... My third son was very, very much affected by the illness. (P13, multiple carer)

In support of this aspect, Jones (1997a) found that carers reported constantly experiencing feelings of divided loyalties between the affected family member and other members of the family. This is similar to the findings of Parker's (1993) study of the family as caregivers to persons with mental illness. Parker suggested that siblings often felt angry as they perceived their needs were ignored because their ill sibling was the focus of their parents' attention. Jeon and Madjar (1998) also identified this aspect when they explained
that, despite the caregivers’ efforts to keep family relations intact, other family members were
affected by the presence of the mentally ill relative. One participant from their study of
caregivers to persons with chronic mental illness gave this description of the impact on other
family members:

Because of his illness it caused a lot of heartache for all the family. As a result, his
brother and his sister are over 30 now and still haven’t married. And so it’s affected
their lives in a very large degree because we are a very close family. ... I was very,
very torn between my husband and T. [the mentally ill son] and T and his brother and
sister, too. Because you ... you know, you have to try to do the best for all of them.
And there are times when the other members of the family get very badly neglected
because you’re spending so much time trying to help him, trying to accommodate his
needs. The other members of the family can miss out [on] what their lives can
become. (p. 701)

Four participants in this study had been brought up in a family where one of their
parents had a mental disorder. While only one of the four participants was currently caring
for their parent, all participants related experiences regarding their childhood: "I had mental
illness in my family which I had been running away from and taking drugs to escape from. I
was blaming my mum [who had schizophrenia]" (P14). The following participant’s father
and sister both had bipolar disorder:

I saw my sister in a bad state, [bipolar disorder] but I just felt sorry for her at the time
I thought it [family history of a mental disorder] was all over and done with, but it
obviously is never over and done with. She has got treatment and she has done well,
she is one of the best you could see [responded to treatment well]. However, my dad
[also had a bipolar disorder] committed suicide. At the end when he was very, very
depressed. (P16)

Another participant explained how she hated Mother’s Day as her mother did not do
any of the things traditionally expected. She felt that she was socially deprived when she was
a child because of her mother’s illness:

I always remember hating Mother’s Day [mother had schizophrenia]. All of the
Mother’s Day cards would be mushie and say things like "for all the things you do".
And I would say "you don’t do anything. You lie around in bed and don’t do
anything". That was hard because just finding a Mother’s Day card that didn’t say how
wonderful, energetic, and the things your mother does. Our mother didn’t do that, so
that was a bit tricky. We missed out on the social things and we were socially naive as
a result. I had never been to a restaurant until I was 14 years old and to me now that’s
just like unbelievable. ... I didn’t know what cutlery to use, I didn’t know what’s the
social norm. I didn’t know, as I had never done it ... I always remember that we did all
the cooking and washing. I left home when I was 18 years old and suddenly you
realise. It’s not until then that you realise that things weren’t so right, because then you
start to see a broader world. (P1, child/adult carer)
The following participant grew up with a mother who had depression and recalled that her mother lay on the couch all day. The participant spent most of her childhood alone and felt deprived of any quality mother-child interactions:

We never did anything. Our mother was always on the couch [mother had depression]. We cooked for ourselves. ... It is hard for children who are living with parents who have a mental illness. ... I am still connecting with the stuff that was missing in my childhood with my own mother [who had depression]. ... It is grief and loss and it is still pretty painful [participant now around 40 years of age]. ... My mother was like a dead person. The only time she came alive was when you kicked her. ... She used to just come home and climb into bed and we wouldn’t see her for days. She would howl and cry, like a dog. That is what our life was like for years, well always basically. We had to battle on alone. (P4 child/adult carer)

Cowling, McGorry and Hay (1995) stated that thousands of children are affected by maternal psychotic illness. A plethora of literature reports the link between a mother’s depression and disrupted mother-child interactions, strains on spousal relationships and family life (Handley, Farrell, Josephs, Hanke & Hazelton, 2001; Hay, Pawlby, Sharp, Asten, Mills & Kumar 2001; Murray & Cooper, 1997). Current research suggests that children whose parents suffer from a mental disorder are at a greater risk, both genetically and environmentally, of developing a mental disorder than any other group in the community (Drake, Racusin & Murphy, 1990). According to Kinsella et al (1996) “family conflict, financial problems, marital discord, social isolation, stigma, and lack of support, all common to families of people with mental illness, have been found to influence an already at risk child’s potential for pathology” (p. 25). Jones (1997a) found that children, growing up in a family where one parent has a mental disorder, often felt they were robbed of a parent and of their childhood. The nature of these relationships were long-term and children often took on caregiving responsibilities from an early age, as the following participant from Jones’ study of caregiver burden described:

My mother has been in and out of mental hospitals since I was 12 years old. My two brothers and sisters don’t want anything to do with her. They are younger and they don’t remember her before the illness like I do. Now I’m the only one that cares about her. ... I feel like I never really had a mother. She was sick ever since I can remember. My father raised us. I feel lucky that he was there. I remember her once spending 6 months in the basement when I was small. I thought it was different but it wasn’t until years later that I realised how weird it was. (p. 86)

Similarly, one participant in Marsh, Lefley, Evan-Rhodes, Ansell, Doerzbacher, LaBarbera and Puluzzi’s (1996) study of the family experience of mental illness provided this
description of anguish and loss: "my loss of a healthy mother, a normal childhood, and a 
stable home" (p. 4). Furthermore, Handley, et al’s (2001) study of children with a parent/carer 
with a mental illness found that these children struggled to make sense of what was 
happening when their parent became ill. They were confused and frightened and faced the 
uncertainty of not knowing what was happening to their parent. The authors found these 
children often blamed themselves for the parent’s illness; they had to deal with family and 
sibling conflicts, they were frightened they too might catch the illness, and they experienced 
personal feelings of embarrassment. The children in Hadley et al’s study hungered for 
information regarding the parent’s illness but were often left without this:

Nobody knew what was going on. I had no idea. I’d sort of had my mother ripped 
from me and she spent weeks crying and not going anywhere ... and you sort of never 
know how she was going to be. ... Nobody said, "Oh she will get over it, she will get 
good". I mean if somebody had said that, I probably wouldn’t have got quite so angry 
with her. ... It was just going to go on forever as far as I knew. (p. 225)

Participants in this study reported that all family members experienced some form of 
grief and loss as a result of living with the affected family member. When the affected family 
member was a parent, the grief and loss experienced by children was particularly significant 
and enduring. All four participants in this study who grew up with a parent who had a mental 
disorder were still dealing with resulting issues from their childhood.

4.3.3.2.2: Family’s interactions in the broader community

Another area in which participants experienced grief and loss of a "normal" family life 
was their interactions within the broader community. These interactions had three 
components: changes in established relationships, stigma (internal or external) experienced by 
family members, and the experience of bringing people into the home environment. The 
family’s interactions in the broader community increased participants’ feelings of 
powerlessness to control what was happening. The loss of friends sometimes occurred 
because participants no longer had time to socialise, particularly when the affected family 
member was the participant’s spouse:

I’m not sure, there are probably three close friends who have been very supportive but 
we have lost friends. Probably because whenever they have rung up I have had to 
make an excuse like we couldn’t do this or that. I explained as best as I could. I guess 
there are quite a few people who we used to socialise with on occasions that we don’t 
see anymore. And Rose [wife] had some friends and they don’t ring her. When they 
did she would either not be able to go or she did go and she found it difficult when 
they asked her "how have you been going?". So from that point of view if we didn’t
have these three sets of friends. Our social life, well our circle of friends is certainly not the same as before. (P7)

Mannion (1996) reported that there was a significant constriction of social activities when the affected family member was the carer’s spouse. Similarly, Fadden, Beddington and Kuipers (1987a) found that 71 percent of spouses reported a reduction in their social activities as a result of their spouse’s illness. This loss of social contact has also been identified by Harvey (2001) and Winefield and Harvey (1993) who found that between one-quarter and one-half of relatives in their studies reported restrictions to their social activities as a result of the affected family member’s illness. Participants in this study also recognised that the affected family member was often the sole content of their conversation when they did have contact with friends and that this may have been hard for their friends to cope with:

I think we lost friends because of the illness [caring for daughter]. I think we lost them we no longer had the interest or the time. Yeah! I guess that is why. Some of them were uncomfortable with it. Yeah! Yeah! But you know who your true friends are. The first five or six years [that daughter was ill] every time we went anywhere the sole content of conversation was Pauline. And that is all we ever talked about. (P2)

Stigma also changed participants’ normal family life within the community and the stigma was either perceived or experienced by participants. Family members did not generally bring people outside the family to their home. They felt embarrassed and conscious of the fact they did not know how the affected family member would react to their friends, as these participants found: "Joan [daughter] is 17 years old. She is very wary of forming a relationship with Jan [daughter who has a mental disorder]. Joan got a lot of teasing at school because of Jan. She only brings one girlfriend home" (P22, multiple carer); "Oh well we didn’t have any friends. We could never take anyone home to the house. We never mixed with people" (P4, child/adult carer); "I think we were always conscious of, embarrassed to bring friends home. The only people we saw socially were our cousins" (P1, child/adult carer); "They [family members] never brought a lot of friends home. They had friends in the neighbourhood" (P9); "It was very difficult to bring anyone home because you never quite knew what John [son] would do" (P3). One participant experienced stigma from her neighbour who appeared to pity her. In addition, her other neighbours did not talk to her because her daughter had schizophrenia:

Zoe ran away in her madness. This lady [a neighbour] she just looked at me. She couldn’t help it, she just looked at me in a pitying way. I suppose it was a nice reaction you know, much better than this other neighbour who won’t speak to me. I guess she thinks she is going to catch it or something. She avoids me and I have no
idea what I can do to help that. ... It is all over the media and you can’t make people believe that a mentally ill person is not [necessarily] violent. Even the two neighbours next to us, I have explained to them that if Zoe is out in the garden not to worry. I told them that she is more likely to run away from you than she is to confront you. But they are suspicious of her. These are neighbours, I know them but I am not social with them. They are a little edgy that this person lives close by. But I would probably be the same. (P6)

One participant described how she lost a lot of friends and neighbours who would walk on the other side of the road rather than confront her when her son was diagnosed with a mental disorder:

I had friends walk on the other side of the road rather than confront me. Even when Josh was in [hospital] reasonably close friends and neighbours actually crossed to the other side of the road rather than say "how is Josh, I hear he is in hospital?". That was pretty lonely. (P13, multiple carer)

Another participant found that because she was open and communicative, telling everyone what was wrong with her son, people stopped coming to the house. She had not been prepared for that response from friends:

I found that because I’m a talker, I told everybody [about her son]. I still don’t see there was anything wrong with that. However, I wasn’t prepared for the reactions. If something bothers me I talk it out. I have to, I have no choice, it is just the way I am. Anybody that would stand still and listen for a few seconds got an earful [what was happening with her son]. Then they [the people she had talked to] stopped letting their kids [children] come over. One of my friends she used to come here with a little baby. She said, "she wasn’t going to come anymore because she didn’t feel comfortable having a crazy [a person who had a mental disorder] around her baby". She just doesn’t understand. That really threw [upset] me. (P9)

The damaging effects of living with a person who has a mental disorder on social and leisure activities was first noted in 1955 by Yarrow, Schwartz, Murphy and Deasy (1955). Participants in their study felt stigmatised and socially discriminated against because of the affected family member’s behaviour. A number of other studies have also noted the restrictions on social activities of those who live with, and care for, a person with a mental disorder (Fadden, Beddington & Kuipers, 1987b; Leff, Kuipers, Kerkowitz, Eberlein-Fries & Sturgeon, 1982). Likewise, Heginbotham (1998) stated:

Society has always needed scapegoats. Mentally ill people living in the community are the most recent, but unlikely to be the last, in a long line of minority groups that society seeks to blame for its problems. Unfortunately there is more than a grain of truth in the public perception that mental illnesses are both unpleasant for the sufferer and can have damaging consequences for others. (p. 1052)
Phelan, Bromet and Link (1998) stated that family members who live with the patient can expect to be exposed to more stigma than those who do not. This occurs because the person’s acquaintances are more likely to know about the affected family member’s illness. In addition interactions with the acquaintance heightens the probability of contact with the ill family member. These authors also reported that spouses are exposed to greater stigma than parents because their social networks and those of the ill family member overlap to a much greater extent.

Several participants in this study reported that other family members also stigmatised the affected family member. Cook et al (1994) also found that among non-parental relatives, rejection of the affected family member seemed to be highest among sisters. In this study, participants reported that some members of the family ignored the affected family member, while others brought people home to see what they described as the strange person:

People don’t like to hear you say that you have a daughter who has a bipolar disorder. There is stigma even amongst her sisters in a way. One of them does not like to have any involvement in the whole thing. ... I try very hard to remove the stigma in any way I can. It is very difficult because June [daughter who is unwell] does not want me going around saying that I have a daughter who has a bipolar disorder. ... There are times when they [female siblings] don’t want to get involved in the whole thing. ... At one stage, I think it was just their way of reacting but a couple of them went to school and they were giggling over it [their sister having a mental disorder]. It was their way of reacting to it and they really did feel sympathetic for her. But they brought their friends home to see this strange person [daughter]. (P16)

One participant described how her neighbours reacted towards her because of her husband’s behaviour. They pitied her and they were concerned for her well being and safety:

When things were going very badly with my marriage, my husband would stand at the front door drunk and mad [husband although not diagnosed with a mental disorder was obviously unwell]. He would shout filthy things. The stigma of that, you just closed the door, I didn’t want the outside world to know about it. I never got close to neighbours but I do now [participant is now divorced]. Later from what I have heard they knew what was happening. However, there isn’t much they can do, particularly if I didn’t go out and seek help. We did have some trouble with my next-door neighbour, something my husband did. And they said, "you are mad you know". He said, "if you don’t go to the police or the doctors he is really going to do something that you are going to be sorry about". They indicated they felt so sad for me. (P5)

Another participant believed the stigma she experienced would have been much worse had she had a son instead of a daughter:

It is better that Zoe [daughter] is a female. Women have much less hardship than boys. It is the carers of men that have a rough time apparently. I guess it is the
hormones that don’t match. So they are not afraid of her physically because she is a woman. If she was a man I think they might be afraid of her physically. (P6)

The following participant was concerned by how the affected family member would react to people in the community who displayed a bad attitude towards them:

The only stigma that I am worried about is when Sky [sister-in-law] comes in contact with people who have a bad attitude towards mental illness as a disease. As a consequence her side effects and behaviours distress them, which in turn distresses her. (P8)

The third component of loss of "normal" family life in the community was the uncertainty for other family members when someone from outside the family was brought into the home environment. Participants felt uncomfortable and apprehensive about what may happen: "I have got a lot of friends and I couldn’t bring them home as I didn’t know how Michael [son] was going to behave. He can be very rude" (P17). "The last gentleman who took me out came to the house to get me. Jan [daughter] asked him ‘are you going to fuck my mum’? People are a bit put off he didn’t know how to deal with that. I didn’t know how to deal with that" (P22, multiple carer); "Robyn [daughter] feels threatened by friends that any of us [other family members] have. I don’t have any male friends. She gets angry if I even have a female friend. ... She really gives me a hard time. ... She goes into this abusive irrational state" (P12). As a result, participants found that many members of their family left home as soon as they could to get away from the affected family member: "Well they say from what I have heard the other kids [children] will leave home earlier" (P16). Another participant provided an example of a sibling’s "flight from the family":

Alan [son] dared to bring Macey [girlfriend] home for the first time. We had heard about Macey and he said, "mum well you have heard about Macey, this is Macey. ... Just then John [son who was ill] came out of his bedroom. Alan went to introduce Macey I think John was on the way to make a cup of tea. Suddenly he turned to Macey and said, "do you suffer from vaginal dryness?". He said it straight out like that. She said, "well as a matter of fact I don’t". I felt that was absolutely incredible. I also thought well we won’t see her again, we won’t see her for dust [participant laughs]. Well as frequently happens Alan left home just as soon as he could to get his social space. (P3)

Similarly, Kinsella et al (1996) found that "flight from the family" (p. 25), first identified by Lidz, Fleck, Alanen and Cornelison in 1963, was a coping technique utilised by well offspring and siblings as a means of dealing with the affected family member’s illness. In summary, participants grieved the loss of the person they knew or expected to know. In
addition, they grieved the loss of a normal family life and their altered relationships with neighbours, friends and members of their family.

4.3.4: Personal cost of caring

Another aspect that caused a sustained threat to self-equilibrium and left participants experiencing feelings of being consumed was the personal cost of caring for the affected family member. The data identified three components to the personal cost of caring: threat to participants life goals and dreams, changes in participants’ health status, and being alone.

4.3.4.1: Threat to life goals and dreams

Participants’ life goals and dreams were threatened by their caregiving experience. Several participants in this study had to give up working or studying to care for their family member because they were unable to manage to do both: "Darcy [husband] had to give up work because we just could not manage to care for Pauline [daughter] properly with both of us working" (P2); "I had to resign my teaching job at one stage. That was another cost I never thought I would do" (P21, multiple carer); "I would like to go back to work but not full-time. I am losing my skills. What opportunities are there for a 57 year old" (P23); "I am on a pension. I am unable to work" (P22, multiple carer); "I can’t even get a job. I could never leave April with a baby-sitter" (P20). Similarly, Chapman (1997) found that many of the costs of caring are hidden, such as having to make occupational changes and choices. Lefley (1987) claimed these occupational changes result not only in financial loss but also loss of opportunity.

Several participants in this study reported that their life goals and dreams were threatened because their marriage or relationship ended or was affected by their caregiving commitment to the affected family member: "Our family was pretty dysfunctional by then [when son was diagnosed with a mental disorder]. Noel [first husband] was unable to talk about it. He was womanising by this time. I knew it was the end. I guess emotionally we had been separated for a long time" (P3); "The boys’ illnesses compounded our marital problems, we are divorced." (P13, multiple carer); "By this time my husband was drinking a lot. ... I decided I couldn’t handle it all with her [daughter who was unwell]. I walked out of my marriage" (P5). Other participants were concerned their marriage may be threatened in the future by their caregiving commitment: "I don’t know if my marriage will continue" (P6).
According to Morse, Bottorff, Neander and Solberg (1991) caring is considered an essential component of being human. As early as 1927 Heidegger (cited in Wilkes and Wallis, 1993) described caring as a universal phenomenon that influenced the way in which people related to the world. Karp and Watts-Roy (1999) agreed, claiming that underpinning many of our public policies and ideologies about caring is the notion that family ties are qualitatively different from any others. However, the author claimed that in reality the sense of obligation, which marks the distinctive character of kin relationships, is much less reliable than generally acknowledged by society. Ties between family members are said to nurture and grow between some individuals more strongly than others and the practical consequences of these ties are, in reality, highly variable. For some members of the affected family member’s family the chaos and turbulence to family life was too great to cope with and they chose to leave rather than continue their obligation to their kin (Karp & Watts-Roy, 1999). Jeon and Madjar (1998), Nuefeld and Harrison (1995), and Parsons (1997) claimed caregiving, for elderly, physical or mentally disabled family members, was often the prime responsibility of one person and that person was usually female kin.

4.3.4.2: Changes in participants’ health status

Participants reported that caring for the affected family member had an effect on their health status: “I was admitted to hospital with a suspected blood clot in my leg. I think what it was it [caring for son when he was acutely ill] was just too much. It was all just too much for me” (P11, multiple carer). Another participant indicated that the changes to her physical health were directly related to what was happening to her daughter. She collapsed and was also admitted to hospital:

I just couldn’t face it [participant cries]. I just couldn’t face all of that [daughter’s behaviour during the initial crisis situation]. So that is when I collapsed. I couldn’t take it any more; it is like your whole world is crashing. So that was it. They took me to hospital too. I had just the weekend in there. (P6)

Several other participants reported similar changes to their health. One participant used the term “carer burnout” to describe the impact on her of caring for her daughter:

I went to a psychiatrist because I felt so overwhelmed by it all and he ended up diagnosing me with caregiver’s burnout. But he also said “you are what we call multi-disadvantaged in that you don’t have a husband, you are not in a situation where neighbours, relative or friends can help, and in terms of lack of support”. The upshot was “there is nothing we can do to help you, bye”. (P20)
Caring for a spouse or being a single parent caring for a child also impacted on the health of participants. The following participant was a single parent and a multiple carer who had no one to help her when she got sick. As a consequence, she continued with her caring role until she became very unwell:

I have had asthma this year but I don’t notice when I am not well. I just go on and on until I am really unwell. I am on my own so there is no one to take over when I am unwell. (P22, multiple carer)

Similarly, another participant gave a description of becoming very run down when her husband was hospitalised and she was left to care for her four young children:

I got to the stage when I thought I was going to die. I asked my general practitioner [family doctor] if he would put me in hospital because I was just so sick. He said “no” and so I had to get it together myself. I was not exaggerating I was so run down. I think it was to do with being run down from when Harry [husband] was in hospital. (P14)

Several participants in this study reported that they experienced symptoms of depression that they believed were directly related to their caregiving role: "I had to go on anti-depressants. So you fool yourself" (P9); "My daughter says my health is affected. She said ‘dad you have to understand I am living with two old people and both of them are clinically depressed’" (P23); "I got referred to a psychiatrist. He put me on to anti-depressants. ... I didn’t like that. ... But I accepted that I needed to do something" (P7); "I usually cry and I take tablets to calm me down. I often feel depressed" (P17). Another participant provided this account of her visit to the doctor and being diagnosed with depression:

He [doctor] was trying to focus on all three of us on once a month basis. If we had seen him once a day maybe he could have coped but once a month was a joke. We had been seeing him for a couple of years and he was convinced that I was depressed. We went through a year where he tried me on one antidepressant after another. But I hated them. I said, "I can’t do this". He tried me on several and eventually he came to the conclusion and said, "forget about it the depression is not in your head it is in your life". It is like a paranoid who is really being followed. ... The doctor said at the time "you can not live with this amount of stress and not have it severely affect you". Being with April [daughter] for 10 minutes is enough to make him want to walk away. So I don’t know how he figured the stress was going to pop out. (P20)

It was apparent that this participant was still unwell as she clearly described symptoms of depression in her interview with me, for example, "I used to sew all of the time and now I can hardly force myself to do any. It is like ‘sew’? Who cares if I wear rags? Who sees it and who cares" (P20). Three of the 27 participants I interviewed in this study described changes
that clearly demonstrated that their caring role posed a threat to their mental health. The following participant described these symptoms:

The other thing is the fatigue. The last couple of years I have felt an increased level of fatigue. Mark [husband] basically leaves it to me. I am the primary carer. He sits back but he is there for me at any time. Sometimes I feel burnt out. The emotions are so close to the surface. (P21, multiple carer)

Another participant explained that, despite expectations to the contrary, even when her daughter moved to a hostel her mental health did not improve:

Well I expected after she left [daughter recently moved to a hostel] that I would come to life again. Like the sleeping princess and that I could have a life again. But instead I feel like a burnt out shell of my previous self. I am not just the least bit interested in life. I have to drag myself and force myself to do anything. I have no interest in any involvement in life. I have nothing that I am looking forward to. I have no dreams, no goals, it is like I feel so weary so jaded, so cynical. There is nothing I want now but death. It is like a dream or goal as opposed to a dreaded thing. Other people fear death. I think "Oh God it is like peace, going to sleep and sleeping for ever". I saw on the Internet a list of bumper stickers and I found my new saying. Instead of "I don’t care, I don’t care, I don’t care" it is now "consciousness is the annoying bits between naps". That is the way that I feel. ... It feels like it is too late. I do not have the energy anymore it is too late. My saying, "I don’t care, I don’t care, I don’t care" has worked. I don’t care anymore. (P20)

The following participant described how she only did the bare essentials around the house. She was always tired and she had to force herself to do everything. She felt no pleasure in life and was clearly depressed:

I am always tired. I don’t spend as much time with them [children] as I would like. I am just too tired for them now. I just do the bare essentials. The little bit of time that I do spend with them is quality time but I feel very, very tired. My youngest is eight and she accepts it and she has never known any different. I do not neglect them but I feel so tired. It never goes away. I only do the essentials I have to drag myself to work. ... I feel no pleasure in life. ... The closeness in our relationship [with husband] is still there we still love each other very much. We are still very close. But I go through the stage when I do not want anyone near me and I know that it is me not him. ... I just feel that I want to be left alone. I do not tell anyone how I feel I do not show it. They would get worried, so I hide it. I am good at that. ... I have always kept things inside I never go into details about what happened. No one knows. (P24)

I then asked the participant how she felt about telling me this information. She replied:

I think it is important to help you to get something down. I think the biggest thing is that I have been blamed for it [husband’s illness]. I think that is a very important issue. I hope that it will help you to help others. I feel pretty good about that. (P24)

For several participants the changes in their mental state as a result of caring for the affected family member were so great that they questioned their ability to continue with such
care. In extreme circumstances, it led these participants to view death as their only option. One participant graphically described how her own death appeared to be her only solution to her experience of being consumed:

A few years after April [daughter] was diagnosed, she got really bad for a few weeks. She was so aggressive and she was destroying everything. I decided I could not take it any more. I decided to try a coward’s way of suicide, to eat myself to death. I started putting twice as much butter on my toast. Even though I would look at it and go "yuck" I would force myself to eat it, things like that. One day when I was driving I would look for something to plough the car into. I was like looking for a concrete embankment or something that would ensure instant death. I was looking around at poles and working out what speed I would need to be going to ensure that I died. I was horrified at myself that I was thinking this way, but the thoughts came unbidden. There were voices saying, "listen to yourself, you are mad. What are you?". I realised then that I am too much of a coward. The coward’s way is to do it where I have it taken out of my hands. I wanted something to kill me because I was too much of a coward to do it myself. I thought well I won’t go to the doctor, I won’t have a pap smear, and if there is anything going on [problem that participant should see a doctor about] I will ignore it. I will continue to smoke; I will eat tons of food. This would all exacerbate my diabetes and by the law of averages I would die soon. I mean you couldn’t live like this forever. (P20)

Similarly, Hill (2000) provided a further example given by a participant in his recent study of carers regarding changes to their mental health posed by the caregiving role:

The more I asked for help from the Department of Community Services, the more they said they couldn’t. I was losing it, and nobody was there to help me. We had no life. It would have been easy to put us all in the car and close the garage and switch on the engine. (p. 23)

Grad and Sainsbury, as far back as 1963, noted changes to carers’ physical and emotional health as a result of their caregiving experience (Grad & Sainsbury, 1963). A recent study of 1500 carers (Hill, 2000) found that 85 percent of respondents reported their level of mental or physical health was worse or much worse than before they commenced their caregiving experience. According to Hill the major effects of caring reported by carers were "being tired, exhausted, back, neck and shoulder problems, high blood pressure or other heart problems, stress, and disturbed or loss of sleep" (p. 23). Baxter and Diehl (1998) and Guarnaccia & Parra (1996) also identified physical problems in carers, such as sleep disturbances, lack of appetite, and psychosomatic complaints.

In summary, several participants in this study found their physical and mental health was altered by their experience of being consumed and this was further supported in the literature. Several of these participants, at the time of being interviewed for this study, were
still experiencing feelings of depression resulting from their experience of being consumed by their experience.

4.3.4.3: Being alone

Another component of the personal cost of caring that posed a sustained threat to self-equilibrium for participants was participants’ feeling of being alone: “When it all boils down, Dianne, you can’t lean on other people. You are alone. Your problems are your own twenty-four hours of the day and you must face them alone” (P11, multiple carer). Other participants stated that even the most caring people really did not understand what they were going through and, therefore, they were alone: "I was still going to church. It was of some help to me. However, so few people in church, even the most caring people, have any idea of what it was like. You are alone" (P3).

Several participants found their experience of being consumed was increased because their spouse or partner had left all of the responsibility of caring for the family member to them. "My husband was completely hopeless [helping to care for son]. ... I suppose it is wrong to say it but I was resentful that he was not aware of how poor old Mary [participant] was coping with it all” (P13, multiple carer); "Here I was coping with three children [two of the three children have a mental disorder] and he [husband] was going to transactional analysis [therapy sessions]. Not wanting sympathy but I would have liked a little bit of understanding." (P11, multiple carer); "Well I have been the main carer for all of these years with not much help from her father.” (P12); "I felt so alone, I was by myself” (P5). Similarly, Yamashita (1998) in her study of family coping with mental illness described the lone struggle of participants: “the majority of whom were mothers, experienced alienation from their husbands, who were described as denying their son’s illness and therefore holding unrealistic expectations of them” (p. 520). Likewise, Chesla (1991) identified four main styles of caregiving and interaction used by parents of young adults with schizophrenia. Fathers frequently used one of the four styles called "distanced care" entrusting the direct role of caregiving to their wives.

For several participants in this study, their feelings of being alone became overwhelming when they were left alone to manage their family member’s escalating abnormal behaviours:

I could see the signs [of daughter becoming unwell again] because she started to get a little jealous of her boyfriend. Things deteriorated in the flat [daughter was living with boyfriend]. She would just sit there all day. ... I knew, there were signs that it was
happening again [daughter was relapsing]. One night Dan [daughter’s boyfriend] rang up and said, "look come and get the bitch [daughter]. ... He had rung me up at work and said, "he couldn’t stand her". She wasn’t working, she wasn’t cleaning the house, and she wasn’t doing anything. She was just depressed. So I went alone one night to the flat to see Carol [daughter], as I knew she needed help. I decided to take her home with me. Dan had friends over and he wouldn’t help me. She started to attack me, she beat me up. She was quite strong and very violent towards me. She didn’t want to go, she wanted to sort this out with Dan. He would not talk to her. So when nothing was going to go her way, she kicked, shoved, and pushed me. Dan [boyfriend] did nothing to stop her. I asked him if he would walk us to the car but he wouldn’t. I finally got her out the door of the flat. We had to walk as I had parked the car up the road. She ran off down Charles Street [a busy street] playing chicken with the cars [running in front of cars]. I was saying "please Carol don’t do this". It was just awful, just terrible. I felt so alone. The cars would stop and she would run up and scream in the car window "my mother is trying to kill me". Finally, she became exhausted and she threw herself down on the footpath. I said, "come on please let us walk to the car". I couldn’t lift her she is a big girl. I finally got her to the car. I was beside myself. (P18)

Other people’s response to their family member also left participants with feelings of being alone. One participant believed that she was the only one who wanted her son to live when he took an overdose while on a family holiday. She was distressed by her husband’s response to her son’s overdose:

We [family] were staying in a caravan on a farm on holiday. Peter [son] was very unwell. Then he told his sister that he had taken all of his tablets. ... He had taken a week’s supply. ... It wasn’t that I was careless. ... My husband just wanted to let him go [wanted to let son die from the overdose]. I said, "I can’t do that, I can’t do that". I was so upset. So anyhow we had to dash to hospital X. By this time he was well and truly showing signs that he had taken the whole lot of his tablets. It took eight staff to hold him down and pump out his stomach [perform a gastric lavage]. I stayed at the hospital with him until he woke up. He said, "mum I didn’t take enough". He would have done the same thing if he had of been at home. He has tried several times since. .... My husband, he wanted me to let him just go. I couldn’t let my son die. I couldn’t. (P11, multiple carer)

While many participants experienced feelings of being alone, the loneliness was also due to the fact that participants were unable to share their experiences with others. This was expressed in various ways, such as, "I never spoke to anyone about it. It was just so difficult. Not even my father, no one" (P24); "I have friends from way back and they sometimes say to me now, because I never really confided in them, they watched what was going on" (P5, multiple carer). Another participant gave this description of not talking to neighbours and verbally isolating herself and her affected family member within her own house:

A lot of neighbours mind their own business. I also found the stranger [more ill] Michael [son] became the more I withdrew. You go down with them to a certain
degree. I am not ashamed of him but you try to protect them. You try to cover it up. You try to keep it within your own house and I would never discuss it. (P17)

The Brown and Stetz (1999) study of carers to people with AIDS revealed similar findings. The authors claimed that while caregivers were challenged to understand the reality of their situation and regularly dealt with a range of emotions, some caregivers chose not to discuss what was happening to themselves and the affected family member with other people. Some participants from the Brown and Stetz study said they didn’t want to "bother" other people whereas others said, "it was just not my style" to share outside the family (p. 188).

Finally, because many participants in this study experienced feelings of being alone, they were concerned with what would happen to their family member when they could no longer care for them. Several participants were caring for adult children in their thirties and forties: "I won’t always be here" (P11, multiple carer). Another participant who was also a multiple carer, had concerns regarding the future of her sons when she could no longer care for them:

My big worry is what is going to happen when I am no longer here. If you say to me "what is the major concern of the whole thing"? I would tell you it is that I am worried about what happens to them when I can’t do it anymore. What the hell is going to happen to them. Brad [other son who is ill] is much younger. (P13, multiple carer)

Jones (1997a) and Winefield et al (1998) reiterated this finding. These authors reported that a main concern for carers was what would happen to the affected family member when they could no longer care for them. One participant from Jones’ study on caregiver burden gave the following description of her concerns:

I’m 65 and my husband is 68; our daughter is 38 and I know we’ll die before she will. What will happen to her? I talk with her everyday and I give the allowance (money) to her. She can’t handle more than one day’s allowance at a time. When she has a bad day we talk for hours on the phone. There is no one else that will do that. Four years ago she tried to take her life and I’m afraid she will do that when we are gone. (p. 85)

Participants in this study were also concerned that in the future other family member’s lives may be affected by caregiving responsibilities to the affected family member:

Well the future is very uncertain, because I have no idea whether she is going to be dependant on us and live at home for the rest of her life. She has been a very quiet person, always has been since the time she has been tiny. So it has not got anything to do with the illness, the quietness. So we may have her there for the rest of her life. That is definitely going to impact on our lives. ... I have no idea if the marriage will continue. There are enough uncertainties in life. What scares me a bit is if I lose, if something happens to my marriage, I can’t work full-time. If my husband left we’ll be
on the carers' pension and what she makes which isn't a whole lot. I don’t really think she’s going to be able to work. ... I have told my other daughter that she must live her own life and not worry that she will be left to care for her sister. (P6)

In summary, the personal cost of caring posed for participants a sustained threat to self-equilibrium. Caregiving to the affected family member threatened participants' life goals and dreams and, in the extreme, altered their established way of life. For some participants the personal cost of caring was evidenced by changes in their health status. Other participants felt alone and this feeling increased their experience of being consumed. Participants were particularly concerned about who was going to care for the affected family member after they were no longer able to do so.

4.3.5: Being overwhelmed

The last aspect that posed, for participants, a sustained threat to self-equilibrium was their experience of being overwhelmed. This occurred when participants became involved in recurring crisis situations. While being overwhelmed was an aspect experienced in both stages of the problem of being consumed, the data suggested that it occurred in each stage for different reasons. In the first stage, feelings of being overwhelmed were linked to participants’ lack of preparation for managing the evolving crisis situation. They did not know what was wrong with their family member, and they had no experience in contacting emergency services or interacting with health professionals. During the second stage participants experienced feelings of being overwhelmed for two main reasons: participants were frightened by having to manage the affected family member's violence, and they were overwhelmed by their own response to the affected family member during the crisis situation.

4.3.5.1: Being frightened by having to manage the affected family member's violence

The crises occurring during this stage were similar in onset to those occurring during stage one of the basic social psychological problem. Some crises occurred suddenly while others were more gradual in onset, as this example illustrated:

I thought John [son] was going to university. He was still leaving home in this old car and driving off as if he was going to university. Then a letter came for him from the administration at the university. After two weeks he still hadn't opened it. I said "John you have got to open it". He ignored me. Eventually I found out that he had not been going to university. He had been going to King's Park and sitting on the grass. Then over the next few weeks he started not being able to speak on the telephone. He also was unable to answer the front door. The blinds were always pulled down in his room. I used to think, "how could you possibly read when there was no light?". He always
left by the back door. Then one morning he started asking me to check the front seat of his car to make sure there was no one there. He didn’t want to sit down if there was someone already in the driver’s seat and offend them by sitting on top of them. So he gave me an umbrella and said, "could you wave this backwards and forwards to see if there is anyone there". He couldn’t trust reality. He didn’t trust what he was seeing. I knew then it [a relapse of the illness] was happening. (P3)

While many participants had developed knowledge and skills to enable them to deal more effectively with crisis situations, they still found that they became overwhelmed by having to manage violence. Several researchers have also noted that the severity of symptoms displayed by the affected family member influenced carers’ level of distress (Cook, Lefley, Pickett, Bertram & Cohler, 1994; Biegel et al, 1994; Greenberg et al, 1997a; Jones, 1996; Mueser, Webb, Pfeiffer, Gladis & Levinson, 1996; Winefield & Harvey, 1993). In addition, Porter-Smith (2001) found that relatives who reported higher levels of symptomatic disturbance in the affected family member, for example, hallucinations, bizarre behaviour and social withdrawal, and who reported these symptoms as troublesome, had the highest level of psychological distress.

In this study, some participants experienced feelings of being overwhelmed when they were confronted with sudden out-of-character changes in their family member’s temperament. One out-of-character change was aggression, and participants stated they were frightened because they no longer really knew the person for whom they were caring. Therefore, they were unable to predict how they would behave. "I never believed that I would ever see my daughter well again. She was somebody else" (P10). Another participant recounted how she was never really sure how her son would react to her:

I said to Michael [son] "I have to get you some decent trousers for the funeral". The next day when I went to pick him up he was inside [his flat] but he would not answer the door. I was outside [his flat] ringing on my mobile. The phone was ringing and he would not answer it. I had to leave him and he didn’t go to the funeral. I would rather have him say, "I don’t want to go. Bugger off [go away] and leave me alone". I really was angry. Anyhow that night he came around [to participant’s house as he had a key] about a quarter to two in the morning. When I woke up, he was shining a torch in my face and asking me to make him a cup of coffee. He came into my bedroom, he had a torch, and he was shining it in my face. That was really unnerving [frightening]. He has a key because I work shift work and there is no food in his cupboards. At least he can get himself something to eat if he comes here [son lives only a short distance from mother]. That spooked me. I think it is harder to watch someone go through it than to go through it. When he is unwell I don’t think he knows. They turn on people who they are very close to. It is a hard thing to cope with. You don’t know when something is going to happen to you. You really do not know them anymore. (P17)
The following participant gave this account of being frightened by her son’s aggression during a crisis situation:

Before we took Peter [son] to hospital Y I put a mattress down on our bedroom floor and locked the door so that he wouldn’t run away. When really running away is not running away from us. It was running away from what is inside their head. It was very frightening for me, particularly his aggression. (P11, multiple carer)

One participant from Yamashita’s (1998) study of family coping gave a similar account of being overwhelmed by fear because of her affected family member’s violence:

When my son was getting discharged from hospital, I sat in the hospital corridor and waited for the doctor. When the doctor came out, I begged him not to let him come home because of his violence. He didn’t listen to me. Since he [her son] came home, he has attacked me and tried to kill me so many times. (p. 519)

The risk of violence to carers was also highlighted by Vaddadi, Soosai, Gillear, and Adlard (1997) who claimed that "given the association between mental illness and violence, more attention should be paid to the risk of domestic violence faced by the relatives of mentally ill people, a significant number of whom may be elderly and particularly vulnerable." (p. 313). These authors found that 50 percent of relatives in their sample had suffered actual or threatened abuse from the affected family member and the likelihood of abuse increased if the affected family member was schizophrenic, had a history of drug misuse, particularly misuse of cannabis, or had a poor relationship with the carer.

While not all participants in this study were exposed to violence, some became overwhelmed by the fear that their family member might be violent in the future. This participant was concerned because there were guns in her house and that, for some reason, her husband may in the future use them:

Tony [husband] never hurt the girls or me he only wants to hurt himself. But I am worried that he might get up one night and shoot the girls, or shoot me. We have guns, they are locked up and he does not know where the key is. I can’t get rid of them, as he would get mad. (P24)

Some participants were exposed to violence for the first time when they were in the second stage of the problem of being consumed. As they had no prior experience in managing their family member when they were violent, they were frightened and experienced feelings of being overwhelmed by what was happening:

Louise [daughter] had been going on for a couple of days [manic]. Her brothers were frightened to come into the house. She was not usually violent. The general
practitioner came to give her an injection. When she arrived Louise threw every glass in the kitchen from one end of the kitchen to the other. We had to get the police. (P5)

For other participants this violence occurred in addition to other crisis situations occurring in the family. One participant was frightened when faced with having to manage her son’s violence in addition to caring for her husband who had only recently returned home from hospital following a stroke:

James [step-father] had just got back home from his first big stroke. We were sleeping in what had once been the carport. Because it had been a carport before it had been made into a big bedroom. It was right at the top of the drive. ... I was trying to get this rose garden established and John [son] was saying the watering annoyed him. James said, "sorry about your needs John, but we need this rose garden too". John said, "you will be sorry". I didn’t know what that meant at the time. He went to see one of his school friends and then at three o’clock in the morning it happened. James had only been out of hospital for two days. We heard this roaring and banging. Suddenly the front of John’s car came through our bedroom window. We leapt out of bed and I thought James was going to have another stroke. It was really scary and I said, "call the police". I saw John he had this great big commercial sized industrial spade. He was smashing James’ car, the windscreen, the lights, everything. The look in John’s eyes, I can understand how they believe in devil possession. He looked absolutely possessed. By then James had got the police to come. It was awful; it was such a shock you know. I was worried for James. ... I had never seen anything like that in my life before. James was shaking. My legs were like jelly. The police came quite quickly. (P3)

Several participants had been managing episodes of violence in their family member from the time the person was very young. While they had developed skills in managing the violence during their exposure to it in stage one, it was the apparent unhappiness, distress, and misery in their family member that was now overwhelming them, and left participants with feelings of being consumed, for example: "She attacked me with a knife, she kicked in a glass plate windows. She could really be out of control through her own frustration, her desperate unhappiness. It was distressing to see" (P15).

Another participant discussed her daughter’s need to break things. While it was distressing for the participant, she preferred that her daughter was aggressive domestically rather than in the general community:

These [participant points to windows in house] are not the real windows, they just fall out. Joan’s [daughter] room has perspex in [the windows instead of glass]. I don’t fix it up anymore it is a danger. I don’t care what it looks like. You live with it. Jan [daughter who is unwell] needs to break things. It is distressing to see but it is better she does it [destroy property] at home than outside [the home]. She has a need to break property. (P22, multiple carer)
The impact of other circumstances in the participant’s life at the time of having to manage violence in their family member may have also increased their experience of being consumed and overwhelmed. One participant had just returned home after being ill to be confronted by her son, who had a history of violence. He was accompanied by a patient and they had both left the hospital and broken into her house. While she had developed skills in managing her son’s violence, she had no experience in managing violence in the person accompanying her son. Furthermore, she was physically and mentally unprepared to manage a violent situation:

When I got home the phone was ringing. I was battling to open the door. My daughter helped me. I pushed the front door open and there was Peter [son]. Now he had brought a girl home with him from the hospital. They had broken in; the door had a huge hole in it. There was no food in the house. I had been with my sister and my daughter for two to three weeks. I had a bad leg and it wasn’t healing. Anyhow they [Peter and the girl] had been there since half past seven the previous night and had forgotten that I wasn’t going to be here. He knows that he is not to come home if I am not there. The girl had slept in my bed she had stubbed her cigarettes out on the carpet. She had used my towels and dropped them all over the laundry. Of course there wasn’t any food to eat. Anyhow Peter was no trouble, but he had also had no medication. She was very aggressive, like he used to be. I had to get the police to come, I could not manage the situation and the staff at the hospital did not help at all. (P11, multiple carer)

Another type of crisis situation that was overwhelming for participants was addressing the affected family member’s recurring suicidal behaviours. This behaviour frightened participants: “She scared me once, we were out walking and, she was talking about suicide as though it was talking about the weather. That scared me because she was just talking about it so easily and casually” (P7). Similarly, Jones et al (1995) found that caregivers in their study were distressed by their affected family suicidal threats and gestures. In addition, participants in this study reported they constantly had to watch their family member: "Rose [wife] made six attempts [overdose]. ... I knew she was pretty bad [depressed]. Sometimes she will tell you what she is thinking, other times she won’t. I have to watch her" (P7). Finally, monitoring the affected family member’s behaviour was overwhelming because participants had to do it unobtrusively so their family member did not know they were being watched:

Barry [husband] had been on a low [depressed] for about two weeks. He was really low, not doing anything, not talking, not seeing anyone. Then all of a sudden he seemed to change within a few hours. He was planning things he was really preoccupied. ... I could see he was in the garage but I could not go out there. I was scared that if I did he would get suspicious. I did not want him to realise how much I
was aware of what he was doing. ... I knew he was up to something. He had left a note [suicide note] I found it later. He had taken some poison, a mixture of things and then he drank some whisky on top of it so I would not smell it. When he came inside I could smell it. I knew he was up to something but I did not think he would do it then [try to kill himself]. I thought he would wait until we went to bed. I knew the smell, it was a spray he uses in the garden. I could not figure out where the smell was coming from. I thought he had been playing with poison because I could smell it on his shirt. I said, "did you take something"? He said, "No, No I didn’t take anything". He had drunk the alcohol so I could not smell the poison on his breath but I could smell it on his chest. ...We went to bed that night and I could smell the poison on him. He woke up at four in the morning vomiting and I knew straight away that he had taken it. I got the ambulance immediately and they took him to hospital. (P24)

4.3.5.2: Being overwhelmed by personal reactions to spouse

While participants were overwhelmed by their spouse’s suicidal behaviours, for example, repeated overdose attempts, they were also overwhelmed and distressed by their own responses during this time. One participant felt guilty and disturbed by his thoughts regarding his wife’s suicidal behaviour. He had recurring thoughts that he should let her kill herself if that is what she really wanted:

Sometimes over the past four years, when Rose has been very depressed and suicidal, when she has gone out walking or driving in the car she has been real late coming home. I feel really bad about how I was thinking. I probably did it last year too. I sort of, I didn’t purposely give her a call on her mobile to see where she was. There were some occasions where I probably thought that if she was going to kill herself I would give her room, rather than be there. I don’t feel good about that because she doesn’t deserve that. I guess it was because things were so bad, I thought at the time that it was a solution for myself. I was finding it very difficult to cope. ... I would stick close to her most of the time when she was like this. However, there were times when she was late and I thought I would just leave it [not call and see where she was]. In the back of my mind sometimes I thought that actually was a solution. (P7)

Another participant was scared and frightened by similar thoughts towards her husband’s suicidal behaviour. She was scared by her thoughts and could not understand how she could have such thoughts:

I was going to wait for Barry [husband had been visiting a friend]. When I heard his car coming I jumped into bed and pretended that I was asleep. He came inside pretty quickly and then he came in to check me [looked to see if participant was asleep]. I had turned the light off and turned on my side so he could not see me. He came inside [into the bedroom] to check me, and then he went back outside again. This was a petrifying time because I did not know what he was up. Then he came back inside, but he did not get changed. He threw his dressing gown on over his clothes and he went outside again. It was very scary the whole bed was shaking. I did not know what to do. Should I see what he is doing? Should I let him go and see how far he will go? By this time I was totally exhausted. The hard part is that maybe you
think; well he may be better off doing what he wants to do. That is the hardest part. I could not understand why I got to the point where I thought that. I asked myself why am I feeling like this, thinking that he would be better off dead? I can understand how he was feeling. You seem to get into that mode as well. That was very distressing to have those thoughts in my mind. That was scary, very difficult to think that I was just about going to give up on him. All these thoughts are going through your head. (P24)

Fadden et al (1987a) also identified feelings of guilt, grief, sorrow, and an increased rate of mood disorders in spouses of people who have a mental disorder. In addition, Mannion (1996) found that spouses of people who have a mental disorder were often isolated people struggling to cope with painful feelings and serious concerns, while simultaneously attempting to maintain their primary responsibility for earning money and raising children.

Finally, two participants (both the affected family member’s spouse) were overwhelmed by their feelings of guilt about wanting to end their marriage. They became distressed over what was happening to their marriage and to their home life. The following participant had thought about leaving but was overcome by his guilt at having such thoughts:

You feel so bad about how you feel, but you know something has to change [can’t continue living this way]. You think about leaving home, leaving the kids and Rose [wife has depression]. I have often thought that I would love to get out [leave the marriage]. Then I feel guilty because I couldn’t do that to her or to the kids. (P7)

Another participant was a deeply religious person with a strong sense of loyalty. Therefore, when he began to have feelings about wanting to leave his wife he felt very guilty:

I do not go to church but I am a deeply religious person. I grew up with a very strong sense of loyalty. I had that very strong religious foundation and all the values. My children asked me “how do you put up with it?”. I said, “I can not turn my back on her” [wife who is depressed]. However, when things were really bad I was hoping that she would move out as the screaming and the yelling was unbearable. I still feel really guilty about that. (P23)

The above examples clearly demonstrate the continual threat to participants’ self-equilibrium posed by their caregiving commitments, and the need to place the affected family member’s needs before their own. Participants in Jones’ (1997a) study of caregiver burden reported similar responses. Those participants described a very positive earlier relationship with their spouse, a dream that was lost, and subsequent ambivalence about their current relationship.

In concluding this section, participants experienced feelings of being overwhelmed during crisis situations for two main reasons. They were overwhelmed at continually having to manage their family member when they were affected by their mental disorder. They were
also frightened of them when they were aggressive. Furthermore, they were overwhelmed by their own reactions to their family member during times of crisis. Participants’ recurring thoughts about letting the affected family member die were particularly distressing.

4.4: Summary

This grounded theory study identified that participants, who were primary carers of people with mental disorders in the Western Australian community, shared a common basic social psychological problem of being consumed. The first stage of the two-stage problem was entitled disruption to lifestyle, and it commenced when participants developed the recognition that something was wrong with the affected family member. All participants could reflect on events that triggered in them a recognition that something was wrong and these events fell into two main categories: the warning signs displayed by the affected family member and the increasing disturbance to the family’s established pattern of life.

When participants acquired the recognition that something was wrong with their family member, they became preoccupied with not knowing what was wrong. This preoccupation consumed participants’ time and impacted on their daily routines and the ability to achieve their planned life goals. They began to spend more and more time focused on what was happening to themselves and the affected family member.

Their preoccupation with not knowing what was wrong resulted in participants blaming themselves for what was happening to the affected family member. They believed that their parenting style, marriage breakdown, or their relationship with the affected family member had caused the problem. In addition, some participants were explicitly or implicitly blamed for causing the affected family member’s abnormal behaviour.

The third aspect of this first stage, disruption of established lifestyle was entitled, being overwhelmed, and occurred when participants were faced with crisis situations involving their family member. The crisis situations evolved when a change occurred in the family member’s established behaviours. This change was usually an escalation in the intensity, frequency, and/or bizarreness of the established behaviours that were already a concern for participants. Participants experienced feelings of being overwhelmed as they were unprepared to manage the evolving crisis situation, they did not know what was causing the behaviour, they had no support or knowledge concerning how to access support, they held perceptions and preconceived ideas regarding the origin and treatment of mental disorders, and many had no prior exposure to or ability to manage violence. During this time the
affected family members were hospitalised for the first time. This experience produced a variety of emotions that ranged from relief to being overwhelmed.

Disruption of established lifestyle (the first stage of being consumed) continued until the family member was officially diagnosed with having a mental disorder. For the majority of participants in this study, stage one lasted between one and three years. When a diagnosis of mental disorder was made on the affected family member participants entered stage two of being consumed. This stage was called sustained threat to self-equilibrium.

When participants entered this second stage of the basic social psychological problem they experienced feelings of being consumed for several reasons: because of the commitment they had made to care for the affected family member, the recognition that this commitment may last for many years, by their feelings of grief and loss, the personal cost of caring for their family member, and by their awareness that they would have to manage further crisis situations. This stage consisted of four aspects, the first of which was the day-to-day caregiving commitment. This consisted of providing food, support, socialisation, monitoring of the family member’s mental state, and seeing that they had an appropriate level of self care. The day-to-day caregiving commitment also included caring for any children of the affected family member, for example, grandchildren.

The second aspect of this stage (sustained threat to self-equilibrium) was the grief and loss that participants experienced. Firstly, participants’ experienced grief and loss for the person they once knew. Most participants commented that their family member was now different from the person they knew prior to the onset of the illness. Secondly, participants grieved the perceived life goals and dreams that had been established for the affected family member. Thirdly, participants’ grief and loss encompassed the loss of a normal family life, particularly the lack of time spent with the other members of the family. Finally, grief and loss also included the loss of the family members’ relationship with the wider community. Participants experienced a change in relationships with friends and the stigma associated with having a family member with a mental disorder. In addition, it was difficult to bring people into the home environment, as participants were not sure how the affected family member would respond to them.

The third aspect of sustained threat to self-equilibrium was the personal cost of caring and this included the threat to participants’ life goals and dreams. Several participants had to give up work or study to care for the affected family member. In addition, other
participants’ marriages or relationships were affected by their caregiving commitment. Furthermore, many participants experienced changes in their health.

The fourth and final aspect of sustained threat to self-equilibrium was being overwhelmed. This occurred when participants continued to be involved in managing crisis situations. While participants had developed more skills in managing these situations they still experienced feelings of being overwhelmed for several reasons. They were distressed by the out-of-character behaviours displayed by their family member, particularly aggression. Some participants, who had not been exposed to violence, became preoccupied with the fact that their family member may become violent at some time in the future. In addition, participants also experienced being overwhelmed at the apparent unhappiness and distress experienced by their family member during times of crisis. Finally, participants were overwhelmed by their own responses to their family member’s suicidal behaviours. Six conditions were identified in the data as influencing participants’ experience of being consumed and these influencing conditions are presented in chapter five of this thesis.
CHAPTER 5
CONDITIONS INFLUENCING
THE BASIC SOCIAL PSYCHOLOGICAL PROBLEM OF BEING CONSUMED

5.1: Introduction

This chapter presents the conditions that influenced the primary caregiver’s experience of caring for a person with a mental disorder in the Western Australian community. The data revealed that the basic social psychological problem experienced by primary carers was being consumed, and that six conditions influenced that experience (See Figure 5). These conditions were: "participants' prior exposure to, knowledge of, and experience with mental disorders", "communication with health professionals"; "the type and quality of emergency services"; "mobility of health professionals", "health professionals’ management strategies”, and "the level of support". Each of the six conditions will now be presented.

5.2: Participants' prior exposure to, knowledge of, and experience with mental disorders

Participants' prior exposure to, knowledge of, or experience with mental disorders was the first condition identified as influencing their experience of being consumed. Although not articulated as such by all participants, the data indicated that the majority of participants experienced a lack of prior exposure to, knowledge of, or experience with mental disorders. Some participants had no idea what to do when they developed a recognition that something was wrong with the affected family member, as this participant explained: "We [parents] had absolutely no knowledge about mental health or anything. We had no idea what on earth to do" (P2). Another participant provided this insight: "Basically, I mean, the average person off the street, what do they know about schizophrenia?" (P8).

The lack of knowledge and understanding prevented participants from comprehending what was happening to the affected family member. The following participant explained that, because of her lack of knowledge, she felt embarrassed by her daughter’s behaviour:
The Basic Social Psychological Problem: Being Consumed

Stage One
Disruption of established lifestyle

Aspects
1. Recognition that something was wrong
2. Preoccupation with not knowing what was wrong
3. Being overwhelmed

Stage Two
Sustained threat to self-equilibrium

Aspects
1. The day-to-day caregiving commitment
2. Grief and loss
3. The personal cost of caring
4. Being overwhelmed

Conditions Influencing the Problem of Being Consumed

1. Participants' prior exposure to, knowledge of, or experience with mental disorders
2. Communication with health professionals
3. The type and quality of emergency services
4. Mobility of health professionals
5. Health professionals' management strategies
6. Level of support

Figure 5: Conditions Influencing the Basic Social Psychological Problem of Being Consumed
When she [daughter] started to deteriorate she would laugh and giggle. People were staring. I said, "don't be so silly, you know, don't". I was so naive and stupid. I would be seeing clients and customers and I would be quite embarrassed by her behaviour. (P18).

Most participants developed the recognition that something was wrong when the affected family member was between the ages of 13 to 20 years. Consequently, these participants linked the warning signs, in the affected family member, to adolescence and the behaviours held as typical for that stage of the life cycle: "She [daughter] was dreadful and we still didn't know, really realise, what was wrong because it is hard to know what is adolescence and what is not" (P10). Several participants thought the affected family member's abnormal behaviour was due to the stress associated with study and commencing life at university: "I said, 'I don't know what is wrong, this is really strange'. I thought it was stress, you know, stress of being at university" (P6).

For 11 of the 27 participants, the affected family member was their eldest or their only child. This was another factor in their recognition that something was wrong, as many of these participants had no previous experience with which to compare their family member's abnormal behaviours. Therefore, participants assumed that the behaviour was due to a very active child or a rebellious, turbulent adolescence and tried to manage it as such within the family environment: "We just assumed it was adolescence. We had no previous experience" (P16); "Because Aaron is my eldest child it was difficult to know. I had no other experience to compare with" (P9).

Several participants in this study were health professionals or they worked in health related occupations. When asked if their prior experience had helped, one participant answered, "I don't think so. I didn't have anything to do with mental health" (P16). Another participant said, "No, it didn't" (P11, multiple carer). These two participants believed that being a health professional had not helped them because their educational preparation lacked experiences related to the mental health area: "I was a nurse. We never had any lectures or anything on mental illness. I have stood by people having shock treatment [electro convulsive therapy] in my first year and it was something I really didn't want to think about"(P5).

For other participants, their preoccupation with the recognition that something was wrong with their family member was clouded by their knowledge that their child was using illicit or non-prescription drugs. Whereas they had little experience with a person suffering
from a mental disorder they knew something about adolescence and illicit drug use and perceived a correlation between this and their family member's abnormal behaviour:

I knew there was something wrong but I didn't know exactly what was wrong. I knew Aaron [son] was doing drugs. Could it be drugs? He could have just some very strange ideas and that is perfectly allowable. It is one of those things, where do you draw the line? How far across the line do you have to wait before you panic? He had left home and he was living in refuges. He didn’t have many friends and he was doing drugs. He had a whole lot of quite bizarre and disjointed conversations things like "I’m God’s witness. I am the only one that knows the truth." (P9)

One participant knew that her son was smoking marijuana but was unsure as to whether he was using any other illicit drugs that could be responsible for the abnormal change in his behaviour:

I thought Michael [son] was on drugs, I really did. I was a fanatic. I used to search his bedroom. I was positive that he was on drugs. He was smoking dope [but participant was also sure that he was using other drugs as well]. It wasn’t until this stormy night when he was sleeping outside that I realised that this is not normal, he is having a breakdown. (P17)

Similarly, Parker's (1993) study of families living with a mentally ill member found that "most of these family members have never met a person with a mental illness before, much less lived with one. Coping with the problems presented are totally outside of the experience of most people" (p. 20). Likewise, Brodaty, Griffen and Hadzi-Pavlovic’s (1990) study on the carers of people with dementia reported that carers’ uncertainty and lack of knowledge greatly exacerbated their level of stress.

When participants in this study developed the recognition that something was wrong with the affected family member, several of them also discovered that there was a history of mental disorders in their spouse's family of origin. Family secrets, regarding mental disorders, meant that this information was not always shared with family members, and certainly not with prospective spouses: "There was a history of mental illness in my husband’s family. However, I did not know this when I was married" (P5). When another participant became aware that there was a history of a mental disorder in her husband’s family, she began to see patterns in her husband’s established behaviour that were similar to those now presenting in her daughter:

We [participant and her family of origin] found out later [after family member was diagnosed with a mental disorder] from my father-in-law that his sister had postnatal depression. It was very severe and she was put in a straight jacket at that time. He wouldn’t talk about it.... I think my husband is also quite unwell. I have always
thought that but his family would never admit that. When you live with someone you see signs, you see excessive signs. ... He will go off on a tangent. I didn’t recognise it at the time but he has gone off and done real estate. He just left me to run the family business and gone off to do these things. It has been hard being a mother, raising three children and running a business. It is a lot of work. (P18)

The following participant elaborated further on her experience of living with a husband who was obviously unwell but not diagnosed as having a mental disorder:

I really didn’t put it into words at the time but my husband had mental health problems and his family they had a real history of mental health problems. His sister used to go into * [psychiatric hospital] every year and you know in those days you didn’t talk about it and I tried not to think about it. That was despite his [husband] behaviour like bringing the running hose into the house and putting it in the piano. We [participant and children] used to get put out of the house, not necessarily put out, but get out for our own safety. I had to drag them [children] out of their beds and drive away until he would go to sleep and things like that. (P5)

In summary, participants’ *prior exposure to, knowledge of, and experience of mental disorders* was a condition that influenced their experience during both stages of the basic social psychological problem, *being consumed*. The majority of participants had no *prior exposure to, knowledge of, or experience with mental disorders* and their lack of knowledge increased their experience of *being consumed*.

### 5.3: Communication with health professionals

The second condition influencing participants’ experience of *being consumed* was participants’ *communication with health professionals*. Participants provided differing views regarding how this communication influenced their experience. Some participants found the communication helpful whereas others did not.

#### 5.3.1: Supportive communication from health professionals

Several participants reported that their communication with health professionals was helpful and positively influenced their experience of *being consumed*: "Generally speaking most doctors and nurses in the hospital spend time answering questions, a shoulder to cry on sort of thing. There are some particularly good nurses around who do that and some of the doctors as well. It really helped" (P8). Other participants believed that some health professionals were genuinely interested in hearing about how they were coping with what was happening to them and one participant gave the following example: "A couple of times
psychiatrists have actually talked to me, telling me to look after myself. It was helpful to me, they were wanting to help me" (P5).

Participants explained that when the health professional, treating the affected family member, took time to talk and reassure them, this was helpful: "I talked to a lady doctor and she was quite nice. She said 'you have done the right thing' [hospitalising her son]. It was a relief when the doctor told me that I had done the right thing" (P17). A time when many participants felt particularly in need of supportive communication from health professionals was when their family member was first hospitalised. The process of initiating their family member's hospitalisation left many participants with feelings of guilt, fear, and self-blame. Several participants spoke of their communication with the health professionals being helpful to them in managing these feelings of guilt, self-blame, and fear:

She [nurse] said "well it is a traumatic thing, but it is also the way you look at it". She didn’t even have to say that. It was just the way that she coped, the way that she talked and the way that she understood. It struck a chord with me I think. It was exactly what I needed at the time. I needed to be told that "yes, you are right" ... You really need a lot of reassurance, it is your baby. (P9)

Another participant provided this account regarding how the communication with health professionals, when her daughter was hospitalised, helped her through the experience:

Zoe [daughter] came home one day and she was just talking nonsense. ... I rang up my husband and told him that she had lost it [was very disturbed]. He came straight away and we took her to the doctor. He sent us to a private psychiatrist. The psychiatrist was fantastic. He explained to us what was happening. She went immediately to hospital. ... The people in the hospital, they were very good, and they had people talk to me. If I was in there [visiting daughter] they were all very kind and helpful. (P6)

In summary, several participants in this study believed that their communication with health professionals was helpful and supportive during stressful times. These participants believed that some health professionals showed that they were genuinely interested in helping them. Participants also valued this support during times when the affected family member was hospitalised.

5.3.2: Communication problems experienced by participants

Despite some participants reporting positive experiences resulting from their communication with health professionals, the majority of participants in this study reported their communication with health professionals was unhelpful. These participants believed
that the communication caused a variety of emotions, feelings, and thoughts to surface, all of which increased participants’ experience of being consumed. Participants spoke of numerous communication problems, between themselves and health professionals, and these were grouped into three areas: the lack of information and education provided by health professionals; health professionals’ exclusionary practices; and health professionals’ uncaring attitudes and responses.

5.3.2.1: The lack of information and education provided by health professionals

The first communication problem identified by participants was that health professionals failed to provide them with sufficient information and education regarding what was happening to the affected family member. During stage one, disruption of established lifestyle, a crisis occurred that resulted in the affected family member’s first hospitalisation. It also brought many participants into contact with health professionals for the first time. Initially, participants felt relieved when the affected family member was seen by health professionals and/or admitted to hospital. One reason for this relief was the belief that participants would be given some information and education regarding the cause of the affected family member’s behaviour. However, most participants found that when the family member was hospitalised it was only for a short time and then they were discharged back to their family environment. This cycle of re-admissions was, for some participants, repeated several times before the affected family member was diagnosed with having a mental disorder. During this time, health professionals failed to provide participants with the level of information or education that they required. The following participant felt like she was not making any progress as she tried to find answers to the cause of her daughter’s problem:

We tried to talk to the psychiatrists at * [hospital] but they were very non-committal. When they put May [daughter] into hospital they said “we will give her a week in hospital, give her a rest and see what happens”. They never treated her. Some family counselling did come out of it... This is where I had the sense that I was in a labyrinth. I was desperately looking for an intervention and then things would seem as if they were going alright and then I would be faced with a brick wall and I would think what do I do next? ... I was puzzled too. We didn’t know what we were doing wrong and what we were doing right. Nobody actually told us. (P15)

Another participant spoke of receiving insufficient information or education from health professionals. Her communication with her daughter’s psychiatrist served only to
increase the participant's feelings of being consumed by what was happening to herself and to her daughter:

When Annie [daughter] was diagnosed at * [hospital] I asked the psychiatrist "what do we do now?". Annie was already involved with a counsellor at a place called * [youth counselling service]. The psychiatrist felt that was it was enough that was quite adequate. It was as if this [daughter] was untreatable so we are not going to do anything. It was like you were born with blue hair you just have to live with it. I asked for a referral to * [psychiatric clinic] for counselling for each of us. It finally came up a few months ago; it took most of the year, an eight-month wait. You go through a crisis and you have to wait eight months before you get any counselling because of the backlog in the health system. The counsellor was a psychologist obviously of the B. F. Skinner behavioural school of thought. The basic approach was we will try to make you act like you are well and then you can say you are well. If it were that simple I would have done it myself. (P20)

Similar communication problems between health professionals and carers of people who have a mental disorder have been reported for many years (Biegel, Song & Milligan, 1995; Clausen & Yarrow, 1955c; Fadden et al, 1987b, Solomon, et al, 1998). Biegel et al (1995) claimed that some health professionals failed to provide carers with adequate levels of knowledge and information on mental disorders, available treatment methods, and practical management techniques. Participants in Biegel et al's study ranked improved communication with health professionals as their greatest need.

In this study, several participants reported that when the affected family member was hospitalised they were overwhelmed by the events leading to the admission and were left feeling extremely traumatised: "Peter was sixteen years old when he was admitted to hospital. There was nothing more horrifying than saying 'goodbye' and seeing them lock the door leaving a child looking very frightened" (P11, multiple carer). Another participant described how the trauma she experienced, associated with her daughter's hospitalisation, increased her experience of being consumed. She explained that health professionals failed to provide her with sufficient information and education during the time when her daughter was hospitalised:

I hated the locked ward that June [daughter] was put into. I found it awful and she hated it too and wanted to come home with us. No one explained anything to us. In the first few days we would go into those locked wards and no one would explain. (P16)

Similarly, Parker (1993) reported that the time when the affected family member was taken to hospital was particularly distressing. Parker stated that family members felt they had
caused or exacerbated the problem or they felt guilty that they had betrayed the affected family member. Furthermore, when they visited the affected family person in hospital, they again experienced feelings of guilt, as the affected family member begged to be rescued. On other occasions the affected family member was extremely angry towards other family members, accusing them of being instrumental in their committal to hospital.

Participants in this study believed that the disparity of levels of knowledge between health professionals and themselves left them feeling isolated: "Health professionals know what’s going on. It is like second nature to them. It is hard for them to realise that other people don’t know what they know" (P1, child/adult carer). Participants spoke of feeling more isolated and alone because health professionals did not provide them with sufficient information and education: "The doctor did not tell me anything. He just said, ‘it is manic depression and we are trying to find the right medication’. He did not explain anything. I read a few books" (P24); "I did not get any feedback. I would call [telephone the doctor] and I would never get any feedback. I never got any social affirmation that I was doing a good job. It is so clinical" (P21, multiple carer).

The disparity of knowledge between health professionals and carers was displayed by the following participant who did not know what was wrong with her son after he had seen a psychologist for eighteen months:

At the clinic the doctor [psychiatrist] suggested we see a psychologist. The doctor had not diagnosed John because he said "he is a very introverted, very disturbed young man but he is still an adolescent so we [professionals] are not going to rush with anything". He suggested we see a psychologist. For eighteen months we saw this lady two hours a week. ... She told us nothing. (P3)

Another participant did not know what was wrong with her ill mother until the participant commenced her education as a health professional when she was 18 years of age:

We [family] never talked about mum’s illness at home. Dad would take her to the doctor, we [children] wouldn’t go in, until we started caring for her when dad got sick. We weren’t even sure what her illness was. It seems really crazy to say that and you think, "how could that possibly happen? How could you possibly be that naive?". When I did [education as a health professional] when we started the psychiatry unit I finally worked out what illness mum had. I thought “I’m eighteen, you know at eighteen years of age to work that out”. You see how the health field let us down as a family. I suppose mum just went to the same psychiatrist for years and years and years. She and dad would do for the appointment. (P1, child/adult carer)
Guanaccia and Parra (1996), Judd and Shanley (2002), and Yamashita (1998) reported similar findings concerning the disparity of knowledge between health professionals and carers. One participant in Yamashita's (1998) study of family coping provided the following account of not understanding what was wrong with the affected family member:

The doctor looked away from me, mumbled that my son had schizophrenia and walked away. I didn't understand what the word meant. He never explained what it meant. Even now I don't know what it is. (p. 520)

Similarly, participants in Rose's (1998) study on professional-family communication reported experiences of being frustrated by the "reluctance on the part of professionals to 'go out on a limb' and make some statement about prognosis" (p. 143). Solomon et al (1998) also found that clinicians frequently lacked an awareness of families' need for information and had limited time available to respond to family-initiated requests. Therefore, families who failed to express their needs effectively found that their needs were not met. Furthermore, Domenici and Griffin-Francell (1993) and Jeon and Madjar (1998) reported that health professionals failed to provide family caregivers with essential medical information concerning the affected family member. A more recent example of the disparity of knowledge between health professionals and carers was provided by an anonymous Western Australian carer (cited in Connect: Mental Health Matters in Western Australia, 2001) of her communication with doctors treating her partner:

The next day [after partner's admission] I went to see the psychiatrist at * [hospital]. I was asked a barrage of questions: Does he take drugs? Any mental illness in the family? About our family relationships. Then a social worker asked me questions about alcohol abuse etc. This was too much. All I wanted to know was what was happening, how he was and how long he would be in hospital. The reply was that they could not work out what had happened to him as he did not fit into any category. (What's a category?) He may be in for a week or two and at the moment he was quite heavily sedated to help him sleep. I needed to know whether to resign from work, when to contact his family about his illness and most of all I needed information about mental illness. So far I had verbally been told he had Schizophreniform. What's that? My only lifesaver to keep from falling apart was my mum who was flying in on holiday for a week to visit her grandchild. (p. 28)

In summary, the lack of information and education by health professionals increased participants' experience of being consumed. The disparity of knowledge between health professionals and participants led to numerous communication problems between the two groups.
53.2.2: Health professionals' exclusionary practices

Participants reported that their communication with health professionals was also hampered by the exclusionary practices employed by some health professionals. Specifically, health professionals did not listen to participants or include them in discussions concerning the affected family member. This resulted in participants experiencing feelings of powerlessness. Similarly, Parker (1993) claimed that the carer's feelings of "powerlessness is compounded by the exclusionary practices of some mental health professionals" (p. 21). The exclusionary practices were highlighted for one participant in this study when he tried to obtain a second opinion from another psychiatrist regarding the diagnosis of a mental disorder that had just been made on his sister-in-law. What he did not anticipate was the difficulty and the emotional challenge of obtaining that second opinion:

Sky [sister-in-law] said, "could you get me another psychiatrist I want to get out" [of hospital]. They all want to get out because they are compulsory patients. So I said "alright". I started compiling a list of psychiatrists and ringing them up to come and see Sky. Do you know what, it is really not the thing to do. You do not do that; it is totally against the rules. Just about every psychiatrist's receptionist I called asked me if I was the patient. I said, "no I am not a patient, I am a carer. I am ringing up for someone who has a problem and needs a psychiatric assessment". I made about 23 phone calls before I got an appointment with somebody. By this time I thought I was going psychotic, because all of the receptionists were wondering if I was. We paid A$250 to this psychiatrist and he confirmed that Sky had schizophrenia. He had a nerve, he talked twenty minutes with Sky and about five minutes with us [participant and his wife] and he charged me $80 for him to consult us. (P8)

Another exclusionary practice used by some health professionals was not to listen to what participants were telling them about the affected family member. This further increased participants' sense of powerlessness and their experience of being consumed: "If they think she [sister-in-law] is fine [not in need of care or follow up from mental health professionals], then what we [family] think doesn't make any difference really" (P8); "I couldn't find anybody [health professionals] who would listen to me" (P17); "The community nurse hasn't really ever listened to me about how things are with Louise" (P5). Another participant gave the following account of not being listened to by health professionals treating her daughter: "My voice is not heard. They don't listen to you. They believe they can interview Robyn in their trained way and get a more informed picture out of it" (P12). When asked how this made her feel the participant responded:

It was devastating. However, as you go on you get used to it [being treated like that by health professionals]. I was very low at that time and could not have coped with taking
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her home. They should take into account what carers say a bit more, whether they use it or not. It is allowing the carer to talk and say things. They take them [patients] and do what they do. Then they send them back to that incompetent person who is a nothing and has none of their professional skills. As long as I can be there nursing her along they will patch her up again next time. They need someone to send her back to but they give you no practical guide. (P12)

Participants’ experience of being consumed was increased when health professionals chose not to listen to what participants were telling them regarding the affected family member’s abnormal behaviours. The following participant explained to the doctor that she believed that her son had schizophrenia. However, the participant’s beliefs were immediately discounted by the psychiatrist:

We knew that we had to get Josh [son] some help. We went to Dr * [family doctor] and told him about the bizarre behaviour. He said "Oh I am sorry. It is out of my hands". He referred us to * [hospital] to be assessed in the psychiatric unit. We [parents] went with Josh and we saw Doctor * [psychiatrist] who interviewed all of us together and then did some individual interviews. When he interviewed me he did not ask me, I told him "my son has got schizophrenia". He said "Oh! What makes you think that?" I said "because of this, this and this [described behaviours] and I know my son and I have looked after him for 18 years". He said, "No, no it is just a personality problem and it is going to be alright". So he brought Josh back into the room and in front of us he said "Josh name an animal with four legs". For ten minutes his father was prompting him. "Where do we go sometimes on Saturday Josh?". We used to take the kids [children] to the races and it took ten minutes for him to name a horse as a four-legged animal. That doctor sat there and said "there was nothing wrong with him". (P13, multiple carer)

Similarly, another participant’s opinion of her affected family member’s condition was discounted and the psychiatrist treating her daughter did not listen her to:

We [April and participant] spent time with the psychiatrist individually and then the two of us. At the end of it all he said it was a bonding problem. April was trying to please me. I could barely stop myself from laughing. I am usually somewhat intimidated by experts. I am a layperson and I was in over my head and I had no idea of what was going on. But in this case it was like you are so far off what is the problem because we are Siamese and joined at the hip [participant inferred there was not a bonding problem and that they were too bonded to each other]. I tried to tell him but he would not listen. (P20)

The participant explained that she was overwhelmed by the doctor’s response and her feelings of being consumed were increased because of his willingness to give up on her daughter, as she went on to explain:

The doctor said, "you have got to accept you are hitting your head against a brick wall. You are looking for an answer, a quick fix. As if you are going to fix her, you
are not. It is like having a child with Downs Syndrome; you have got to learn how to live with it". I looked at the doctor and thought like you are mad! It is like learning to live in piss [urine] and shit [faeces] knee deep in your house. You don't tell someone to "learn to live with this" [gets angry]. I have got to clean this mess up. I can't live like this. It is mad nobody can live like this. I want to murder her [daughter] every minute of every day. You can't live like this. (P20)

Parents on an Australian television program "Four Corners" on the mental health care system in crisis (Channel 2, 2030hrs on the 9th September, 2002) also spoke of not being listened to by health professionals. The parents called the hospital late at night to tell staff that their son had just phoned and told them he was going to commit suicide. The parents were not listened to and health professionals told them that their son was fine. He killed himself in the early hours of the morning. Similarly, Jeon and Madjar (1998) also reported that participants were not listened to by health professionals and that the assessment of the affected family member's mental state was not valued. As a consequence, caregivers had to "battle to get help" (p. 702) and were left to manage the affected family member during crisis situations. Moreover, Rose (1997) found that participants in her study reported that health professionals did not acknowledge the family perspective when setting realistic goals for the affected family member. One participant, a spouse of a patient with bipolar disorder, provided this example: "In conversations I've had with the doctor, he's told me she's capable of taking care of the children. I have this huge reservoir of experience, of observed behaviours with this woman. Nobody has asked." (p. 20).

Brown and Stetz (1999) and Hardwick (2001) also reported that carers were angry with health professionals because they were not acknowledged, involved, or supported. These authors asserted that the carer's relationship with health professionals was a priority area of concern for governments and policy makers. According to Hardwick "the lack of consultation with carers regarding medication, treatment, and support issues creates additional pressures for carers and difficulties in caring" (p. 31). A recent Australian study on mental health care claimed that mental health workers disregarded families of the mentally ill and failed to acknowledge the impact of the illness on carers' lives (Gauntlett, 2002).

In this study, another participant experienced additional stress and financial hardship, which increased her experience of being consumed, because health professionals did not listen to her when she provided them with information about her husband:

They [health professionals] don't listen. Barry [husband] was high [manic] and they let him out of hospital to catch a plane to Italy. I spoke to the doctor and I said "will
he be alright?". He said "Oh a fifty-fifty chance". I hold the money, but he convinced the doctor so I had given the ticket to him. The doctor said "he will be home in four weeks". I said "he will be in hospital in four weeks". I spent $800 on phone calls to support him [in Italy] until I could get him to come home. A friend had to accompany him. He had to go to hospital when he arrived home. Sometimes I think that they just don’t listen. His family had no idea of what was wrong with him. My Italian is not that good and it was very hard. (P24)

Even after repeated contacts and calls for help, some participants explained they were still excluded by some health professionals and not listened to:

I appealed for help [to case manager] and he [nurse] sat and listened to her [daughter] but he never gave me any feedback on it. ... He never ever talked to me. He never listened to me. All I could do was leave him a message on the telephone. He would go and listen to her [daughter]; I would ask her what he had done to help?. When she was becoming unwell her language would become a bit off and she said, “sweet fuck all”. (P5)

Some health professionals also used exclusionary practices when the affected family member was hospitalised giving participants the impression that the health professionals did not want participants to be at the hospital:

The nurses were wonderful. I think the doctors, the impression they might have given at times was that they didn’t like to have a mother around [visiting family member in hospital]. I think Carol [daughter] would have been quite happy not to have me around too. That would have been fine but I couldn’t have understood what was happening if I had not been around. I felt that I had to go every day to see what was happening, just to reassure myself. (P18)

In summary, the exclusionary practices employed by some health professionals created communication problems between themselves and participants. As a result, participants felt powerless due to their communication with health professionals. These exclusionary practices increased participants’ experience of being consumed.

5.3.2.3: Health professionals' uncaring attitudes and responses

Another communication problem reported by participants was that some health professionals demonstrated uncaring attitudes and responses towards them. Several participants believed that this problem was so bad that their communication with the health professional became a hindrance to their well being: "Yes, well we [parents] haven’t had a great deal of help, support, or information from professionals. They have been quite a hindrance really. There was no help with Peter [son]. We were travelling blind" (P11,
multiple carer). Another participant provided this example regarding how a two hour a week visit to the clinical psychologist was a hindrance that impacted on her and her son’s mental, emotional, and physical well-being:

It [the contact with clinical psychologist at mental health clinic] did not help at all. She couldn’t see that we had anything to worry about. She said “if John [son] worried us we should just wall him up [shut him up] in his bedroom and leave him there if his continued inactivity bothered us so much”. ... I mean by then he had withdrawn completely into the bedroom socially. She suggested that we [parents] were trying to substitute him for the son we had lost [another son had been killed]. She suggested we [parents] had problems and John was our scapegoat. She told us everything, except the suggestion that it could be an authentic medical disorder problem. She [clinical psychologist] wasn’t concerned. She also thought that teachers [participant was a teacher] had problems too and expected lots from their kids [own children]. (P3)

The participant was angry about the clinical psychologist’s response to her questions, regarding her son, as she could see that her son was getting worse and this increased her experience of being consumed:

It was infuriating. I was teaching by then and I was knocking on his door in the morning before I went saying, “John how are you?”. We were being told by professionals “well don’t ask”. I could see from the scribbling, in a lot of the drawings, that there was a black humour. There were gallows, there were bottles of pills, there were desperate people jumping under trains. I mean it was all just so morbid, so incredibly morbid and depressing. It spoke volumes about his state of mind. He clearly wasn’t coping and all we were getting from the psychologist was that this was none of our business. (P3)

Participants believed that they were also hindered by casual, unhelpful, and often hurtful remarks made by health professionals about the affected family member. These remarks increased participants’ experience of being consumed as they then felt they no longer had anyone to turn to for help: “He [doctor] said ‘never mind Mrs Brown, when he is eighteen you can kick him out’ [make him leave home]. I said, ‘I don’t want to kick him out. I want to get help for him’” (P11, multiple carer). The following participant gave a similar account of unhelpful communication: “Peter [son] had piled everything on his bed and set it alight. I was told by the social worker at * [hospital] (she was about 22 years old) that it did not matter if he burnt the house down. Well I said, ‘it matters to me’” (P11, multiple carer). The next participant was traumatised when her son drove his car through her bedroom window. She recalled the conversation with the social worker treating her son when she visited him in hospital the next morning:
When I arrived at the hospital I went straight to see John's social worker. He said "Oh yes, very interesting". I said, "can you explain why he did it" [dove his car through parent's bedroom window]. He said, "Yes, he was making a statement". I said "could he not have made it with a spray can, now I have a big hole in my house" [participant laughs]. He said "he was making a statement you know relevant to his relationship to his step-father". He [social worker] was so naive. (P3)

Similarly, another participant spoke of a series of conversations with several doctors over the years, regarding her son's attempted suicide when he was a teenager. She found their attitudes particularly distressing:

Melvin [husband] had wanted to let Peter [son] just go [die from overdose] but I couldn't let my son just die. The doctors have asked me since if I had known what was ahead [son's long history of severe paranoid schizophrenia] would I have [let him die]. I still wouldn't have done anything different. If they take their own lives then that is an entirely different matter. Several doctors have asked me that. (P11, multiple carer)

The following participant was also left feeling very distressed after her interaction with a group of health professionals when she was told her daughter, at some time in the future, would most probably commit suicide:

They had a case conference at * [hospital]. There was Robyn's [daughter] social worker, general practitioner, a clinical psychologist, and a psychiatrist. They had a conference and they asked me into the room. Mainly the psychiatrist was talking. He said I should only expect a one percent improvement in Robyn. He said that she possibly would achieve what she is aiming to achieve, that is suicide. He said, I have got to back off, but I still have to be there for them [professionals] to work through. I came away and cried all the way home. I thought they just don't understand. They have just told me that my daughter will commit suicide. I have this life sentence to keep living with this. I came away totally devastated. (P12)

Participants in Rose's (1998) study on family-professional interactions also related accounts of unhelpful comments made by health professionals, for example, "she's going to crack" or "she will never get any better" (p. 143). A participant from Rose's (1997) study of caregiver's perceptions of social support described that the information provided to her by doctors as: "the same thing - that he will be sick all his life. They even said when he gets violent to try and control my temper. You know, don't get angry, don't yell because he yells." (p. 20). In a like manner, a participant in Yamashita's (1998) study of family coping reported the same style of distressing communication style: "I felt hurt. Hurt and amazed that a doctor could be like this. I was so upset" (p. 519). Rose (1998) also reported that health
professionals made suggestions that carers felt were not acceptable and, therefore, the alliance between them was not established.

Other participants in this study felt blamed and believed that their experience to date was trivialised as a result of health professionals’ uncaring attitudes and responses towards them. The following participant gave this description:

They make you feel like you are a child abuser or that you are hurting your child. You are such a terrible mother that you have created this problem and warped this poor innocent child. You pick it up in their body language, the way they ask questions, a thousand things. It is really a put down, another whingeing [complaining] mum. They don’t believe you when you try to get it across to them about how bad it is. They say, “you are full of shit lady”. You can see it on their faces that they think you are making it up. In fact they have no idea how bad it is. And then they say, “learn to live with it”. You think, what! I got a lot of feedback that it can’t be that bad. You get a lot of raised eyebrows and expressions on faces that it can’t be that bad. What mother would do that? (P20)

A participant from Yamashita’s (1998) study provided a similar account of uncaring attitudes and responses by health professionals:

Doctors are very uncaring. This is what he’s got and good-bye. Be gone with you, that sort of attitude. This one doctor was callous. He’s got schizophrenia, and he’ll probably never be able to do anything. Don’t bother me, that sort of approach. (p. 519)

Similarly, participants in Parker’s (1993) study also reported that family members were often treated in an unsympathetic or unhelpful way by health professionals. According to Parker "they are often actively shunned." (p. 20). Participants in this study believed their level of self-esteem, as well as that of the affected family member, was negatively affected by health professionals’ uncaring attitudes and responses. The following participant felt that her experience of being consumed was increased by the nursing staff’s reactions when she sought information from them during her daughter’s hospitalisation:

The nurses tend to sit in the nurses’ station. They sit there chatting to each other. There are the good ones and there are the bad ones. The good ones are less than fifty percent. They come out and they talk to the people and just talking to them makes them feel better. They are prepared to talk one to one in an ordinary way. ... We really did not understand the whole system at all [know what usually happens in hospital and their rights as a carer]. We [parents] also got the same kind of treatment. You would go to the nurses’ station and they would say "Oh wait". They were talking about what they were doing tonight or the recipe they had. They were just personal things and they didn’t have to treat us like that. (P16)

I asked the participant how this made her feel and she replied:
If you have to knock on the door of the nurses' station to get them to talk to you that lowers your self-esteem. It made me cross. I could see that June had to do it as well. She really thought she had to knock on the door and stand back until she could talk to staff. At * [psychiatric hospital] they will just sit back and make it obvious that you can't talk at the moment. They have their glass [office has a glass window that looks out over the ward] and they look through at the people [patients]. You wonder who is looking at whom. Eventually they would come out and you could talk to them. At * [a different hospital] it was definitely a knock on the door. Then you could talk. (P16)

Jeon and Madjar (1998) also reported that a lack of understanding by health professionals affected carers' level of self-esteem. Furthermore, Parker (1993) asserted that when the affected family member was hospitalised, their relatives should be allowed to view the ward where the affected family member was staying. This process could reduce carers' level of anxiety and dispel misconceptions about psychiatric hospitals.

Several participants in this study also reported that they felt "put down" as a result of their conversations with health professionals, and the following participant spoke of this example:

The first panel of doctors that we saw they put me down a little bit. I said to Josh's father "I felt like they were saying that I was crazy that I needed help when I suggested that Josh might have schizophrenia". They said, "What makes you think that? No, No, No". So in a way they did put me down. (P13, multiple carer)

Another participant experienced feelings of being "put down" during her conversations with health professionals and believed that health professionals used this technique with her because she was articulate and intelligent:

I have found that if you are intelligent, if you are articulate, it is held against you. They [health professionals] think that you should be able to help yourself. If you come across as somewhat dopy [not intelligent] they will try to help you. However, if you are intelligent they resent you for being intelligent. It works very much against you. (P20)

Biegel et al (1995) also reported that mental health professionals considered that caregivers at the lower socio-economic level needed more assistance because of greater strains in their daily living.

Another participant in this study described feeling "put down" by health professionals when she questioned the care the affected family member was receiving:

Well they [nursing staff] should listen and act on what the carer says. For instance, how regularly to change them [husband has dementia]. I did not want him [husband]
to get sore [from being incontinent] it would affect his walking. They try to pull the wool over your eyes [not tell you everything] you know. They talk down to you as if you don’t know anything and they know it all. Well I understand that they think that they know what they are doing. It is very irritating really but you can not say anything to them. You have got to get along with the nurses you know. However, it is very difficult, very frustrating to be spoken to like that. (P25)

Participants also spoke of feeling “put down” when health professionals treated them like a “nobody”. These feelings increased participants’ experience of being consumed as the following participant explained: “You are just a nobody. They don’t want to know what you think” (P2). Another participant gave similar account of being made to feel like a “nobody”:

Anytime you contact a department or organisation they say, “Where are you calling from? When you say, “I am the mum” they say “Oh”. Then they put you on hold [make you wait on the telephone] for five minutes and try to figure out whom you can talk to because you are just a mum. You know what I mean? … you are not coming from a position of strength. You are not an authority, you are not a professional, and you are not a psychologist, or a psychiatrist, or even a social worker. You are a nobody, you are just a mum. You know nothing. (P20)

Participants in Mohr’s (2000) study of professional attitudes in the clinical setting also described being “put down” by health professionals “They talked to me in a way that did not make me comfortable. They seemed to be talking down to you” (p. 604).

Another way in which health professionals portrayed uncaring attitudes and responses to participants in this study was when they made judgements about participants and then passed these judgements on to other health professionals. Some participants felt the behaviour of these health professionals was symptomatic of a larger power game!

Robyn’s [daughter] behaviour had been very up and down [not well]. I went in to hospital and she was being very hard to get on with. I was talking to her and we were having a pleasant visit. When her meal came, the nurse came in. At that time, Robyn had a phone call. The nurse made a comment that my visit was not having a good effect on Robin. She said to me “she was happy when her friend rang, but unhappy when you are here”. And that message got to the general practitioner [family doctor] and people interpret that little window. … When you are feeling a bit frayed around the edges [emotional strain] from dealing with her you need someone to put their arms around you and say, “I know it is a hard road you are travelling”. Instead they tell you that you are there too much and that you are not helping her. That really upset me because if I walk away what does her future hold? I control my responses to her situations as much as I can but you have to be there. (P12)
Another participant became very distressed when she saw her husband restrained by staff in the bathroom and given an injection. When she questioned the staff’s management techniques, they were rude to her. A power game between her and staff then began and this was very distressing to the participant and increased her experience of being consumed:

Larry got really violent with them [staff] so they injected him [gave him an injection to sedate him]. They had three people to hold him down when he was in the bathroom [while they injected him]. The nurse had a rather authoritarian voice; it was like being in the Army. One of the nurses said to me later "the male nurse did not know how to treat that type of patient" [aggressive behaviours related to dementia]. There are some extremely good nurses and there are old nurses who are not adaptable and can only do what they have always done. They did not want to hear any complaints. When I asked them about how they treated him they were nasty to me. I could hear them talking about me when I was down the other end of the corridor. I could hear the moaning and laughing and it is not very nice. Then I heard them talking to someone else [other staff] and they were saying, "she is always here". (P25)

Mohr (2000) provided another example of how health professionals’ communication can add to caregivers’ stress levels and can turn into a struggle for power. One participant from Mohr’s study of professional attitudes in the clinical setting was not allowed to see her daughter and found herself on the receiving end of hostility from health professionals who would not provide her with any information: "So they wanted to dictate everything, and it turned into a power struggle. ... They were trying to maintain the control over the situation, they wanted me to be passive like all the other parents." (p. 603).

The uncaring attitudes and responses of health professionals were also demonstrated when the affected family member was hospitalised. Participants in this study explained they felt they, as well as the affected family member, were being assessed and judged during their interactions with health professionals:

I got the drift I was an overbearing father. The psychiatrist was looking for something in the family. And another thing was that we didn’t scream or argue. We talked things through as a family. The psychiatrist had a problem with that and made out that we were frightened of anger, we were frightened of arguments, that sort of thing. (P10)

The following participant also believed he was being assessed by health professionals. As this was already a stressful time for him, the additional concern was very intimidating:

You are a relative and because a sudden episode has blown up you are distressed. Because of this you might be going blah, blah [very emotional and not always speaking coherently]. You feel the doctors and staff are assessing you, as there is obviously a genetic component to mental illness. So you get the feeling that they are assessing you as well. (P8)
Several participants also found they had to defend themselves during their conversation with health professionals as they found many of the questions asked of them demeaning. The following participant provided this example:

Well, I think a lot of the questions that they [health professionals] ask are very demeaning. I am sure that they have to go through some sort of screening procedure but it is almost as if you have to defend yourself in every circumstance. (P20)

Finally, some participants reported they had hostility directed towards them by health professionals at a time when they were already under a great deal of stress. One participant’s husband had to challenge the doctor who was treating their daughter regarding his attitude and communication style:

Natalie [sister] went into the house and found May. She had sprayed Morotein [fly spray] into a bag and she had that around her head with a strong rubber band. .... We took her to the emergency department at * [hospital]. The harassed doctors there they did not want to see her and they turned on us. They were so tired they didn’t know what to do. I can remember one bloke [male doctor] he was beside himself. He said, "for Christ sake what do you expect us to do?" We [parents] said "could you, would it help if she went to * [psychiatric hospital]?" He said "for Christ’s sake why are you asking me?". My husband had to pull him into line a little. He said, "look doc [doctor] I can see that you are tired, but unfortunately we are tired too. We don’t know what to do. We are at a loss". (P15)

In summary, participants differed in their perceptions as to how their communication with health professionals influenced their experience of being consumed. Some participants found that health professionals were helpful and that the outcomes of their communication decreased their experience of being consumed. However, the majority of participants described communication problems between themselves and the health professionals with whom they had contact. These communication problems increased participants’ experience of being consumed and fell into three areas: the lack of information and education provided by health professionals, health professionals’ exclusionary practices, and health professionals’ uncaring attitudes and responses.

5.4: The type and quality of emergency services

The type and quality of emergency services was another condition that influenced participants’ experience of being consumed. Bernheim, and Lehman (1985); Carpentier, Lesage, Goulet, Lalonde and Renaud (1992); Goldman (1982); Griffin-Francell, Conn and Gray (1988) and Sommer, Williams and Williams (1984) also reported there was a
correlation between the organisation and delivery of mental health services and level of
distress experienced by family caregivers. In this study, the type and quality of emergency
services that impacted on participants' experience of being consumed were divided into three
areas: emergency services provided by members of the Police Force, emergency services
provided by the Psychiatric Emergency Team (PET), and emergency accommodation in the
community.

5.4.1: Emergency services provided by members of the police force

When participants became embroiled in a crisis situation involving the affected family
member they sought help and advice from emergency services regarding how they should
handle the escalating situation. Many of these emergency calls were to the police. For several
participants, their first contact with the police occurred during stage one of the basic social
psychological problem, disruption of established lifestyle. One participant gave this account
of her first involvement with the police:

The second time Michael [son] was taken to hospital he was taken from his flat. The
sheriff had already been around and put locks on it. His father and I, we arranged with
Homeswest [a government department as son lived in a government flat] to get the
flat cleaned. We went with a trailer to get his stuff [belongings] but Michael wouldn’t
let us in. So the police had to come and remove him. Homeswest just loaded
everything on to the trailer and they sent it to my place. Michael came running out
when the furniture arrived. He said to the man "you are not leaving that here. My
mother put me in a mental hospital". The poor furniture removers had to unload it, as
they couldn’t drive around with it. So they rang the police. The doctor had been out
and had already called for the police. Anyway so we had the furniture removers and
the police. All the neighbours saw that, we were sitting outside at the table on chairs
and he was handcuffed. (P17)

Unlike the above participant, other participants had already had contact with the
police over several years. This contact had occurred in situations, for example, where their
family member had been caught stealing or had been aggressive from a very early age, as the
following participant described:

I have had to deal with the police on many occasions from when my daughter was
very young. I have had contact with police in several States of Australia. They have
been unfailingly good listeners, caring, concerned, very, very nice people. They have
been really nice. I hear people criticising the police but they have been wonderful
individuals that we [parents] have dealt with. They have been super and I cannot
speak of anything but praise for the police. Their judgement has been really admirable. (P15)

Participants’ contact with police continued throughout both stages of the basic social psychological problem, being consumed, and encompassed a variety of situations. The police were called when the affected family member was violent, to transport them to hospital, to search for them when they had run away, or because the family member had committed a crime.

Of the 27 participants in this study, only two participants reported negatives experiences as a result of their interactions with members of the police force. These participants believed that their experience of being consumed increased because the police officers attending the situation would not listen to what participants were telling them. The following participant explained that the police were not interested in information she wanted to provide regarding her son’s condition:

I have had to get the police twice [to come to the house and take her son to hospital]. One lot [group of police] said "don’t interfere, we are questioning your son". I said, "my son is very sick". One policeman said, "What is actually going on here, he seems alright?". I said, "of course he is alright because he is frightened of you. Of course he is all right in your eyes. Keep right out of it please". I was very angry. (P13, multiple carer)

The other participant recounted a situation where the police also did not listen to her and passed her daughter over to the ambulance service to transport to hospital. This resulted in her daughter absconding as soon as she arrived at the hospital. This increased the participants experience of being consumed when she was already feeling overwhelmed by what was happening to her:

They [the police] took April, then they called an ambulance. They said, "this is not a police matter". I am saying, "yes it is. She is violent, she is destructive, get her out of my house. Take her to the lockup [police station] do with her whatever you do with juvenile criminals". They ended up calling an ambulance without discussing it with me. She had locked herself up in the bathroom. They ended up getting her out and taking her and dropping her off at * [hospital], just dropping her off. Of course she just walked out. Oh you should have seen me when they tried to bill me for service a fee of $350. I went off my face [got angry] at them on the phone. I said "I would love for you to sue me, take me to court. Talk about criminal negligence. You take a 14 year old child with psychiatric problem [from their home] and drop them off in the city at night". (P20)
While two participants recounted negative experiences regarding their interactions with the police, the majority of participants found the police were invaluable to them in the emergency situation. These participants commended the police for being sensitive, caring, and competent when communicating with themselves and the affected family member:

The police have been marvellous. They have always come. They have always treated Peter [son] with the utmost respect. They are taught better now [more education regarding how to deal with people who have a mental disorder]. I never had any problems, he has never been manhandled and he has given them [the police] a lot of abuse. (P11, multiple carer)

The sensitivity, caring, and competent manner in which police managed people who have a mental disorder was also commented on by carers on an Australian television program “Four Corners” on the mental health care system in crisis (Channel 2, 2030hrs on the 9th September, 2002). In addition, the father of a gunman who held two German tourists hostage in the Northern Territory in September 2002 also spoke of the sensitivity of the police towards his son’s condition. He thanked the police for all of the care given to his son, who was a mental health consumer (Channel 7, Sunrise, 0600hrs 10th September, 2002).

Participants in this study while commenting on the support given to them by police, also acknowledged the increasing level of skills in younger members of the police force in managing people who have a mental disorder:

I have a letter from the psychiatric department telling the police that these are the things that they need to do [when participant calls them because her daughter is being extremely violent and has been for many years]. That is helpful. The younger ones are really good. The older officers look at it as an adolescent problem. That we will get over it. That is difficult for me to handle. (P22, multiple carer)

Participants spoke of how grateful they were regarding the range of services provided to them by police during crisis situations involving their family members. In all aspects of this work the police showed empathy and compassion as the following participant explained:

It is just my experience but I have found the Western Australian police force absolutely excellent in terms of their handling of mental health patients. ... Their sensitivity, their patience, and their effort as you will see later on when Sky was hospitalised for the second time. She escaped [ran away from the hospital] several times. The police each time patiently brought her back and they treated her very well. One of the times we knew she was in danger a friend who alerted the family spotted her and we went hunting for her. The police were just wonderful we gave them the photos and they made an enormous effort to try and find her. So they were great compared with some of the people, some of the nurses on the mental ward [hospital ward where Sky was] who couldn’t give a stuff [who did not seem to care]. They
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[police] were real sweethearts. Generally speaking the police dropped charges as soon as they found out the story [that she was mentally ill], they dropped the charges [Sky had broken into a house and stolen things and assaulted someone in the community]. (P8)

In summary, the majority of participants found that their interactions with members of the police force were helpful and decreased their experiences of *being consumed*. Participants described that the police were caring, sensitive, and attuned to their needs. In addition, participants believed that the police treated the affected family member respectfully and in a humane manner.

5.4.2: The emergency service provided by the Psychiatric Emergency Team (PET)

The other major emergency service frequently contacted by participants was PET. Participants conveyed a variety of experiences regarding the level of service offered to them by PET and how this service influenced their experience of *being consumed*. One participant was surprised when he contacted PET to find the staff would not do anything until the police arrived. "There is one infuriating thing about PET. It is not their fault but when they arrived they said 'Oh we can't do anything until the police get here'" (P8). Several participants felt the staff from PET were very supportive and their management of the crisis situation was very good. "They were fantastic. They rang us up and told us they had got June [found daughter who had run away] and they had taken her to hospital" (P16). Another participant provided a similar account:

With Josh [son] I have had to get in contact with PET [because of son's condition]. They were out straight away. They said, "Yes, he is psychotic and needs hospitalisation". They organised the police and ambulance and stayed there until that was looked after. I can speak very highly of PET. (P13, multiple carer)

Although these participants were happy with the service that staff from PET provided to the affected family member, participants believed they too could have benefited from a greater level of support and explanation from staff at PET, as one participant explained: "their [staff from PET] attention is solely on the person who is sick. It might have been good to have someone to stay behind and talk to me for a while. I remember the very first time he was committed I was very upset" (P13, multiple carer). Another participant provided a similar account of her need for reassurance from staff at PET:
One thing they [PET] don't do is to let you know what is going on. They should because you are the one who is looking after her [daughter] and watching out and over her. Things tend to get very frantic when the situation is looking bad. You want some reassurance and you feel that everyone is just saying, "Who is this silly person?". Whereas in actual fact I don't mind them saying "it was silly" but I would like them to know and acknowledge that I am worried. (P16)

Likewise, Solomon et al's (1998) study of family education reported that participants, whilst being satisfied with the care given to the affected family member by professionals during the emergency, were not satisfied with the service provided to them.

Another concern for participants in this study was the availability of emergency services if the affected family member was less than eighteen years of age:

I have been through so much. Did you know that PET is only for people 18 years and over? If you are under 18 you are not allowed to have a psychiatric emergency. I talked to them [staff at PET] and tried to find out how to prepare for the next emergency in that what do I do Saturday night at two in the morning? They said, "well we don't know. If you find out will you let us know as we are desperate too". Now to the government these people do not exist. There is no such thing as a psychiatric emergency at 17 years of age but there is at 18 years of age. (P20)

The lack of support provided to carers during crisis situations has also been documented extensively in the literature. Rose (1998) claimed that families wanted more ease of access to mental health care during emergency situations because lengthy waiting periods with highly distressed family members only served to increase carers' levels of distress. The participants in Rose's study of family-professional interactions stated "wouldn't it be nice if there were specialised emergency departments where staff immediately knew what to do and the family member was admitted quickly" (p. 145). Similarly, Jeon and Madjar (1998) found the delays in obtaining help often occurred because carers were not taken seriously, and this meant that by the time they obtained help the worst of the crisis was usually over. As a result health professionals' perceptions that the caregiver had exaggerated the crisis situation were reinforced. Eighty-one percent of participants in Hatfield, Gearon and Coursey's (1996) study of family's rating of the value of mental health services found that emergency services were vital to their ability to care for the affected family member.

Several participants in this study, caring for an affected family member displaying self-harming behaviours, reported that staff members from PET were not helpful when contacted during a crisis situation. The participants explained that staff from PET failed to understand the distress participants experienced when the affected family member was self-
harming. The following participant’s daughter was self-harming and when the participant rang staff at PET they said, "well from what you tell us it doesn’t seem like she is going to harm herself or anyone else" (P5). This participant was overwhelmed by the lack of support given to her during crisis situations and was concerned that the affected family member, displaying self-harming behaviours, did not fit into any pigeonhole within the health care system. The following two examples of phone contacts with staff from PET, provided by participants, seem to convey that family members were also used as ‘safety nets’ and asked to continue to care for their very ill family member by service providers. The first participant contacted PET, during a crisis situation, when her daughter was displaying self-harming behaviours. She was overwhelmed by the lack of support she received from staff at PET and was left to manage her unwell daughter and to care for three other children all of whom had disabilities:

The Psychiatric Emergency Team [PET] has not been that helpful. I rang them and I spoke to a chap [man]. Jan [daughter] had broken all the windows in her room and she was sitting on the floor slicing [cutting] herself up with the glass from the window. She was singing at the top of her voice. I rang them [staff from PET] and said "I can not get into her room she has barricaded the door". He [member of PET] said, "is that her singing?". I said "yes". He said "oh she seems happy enough". I said, "she is actually hurting herself and I fear for her safety". He said, "Oh adolescents have tantrums". It was not very useful advice and I have had that reaction from them a few times. I could really have done with some help. (P22, multiple carer)

Another participant provided a similar example when her daughter was also self-harming. The lack of support from PET staff increased the participant’s experience of being consumed and did little to resolve the crisis situation the participant was embroiled in:

Robyn [daughter] was very aggressive. She was going to run out onto the road. We were trying to get some advice and help. It was about one o’clock one morning... She also found a key to the door and at one in the morning she is out on the road. My son and I were there too in our night- clothes. We rang PET. They [staff from PET] were saying, "Is it life or death?". They were saying "Oh she won’t walk out on the road". My son was talking to them on the phone and we really wanted someone to come, someone to help us. We had to sit with her all night. I find it very difficult. She is now into overdosing and self-harming. She has got really bad but she does not fit into anybody’s pigeonhole. It is really hard to get help (P12).

Carers on an Australian television program “Four Corners” on the mental health care system in crisis also spoke of emergency services not providing the support they required when the affected family member was unwell (Channel 2, 2030hrs on the 9th September, 2002). Another participant in this study explained how emergency services established to
help people could be extremely difficult to access and this exacerbated their experience of 
*being consumed*:

One important thing that comes to mind after dealing with services for so many years 
is that there are so few services for so many people in need. The sole purpose of their 
[staff working at the department] side of the conversation appears to be to try to get 
rid of you. Here you are turning to someone in desperation and seeking help when 
things are so bad. You have gotten to this really low point where you are willing to 
pay the price of reaching out for help. You are emotionally vulnerable. What you get 
is someone out there that is trying to get rid of you because they have ten places and 
one hundred calls per day. So they have to come from "we have to get rid of all that 
we can, we will brush you off, we will send you somewhere else, and we will 
convince you that you don’t need help". They seem to have a list. One, you are not in 
our area, two, you are too old or too young, three it is not serious enough. I am sure 
they have a list because you can hear it in their voices by the questions they ask that 
they are trying to get rid of you. The places you are supposed to go to for help are 
trying to get rid of you. (P20)

Similarly, Griffen-Francell et al (1988) reported that family members felt deserted by 
mental health professionals. Participants in Griffen-Francell et al.'s study of caregiver burden 
described how carers had difficulties in accessing professional help during crisis situations, 
particularly if the crisis occurred during the evening or over the weekend. The authors claimed 
that these practices, employed by health professionals, contributed to caregivers’ feelings of 
abandonment, helplessness, and of being exposed to danger. Mohr (2000) gave a similar 
example, in her study of professional attitudes in the clinical setting, claiming participants felt 
marginallised when they communicated with health professionals: "They just keep passing you 
on. ‘Well, let me get this person, let me get this person,’ and finally, after the third or fourth 
person, they’d go, ‘Oh, this is who you need to talk to, and they’ve gone home.'" (p. 604).

Greenberg et al. (1997a) and Saunders (1997) also found that family members were 
ofen used as a ‘safety net’ and left to cope with the affected family member during a crisis 
situation. These authors suggest that the use of families in this way is a reflection of the 
mental health care system’s solution to coping with the dilemma of allocating limited 
resources to treat people who have a mental disorder. In addition, these authors suggested the 
use of families as ‘safety nets’ was further exploited by service providers because as the 
affected family member was being constantly monitored by their family they posed less of a 
risk than other ill people without family support. Participants in Yamashita's (1998) study of 
family coping with mental illness voiced similar concerns regarding the availability of help 
when it was required during crisis situations: "We didn’t know what to do anymore. There
was no help out there. Don't you kid yourself that there is help out there, because there isn't" (p. 519).

In summary, participants in this study had differing perceptions as to how staff from PET influenced their experience of being consumed. Some participants found the staff very helpful to both themselves and to the affected family member. However, other participants reported their interactions with health professionals during emergencies were not helpful and served to increase their experience of being consumed.

5.4.3: Emergency accommodation in the community

Several participants in this study voiced concerns regarding the accommodation available in the community to support people who have a mental disorder. One participant found that it was very hard to find appropriate accommodation for her elderly mother who had been cared for at home for most of her life: "We got mum into an age care hostel which is a much better environment for her than a psychiatric hostel. She was at home for most of her life so she wasn't used to being with other people who had a mental illness" (P1, child/adult carer). Similarly, Rose (1998) identified the need for relevant community care with adequate housing for consumers of mental health care. Another participant gave this description of an inappropriate emergency admission of her daughter to a hostel for young homeless people:

April [daughter] went to this emergency hostel. You know it is one that accepts people on the spur of the moment. In fact when I was there visiting her the police arrived bringing this ten-year old boy they caught on the street sniffing glue. It was a horrible place, it is dreadful. It was like being in prison in terms of being with thieves and other stuff. The people who were there at the time were 17 or 18 years old and they were shooting up on heroin. They were violent. ... She hated it there, she had all her clothes stolen. The people who ran the place said, "she does not belong here". They just took one look at her and said, "this child does not fit in here". (P20)

In concluding this section, the type and quality of emergency services was a condition that influenced participants' experience of being consumed, particularly during crisis situations when participants were overwhelmed by what was happening. While participants were generally happy with the services provided by the police, they had differing experiences with staff from PET. Participants caring for family members displaying self-harming behaviours felt particularly isolated and unsupported during emergency situations. In addition, participants described problems associated with the availability of services provided
for both themselves as well as the affected family member in particular they spoke of a lack of emergency accommodation.

5.5: Mobility of health professionals

The mobility of health professionals was another condition that impacted on participants’ experience of being consumed. Participants found that health professionals were constantly changing and it was difficult to know who was responsible for the care of the affected family member. The mobility of health professionals also affected participants’ ability to establish rapport with health professionals and as a result participants believed this had a negative affect on the overall care of the affected family member.

Building rapport with health professionals was viewed as very important and participants felt the affected family member, as well as they themselves, benefited when a good rapport was established with health professionals: "The psychiatrist was fantastic, he explained everything to us" (P6). Another participant gave this account of the rapport she had established with her son’s nurse:

Michael’s community nurse is very good. The doctors seem to come and go a lot [change frequently]. The first doctor was marvellous to me but he moved to another hospital, if it wasn’t for Patrick, Michael’s nurse. If he ever leaves I just hope he never goes. I would be stuck, he is my rock". (P17)

However, the majority of participants recalled situations regarding how the mobility of health professionals increased their experience of being consumed. Participants found that each time they accessed the health care system they were forced to interact with a new group of health professionals: "There are a lot of inconsistencies in the public system because of the change-overs [mobility of health professionals]" (P13). Participants were also concerned that many of these new health professionals were undergoing training: "They are always different [health professionals are always changing]. Hannah was looked after but they [health professionals] are a lot of learners [participant laughed and implied that health professionals who dealt with her daughter were learning]" (P11, multiple carer). Another participant gave this description of the problems associated with the mobility of health professionals:

When you go to one place [clinic or mental health centre] you start developing rapport. You develop the right sorts of supports to ring up when you need to [know which staff to ring for advice or information]. The nurses, you get to know them and you can ring them up. When you move or they move you have to start convincing people, you have to be quite forthright unless you have a regular community nurse [have to begin the process of establishing rapport, which can be difficult in an
emergency situation]. ... I think the psychiatrists change over so quickly [move from one place to another] that you do not get a chance to know them. (P14)

Several participants in this study were concerned with the number of doctors and nurses that they and their family member had contact with during periods when the affected family member was hospitalised. This made the process of establishing rapport and any long-term relationship with the health professional difficult:

In *[hospital] Sky [sister-in-law] was there for four months and she had about ten doctors. ... There is the main psychiatrist and then there are the junior doctors. Then there is a whole shift of nurses. When the patient moves from the closed ward there are new doctors. Sometimes that is good because if you are stuck with a lousy [bad] doctor the next time you might get a good one. On the other hand the reverse is also true. It is very destabilising for Sky. Each new doctor, each new treatment method, it is difficult you know if they [patients] are in this mental haze [mentally unwell]. ... I think it is a big issue that needs to be addressed. (P8)

The lack of rapport with doctors also led to problems for participants. One participant’s husband [affected family member] told the doctor that he had separated from his wife. As neither the psychiatrist nor the social worker knew the patient, the participant’s pension was cancelled despite the inaccurate nature of the claim. This caused her, and her four children considerable hardship and increased the participants’ experience of being consumed:

Because the social worker was learning the system [was new] and I did not know the psychiatrist I could not convince him to help me stay on the pension. She wanted me to fill in the forms for a single parent allowance. I said, "we are not separated, he is just saying that". (P14)

Yamashita (1998) also found that the mobility of health professionals was a major problem for caregivers, claiming it led to fragmented care, poor communication and the use of uncaring and callous manner by health professionals towards cares. One participant from Yamashita’s study of family coping provided this account: "An awful lot of different people have seen my son. ... So somebody takes him on, and they’re all excited about him, and then the first thing you know they’ve moved and somebody else has his case. (p. 519). Winefield, et al (1998) also identified this aspect as a problem for carers and one participant from Winefield et al’s study of support for caregivers reported: "I still feel I have not got one professional person to turn to who I can trust and speak to. This gives me a feeling of helplessness and isolation" (p. 105).
In this study, another issue influenced by the mobility of health professionals was to do with the medications prescribed for the family member. Participants felt that dealing with new doctors on a regular basis affected their family member's ongoing stability. New doctors frequently changed or ceased medications. "When there is no rapport, when there is someone new you get the drug problem coming back again" (P8). Another participant gave this description of how a new doctor took her mother off all of her medication and as a result it took about a year to get her mother back to her normal level of functioning:

Her [participant's mother for whom she was caring] new psychiatrist took her off her medication because she had been doing so well for so long. He said, "let's reduce it". Then he took her off it and that was when she went really paranoid. That is what precipitated us having to get into a care situation [could not care for her mother any longer at home]. I'm trying to think whether he consulted us first about taking her off the medication. I don't think he did. ... It took about a year to get her re-stabilised so I was quite angry about that. (P1, child/adult carer)

Participants also reported that due to the mobility of health professionals they felt emotionally drained when they encountered a new health professional, as the following participant explained:

It is so frustrating because every time you have contact with them [health professionals] you meet someone new. You have to start all over again right from the beginning. You have to explain to somebody what has been going on and what you are looking at in terms of support or help. That is so emotionally draining having to talk to all sorts of people with all sorts of attitudes about what you are going through. (P20)

Continuity of care problems resulting from the mobility of health professionals were also identified by Griffen-Francell et al. (1988). These authors found that because of the mobility of health professionals, families reported a lack of continuity in treatment approaches and medical therapy. In addition, family members expressed anger that they were repeatedly questioned by a variety of health professionals each time the affected family member was hospitalised and it was difficult to develop rapport with any one professional and, therefore, the affected family member's continuity of care was compromised.

In summary, participants in this study reported that the mobility of health professionals influenced their experience of being consumed because it was difficult for participants to establish rapport with health professionals and, therefore, problems related to continuity of care frequently occurred.
5.6: Health professionals’ management strategies

Health professionals’ management strategies were another condition that influenced participants’ experience of being consumed. These management strategies were grouped into three areas: health professionals’ application of the principles of patient confidentiality, problems associated with the trend towards briefer periods of hospitalisation, and the management plan used by health professionals.

5.6.1: Health professionals’ application of the principles of patient confidentiality

Patient confidentiality, the privacy of privileged information shared between consumers and health professionals, was a major concern for participants who believed some health professionals did not understand the law, and hence participants were not given information and were “kept in the dark”. Participants explained that this lack of understanding about the law occurred because health professionals were unable to differentiate between information falling within the bounds of patient confidentiality and more general information that could be shared with the ill person’s family: "With patient confidentiality most of what is happening [problems and care of the family member] is hidden. That is the whole problem" (P2); "This holy grail, this confidentiality thing. ... I just wanted to feel that I was doing things along the same lines, things that were advisable or helpful. I want some guidance" (P3); "I am concerned with confidentiality as unless I know the details [how to care for daughter] you are unable to deal with it." (P21, multiple carer); "You are supposed to be actively involved in the treatment, part of the treatment team but you stumble through and pick up the pieces. After, if you do it wrong, they [health professionals] won’t pick you up as well" (P9).

Participants felt that health professionals’ application of the principles of patient confidentiality meant that information which was essential to their ability to care for the affected family member was withheld from them. In turn, this increased participants’ sense of powerlessness to manage, and to understand, what was happening:

Confidentiality is a problem in as much as if you need to see a doctor. For example, if Aaron needs to see the doctor regarding this administration order [management of financial affairs order] he has to organise it. However, when he is not well there is no way he is going to do it. I can’t do it for him, there is no way I can change appointments for him and I can’t get information for him. It doesn’t matter how involved I am in his care. It is frustrating. I have got him on one hand saying "can’t you do it" or him saying, "I am not going to go, so you will have to cancel it". On the
other hand they [health professionals] say, "Aaron has got to do it". They say, "we [carers] can't be involved in this, we [health professionals] can't tell you anything, and we can't tell you why". Then Aaron is saying, "just ask the doctor" and the doctor is saying, "I can't tell you". So you end up between the two. There are ways around that. I generally go with Aaron when he has a doctor's appointment. He invites me in, I am his security blanket. However, sometimes when he is really angry he doesn't want me there. Then he won't tell me about things. If it is anything important I feel they [health professionals] should be able to tell me. So you sort of live under this constant threat that if there is something really drastic going on, they are hiding it from you. It may not be true but that is the impression you get. They [health professionals] expect you to care but they take all of your weapons [resources to obtain information] away. (P9)

Another participant spoke of how her feelings of being consumed were increased because of the way health professionals used patient confidentiality laws in regard to her daughter:

They [health professionals] are very arrogant people who would not talk to me without Robyn [daughter] being present. This cancelled out everything [makes it difficult to talk when daughter is there]. They treated me like a huge intrusion in Robyn's life. She had two long stays there * [psychiatric hospital] but I would not send her back. It was mainly the doctors. They were dealing with Robyn and they didn't want to deal with anyone else. It makes it very difficult [for the carer]. (P12)

Several participants reported only being contacted by their family member's doctor during times of crisis: "The doctor would ring. She won't go into any detail but she said, 'Pauline [daughter] is in trouble'. I said, 'what do you want me to do?' [as the doctor did not tell the participant any details she was confused as to how she could help]" (P2). However, participants were not provided with enough information to fully understand what was happening: "My wife's psychologist wasn't interested in seeing me... She rang me once to let me know that Rose [wife] was feeling suicidal and told me to keep an eye on her. That's the only discussion I ever had with the lady" (P7).

Another participant described how her daughter was incapable of managing her affairs due to a head injury she had sustained and, as such, the participant had been appointed as her legal guardian. However, from the psychiatric position, information was withheld on the grounds of maintaining patient confidentiality:

The amazing thing is, and I don't know how you overcome it, when she was awarded her damages award they [disability services] straightaway said she was incapable of managing her finances [daughter had a motor car accident]. However, in all of these instances [behavioural change resulting from the accident that caused her admission to psychiatric services] when she is behaving irrationally they [health professionals]
can only do what is her choice. It is very contradictory. It is so consuming and I feel if I don’t find some kind of solution I don’t know what I will do. (P12)

Similarly, the following participant described her perspective of health professionals’ application of the principles of patient confidentiality on her ability to care for her daughter:

We [participant and husband] don’t like that confidentiality ourselves. When June is in hospital the doctors don’t like to talk to us. They say, "confidentiality is a big thing". When she was first in there it was fine. But now unless she agrees, unless she can be there in the interview, and unless this and that we don’t find out anything. We keep arguing that it is wrong. We have to watch out for her so why shouldn’t we find out about things. We just think it is wrong to have that level of confidentiality. ... We really want to know what are the signs to look out for, which we probably know already. We want to know which ones to really look out for rather than ones that are silly to watch out for. We want to know where we really ought to go [how to help their daughter] and that sort of thing. And they say they will give us a name of someone that we can really talk to. Then things change when it comes to the situation [they never get to talk to the person who has been nominated]. (P16)

Participants spoke of how difficult it was to manage day-to-day issues or to work with case managers due to health professionals’ application of the principles of patient confidentiality:

Michael [son] is 24 years old. If he says they are not to tell me anything I don’t get to know anything. At the moment the nurse is very good. ... He visits Michael and I phone him from time to time. He says, "he is as well as can be expected but there is nothing I can do. My hands are tied" [regarding issues of confidentiality]. ... I respect Michael’s privacy he is an adult. He doesn’t want me to know everything and I don’t want to know everything. ... I would be happy if he didn’t need me to prop him up. I would love him to do all of this himself. ... I don’t want to know everything that Michael discusses with Patrick [nurse]. I want him to have people he can talk to. It is not healthy for him just to have me and for me just to have him. I just want to know how to manage things better. (P17)

For some participants, health professionals’ application of the principles of patient confidentiality meant that participants were not informed when the affected family member was discharged from hospital. This led to increased family stress, as one participant explained:

Peter was discharged from * [hospital] and caught a plane to Sydney [a four hour flight from the west to the east coast of Australia]. He was 21 years old. Nobody told me [that son was being discharged and going to Sydney]. ... I got a phone call from my sister [who lived in Sydney] and she said, "guess who I have got here". I said, "I have no idea". She said "Peter is here". He had arrived at her place with a new computer, a new TV [television] and a guitar. He had no money to pay any board. He
also had no Medicare card [health care card]. He was still quite psychotic. She had four children and Peter to deal with. (P11, multiple carer)

Participants considered that health professionals' application of the principles of patient confidentiality also compromised their relationship with the affected family member. While communication between the health professional and the affected family member was not shared with participants, the communication participants had with health professionals was often relayed by the health professional back to the affected family member. As one participant explained, in a follow-up interview for this study: "This one-way process of patient confidentiality impacts not only on our ability to care but also on our relationship with our ill family member" (P3).

Several participants stated that as a result of patient confidentiality they had not established rapport with health professionals treating the affected family member. Participants explained that this lack of rapport compromised their level of well-being as the following participant explained. The participant had been caring for her son for four years and yet she had little understanding of schizophrenia. It was apparent that the participant was at risk when her son was unwell as she became very violent and paranoid:

I have read as much as I can on it [schizophrenia]. I don't fully understand it. I know it is a chemical imbalance in the brain. I know that his symptoms they are never able to complete anything. Is that right? I hope one day he is going to get better. (P17)

Griffen-Francell et al (1988) and Winefield et al (1998) also identified that one of the worst problems encountered by carers was patient confidentiality and hence the lack of information carers received regarding their family member's health. Domenici and Griffen-Francell (1993) asserted that patient confidentiality was often used as a barrier to providing information about the patient. Similarly, in a study on carers of cancer patients, Morris and Thomas (2001) also reported that patient confidentiality, particularly the sanctity of the doctor-patient relationship, meant that crossing the boundary into the medical world was more complicated for carers than patients. Marshall and Solomon (2000) claimed that obtaining information from health professionals required much personal effort on the part of the carer, who was forced to learn specific questions to ask in order to understand the mental health system and the treatment their relative was receiving.

Parker (1993) suggested that in regard to patient confidentiality caregivers need to know, at a minimum, the ill person's diagnosis, the nature of the illness, and the medication
and side effects of the medication prescribed for the affected family member. Similarly, Marshall and Solomon (2000) found that because client consent is needed to release information, family members expected health providers to initiate this release process. However, in reality, this process does not occur and becomes problematic for carers, as one participant in Marshall and Solomon’s study of families of people with mental illness explained: "My daughter was a patient at hospital X three times in 1998. Twice when I inquired about her condition or asked to speak with her, I was told that I wasn’t even supposed to know if my daughter was a patient." (p. 1010). Another participant from Griffen-Francell et al’s (1988) study of the role of family education gave a similar account of the impact of patient confidentiality laws on caregivers: "... they shouldn’t allow their ridiculous confidentiality laws to exclude the family when they [the state] give them [the family] the job of caretaker, case manager, support person, and everything else." (p. 1299).

In addition, Bogart and Solomon (1999) found that carers were frequently the first to recognise warning signs and symptoms when the affected family member was relapsing. However, health professionals’ application of the principles of patient confidentiality often prevented participants from being given information that was helpful to this process. Marshall and Solomon (2000) reported that while current treatment guidelines recommended family involvement in all aspects of the treatment process, patient confidentiality frequently inhibited family involvement on any ongoing basis. Furthermore, Bogart and Solomon (1999) claimed that providing information to carers about their relative’s illness decreased the affected family member’s relapse rate and number of readmissions to hospital. However, the authors stated “without ongoing contact with providers, families may observe signs of relapse but have no means to share this information with providers” (p. 1323). Bogart and Solomon (1999) argued that family members could be provided with information about their family member’s illness without disclosing any confidential information. Griffen-Francell et al (1988) agreed, claiming that caregivers must have access to information about their relative’s illness and treatment in order to provide effective carer. In summary, health professionals’ application of the principles of patient confidentiality laws increased participants’ experience of being consumed and impacted on all aspects of their caregiving experience.
5.6.2: Problems associated with the trend towards briefer periods of hospitalisation

Another management strategy that influenced participants’ experience of being consumed was problems associated with the trend towards briefer periods of hospitalisation. Briefer periods of hospitalisation have occurred due to the reduction in the number of inpatient beds and the expansion of community mental health care. Hence, the underlying philosophy is to treat the consumer in their community and preferably in their home.

The problem associated with short periods of hospitalisation was raised numerous times by participants in this study. When crises occurred, participants were relieved that their family member was hospitalised. However, for many participants the relief was short lived when the participants began to suspect that the affected family member was discharged from hospital too early. One participant provided this account when her son was discharged from hospital after a few days: "Our life was a hell. Michael was terrible. I was quite devastated when they let him out a few days later without any help. We were back to square one again" (P17). The early discharge of people from mental health care facilities was also commented on by carers on an Australian television program “Four Corners” on the mental health care system in crisis (Channel 2, 2030hrs on the 9th September, 2002).

Other participants in this study found they were pressured by staff to take the affected family member home as soon as possible: "They didn’t keep him in hospital very long. They kept him in over the weekend. There is a lot of emotional pressure to stand into that role [of being a caregiver and taking son home] and to a large degree the system plays on that" (P9). Another participant provided this similar description:

We got the Psychiatric Emergency Team to go and have a chat with Sky and she was totally off the planet [very unwell]. They took her to hospital. We were really not given any information and she was sent home to us after a very short time. We were really surprised. She got 48 hours care and then she was out again and nothing had been resolved. (P8)

Similarly, Domenici and Griffin-Francell (1993) asserted that families did more than "their fair share, bearing, in many cases, a nearly intolerable burden" (p. 32). These authors claimed the mental health care system "lacked continuity of care and provide inadequate, fragmented, or conflicting services" (p. 31) and "these fragmented services masquerade as the so-called ‘mental health system’. In reality, a true system- a multi-system- does not exist" (p. 32). A participant in Rose’s (1997) study of caregiver’s support gave a similar account of hospitalisation being used to manage the affected family member’s immediate problem but
little else. The participant discussed his view of the cycle of inpatient treatment and community care: "The doctor says, 'I'll put her in the hospital for a couple of weeks.' She comes in and they help her and she's back out and we try again" (p. 20). The impact of the trend towards shorter periods of hospitalisation was highlighted by Walker (2002) who claimed that twenty years after the process of deinstitutionalisation began in Australia the mental health care system is in crisis. According to Walker the latest statistics reveal that there are only about 5000 beds available for the mentally ill and this number is 63 percent fewer than a decade ago. Recent statistics issued by the Australian Institute of Health and Welfare show that more than one third of all people admitted to hospital needing psychiatric services were discharged the same day. People with schizophrenia who were admitted to public hospital had a median length of stay of 13 days (Walker, 2002).

Many participants in this study spoke of there being little change in the affected family member's condition when they were discharged after a brief period of hospitalisation. The problems associated with early discharge were linked to follow-up support and to medication issues. One participant was concerned regarding the lack of support for the affected family member following her discharge from hospital:

We [family] thought there would be a day care [when daughter was discharged]. They [health professionals] would come and take her [during the day]. A club and a lot better support. I mean she had been on a lock-up ward [intensive care unit] for a month. When they get out, there is nothing. The community nurse only came for a couple of months. They probably thought I was doing such a good job so why bother. (P18)

Similarly, Winefield et al (1998) found that when the affected family member was discharged from hospital, carers experienced an increased level of psychological distress due to the lack of follow-up care. These authors claimed that health professionals provided carers with primarily hospital orientated information and were not aware of needs or the resources available for carers in the community. Furthermore, Domenici and Griffin-Francell (1993) found "it extremely hard to enter the system, but extremely easy to exit, to lose people" (p. 32).

Other researchers have also found that the affected family member was discharged back to the family after only a few days treatment in hospital and as a result family members experienced increased distress because they had to manage a relative who was still extremely unwell and angry at them for initiating hospitalisation (Griffen-Francell et al, 1988). In
addition, these authors claimed caregivers lived in fear, as they perceived that hospitalising the affected family member was no longer a viable option for them.

Grad and Sainsbury in 1963 were the first to highlight the emotional strain on families as a result of the trend towards briefer hospitalisations. These authors used the term family/caregiver burden (Saunders, 1997). Hoenig and Hamilton (1966) differentiated between subjective and objective burden experienced by family members. Objective burden refers to the consequences of the affected family member’s abnormal behaviours on the other family members, for example, social isolation and financial issues. Subjective burden, on the other hand, refers to the psychological consequences and includes the family member’s [carer’s] mental health, level of subjective distress and burnout. More recently, Solomon and Marcenko (1992) interviewed family members [carers] one month and one year after their family member was discharged from hospital. After one month they found that more than half of the caregivers in their study expressed concern regarding the affected family member’s readiness to live in the community. This level of concern had not changed after one year.

Participants in this study stated that health professionals needed to stabilise the affected family member’s medication regimes before sending them home. They considered that if this happened the family member had a better chance of remaining well:

Sky [sister-in-law] was only in hospital for about three weeks. I thought it was much too soon for her to come home. They said "the depot medication takes a month to six weeks to kick in and some of the tablets are not that much quicker". Yet they sent her home. If they kept her a little longer the medication would have been established and we would have more chance of stabilising her and keeping her out of hospital. (P8)

One participant indicated that the structure of the health system decreased her son’s chances of recovery each time he was hospitalised. As he was unable to receive any help until he was really unwell, his recovery then took much longer:

Because Aaron [son] doesn’t think he has an illness he doesn’t want to take medication. In addition, he has to be really, really unwell for them to put him into hospital. Each time he becomes unwell his chances of recovery become that much less. So in a way the system and not the people within it, the system itself is encouraging him to become permanently unwell. (P9)

Another participant voiced concern about the role of the Mental Health Review Board on their family member’s progress following discharge from hospital. The participant claimed his affected family member was just beginning to be stabilised on medication when
the Review Board stopped her Community Treatment Order (CTO). When this occurred the affected family member then refused to continue to take her medication:

Once the person [who is mentally ill] is stabilised [on medication] and all of the rationality comes back and everything comes together. They get confidence and they start growing again. Who knows but if it had been a couple of months longer. Sky [sister-in-law] was hospitalised for four months and then she was on a CTO for six months. Now the doctors and us had planned that during those six months Sky was going to be closely supervised in the beginning with her oral medication and then gradually tapered off as she takes more and more responsibility on board. We built her up to the phase where she was intelligent, rational, calm and all of the rest of it. She goes to see the Mental Health Review Board [for review of her community treatment order] who say "I am crazier than this woman, let her go" [come off the CTO]. From there the whole thing started to fall apart, she still lived with us but she said that she would continue to take the medication and then I started to find bits of Resperidol [medication] under the couch and in corners of the room. It started to go downhill and she became very ill. (P8)

Other participants were concerned that the appointments their family members had in community clinics with psychiatrists were short and this prevented the psychiatrist from fully understanding what was really happening:

Anna [mother] would be in there [appointment with psychiatrist] for five minutes. He would check medications and tell her she must do things. He told her "try and be active and don't lie in bed all day". When I took her to see the doctor after dad died I thought the doctor wouldn't just say that, but he did. (P1, child/adult carer)

Another participant gave a similar example of how very little was achieved during a visit to the doctor in the community setting:

One thing that disappointed me was the medical profession, the doctors who were specialists in attention deficit disorder (ADD) [daughter has ADD, borderline personality disorder and depression]. They are seeing hundreds of patients; they must know a lot more about it [ADD] than I do. They must know that these patients should be getting a multi-modal approach to treatment [approach that deals with many sources of intervention eg. psychosocial, behavioural, and medical]. Yet they would see us [participant and daughter] every three months for five or ten minutes, give us a new script and send us away. (P20)

In summary, participants' experience of being consumed was increased by the trend towards briefer periods of hospitalisation for consumers of mental health care. Participants claimed that when the affected family member returned home following hospitalisation nothing had changed. They were particularly concerned that the affected family member was not kept in hospital until their medication regime was stabilised. Participants also felt that the
follow-up care, when the affected family member was discharged, was inadequate and, therefore, the affected family member’s chances of remaining well were greatly reduced.

5.6.3: The management plan used by health professionals.

Another component of health professionals’ management strategies that impacted on participants was the management plan used by health professionals. One type of management plan that impacted on participants’ experience of being consumed was the family member’s treating psychiatrists’ beliefs concerning the cause and treatment of mental disorders. Participants lacked knowledge and understanding that psychiatrists have different beliefs and treatment strategies and did not know there were several schools of thought regarding how to treat different types of mental disorders. While these different treatment options are healthy to the development of psychiatry none of the participants, or their family members, were told there were other treatment options available.

The following participants (set of parents) were advised by the affected family member’s treating psychiatrist to take their daughter to an isolated area of the country in Western Australia to control her manic (overactive) behaviour as the psychiatrist did not believe in the use of drugs to control the manic behaviour. The participant did this for five months:

Well it was unbearable in * [the country town they went to] on the farm. She was really aggressive and manic. She hated us and she didn’t want to be near us. That was the worst time I found. She would take off and we wouldn’t know where she was. It was unbearable. We kept her on the farm and we tried to control her. The psychiatrist said it was environmental. (P10)

Similarly, another participant recounted a harrowing experience of managing her unwell family member for several months and not knowing that alternate methods of care were available if she had contacted another psychiatrist:

I sent Zoe [daughter] to an art therapist that was the biggest mistake I ever made. She didn’t help her very much. I wasn’t too impressed but I thought it was going to be alright. ... The art therapist got sick and I got this call at home. She said "I can not practice, I have transferred Zoe to a psychiatrist". He was not the one we had originally been to; he [the new one] didn’t do anything for her. I said to him "is there any sort of medicine you can give her". He said, "No, I can’t really". It turned out that he was a Jungian psychiatrist. The Jungian’s I don’t know what they do but they don’t believe in drugs. I guess they think it was all because your mother was mean to you when you were two. Anyway he didn’t help her. I said to him one day because he interviewed me as well as her. I said "she is getting worse, isn’t there anything you
can do for her?". I knew she had been on medication before [during first presentation of illness]. He said to me "Mrs Blake she will probably get worse before she gets better". Well I kept on with him and he saw her a few times. Then the art therapist got better and she went back to her. By this time she was pretty sick. Then she started throwing the crockery. All of a sudden she would pick up a plate and throw it. She threw a cup out of the window one night. My husband and I just looked at each other. ... When she started throwing the plates we said, "we have got to do something". I said to my husband "look either we go back to the original psychiatrist or find someone else. We can't keep on like this". Basically the second psychiatrist just didn't help. She just got worse. (P6)

Domenici and Griffin-Francell (1993) asserted "perhaps, surprisingly, many providers lack current researched-based knowledge of the etiology [sic] and psychopharmacology of mental illness. As a result, they fail to provide family members with essential medical information" (p. 31). Participants also recalled health professionals' management of the affected family member during periods of hospitalisation, which increased participants' experience of being consumed: "I got angry the first time I met Dr Smith. I might have sounded aggressive but I was at the end of my tether. I was not going to sit there when decisions were being made about Jill [daughter]" (P10).

Another participant gave this graphic account of how her husband, who had dementia, was treated when he became aggressive to staff. The participant felt very angry with the way he was dealt with and after this incident she went to the hospital everyday as she felt she could no longer trust the nursing staff:

I did feel I needed respite. I had got to the stage where I could not go on. I was under the impression that I would have a fortnight's holiday and then I would have Larry [husband who had dementia] back [home]. They [health professionals] said "they did not want to see me for the first week until he settled in". They said, "they could deal with him better if I did not visit him". I am really angry about that. My son visited and the staff said "Larry was being difficult with them, but they had him under control". I did not realise the implication of that. When I came back [from holiday interstate] they said, "I could come in on the Tuesday". When I saw him he was like a broken man. I have a photograph at home. He was restrained in a chair in his room and he was drugged to the hilt. ... When they were dressing him, he was kicking at them. (P25)

The participant was particularly distressed by the cruelty displayed by nursing staff to manage her husband's aggression:

They had a very old nasty table, it had a sharp strut between the legs of the table. When he kicked they put the table in front of him and he would kick out and hit this sharp edge. He had marks on him that was unkind. You see there is unkindness there. It was an awful table and that is unkind. They would be aware
that he would hurt himself on the table. I came in and said "what is that mark on his leg?". It was beginning to heal and I hadn’t seen it as I was away. It was a huge mark. I asked, "How did that happen?". Then I saw this table in his room and I wondered why it was there. Then I realised what they were doing with it. If he kicked they would bring in that table and that is nasty. (P25)

The participant explained that she believed that some of the practices used by nursing staff were to make life easier for them and were not used in the best interests of patients. The loss of trust in the nursing staff further increased the participant’s experience of being consumed, as she explained:

The restraining I saw in * [hospital]. My friend’s husband [met her at the hospital] he was restrained and confined to his room because he shouted a lot. I didn’t tell my friend. They restrained him with the belt. He slipped down, he had no clothes on, because he had taken all his clothes off. He must of been cold because the air conditioning was up and cold for these people and he had one blanket. I used to take four blankets in for Larry. It is only because they don’t want to have a lot to change [dirty linen if patient is incontinent]. It was for their convenience and that is not right. I took food as they give them vitamised food. I think that is also for their convenience. After that I went every day. I just did not trust them at all. I went for three hours every day and three hours every night for 14 months. (P25)

Participants reported that they noticed differences between how the members of the health team worked. Some doctors wanted to keep control over the management plan of the affected family member while other doctors used a more democratic team approach in addressing their family member’s needs:

With some doctors we [carers] have found that even though we have built up a rapport over months there are some doctors that like to keep solid control over everything. Others have a more relaxed attitude, more teamwork attitude towards looking after the patient’s needs. (P8)

Several participants were concerned regarding the management of the affected family member’s mental disorder and illicit drug problem (dual diagnosis issues), and these participants reported there was no real management plan for the affected family member’s dual diagnosis problems:

There are little things like dual diagnosis because Aaron [son] has schizophrenia and he is a drug user. It has a psychological effect on his mental state. It seems that he is either being treated for one thing or the other, there is no treatment for both. Aaron isn’t an isolated case because a lot of them seem to go for drugs. It compounds the problem or causes the problem or it is their solution to the problem. It doesn’t seem to be dealt with very much. (P9)
Clarke and Drake (1994) claimed people who have a mental disorder with substance misuse problems were often aggressive and disruptive and provide multiple problems for health providers and caregivers. In addition, these authors asserted this group of consumers comprised a considerable percentage of the homeless population. Sitharthan, Singh, Kranitis, Currie, Freeman, Murugesan and Ludowici (1999) and Winefield et al (1998) highlighted the lack of services available to people with dual diagnosis issues. Sitharthan et al (1999) reported patients with a co-morbid substance use disorder received less outpatient treatment because they were considered difficult patients. Furthermore, psychiatric patients with alcohol problems felt unwelcome in alcohol treatment agencies. These authors reported the liaison between psychiatric and drug and alcohol services were inadequate and many psychiatric patients did not respond to the demands placed on them by drug and alcohol agencies. Moreover, these factors often lead to relapses and non-compliance with pharmacological and psychosocial interventions. More recently, Gauntlett (2002) claimed that Western Australian health services were not equipped to deal with people who have a combined mental health and substance abuse problem.

In summary, health professionals' management strategies influenced participants' experience of being consumed. These management strategies were divided into three areas: health professionals' application of patient confidentiality, problems associated with the trend towards briefer periods of hospitalisation, and the management plan used by health professionals.

5.7: Level of support

The level of support was the last condition identified as influencing participants' experience of being consumed. Participants experienced support from family members, friends and neighbours and from support groups in the community. In addition, some participants reported a good relationship with the affected family member and this was helpful.

5.7.1 Level of support from family members

Participants experienced differing levels of support, particularly from their family members: "The family support can either hinder or help the person" (P8). Some participants
indicated that their family members were supportive and this was helpful: "Two family members are nurses and they were quite helpful. They were extremely good. They helped Jill [daughter] and they helped me. ... My daughter was very supportive. I talked to her about different things" (P10). Another participant gave this description of limited support provided by her sister:

My sister got some of these [internet] sites and she found this [article on borderline personality disorder]. My relationship with her [sister] has sort of been a bit up and down, on and off over the years. More recently we are spending more time with each other. She has had her own problems and has not been in the position to help much until the last year. In the last year or so she would take April [daughter] for the occasional bit of time maybe overnight. Overnight does not really do anything for her and when April would go over there I would plan out my whole evening. I can have peace and quiet with nobody interrupting, but it went too quickly back to the nightmare. I don’t know, the way April has behaved is so horrifying for most people. Being in her company for a little while for most people they would have to go home and spend three days recovering form it. It is horrifying just the stress, the anger the mishaps, the tears, and the screaming and the banging. (P20)

However, other participants reported their family members were not supportive and this lack of support increased their experience of being consumed: "Everyone [family members] kept saying, particularly Hannah’s [daughter] mother-in-law, ‘you would be better off your medication’. That was not helpful" (P11, multiple carer). Several participants reported that their mother was not supportive to them and this was particularly distressing for the participants. One participant believed her mother was very critical and was always telling the participant what she should do:

My mother was not helpful, she was full of what we should do. You should do this, you should do that, she shouldn’t be doing this, she shouldn’t be doing that. She never understood. She is the one I would really have liked support from but I never got it. (P10)

Similarly, another participant reported her mother did not understand what was happening and, her comments were unhelpful:

My mother who is dead now, she did not understand, she was from the old school. Mum was in her mid 70s when Josh [first affected son] got sick. She told me “there is nobody in our family who is mad. Don’t bring Josh or Lance [second son with a mental illness] anywhere near me”. She used to turn her back on them. (P13, multiple carer)
5.7.2: Support from friends and neighbours

Participants reported the reaction of their friends and neighbours also influenced their experiences of being consumed. Some neighbours and friends were very supportive: "My husband worked night duty sometimes and he [neighbour] would call out last thing at night to see if I was alright" (P11, multiple carer); "I had a neighbour ... she could see that something was wrong. She had a brother with a mental problem ... so she could relate to me" (P6). In addition, some participants also found their employers were very supportive to them: "I had to go to work or else I would lose my job. I was lucky that I had a boss who I had worked for six years and he knew me very well and he knew Tony [husband] was not well" (P25). However, others participants were disappointed by their friends' responses. The following participant felt let down by a friend whom she considered could have provided vital support to her:

I was disappointed in one [friend]. I wrote to a woman who was a very close friend. I knew she had a boy who had a bipolar disorder [mental disorder]. I wrote to her, and told her what was happening and asked if she could write to me and give me some words of advice or something. She never answered for months and when she did she wasn't really interested. (P10)

Participants suggested that some people just did not understand what was happening and as such said things that were upsetting. Participants were particularly distressed when people made inappropriate comments in front of the affected family member:

I am disappointed in ignorant people. Friends who say "why don't you just make him go out and get a job. He is a bloody dole bludger sitting around doing nothing. Get him out there. Why don't you just force-feed him his medication if he won't take it. Why don't they just keep him locked away forever". It is destructive because they will say it in front of him. He becomes invisible. They irritate me. It is not just hurtful but it is very frustrating and it makes me angry. I think that it is a lack of understanding. People need to learn a lot more about mental illness so that if it ever comes to a situation where they have to deal with it, as we did, they have some knowledge. (P9)

Other participants found that it did not help when they spoke to friends because their friends had no idea what participants were going through and their comments were sometimes perceived as being demeaning:

I did not find it helpful to talk to friends. They [friends] tried to be helpful but they have no idea of what you are going through. They are trying to be helpful from their perspective of their children. It seemed to do more harm than good. Instead of being helpful it was confusing. I found it upset me. I found it upsetting, demeaning and confusing. It was like the old argument, hereditary versus environment. (P20)
5.7.3: Support groups in the community

Many of the participants in this study had contact with self-help, community, or carer groups. Participants differed regarding their perceptions of how these groups influenced their experiences of being consumed. Some participants in this study found the groups particularly helpful. "Our main support has come from the various volunteer organisations" (P8). One participant found the Association for Relatives and Friends of the Mentally Ill (ARAFMI) was really helpful and she stated that every new carer should be given a one year subscription to ARAFMI:

ARAFMI has been really good, for just getting the information. I wish my dad had this information, if the doctor had only given us some pamphlets. I really think it should be compulsory that every new person to the psych [psychiatric] area should just be given a complimentary one-year subscription to ARAFMI. I think that would solve heaps and heaps of problems. (P1, child/adult carer)

Another participant felt that it was a major breakthrough for her when she first went to ARAFMI as other people there could relate to her experiences:

I thought I would go in and see this place called ARAFMI. Well that was a big breakthrough. At last I found people that knew what I was going through. ... You couldn’t tell them anything that shocked them. So for a couple of years I used to get Friday morning off and go to the drop-in centre. After I had been there about six months I finally could attend without bursting into tears. It made me realise that I wasn’t alone. Just being informed about the illness you know. ... It was like sailing into a safe harbour after being in the storm. I found over the years consequently that people that are there are just so courageous. You know they are just some of the best people on earth you know. They are little insignificant people that just contribute to everything and so that’s why I stayed with ARAFMI. (P5)

ARAFMI decreased the following participant’s experience of being consumed because it was helpful to finally find someone he could talk to about his situation:

I eventually found out about ARAFMI. I saw it in a community newspaper. That was two and a half years after my wife’s illness that I eventually found out someone that could help me. So I went along to the council there and that was good because it lifted a whole load off my shoulders. I could actually talk to somebody who could understand. I used to go back there quite a lot. Well it gave me a fair bit of knowledge about depression and anxiety, about how to treat the person but also about how to look after yourself. So I think from that time on it helped. I think it is quite terrible actually that professionals, in both the public and the private don’t involve you automatically. (P7)

Other participants believed the courses given by ARAFMI were particularly informative and helpful:
Well we first went to ARAFMI when the staff at the hospital said "do a course on mental illness". There were only about three or four mothers. That was quite helpful. I tried to get Carol [daughter] to go. But because I am busy it is very hard. I never really got in touch with them after that. (P18)

Similarly, Katz and Bender (1976) claimed self-help groups are particularly useful to carers during times of "social fragmentation and unrest, characterized [sic] by loss of relatedness and alienation" (p. 266). Chapman (1997) asserted that carer groups not only provide support to the carer but they also acted as advocates for change. However, not all participants in this study found carer groups were helpful: "I went to one meeting at ARAFMI. I didn't really get much out of it. I might be better now but for a long time I would cry all of the time" (P17); "I haven't been to ARAFMI. I want to be with happy people. I have a friend who has a son who is bipolar [disorder] and she wants to talk about him all the time. I keep thinking ARAFMI will be like that" (P12). Another participant gave this account:

I don't like ARAFMI from that point of view .... I think that ARAFMI plays a big role for some people but not for me. I find that there are a lot of people, I have been to a couple of groups and they seem to be full of talking about the illness or talking about how they feel. I don't want to do that. I just want to be there for June. I don't want to hear about other people's problems I don't want to be understood and go all weepy about it. (P16)

The following participant, although not needing the support of carer groups, was glad to know they were there if she did require help at some time in the future:

I went there [to ARAFMI] with a friend for a while. However, I just couldn't tell my story every week, which they wanted me to. Sometimes you go there and they want you to tell what had happened to you. I didn't go anymore but they are always there for me if I needed them. (P2)

Jeon and Madjar's (1998) study of caring for a family member with chronic mental illness found that not all family members valued the support and information they received from support groups. For example, the authors stated that support groups were only useful to those carers who were ready to seek help. In addition, the authors reported carers found learning from their own and other people's experience was a slow and often frustrating process, which added to their feelings of floundering in the dark.

Participants in this study also had contact with other support groups, for example, the "First Psychosis Support Group". Their reactions regarding how these groups influenced their
experiences of being consumed differed and as the following participant explained she found it difficult to listen to how well other carers’ family members were doing when her son was still very unwell:

I am beginning to feel as if I have outgrown this particular carer’s group because it is the early episode one. I am starting to find it difficult to go and listen to people saying “my son is really well, he has got a job and he has got a place to live”. My son isn’t doing well. I am finding that hard. (P9)

5.7.4: Relationship with affected family member

The relationship with the affected family member also influenced participants’ experience of being consumed. Some participants reported they did not have a good relationship with their family member and this increased their experience of being consumed: “She blamed me for what happened to her” (P2); “I don’t really know him anymore. I am not sure how he will react when I talk to him” (P17). Another participant gave this account:

I fail miserably every time I speak to her. I did not know how to deal with her when she is manic. Everything you say she wanted to fight you about. I had to be very, very careful how I said what I said. I found that the most difficult thing of the lot, just knowing what to say and how to say it. That was the thing I had to focus on and I failed miserably nearly every time. I felt I let myself down and I let Jill [daughter] down. (P10)

Participants’ relationship with the affected family member was influenced by how well participants got on with the affected family member’s spouse or other significant people:

Louise went into * [hospital] and met a guy there. He had mental health problems too. She married him and the marriage lasted about five years. It was very traumatic. There were dramas. We did not get on very well. There were always upheavals. (P5)

Some participants were concerned about the influence other significant people had over the affected family member:

This boyfriend has never been with her when she has been really unwell. He knew her before but he never came to see her in hospital. When she came out they made friends again. He has a very strong influence over her. ... I always try to be polite and say “hello how are you”. However, I don’t get on with him and it is really difficult now they are living together. (P18)

In summary, participants reported differing levels of support from family, friends, and community organisations. Some participants found they had a good relationship with the
affected family members while others found support from their relationships with friends of from contacting community groups such as ARAFMI.

5.8: Summary of conditions influencing the basic social psychological problem of being consumed

The substantive theory developed from this grounded theory research identified that participants shared the basic social psychological problem of being consumed. This problem consisted of two parts: disruption of established lifestyle and sustained threat to self-equilibrium. The data identified that six conditions influenced participants’ experience of being consumed and these conditions were present throughout both stages of the problem. They were: "participants prior exposure to, knowledge of, and experience with mental disorders"; "communication with health professionals"; "the type and quality of emergency services"; "mobility of health professionals", "health professionals’ management strategies", and "the level of support".

The first condition was participants' prior exposure to, knowledge of, and experience with mental disorders. The majority of participants had no prior exposure to, knowledge of, and experience with mental disorders and this increased their experience of being consumed. Eight of the 27 participants had prior exposure to, knowledge of, and experience with mental disorders and these participants spoke of their prior experiences being helpful. The second condition influencing participants’ experience of being consumed was participants’ communication with health professionals. Some participants found that their interaction with health professionals was helpful; however, the majority of participants explained that the communication increased their experience of being consumed. Participants felt they were not listened to by health professionals and, therefore, prevented from understanding what was happening to the affected family member.

The fourth condition, the type and quality of emergency services, influenced participants’ experience of being consumed. Participants spoke highly of the service and level of support provided by the police force. Participants explained that while the emergency service cared for the affected family member, staff from PET did not identify or manage carers’ needs and did little to help participants’ experience of being consumed. Participants expressed that they were used as “safety nets” by emergency staff and they were left to manage crisis situations alone.
The mobility of health professionals was another condition that influenced participants’ experience of being consumed. Participants spoke of dealing with a different health professional each time they accessed the health service and, hence, there was no sense of continuity or rapport established between health professionals and participants. Participants explained that they had to repeat their story each time they had contact with the health care system. On most occasions when meeting a health professional for the first time participants felt like they returned to the beginning of their caregiving experience. Participants were concerned with the effect of the mobility of health professionals on the affected family member’s treatment and in particular their stability of medication regime.

Health professionals’ management strategies were identified as another condition influencing participants’ experience of being consumed. Participants did not understand that psychiatrist had differing beliefs about the cause of mental disorders and hence used different treatment methods. The methods used by some psychiatrists increased participants’ experience of being consumed. In particular, participants’ experience of being consumed was influenced by health professionals’ application of the principles of patient confidentiality. In addition, the brief periods of hospitalisation offered to the affected family member did little to help and participants spoke of the affected family member being no different when they were discharged from hospital.

Participants’ level of support was the final condition influencing their experience of being consumed. Participants received support from friends and from family members. Their relationship with the affected family member was also a factor influencing their experience of being consumed.

In an attempt to address the problem of being consumed with caring for a person with a mental disorder in the Western Australian community, participants’ engaged in a basic social psychological process entitled "seeking balance". Part three of this thesis details that process.
PART THREE

CHAPTER 6

THE BASIC SOCIAL PSYCHOLOGICAL PROCESS: SEEKING BALANCE

CHAPTER 7

CONDITIONS INFLUENCING THE BASIC SOCIAL PSYCHOLOGICAL PROCESS: SEEKING BALANCE
CHAPTER 6

THE BASIC SOCIAL PSYCHOLOGICAL PROCESS: SEEKING BALANCE

6.1: An Overview

When the basic social psychological problem experienced by those caring for a person with a mental disorder in the Western Australian community was identified as being consumed, further data collection and analysis were undertaken. This was done to clarify the emerging basic social psychological process (BSPP) in which participants engaged, in order to address their experience of being consumed. Data analysis revealed that in an attempt to deal with the two-stage problem of being consumed, that is disruption of established lifestyle and sustained threat to self-equilibrium, participants engaged in a process entitled "seeking balance".

Several definitions of the words "seeking" and "balance" were obtained to extract the scope of the meanings of these two words to confirm a fit with the data. The Australian Concise Oxford Dictionary defined "seeking" as "to endeavour to do, ... to search for" (Turner, 1984, p. 1012). The Macquarie Dictionary provided additional meanings "to go in search or quest of, ... to try to find, ... to search for a solution, ... to try to obtain" (Delbridge et al., 1997, p. 1923). Definitions of the word "balance" were "a state of equilibrium, ... mental steadiness, ... calm behaviour, judgement, etc, ... harmonious arrangement or adjustment, ... bring to or hold in equilibrium, ... to arrange, adjust, or proportionate the parts to be equal" (Delbridge et al., 1997, p. 154), and "to bring into or keep in equilibrium, equal or neutralise the weight of, have two equal sides" (Turner, 1984, p. 71).

In the context of this study as identified in the data, all of the above meanings of seeking and balance were relevant. For participants, the process of seeking balance allowed them to move towards neutralising their experience of being consumed. In seeking balance participants began to search for, obtain, and maintain a state where their self-equilibrium, mental steadiness, and other aspects of their lives were increasingly more balanced, harmonious, and calm. In seeking balance participants made adjustments that resulted in their caregiving commitment being perceived by them to be more proportionate to other areas of their lives. In seeking balance participants saw the necessity to step-back from always being there for their family member, allowing the person to acquire independence. The importance of seeking balance was clearly described by the following participant who explained that
finding a balance was crucial to her ability to continue to care for her affected family member: "I got to the stage where I could no longer give the same level of commitment to my daughter, it was too much for me. ... I looked for a way to find a balance" (P18). Another participant spoke of the importance of caring for herself as well as her daughter: "To care for my daughter I also realised I needed to care for myself. There has to be a balance" (P16). Finding a balance as a carer was also viewed as important to the affected family member’s future as the next participant explained:

When Aaron [son] went to Social Security [Government Department] to ask for a business loan to start up this "algae in space venture" I wanted to go with him. I wanted to ring them up and say, "I am really sorry, but he's not very well". I suddenly realised what I was doing. How dare I do it! And from speaking to other carers I don’t think that sometimes they understand that. Sometimes, I think they continue to sacrifice themselves to the detriment of the person with the illness. It is a hard thing to explain and I don’t for a second imagine that I have got all of the answers because I keep tripping myself over [making mistakes]. However, I have to keep looking for the balance. You must move forward in your own life, and you must encourage them [affected family member] to live their own life. I think that it is really sad that some people don’t know there is a balance. (P9)

Prior to the first stage of the basic social psychological problem, disruption of established lifestyle, participants' perspective on life was influenced by their experiences to that time. This included their aspirations, life goals, and dreams, which they held for others as well as for themselves. For most participants their life was, to a large degree, in balance and they lived each day with a reasonable sense of continuity and equilibrium. When participants experienced a disruption of established lifestyle, their existing life perspective was shattered and they became consumed by their recognition that something was wrong with the affected family member and by their preoccupation with not knowing what was wrong. When a diagnosis of mental disorder was made on the affected family member, participants’ experienced a sustained threat to self-equilibrium.

To address their experience of being consumed participants engaged in a three-phase BSPP of seeking balance. Phase one of the core process was called utilizing personal strategies to reduce the problem of being consumed, and this phase was most prominent in the time prior to the affected family member being diagnosed with a mental disorder. The remaining two phases, restoring self-identity and reaching out to make a difference, occurred after participants became aware the affected family member had a mental disorder. Data analysis also identified the presence of a sub-process of seeking balance, called trying to
make sense of what was happening, running parallel to the core process. The sub-process was also comprised of three phases and each phase of the sub-process was linked to the corresponding phase of the core process (See Figure 6).

At the time of being interviewed for this study, one participant was identified as being engaged in phases one of the BSPP of seeking balance, ten participants were engaged in phases two and 16 participants had progressed to the third phases. Participants’ passage through the phases of seeking balance was not determined by the length of their caregiving experience but by their experience of seeking balance and the conditions influencing the process.

Other researchers have previously identified the importance to carers of seeking balance in their lives. Strauss, as early as 1978, reported that seeking balance was a process whereby carers tried to help the ill person without becoming engulfed in their misery (Strauss, 1978). Similarly, Karp and Watts-Roy (1999) reported that carers "try over and over again to find a balance between the requirements of care and the maintenance of their own well-being" (p. 472). Frank (1991) elaborated further on the importance of carers finding a balance in their caregiving, claiming, "eventually a balance must be worked out between what the ill person needs and what the caregivers are able to provide" (p. 47). Likewise, Saunders (1997) spoke of the importance of carers finding a balance in the caregiving process: “learning to identify and balance the needs of a family member with a mental illness with the needs of healthy family members becomes a new, and often difficult challenge ....” (p. 10).

The three phases of the core process will now be presented. Furthermore, the sub-process, trying to make sense of what was happening, will also be detailed. As the sub-process was separate from but inter-related to each phase of the core process, the three phases of the core process will be presented first followed the sub-process of seeking balance.
FIGURE 6: THE BASIC SOCIAL PSYCHOLOGICAL PROCESS: SEEKING BALANCE
6.2: PHASE ONE: UTILISING PERSONAL STRATEGIES TO REDUCE THE PROBLEM OF BEING CONSUMED

6.2.1: Introduction

Phase one of the BSPP, *utilising personal strategies to reduce the problem of being consumed*, was experienced by participants predominantly during the time when the affected family member's abnormal behaviour first began to come to their attention. The change in the affected family member's behaviours resulted in participants developing the *recognition that something was wrong* with the person. Participants then became *preoccupied with not knowing what was wrong*. In addition, at times when faced with crisis situations involving the affected family member, participants reported experiencing feelings of *being overwhelmed*.

The first phase of the core process of *seeking balance* consisted of two aspects. Participants used their established coping responses, which had been helpful to them in previous stressful or crisis life situations. In addition, participants began to use different trial and error approaches in the hope of finding a solution to their problem. Each of these two aspects will now be presented.

6.2.2. Participants' use of established coping responses

In searching for ways to manage their experience of *being consumed*, participants employed the use of their established coping responses. These coping responses had been successful for them in the past when faced with stressful life situations. Participants reported the use of both conscious and unconscious coping responses. Some participants described the use of denial, an unconscious coping response, to protect themselves from the overwhelming feelings evoked by their experience of *being consumed*. The following participants provided examples of the use of denial: "You try to forget all about it [daughter's behaviour]. Out of sight, out of mind. You don't keep thinking about it everyday" (P18); "I just hung [stayed] around and waited hoping that it [the change in son's behaviour] would go away. Yes I did. I thought that one day I would wake up and Michael [son] would be normal" (P17). Another participant described how he denied what was happening and functioned in a practical mode doing things like cooking and cleaning in an attempt to cope:

I guess I had known how bad [sick] Rose [wife] was, but I denied it. I tried not to think about it. I probably tried to ignore it. I hoped that it would go away. When I
came home, I just did what I had to do with the kids [children]. Things like cooking or cleaning. I was in a practical mode, just carrying on. (P7)

Other participants used denial to protect themselves from facing the reality of what was happening:

Reading is an escape and sleep is an escape. You can pretend that it [daughter’s behaviour] is not happening. You can remain in denial. I smoke a lot too, it is a crutch. ... I think that my intellectual reaction was “I don’t want to think about this”, like Scarlet O’Hara, stick my head in the sand. It is like I don’t want to swallow this, it is too horrifying, it could not happen to me. (P20)

The use of denial also helped some participants carry on with their daily routines. It allowed these participants not to think too deeply about what was happening to themselves or to the affected family member. Denial protected them and provided these participants with a degree of hope that things would be alright:

You always hold out hope that maybe you are wrong. Maybe a couple of weeks at home with no drugs and he [son] will be fine. You have to reach at something and hold on to it. ... You tend to go into a coping mechanism. You stop thinking about it. I knew it was there in the back of my mind. If I didn’t think about it consciously, I could get on and do day-to-day stuff, and that was alright. (P9)

Denial, an unconscious response, is useful when experiences are too stressful or painful for a person to contend with. For example, Kubler-Ross (1991) described the use of denial by people during the first stage of the process of dying. Although denial is generally recognised as a maladaptive response to stressful situations, Niven (2000) claimed it also provided valuable ‘breathing space’ allowing the individual time to consolidate other personal coping resources.

Participants in this study also used conscious coping responses, including a variety of intrapersonal, interpersonal, and social factors. Several participants used work as a means of coping with their experience of being consumed. Immersing themselves in their work provided participants with an outlet that allowed them, for a short period of time each day, to forget about what was happening and, thus, protect their mental well-being. The following participants provided examples of the importance of work: "I have to drag myself to work but I knew I would feel better if I went to work. If I stayed home I would be worse. I think I would be a danger to myself, if I stayed at home" (P24); "My work has been helpful, it gave me an outlet" (P16); "Work is important. It helped me to forget about what was happening at home" (P18); "I needed to work for my own peace of mind" (P17). The following participant
suggested that work kept her both fit and sane. She described her work as her lifeline, as the one thing that kept her going and prevented her from becoming completely consumed by what was happening to her:

My work has kept me going. I can think "well I have worried about you Lance [son] and I have worried about you Josh [son] for an hour today". I switch off completely and if, for example, I have got to go and do an aerobics class, my mind is completely based on that. I have always said that my job has been my lifeline. If I did not have it I would probably have gone down too. Having that job kept me sane. It kept me able to cope because I am extremely fit. It has kept me fit and able to do what I can for the boys as well as work full-time. (P13, multiple carer)

Several participants indicated that achieving personal goals, for example, the completion of tertiary studies, were helpful conscious coping responses as they provided participants with a sense of personal achievement: "I am studying social work, it is really difficult. I do most of my work late at night, but it is satisfying to know I am achieving and meeting my goals" (P22, multiple carer). Other participants found that going to the movies or to visit friends was a break away from the affected family member, aiding their ability to cope with what was happening: "I used to try to get out a bit myself, go to the pictures by myself. I would go and see friends by myself" (P7).

Similarly, participants in Kinsella et al’s (1996) study of coping and strengths of siblings and offspring of mentally ill people described physically or mentally escaping from their environment in order to gain relief from the pressures of living with a mental health consumer. One participant from Kinsella et al’s study gave the following example of escape from the disturbance to family life caused by her ill brother:

I would go to my room. I would leave. I kept myself real busy. I always had piano lessons, baseball, softball, all that sort of stuff, so I kind of kept busy. Kind of tried to stay away and yet I was still close to my brother. (p. 26)

The usefulness of coping responses in protecting the individual from anxiety or stress has been recognised for many years (Johnson, 1997). Stuart and Laraia (1998) defined coping responses as "any efforts directed at stress management" (p. 75), and these authors asserted that coping responses are also useful in helping people find meaning in what they are experiencing. Furthermore, Billings and Moos (1981) alleged that during times of stress, people used responses they had successfully used during previous stressful situations. These authors suggested that past experiences could also provide alternative strategies to lessen the stress associated with the current experience.
In utilising personal strategies to reduce the problem of being consumed several participants in this study spoke of the importance of religion in their lives, claiming their religious beliefs helped them to cope: "I went back to my religion and I derived comfort from it" (P15); "My faith has given me the most support. I have had many instances of my prayers being answered" (P21). Some participants explained that people from their church facilitated their ability to cope by providing them with advice that was helpful and which they valued:

I'm a religious person. I go to church and people in the church helped me a lot. They are sort of in the middle [can see both sides]. I know them, they are my friends. They are mainly older than I am and they have much more wisdom than I do. (P6)

Religion provided another participant with long-term prayer partners who were supportive and understood her life circumstances and, as such, they were helpful to her:

We are Christians and I always pray [for help]. I always get the support of other Christians to pray about it [husband's behaviour] as well. I find that God always undertakes, really. ... I have two prayer partners and we are very open with each other. We have known them for five years now, so they know my situation. We pray for each other through all our problems. (P14)

One participant from Kinsella et al's (1996) study of coping and strengths of siblings and offspring of mentally ill people provided a similar account of the importance of religion in her life: "I've always had faith in God that God cared for me. So I always prayed. I always believed that He would hear me, so I never gave up, and that's how I kept going, otherwise I would have quit" (p. 27). Billings and Moos (1981), Waldfogel and Wolpe (1993), Porter-Smith (2001); and Rammohan, Rao and Subbaskrithana (2002) also found religion was an emotion-focused coping response that people used during stressful times as it provided them with comfort, support, and answers.

Physical exercise was another conscious coping response that participants in this study employed: "I am extremely fit, that is important to my ability to be able to cope" (P13, multiple carer). The following participant articulated that she believed that exercise, and having time alone, was important to her father's ability to cope with his experience of being consumed when she was young and he (her father) was caring for her mother:

We had some land [suburb of Perth]. Dad [daughter now cares for mother] used to cope by going out to his land and he would dig and shift the creek [stream]. There was no building on the land just land he used to dig. I can see now he did that probably as a bit of a relief from mum [affected family member], it got him away from mum. (P1 child/adult carer)
Like participants in this study, Barkhru (2001) highlighted the importance of exercise in fighting stress, claiming that it provided recreation and mental relaxation, while keeping the body healthy. Exercise according to Barkhru is "nature's best tranquilizer [sic]" (p. 2).

Participants in this study spoke of making conscious changes to their established daily routines to free up their time during the day to spend with the affected family member: "I used to do my cooking and cleaning at night. I used to get up in the middle of the night and put the washing through, as I knew in the morning I would have so much to do" (P11, multiple carer). Other participants developed a different framework to use when they were faced with stressful situations. One participant used a specific coping strategy as a way of managing her experience of being consumed by what was happening:

I would say 100 times per hour "I don't care, I don't care, I don't care", over and over again. I would walk around all day repeating this to myself "I don't care, I don't care, I don't care" as April [daughter] went around destroying things. (P20)

Another participant became focused on her need to keep strong, well, and not to lose her job. She knew these factors were vital to her ability to be able to cope with what was happening to herself, her husband, and to her children:

You just have to say that Barry [husband] is number one. You have got to keep your job. You have got to look after the girls [children]. You have got to look after the house. If you get sick, if you let it get on top of you how are you going to cope? (P24)

Some participants employed a conscious strategy of only focusing on the present and trying not to think of the future. Participants found that thoughts of the future were problematic:

Geoff [husband] and I only worry about today. We do what we can today and deal only with today. When we begin to think about what if, what if, we get into trouble. So both of us have agreed that we only think of today as far as dealing with the girls. (P21, multiple caregiver)

Similarly, Jeon and Madjar (1998) reported that caregivers use the technique of focusing on the present and not thinking about the future. One of Jeon and Madjar’s participants stated: "I just take each day as it comes. ... You just take each day ... when you survive that, you take the next day (laugh)" (p. 699).

Finally, several participants in this study spoke of the importance of having an optimistic mindset and being able to appreciate humour as being important coping responses. One participant described the importance of staying positive in this way: "We [parents]
always believed that we would get to the bottom of it [daughter’s behaviour]. We would deal with it and we would all come through. We never gave up" (P10). Another participant recalled the importance of laughter and humour to her overall ability to continue to cope:

My husband said, "You can not afford to lose your laughing gear [sense of humour]. When you lose you laughing gear you are history". ... As I went to answer the phone the other day I noticed the dog had vomited on the floor. I thought if that is all I had to deal with in a day, dog vomit, wouldn’t I be a lucky person [participant laughs]. (P21)

Davidhizar and Bowen (1992) also identified humour as a constructive coping behaviour that was helpful to people during times of stress. Furthermore, Pasquali (1990) asserted that if a person was able to express humour they would be able to express other feelings that are troubling them.

In summary, during the first phase of the core process of seeking balance, participants used their established coping responses to manage the stress associated with their experience of being consumed. Some coping responses, such as denial, were unconscious and protective processes that have been identified as useful during times of stress (Kubler-Ross, 1991). Other responses, for example, exercise, were conscious coping responses employed by participants and were part of an established routine, viewed by participants as being important buffers against stress.

6.2.3: Utilising trial and error approaches

The second aspect of utilising personal strategies to reduce the problem of being consumed commenced when participants began using different trial and error approaches. This occurred when participants began to formulate their ideas regarding what could be causing the affected family member’s abnormal behaviour and, therefore, initiated what they believed may be solutions for both themselves and the affected family member. Some participants searched for solutions using traditional methods, and the following participant sought help from staff at her local mental health clinic, as she was convinced that her son had a mental disorder. She was consumed by what was happening to her and needed to find a solution to the problem:

We had to cut short our trip to England and return home [because of son’s behaviours. He had run away, been rude, and aggressive]. We had a terrible time with John. When we got back here [to Australia] I said "John we are going to the mental health clinic. We have to get on top of this. We have to find out what is wrong". I took myself to * [psychiatric] clinic and I knew [son had a mental disorder]. I felt I was out of my depth. It was a self-referral. I didn’t have to go to the doctor. (P3)
Using this trial and error approach, other participants encouraged the affected family member to use non-traditional, complementary, or alternative health care approaches in the hope the therapy would decrease the affected family member’s abnormal behaviours, for example, depression and/or sleep disturbances: "June [daughter] was having treatments like Chinese medicine and acupuncture" (P16); "I took Carol [daughter] everywhere. I took her down to the health thing at Claremont Showground [convention on complementary therapies, health, and well-being]. We tried everything, diet, health, eat well, vitamins, everything" (P18); "We [participant and his wife] went to a doctor of Chinese medicine and she helped Melinda [wife]. We were boiling herbs and having acupuncture twice a week" (P23).

One set of parents tried to manage their daughter’s behaviour by taking her away from everything to an isolated farm in the country for five months:

We [parents] had the choice really, to put her in hospital under heavy medication or take her away from everything and everyone. So we went out to one of the houses on the farm [in an isolated part of country Western Australia] with her and that is where we slugged it out [tried to cope] for about five months. (P10)

Other participants believed that in some way they were responsible for their family member’s abnormal behaviour, which further increased their experience of being consumed. Using a trial and error approach, participants began to change their behaviours, for example, their established parenting style, believing these changes may be the solution:

I think that you do try to cope with it on your own. Getting books from the library, buying books trying to improve yourself. You try to live with it. ... I can remember at one time thinking “okay, I have got the worst behaved kids in town. I need to be strict and put more time, and effort, and energy into child rearing”. I turned into a sergeant major. I ran our days, and our minutes, as if it was a boot camp. We had token systems we had star charts. Every minute of every day was accounted for. You had fifteen minutes of free time here and fifteen minutes there. I decided that I was going to crack down [become strict]. In addition to all of the other punishments [token economy system] I had a big wooden spoon. If you needed it [discipline] you got a good whack [hit]. After months and months of this, nothing changed. (P20)

In the past, most participants had not been successful in seeking help and advice from health professionals (sometimes for a period of up to three years). The majority of interactions with health professionals had left participants feeling more confused about and consumed by their situation. In using trial and error approaches some participants began to compile dossiers on health professionals and to seek out those professionals whom they thought could be helpful. One participant was looking for a doctor who could not only help her son, but also
someone who, through their compassionate nature, could help her life to be more balanced, harmonious, and calm:

I heard about Dr [psychiatrist]. I had heard that he was a compassionate man. I was desperate, I needed to find a solution, I needed to be heard. I wanted some appropriate intervention and it wasn't happening. So one day I took a whole folder of John's [son] drawings, art, and poetry and went to see him [psychiatrist]. I didn't care if I waited all day. I thought, "I have got to see this guy [doctor], I have got to see this guy". Anyway he came out and I was just sitting there, you know as tense as can be with this folder on my arm. I said "look, can I see you doctor? It is about my son, John". He said, "you look as if you have been through a bad time. I suppose I can make room". He said, "come in and I will make you a cup of tea". I started talking and he looked at all the stuff [drawings, pictures etc.], he read the poetry. He said, "look, he is a very, very sick boy, very disturbed. I believe I could help him". Then he turned to me and he said, "what about you?". I burst into tears because it was the softness of it, the gentleness of it [his manner]. Nobody else listened, he was the first one. He said, "You can make an appointment and come and see me. I believe I can help him". ... I was just so grateful. I thought even if I can't get John [son] to see him it has helped me for him to say "there is something desperately wrong with him". ... I emerged with my self-esteem just about half an inch higher. Having thought that I was worth absolutely nothing, the feelings of helplessness, worthlessness, and sheer failure were just overwhelming, you know. (P3)

A manifestation of the trial and error approach was that some participants began to exaggerate the affected family member's problems when they contacted health professionals, hoping that this would ensure that they received the help they required:

You have all this history of how hopeless it is [contacting health professionals]. You know how worthless it is to try and get help because you can't get it. When you seek help you bare your soul, your dirty linen to total strangers as you seek help. To deal with this hopelessness you begin to exaggerate the problem rather than mask it. You present it full-blown in all its ugliness. (P20)

Sometimes participants became loud, dramatic, and out of control in their communication with health professionals in order to get the assistance they required:

Now I can remember when April [daughter] did go to * [hospital]. I had been having a long time of things going down hill [things were getting really bad]. I was at my wits-end [could not cope anymore] I was going crazy with it [daughter's behaviour]. I knew that I had to do something. My experience of seeking help had met such a stone-wall [not been successful in the past]. I finally decided in desperation, I am tired of being reasonable because it gets you nowhere, being reasonable. So I phoned up * [hospital] and as soon as the receptionist answered I said, "I am going to kill my child, I am going to kill my child. Either you come and get her and take her away or I will kill both of us. I can't stand it [the situation] another minute. This child is driving me crazy. I will strangle her, I will hit her over the head with the frying pan. I don't care what I do, I just want her dead". I was loud and dramatic and as out
of control as I could possibly make myself. I did this cold calculating thoughtful pre-meditated plan to make their [health professionals'] lives unreasonable. They said, "bring her right over. Bring her right over this minute". I said, "right". I brought her right over and they kept her for two weeks. Right, being unreasonable, this is very effective. Just sound totally troppo [can't cope anymore], like you have just lost it, it is very effective. Now that is hard to do if you are an intelligent reasonable person, to make yourself act like an idiot. But I mean what a world we live in when you have to do things like that. You can't be effective until you act like an idiot. (P20)

In using trial and error approaches to reduce the problem of being consumed, other participants resorted to seeking professional help for themselves. They did this because they realised they could not continue alone to manage what was happening to them:

In hindsight I know that I should have got some help earlier. ... I probably should have sought help earlier. I really didn't know what was going to happen. You reach a point where you think you can't go on like this. I organised my own psychologist when Rose [wife] was in hospital for five weeks. She was terribly bad at that time. Every time I went to visit her she was crying. She was so bad that I organised a psychologist myself. This is when I was trying to look for help. (P7)

Several participants had lost confidence in themselves, particularly their parenting skills and, therefore, experienced feelings of self-blame with regards to what was happening to the affected family member. In using trial and error approaches to reduce the problem of being consumed they sought help from community services: "I went to the Women's Health Centre to get some support. I needed to talk and they were really helpful" (P18). Another participant suggested that seeking professional help was useful to her in obtaining more balance in her life. She had lost all confidence in herself as a parent and the professional help allowed her to view her situation differently:

I went to the Samaritans because I did not know what to do, they were excellent. ... I did a course on TA [Transactional Analysis]. One of the things I liked about it was that I had lost all confidence in myself as a parent. I had become so dependent, so fixated on May [daughter] that when she would go down, I would go down too. So attending this course helped me. It taught me that everyone is different. It taught me that May was making sense of the world in her way. (P15)

To sum up, participants used a variety of trial and error approaches in an attempt to reduce their problem of being consumed. While some of these approaches were conventional, participants also used alternative or complementary health practices.
6.2.4: Summary

Phase one of the core process, seeking balance, was called *utilising personal strategies to reduce the problem of being consumed*. It occurred predominantly during the period of time prior to when the affected family member was diagnosed with having a mental disorder. The phase consisted of two aspects: participants’ use of established coping mechanisms and utilising trial and error approaches. Participants reported the use of both conscious and unconscious coping responses. In addition, in *using trial and error approaches* participants used conventional as well as alternative or complementary health practices and approaches in seeking balance and trying to lessen their experience of being consumed. They sought help for both themselves and for the affected family member. When the affected family member was formally diagnosed with a mental disorder the majority of participants became engaged in phase two of the BSPP entitled *restoring self-identity*. This phase will now be presented.
6.3: PHASE TWO: RESTORING SELF-IDENTITY

6.3.1: Introduction

The second phase of the BSPP, seeking balance, was entitled restoring self-identity. Definitions of the words "restoring" and "self-identity" were obtained to explore the scope of the meanings of these words. The Macquarie Concise Dictionary (2000, no pagination) defined "restoring" as "to re-establish, ... to bring back into existence, ... to bring back to former, original, or normal condition, ... to bring back to a state of health, soundness, or vigour". The Australian Concise Oxford Dictionary provided additional meanings of the word "to give back, ... to make restitution, ... to bring back to original state" (Turner, 1884, p. 945). "Self-identity" was defined, as "one's own self, ... one's nature, character" (Macquarie Concise Dictionary, 2000, no pagination). Turner (1884, p. 529) added these additional meanings "individuality, ... the condition of being a specified person". The data indicated that all of the above meanings of the words "restoring" and "self-identity" were relevant in the context of this study. Participants had experienced feelings of self-blame, guilt, and worthlessness resulting from their belief that in some way they may have caused the affected family member's abnormal behaviour. In addition, some participants had been implicitly or explicitly blamed for causing the affected family member's abnormal behaviours.

Furthermore, when seeking help from health professionals, participants had experienced lowered levels of self-esteem and self-worth as a result of those interactions. They recounted how health professionals trivialised and minimised their experiences. In seeking balance, through restoring self-identity, participants re-evaluated what they had been through and began planning for the future. As a result of this process participants began to make changes to their lives. They acquired special skills that helped them to more effectively manage the affected family member's abnormal behaviours and developed new communication strategies to use during their interactions with health professionals.

This phase commenced for the majority of participants when the affected family member was formally diagnosed with a mental disorder. The phase continued until participants attained some degree of mastery and control over their caregiving role and, as a result of this, their self-identity was restored. When this occurred participants found that balance was returning to their lives. The length of this phase was different for each participant and the time participants spent in this phase was not determined by the length of their
caregiving experience, but by their experience of *seeking balance* and the conditions influencing that experience.

Phase two of the core process consisted of three aspects: *participants’ continued use of coping responses, regaining self-control, and taking control.* Participants’ continued to use their *established coping responses* but these responses were now also employed to help them manage feelings evoked by their awareness that the affected family member had a mental disorder. *Regaining self-control* was the second aspect of this phase whereby participants reviewed their experience to date and began to plan for the future. This largely cognitive process allowed participants to re-evaluate many issues that had influenced their experience of *being consumed,* for example, beliefs that they had caused the affected family member’s abnormal behaviours. In *regaining self-control,* participants also began to make adjustments to their life, for example, lessening their commitment of always being there for the affected family member. These adjustments were *helpful to participants in their movement towards seeking balance* and in making their caregiving commitment proportionate to other areas of their lives. The third aspect of this phase was called *taking control,* and participants’ acquired special skills that helped them to improve their care to the affected family member. Participants learned new communication strategies to use during their interactions with health professionals. This was particularly important as four of the six conditions influencing participants’ experience of *being consumed* were related to their interactions with health professionals. The use of these newly found skills and communication strategies provided participants with increased feelings of control over their lives. They now had more capability to influence the outcomes of their interactions with both health professionals and the affected family member. The three aspects of *restoring self-identity* are outlined in Figure 7 and each aspect will now be presented.

**6.3.2: Participants’ further use of coping responses**

During the second phase of the core process participants continued to employ established coping responses that had previously been helpful to them with the aim of *restoring self-identity.* As participants now knew what was wrong with the affected family member, the coping responses were also focused on helping participants to prepare and
Phase Two

- Participants’ further use of coping mechanisms
- Regaining self control
  - Reviewing the past
  - Preparing for the future
    - Stepping back
    - Encouraging affected family member to live as normal a life as possible
    - Being honest
- Taking control
  - Developing strategies to use during interactions with health professionals
    - Planning and preparing to interact with health professionals
    - Becoming more assertive
    - Developing strategies to "play health professionals bluff"
  - Acquiring the tricks of the trade
    - Assessing the affected family member’s mental state
    - Managing crisis situations
    - Setting limits
    - Acknowledging improvement in the affected family member
    - Issues surrounding the affected family member’s prescribed medication

FIGURE 7: PHASE TWO OF THE BASIC SOCIAL PSYCHOLOGICAL PROCESS OF SEEKING BALANCE
manage the caregiving role to which they had committed. Strategies such as religion, work, and exercise continued to be used by participants in their movement towards restoring self-identity and seeking balance. Some participants carried through their use of denial into the second phase of the core process and these participants spoke of trying not to think too deeply about the affected family member’s illness: “I had to shut off and tried not think too deeply about him [husband] otherwise it gets too hard. You can’t get too deep” (P24).

During this phase, having been made aware of the nature of the affected family member’s disorder, participants made conscious adjustments and purposeful changes to their established family and personal routines as a way of coping: "You know when somebody is sick [in the family] you just adjust to the sickness, you know you just give a little bit" (P6). Other participants began to alter their employment patterns: "When the girls were really bad I did not work or I worked part-time until things settled down. You make the adjustments" (P21, multiple carer). Participants spoke of coping more effectively when they recognised and accepted that some things associated with their caregiving role were beyond their control: "You just get on with it. I take one step at a time. I must accept that this problem [daughter’s pregnancy] is beyond my control" (P22, multiple carer).

Participants also began to identify goals for both themselves and for the affected family member, and to recognise when these goals had been achieved. Goal setting became important to participants’ ability to move towards seeking balance in their lives as they provided them with identifiable outcomes:

The doctors convince him to take his tablets, that’s, a milestone. Aaron actually says, "yes I will go to hospital because you want me to", that’s a milestone. There are control situations, they may be Aaron’s control situations if he says "I have decided that I am not smoking dope anymore until tomorrow." He might say, "here is the $20 you lent me last week. I am giving it back. I will come back tomorrow and ask for it back again but you have got it now" [participant laughs]. So you do find that you start to do that. The little situations that are in control, they are the signposts. If you can learn to manufacture them it makes life a little bit easier. (P9)

Doornbos (1996) also found that carers responded to an overwhelming number of stressors by the use of a variety of positive, healthy coping responses. These healthy coping responses were vital in mitigating the psychological stress of caregiving (Greenberg et al, 1997a). For other participants in this study, exercise, as well as religion, were important coping responses for restoring self-identity. The following participant viewed exercise and religion as sources of renewal and were completed each day, irrespective of weather conditions:
I walk around the lake every morning and I find that very good. I pray when I walk. I
walk if it is fine, or if it is raining. It is my escape. My dogs go with me. They are with
me and they do not take from me. (P21)

Another participant described how her work and exercise had helped to restore her
self-identity and provide her with the strength to cope with caring for four sons (two of whom
had mental disorders):

I have always said that my job has kept me going. I was working in the industry when
Josh [son] got sick. I have always said if I had not had that life-line [work] I probably
would have gone down too. Having that job kept me sane and able to cope because I
am extremely fit. My job keeps me fit and able to things. Even now it helps me to do
what I can [for both her sons] as well as work full-time. (P13, multiple carer)

For other participants, work and job satisfaction were important in restoring their self-
identity:

It has been hard being a mother, raising three children and my job is a lot of work. It is a
hell of a lot of work but I love it and I wanted it. It gave me so much satisfaction so I never
complained about it [the hard work]. I just kept on doing it [working]. (P18)

In short, during the second phase participants continued to use the coping responses that had
been helpful during phase one of the core process. However, during the second phase, the
coping responses helped participants in restoring self-identity. The coping responses assisted
participants to manage feelings evoked by the awareness that the affected family member had
a mental disorder. Additionally, coping responses were utilised to assist participants to
evaluate what the affected family member’s disorder meant within the context of their own
and their family member’s future. As a result, participants made adjustments to their life
enabling them to cope more effectively. Furthermore, they set goals that provided identifiable
outcomes for both themselves and for the affected family member.

6.3.3: Regaining self-control

During phase one, utilising personal strategies to reduce the problem of being
consumed, participants felt a lack of self-control over what was happening to both themselves
and to the affected family member: "The whole thing [what was happening] is so out of
control and beyond [my] control" (P9). Many participants blamed themselves. Several other
participants reported they were implicitly or explicitly blamed. As a result, participants were
left with a lowered self-esteem and decreased feelings of self-worth and identity. They felt
consumed by what was happening and powerless to exert any control over the situation.
However, when participants became aware that the affected family member had a mental disorder, they began to use strategies to regain self-control over their lives.

The Australian Concise Oxford Dictionary defined "regaining" as "to recover, ... to regain confidence" (Turner, 1984, p. 928). Definitions of the word "control" included "to exercise direction over, ... to act, ... to command" (Macquarie Concise Dictionary, 2000 no pagination) and "to exert control over, ... personally directing actions, ... to hold in check" (Turner, 1984, p. 222). All of the above definitions of the words "regaining" and "control" were pertinent within the context of this study. Participants began to regain confidence as they reviewed their experience to date and realised they were not responsible for what had happened, either to themselves or to the affected family member. They began to plan for the future and to exercise direction over the changes they needed to make in their lives. These changes included an adjustment to the level of commitment made to the affected family member, encouraging a more proportionate approach to their caregiving role. This process assisted participants in *restoring self-identity* and in their movement towards *seeking balance* in their lives. *Regaining self-control* focused on two areas: reviewing the past and preparing for the future (See Figure 7).

6.3.3.1: Reviewing the past

The first component of *regaining self-control* was identified as reviewing the past. As mentioned earlier, when a diagnosis of a mental disorder was made in relation to the affected family member, some participants expressed relief. For several participants the relief was directly linked to their harboured feelings of guilt. These participants believed they had in some way caused the affected family member’s abnormal behaviours (some had been blamed implicitly or explicitly). In *regaining self-control*, participants’ confidence was restored as they realised they were not to blame for the affected family member’s problems: "When the diagnosis [of mental disorder] was made [on son] there was no more talk about dysfunctional families, poor parenting, or marital difficulties, which had been projected [participant had been blamed for projecting her problems onto son, for wanting a sick son]. It was just such a relief" (P3); "I came to the realisation that I wasn’t to blame [for daughter’s illness]. ... I have given up blaming anything or anybody. It was a combination of factors and Carol [daughter] was going to end up somewhere along the track with a mental illness" (P18); "I have become a bit of a fatalist, if it [son developing a mental disorder] was going to happen, it was going to happen. It was nobody's fault" (P9); "I have learned that self-blame is just a waste of time"
(P12); "I felt really guilty to start with. ARAFMI and other people have helped me out. They have told me it is not my fault" (P2). For another participant who had a family history of a mental disorder, the acknowledgment provided by her husband and her affected family member that it was not her fault helped her resolve her feelings of guilt:

He [husband] has been very good. In the beginning, I tended to blame myself but he said, "well it could be there is something in my family that I don’t know about" ... He said he felt guilty too about how he treated her [daughter]. ... I just had to realise that it was genetic. ... I gradually realised that I didn’t even know about my father and my sister [both had bipolar disorder] when I got married. I spoke to June [daughter] and asked if she is cross with me. She said "no, that is just how it is". She does not want things changed. She wants to be who she is, that’s just how it is. (P16)

Other participants sought professional help, which proved useful in resolving feelings of guilt, restoring confidence, and regaining self-control over their experience:

He [psychologist] had been seeing May [daughter] for some time. He said to me "Sheila I must say that when you first came to see me I felt that this woman is so driven that she is the problem". However, he said, "over the time I have got to see May and I have seen the way you have tried to adapt and step back". He said, "I think you and Ralph [husband] have been very unlucky. I think that poor May is wired up in a certain way and it is nothing in particular that you have done wrong". In fact he said, "you have done a hell of a lot right". I needed to be told that, it made a huge difference to me as far as the guilt I experienced. (P15)

Participants began to make changes to their lives as a result of this review process: "I just started to accept things about living my own life. For years I just hung around and waited, hoping that it would go away" (P17). Participants’ contacts with other carers helped this process as it forced them to compare other people’s experience with their own. As a result of this review, some participants began to view their experience as trivial in comparison to other people they had met: "I guess we [parents] have been fortunate in comparison to what other people have gone through" (P16); "Other people [at the carers’ group] had a lot worse stories [regarding what had happened to them] than we [parents] had" (P2). The review made one participant feel guilty when attending a carer’s group, as other people seemed to have had much worse experiences:

Well we [parents] found out that everyone [people going to carers’ group] went through worse than we did. Really, after a few meeting, I felt guilty going there because Jill [daughter] was getting better. Some people, their situation was hopeless [the affected family member was very unwell]. Some people go through, put up with so much [very consumed by the experience] and there never seems to be a light at the end of the tunnel for them. (P10)
As a result of the process of re-evaluation another participant believed she was better off than many other carers:

Zoe [daughter] can just stay home and I can go out. I do take her shopping and things. She goes her way and I go mine. I pick her up afterwards. You know compared to some of the carers I am so lucky. She seems to be of this new generation, of this long-term steady rather than up and down, up and down. ... I am lucky I haven't got any trouble with Zoe. I don't have those hassles [problems] of having the baby, running away and leaving it to me. My daughter is very quiet and you know at this time I can't ever see her doing anything like that. (P6)

Rose (1998) and Winefield, Barlow and Harvey (1998) also found that when carers compared their experience to that of others they began to look at their situation differently. Similarly, Mannion (1996) identified that caregivers went through a process of reviewing the past, resulting in a reassessment of their experience. One participant from Mannion's study of resilience and burden in spouses of people with mental illness explained that: "Having major life dreams drastically altered made me face harsh realities that led to good changes" (p. 17). Similarly, Kimble and French (2000) asserted that our assessment of ourselves exerts a powerful influence over how we feel. According to these authors reviewing and altering our interpretations, called cognitive restructuring, allows people to carefully re-think automatic responses and to develop more reasonable interpretations of threats, failures, and successes.

To sum up, in this study reviewing the past was an important component of regaining self-control. It allowed participants to develop a different perspective of their experience and to regain control over the future direction of their lives. They also began to compare their experience with those of other carers they had recently met. As a result, many participants described how their confidence was being restored.

6.3.3.2: Preparing for the future

The second component of regaining self-control was referred to as preparing for the future. When participants were told that their family member had a mental disorder, they grieved the loss of the person they once knew. They also grieved the loss of the anticipated life goals and dreams they had established for the affected family member and for themselves. In regaining self-control, participants recognised the need to re-evaluate their expectations for the future, as well as those held for the affected family member. Preparing for the future had four major components: altering future expectations of the affected family member, stepping
back, encouraging the affected family member to lead as normal a life as possible, and being honest (See Figure 7).

6.3.3.2.1: Altering future expectations of the affected family member

In regaining self-control participants began to alter future expectations of the affected family member. This was important, as participants had been consumed by their grief and loss of the person they once knew or expected to know. The realisation that the affected family member would never achieve previously established goals forced participants to set new goals and expectations of them: "I can't put my expectations on Peter [son]. If he does anything extra [such as being involved in family life or going out] I am thrilled to bits because that is more normal" (P11, multiple carer). Another participant gave this clear description of her altered expectation of her affected family member:

We [parents] are noticing now after this year that it [medication] really does tend to be working for June [daughter]. She is much more orderly now, much like the person we had before. She is not the same person though it has changed her. If [the illness] has also changed the way we respond to her. She was a very reliable person with lots of ambitions. She has still got all of those ambitions. ... She has just changed. Our expectations of her have changed too. That is the main thing that has changed. Our expectations [of daughter] have changed enormously. We just hope that she will find a life and be happy. We hope that she will find someone to be her partner and we hope she will find a job. (P16)

The following participant described how she had re-evaluated her future life goals and dreams for her son from those she had previously held for him. All that was important now was that her son was happy:

What I now want for Michael [son] is for him to be happy. I know now that he will never reach his potential but that does not matter now. Actually it has become quite unimportant. I just hope that he is going to be alright some day. (P17)

Karp and Watts-Roy (1999) also reported that once carers acknowledged that their family member's mental disorder was never likely to disappear they developed a different view of their relationship with that person. According to these authors "once that question arises in their consciousness, wholly new perceptions and emotions about their role in an ill person’s life become possible" (p. 483).

In preparing for the future, participants in this study came to realise and accept that the affected family member would most likely have future relapses including crisis situations:
"Now I will expect it [relapse] to happen again" (P18). Similarly another participant gave this account:

Sometimes Zoe [daughter] gets a lot of things wrong in a day and I think, "are we going again. Is the beginning of it [relapse] again?". ... It's happened before and you never know when it will happen again, you really don't. (P6)

In summary, altering future expectation of the affected family member allowed participants to resolve many of their feelings of grief and loss and to look towards the future with new goals and dreams for both themselves and the affected family member. This gave them more control and direction over their situation and it was important to participants in restoring self-identity.

6.3.3.2.2: Stepping back

Initially, when their family member became unwell, participants had protected them from the outside world to ensure they were not hurt or taken advantage of by unscrupulous people. The desire to be there to protect their family member had been one of the most consuming aspects of participants' experience to date: "You want to wrap them [affected family member] up in cotton wool, lock them away in a room until they stop babbling. You want to save them from everything, keep the world away" (P9); "The world is full of unscrupulous people who will take advantage of them. You need to protect them" (P6). In regaining self-control, upon realisation that the affected family member had a mental disorder, participants began to re-evaluate their beliefs about always being there for the affected family member. In seeking balance participants realised they must let their family member live their own life, allowing participants to step-back: "I think we watched June [daughter] a bit too much and we tended to be a bit too observant. We are backing off a bit now and we are pretty orderly about it" (P16); "I didn't want to go on looking after her [daughter]. I have my own life, so I was always encouraging her" (P18).

Other participants spoke of stepping back to let the affected family member become independent and make their own decisions and mistakes in life. Some participants learnt the importance of stepping back when they spoke to other carers at support groups. One participant gave this description of how people at support groups helped her to be less protective of her daughter:

The Association for relatives and friends of the mentally ill (ARAFMI) has been great. They told me how to cope and what to do. They have told me things like "you don't
try to keep them [the affected family member] under your thumb". In other words you have to go against your instincts with them [to protect them]. They have to be independent. ... I am starting to do that [let daughter become independent]. If she goes out, I don't say anything about it. (P6)

Similarly, Winefield et al (1998) found that, after talking to other carers, participants felt less guilty and more willing to step-back and let the affected family member manage their own life. Participants in this study reported that some health professionals were helpful in teaching participants the importance of stepping back and moving on with their lives:

He [psychologist] said "Sheila, you are too close [to daughter], disengage. Her happiness is not your responsibility and your happiness is not hers. Step back, step back". So I think that was very good advice. I will tell you who else helped me, it was the Samaritans. ... He [Samaritan] said, "I think you have done too much. I think that is where you may have gone wrong. It has allowed May [daughter] to see that you will be driven". I took that on board and stepped back. (P15)

Baxter and Diehl (1998) also reported that caregivers were constantly balancing the dilemma of how much protection of their family member is necessary and how much independence was achievable. These authors asserted that the process of adjusting caregiving expectations and withdrawing from always being there to protect the family member was essential for carers in seeking balance in their lives. Furthermore, Duff (1993) claimed that "not only is it better for the sick to be left alone at times, it is also better for the well to leave them at times " (p. 83). Karp and Watts-Roy (1999) elaborated further on the need for caregivers to step-back from their ill family member: "Healthy people can be contaminated by the gloom and depression of the ailing if they come too close or have too much sympathy" (p. 477).

As participants in this study became more experienced as carers they recognised the importance to them of pursuing their own life goals and dreams:

Our attitudes [towards the affected family member] have changed over time. I mean we have gone from the count down [being very rigid and controlling] to the relaxed. It is just part of the learning process as a carer, you know from the point of view of trying to really give the person, your loved one, the best possible life they can have. (P8)

A participant provided a similar insight to that above when she realised that she could only do so much for her son. This was helpful in restoring self-identity and in her movement towards seeking balance in her life:

I can look back now at things and think "well I should have been a bit less rigid. I should have accepted things as they were. I should have not got stressed about them".
... I have learnt that "this isn't my control situation and I don't want it. You [son] are in charge, take charge". ... We [mother and son] have become more like friends. I am not his mum so much any more, or a controller, without realising that is what I was doing. I was trying to put him into a mould, shape him how I wanted him. I don't do that quite so often now [laughs]. (P9)

Participants also began to let the affected family member take more responsibility for their own actions and this strategy helped one participant in regaining self-control. Her husband had caused a problem in the community and, therefore, she must let him accept responsibility for the trouble he had caused:

Harry [husband] gets manic and then he writes bizarre letters. He was writing these threatening letters to people in high positions, like Paul Keating [ex Prime Minister of Australia] and Bill Clinton [ex President of the United States of America]. We had two Commonwealth police [Federal police] come around one day to see if he was one of these crazy people that was going to do some damage [hurt somebody in the community]. I just told them that he had a mental illness and that he was under the * [psychiatric Clinic]. They [police] had to check it out. Australia Post contacted the Commonwealth Police. I said, "why don't you ring up the psychiatrist to verify it". They came back when Harry was home and they talked to him about it. I was glad they did it themselves because he needed that bit of a jolt [to be talked to about what he was doing]. It didn't worry me because it really was not my problem. It was something that he had to deal with himself. He needed someone like that to give him a bit of a shake up. So I was quite glad they came around and caught him at home and told him personally. I didn't see that as my problem. He had to recognise that when he gets manic or unwell he can't behave in that way because it is unacceptable to society. (P14)

Guilt had been a major issue for some participants and it had increased their experience of being consumed. In regaining self-control, participants began to check themselves and learnt to step back from their feelings of guilt. One participant had recently experienced the death (suicide) of her daughter and in regaining self-control she developed a perspective of her daughter's death that allowed her to move on to restore her confidence, self-identity, and movement towards seeking balance in her life:

They [staff at the Samaritans] said to me "a lot of people say suicide is the coward's way out. It is not, it takes a lot of courage to take that step. Although you have done your best to keep May [daughter] alive, try to respect the fact that she is in charge of her life. If she decides something then let it be because she really finds life a great burden and terribly difficult. Every day for her is a milestone because of these torments and the psychological pain she endures". She [staff at the Samaritans] said, "another way to look at it my dear is that it could be a bit of relief". I said, "yes, it would in a way. All this nightmare would be at an end for all of us". I suppose I should have felt guilty saying that but I really felt that this woman really knew what it was like to walk in my shoes. ... It was terrible, the grief [daughter committed suicide]
but in another way it was not like dealing with, say, if your child is in the pinnacle of their life and they come down with cancer. Then you have a whole set of things to deal with. You have their lost life, their hopes, and aspirations dying with them. You have the snuffing out of a life that was taken reluctantly. I know that May [daughter] did her best and that she stayed alive for us [parents] for an awful long time. She really, really found coping with life just beyond her. ... When I saw the arm [daughter nearly severed her arm in a suicide attempt] I knew that it [a successful suicide] would not be far away. I thought "the sooner the better". I thought, "if she is in that kind of torment I do not want to see her suffer anymore". I thought, "she has really given this her real shot [done her best to stay alive]". ... She was determined to do it [kill herself] and she did once go to the railway line [to jump in front of a train]. She went to the station, but she told me later that she was unable to do it. I would not be able to do it either. She gassed herself [killed herself by carbon monoxide poisoning] three days later in our car [in the home garage]. We still drive the car [participant cries]. In a way I love that car. She could have driven it into a tree and we could have found her that way. Instead she died so peacefully she just went to sleep. (P15)

Stepping back was important to participants in seeking balance in their lives. It reduced the intensity of their experience of giving constant attention to the affected family member. Therefore, in stepping back participants began to focus less on the affected family member and more on regaining self-control over their lives. This was helpful in restoring self-identity and in their movement towards seeking balance in their lives.

6.3.3.2.3: Encouraging affected family member to live as normal a life as possible

Encouraging the affected family member to live as normal a life as possible was another component of preparing for the future. One participant explained that she expected her husband (affected family member) to participate in family life and to do his share of the household tasks:

From my point of view I accept that Harry [husband] has a mental illness and we just get on and live a normal life in spite of it. ... As long as the illness is under control people can be normal and get on with their lives. They can be good fathers, good husbands, they can get back into the work force. ... I find it is important to live as normal a life as possible. I think by doing all these things, Harry [husband] has four kids and his life is a lot more structured than it was before we had kids, he is better off. ... I accept the fact that we are on the pension [invalid] and Harry [husband] has a mental illness. In spite of the fact that he has a mental illness, he still has to live a normal functioning life and pull his weight. He has to do what needs to be done in the house. ... I know Harry has a mental illness but he still has to do what he would be doing if he didn’t have a mental illness. (P14)
Similarly, Neufeld and Harrison (1995) reported that reciprocity in relationships between carers and consumers was important and the degree of intimacy between those involved in the relationship influenced the expectations for reciprocity.

Participants in this study knew that living as normal a life as possible was important to the affected family member’s ability to integrate into the larger community. Their successful integration would, in turn, allow participants more time and freedom to pursue their life goals and dreams:

A carer is really trying to sort of program the person and help them [the affected family member] to handle life. For a start there is a daily medication issue, a hygiene issue, and then there is the social issue of behaving as a member of the house and stuff [things] like that ... We have been told by the doctors that a person with schizophrenia has to look after their own medication, or at least have some input into it. Otherwise, it leads to a long-term problem. I suppose when the carers die, for example, eventually the person must embrace their management. (P8)

An important component of encouraging normalcy for the affected family member was related to where the affected family member lived. Seventeen of the 27 participants did not have their family member living with them. Most of the participants believed that having the affected family member living with them would be detrimental to both their own and the affected family member’s future well-being: "After several hospitalisations we said 'well we can't handle having you in the house anymore'. So Pauline [daughter] moved close by to her own flat" (P2); "Others around me try to tell me that Robyn [daughter] should be somewhere being cared for. You think that maybe you should be doing that but I know it would not work" (P12). Participants believed that having the affected family member living at home with them would prevent both of them from reaching their full potential. Another participant explained that it was a hard lesson for her to learn but in regaining self-control and moving towards balance in her life, it was one that she must pursue:

Peter [husband and Aaron’s stepfather] and I still have difficulty discussing what is best for Aaron. He still wants to move home. Peter says, "no you will kill yourself because you will go all out to try and help him". ... As parents you have to be really cruel and say, "no you can't come home under any circumstances even if you have to sleep in the park". He says "but you are my mum so you should say that I can stay here". This has been going on for three and a half years. You know he stayed with us for over a year full-blown [very unwell] in and out of hospital. It was destroying us all. He becomes very stressed all of the time. He wanted to change and improve us and we don’t want to and that stresses him. He gets bored and that stresses him. ... I could smother [over protect] him very easily especially now the girls [other children] have moved out. It would be very easy to bring him back here [home] and look after him. Let mum take care of you, let mum look after you, forget about all of those horrible
things that happen out there. I could say, "you don’t have to be in pain, it doesn’t have to hurt, and you don’t have to be hungry". However, that is wrong as that would harm him, and it would harm me too. The fact that it would harm him hurts. He doesn’t learn to live. The way he is going to live is not going to be the way I lived, or the way I would like him to. He has to find out for himself how he wants to live. He can’t do that at home with me smothering him. It is a hard thing to learn. (P9)

Another participant gave a similar account of realizing that having her son live with her would be a mistake for both of them:

Michael [son] wanted to move back home with me. I spoke to Patrick, his nurse, and he said "What is it for you?" I said "there is nothing in it for me but at least I will know that he is eating properly and his clothes are washed". I knew it would be the wrong thing, I just felt that it would be the wrong thing so I did not allow it. ... He would be better off here but then my mental health would be affected and I think his would be also. (P17)

Participants’ need for space and time to pursue their own goals were considered important in regaining self-control over their lives and in their movement towards seeking balance:

Peter [son] was given a choice of where he would like to go [which hostel he would like to live in]. It is their life but I did have a little bit to say that I would like him to come to *hostel as it was close to me, that is if he liked it. He loves it there. They [rehabilitation staff] took him around to about six hostels; he had a choice. No, he was ready to come out [of hospital] he had been there [in hospital] for a long time. ... He just loves to come home [a couple of nights per week]. But if I had him home all the time I wouldn’t be free to do the things I need to do or like to do; he would be lonely. He wouldn’t have the peer group company that he has at the hostel and I won’t always be here. I don’t want to bring him this far to be so dependant on me. When I am not here there would be a huge hole in his life but he will be used to living in the community as part of the wider family. (P11, multiple carer)

Likewise, other researchers have identified that when the affected family member lived at home, carers were likely to experience more disruptions to their lives (Tessler & Gamache, 1994) and to experience higher levels of subjective burden (Jacob, Frank, Kupfer & Carpenter, 1987).

Even when the affected family member did not live at home participants in this study actively sought to find them accommodation close to where they lived so they could continue to have frequent contact with them. This arrangement was helpful to participants as it gave them space from the affected family member but allowed them to remain in regular contact with them:

I had to write to Homeswest [Government Housing Department] asking them to give my son a unit close to * [suburb of Perth] where we live. One day I got a phone call. A
nice little brand new unit was available and they said, "it is your son’s turn. Would you like to go and have a look at it and see if it is suitable?". That is what we did and Lance [son] has lived there ever since. He gets Silver Chain [support community service] to help with his meals. He has a cleaning man once a week and myself and his father support him as much as we can with extra food and stuff like that. ... Josh [other son who is mentally ill] lives in a different Homeswest complex. I would visit him four times a week, top up the food in his unit, have him over here for meals, take him out occasionally. (P13, multiple carer)

One participant who was caring for an ageing mother had difficulty in finding her mother appropriate care in the community when she could no longer manage to look after her. Although her mother had schizophrenia, she had been cared for in her home for most of her life and would have found it very distressing to be placed in a psychiatric hostel. With great difficulty, the participant eventually found her mother appropriate aged care. When this happened the burden of caring for her mother was resolved:

All the problems are resolved; it’s not a burden anymore. She [mother] is in a place where she’s cared for [nursing home]. She’s got a permanent position there, so we don’t have to, like if she gets really sick again there are people there, like if we can’t deal with it either emotionally or we are away or whatever. There are people there who are going to look after her and staff are really good, so it’s like we never have to worry about her again. (P1, child/adult carer)

While some participants’ affected family member currently lived at home there was a future expectation that the affected family member would leave:

They [other carers] told me outright, they just said, "they can stay home for a while but it just doesn’t work". They said that, because they had been there and they knew that, eventually she [daughter] will have to leave home. She will mature even though she is ill. ... It was so objective you know because they had been there and done that. (P6)

The stigma directed towards some participants and their family member affected their own and their family member’s ability to lead a normal a life as possible. Therefore, in an attempt to reduce the stigma, participants tried to explain what mental disorders were to people with whom they regularly came in contact:

I try to get Rose [wife] out, especially when my son is playing cricket. Sometimes she could come and sometimes she couldn’t. She got anxious because she knew people were going to ask "how are you and what’s wrong?". I spent a lot of time trying to explain to people what her problem was but I could see that people just didn’t understand. Most people couldn’t grasp what she was going through. (P7)
However, participants found that despite attempted explanations, generally people were dismissive of the impact of mental disorders on both their own life and that of the affected family member:

I have to say a lot of people at church are dismissive of the fact that you have got an ongoing problem. You know, they will ask about everybody else. They will ask about James [second husband] who has had several strokes, he’s got emphysema, angina the whole thing. It is very, very hard. I try to explain the incidence of mental illness and that it is an authentic organic disorder, we are talking about the nervous system, we are talking about biochemistry, and neurochemistry. I suppose it is the sort of myth that, alright, if you have got a mental illness that’s bad but you go to the doctor and get put on the appropriate medication. Then you stick with it and you are normal again. And of course there isn’t any normality, there are episodes and there are better periods. (P3)

One participant found some people at her church said things that were not helpful and, therefore, she needed to be forthright and firm with them to manage the impact of their stigma on her:

I speak to people because people don’t always understand because it is a mental illness. Especially Christians at church, they don’t always understand. So sometimes I have to be quite firm. ... I have to be forthright. I make my needs known as much as possible because by doing that it makes it just a little bit easier to continue to go on living a normal functioning life. I think that is as important for Harry [husband] as it is for me. ... I think, there needs to be a lot more education about the stigma and misconceptions of mental illness. (P14)

In summary, in preparing for the future by encouraging the affected family member to live as normal a life as possible participants were able to restore self-identity and to seek further balance in their own lives. The affected family member’s increasing independence allowed participants time to pursue their other life goals and dreams. To assist the affected family member’s integration into the larger community, participants also tried to decrease the stigma that both they themselves and the affected family member were exposed to.

6.3.3.4: Being honest

Being honest was the final component of preparing for the future. Participants became aware that their ability to manage interactions with the affected family member varied from day to day. This was important to participants in regaining self-control and in restoring self-identity as they had been consumed, and at times overwhelmed, by having to manage the affected family member’s abnormal behaviours. Being honest allowed participants to distance themselves and to be available to the affected family member only when they felt strong
enough. Some participants became aware of the importance of being honest with the affected family member from attending courses:

Something I learnt from TA [transactional analysis], you feel what you feel. Nobody can tell you how to feel, what you must feel. You can only cope with what you believe you can cope with. ... Some days you can cope better than others. (P15).

Other participants became aware of the need to be honest as they became more experienced as carers. They realised that being honest was necessary to stop the affected family member from becoming too dependent and to avoid their caregiving role becoming a parasitic relationship resulting in their inability to continue providing care. Being honest with the affected family member was important to participants in regaining self-control over their own lives and in restoring self-identity:

You have to be honest with yourself. You have to be honest with the person with the illness and say "well I can't cope with this today. Go away, don't come visiting. I don't want you today". If you can't do that, it almost becomes a parasitic relationship in [that] they [affected family member] feed off you until you die. It sounds like a horrible way to describe it but if you keep on giving, you turn them into a parasite. It is not [that] they are one, you create one. You need to be able to say, "stop that now". (P9)

Similarly, a participant from Karp and Watts-Roy's (1999) study of how caregivers assess their obligations provided a similar picture of forcing the affected family member to become more accountable and less dependent on their carer: "Take charge!!!! Don't think that it's somebody else's responsibility" (p. 484 - 485).

To sum up, regaining self-control was the third aspect of the second phase, restoring self-identity. It was a process whereby participants reviewed past experiences and began to prepare for the future. In doing so, many of the issues that had led participants to experience feelings of being consumed were seen as being resolved or perceived by participants as less threatening to them than they previously thought. This review assisted participants to regain control and to restore their own self-identity. Consequently, participants experienced further movement towards seeking balance in their lives.

6.3.4: Taking control

The last aspect of phase three, restoring self-identity, was called taking control. Taking control was primarily an interactive ‘doing’ process whereby participants gained a sense of control and mastery over what was happening to them and, consequently, over their lives. Definitions of the words "taking" and "control" were sought to verify fit with these data.
The Macquarie Concise Dictionary (2000, no pagination) defined "taking" as "to seize, catch, or capture ... to grasp, grip, or hold, ... to get into one's hold, possession". The word "control" was defined in the Macquarie Concise Dictionary (2000, no pagination) as "to exercise restraint or direction over, ... to hold in check". In the context of this study all of the above definitions of the words "taking" and "control" were important. During this phase, participants began to acquire special skills and new communication strategies that enabled them to facilitate improved outcomes for themselves and for the affected family member. This was particularly important as four of the six conditions that influenced participants’ experience of being consumed were related to their interactions with health professionals. The following participant spoke about taking control. She achieved this when she learnt that being assertive was a successful technique to use when interacting with health professionals:

In the position I am in, I hold a responsible position in my work. I have to be assertive I have got to make decisions. I have a big staff working for me, so I guess it is my lifestyle. It is who I am. ... I am very assertive. They [doctors] pay attention. I have always said, "the squeaky wheel gets the attention, gets the oil". Bearing that in mind, that is what I use. That is my ammunition. I guess I have become a little hardened, but I will continue to use that strategy because it gets me places. It gets help for my son. ... I am no dummy and so I don’t want to be fobbed off [ignored] anymore. I won’t be fobbed off anymore. (P13)

Participants developed new strategies to take control over what was happening to them from a variety of sources. Some participants read extensively: "I read as much as I could. Knowledge empowers you, knowing what to expect" (P6). Other participants learnt new approaches from their interactions with other carers and health professionals, or as a result of using trial and error approaches. In addition, participants also utilised plans that they had successfully used in other areas of their lives. These approaches focused on two areas: developing strategies to use during interactions with health professionals and acquiring “tricks of the trade” (See Figure 7).

6.3.4.1: Developing strategies to use during interactions with health professionals

In taking control, participants began to purposefully develop and use new strategies during their interactions with health professionals, with the aim of facilitating improved outcomes for both themselves and for the affected family member. While some participants reported that their interactions with health care professionals were helpful and positively influenced their experience of seeking balance, the majority of participants reported these interactions had increased their experience of being consumed. Participants reported
experiencing feelings of guilt, anger, resentment, and a lowered level of self-esteem as a result of their interactions with health professionals. In addition, they described feeling isolated, lonely, and unsupported, which was compounded by the lack of information regarding what was happening to their family member. They experienced trauma from: 1) the hostility directed towards them from some health professionals, 2) the experience of having their family member hospitalised, 3) the quality of care they witnessed during their family member’s hospitalisation, 4) feelings that they, as well as their family members, were being assessed, 5) having their experiences minimised and trivialised by health professionals, 6) being treated like a nobody, 7) not being listened to, 8) the type of interventions offered during emergency crisis situations, 9) the lack of services for the young and people displaying self-harming behaviours, 10) the lack of ability to establish rapport with the health professional, and 11) the management strategies employed by some health professionals.

In taking control, participants realised that they needed to utilise new strategies during their future interactions with health professionals so as to facilitate optimal outcomes for both themselves and for the affected family member. As a result, participants were able to move towards restoring self-identity and balance in their lives. The strategies focused on three components: planning and preparing to interact with health professionals; becoming more assertive, and developing strategies to "play health professionals’ bluff".

6.3.4.1.1: Planning and preparing to interact with health professionals

In restoring self-identity, participants began to mentally prepare themselves to manage the responses they expected to get from health professionals. Many participants, in their previous interactions with health professionals, had felt put down, belittled, or treated like a "nobody". In seeking balance participants realised that displaying emotional reactions to their treatment by health professionals was not helpful in the long-term for either themselves or for the affected family member. Therefore, they began to mentally prepare themselves for all of their future interactions with health professionals: "Oh I had to toughen myself to it [how participant was treated by staff in hospital]. It was not going to get me anywhere if I felt any emotions over what they were saying. I had to accept it and keep on [trying to get the best care for her husband]" (P25). Participants began to use a range of strategies to obtain the best outcomes from their interactions with health professionals. Some participants took other family members with them for support when they spoke to health professionals: "My sister Maude came with me, it helped" (P12). Other participants began to write down the questions
they wanted to ask the health professional prior to the meeting, while simultaneously
documenting what happened when the meeting occurred. Obtaining knowledge about the
drugs the affected family member was prescribed was also important as the following
participant explained:

I would gang up on them [health professionals]. Mum and my sister would come in
with me [to see the health professional]. You have got to know these things [important
to learn this]. Take a pen and paper with you and write things down. I mean I could
not have understood the drugs [daughter was taking] otherwise. (P18)

In summary, preparing and planning to interact with health professionals was an
important strategy used by participants in taking control and for restoring self-identity. Many
of participants’ prior interactions with health professionals had left them with the experience
of being consumed and this purposeful strategy of preparing and planning their interactions
assisted in their movement towards seeking balance in their lives.

6.3.4.1.2: Becoming more assertive

In taking control participants became more assertive in their interactions with health
professionals in order to gain the outcomes from these interactions that they required.
Participants spoke of their need to be included in the decision-making process regarding the
care of the affected family member:

If we [carers] are looking after our sick person, when we tell the doctor something
they should act on it. We live with it all the time. ... They [health professionals] really
should listen to what we are saying. ... It would help if psychiatrists would talk to you
and tell you things. You don’t expect them to solve all your problems but it would
help if they just included you. (P11, multiple carer)

Participants reported difficulty contacting and speaking with their family member’s
doctor: "You know you can never get to see a doctor [when affected family member is
hospitalised]" (P13); "He [consultant psychiatrist] was quite short [dismissive] with the
family. He did not have time for us" (P8), "Her [daughter’s] psychiatrist, he refuses to talk to
us" (P16). In managing this response from health professionals, participants used increased
assertiveness to improve their chances of gaining access to doctors, as this participant
described:

To deal with this [not having access to doctor] I stray [walk] down the corridor [when
son is hospitalised] and say "are you doctor so and so? I need to speak to you. I would
like five minutes of your time". ... So I nail them down [find them]. If I don’t
understand, I will ask them to repeat it. Sometimes I will go and read up on it. I guess
I am a bit lucky like that, I am independent. My belief is that at the end of the day you
can have all of the people, all of the carers, all the friends, but you still have to do it [caring] yourself. (P13)

Other participants believed that the lack of accessibility was not necessarily linked to patient confidentiality (as was often implied by health professionals), or to the doctor being busy. Participants explained that inaccessibility was a perception that doctors liked to foster. However, participants' increased assertiveness helped them to more effectively manage the problem of accessibility to doctors:

I always just ask around for someone [ask to see the doctor] and generally I get access to the doctor. Getting to see the doctor is something that is quite difficult, but I am learning how to overcome that. I think there is a perception thing also that you shouldn't go and bother a busy person [the doctor]. They [doctors] foster that impression [participant laughs]. (P9)

Participants openly acknowledged how helpful an assertive communication style was to them during their interactions with health professionals: "I am a very assertive person and that is the reason why my mother is now treated so well" (P1 child/adult carer); "If I was seeking help [personally] I perhaps wouldn't be so pushy but when I need to defend my kids [children] I am assertive" (P9). Other participants, although not directly stating they were assertive, demonstrated their assertiveness through their actions:

I rang * [hospital] and said, "Peter [son] needs to be seen. He is doing this and that". They [staff at the hospital] said, "well see his nurse" [his community nurse]. I said, "no he needs to be seen now. I am trying to go to work and I can't leave him". So I took him down [to the hospital] and the doctor was not very happy [because participant has taken her son to the hospital]. However, he was admitted and he had six ECT's [electro-convulsive therapy treatments] because he was so suicidal. He was in hospital for a long time. He needed to be seen and nobody would do anything. So never again, if I consider that Peter is not safe to be home, I don't have him. I don't think any family should be disrupted. I don't want the whole street disrupted. I am not ashamed of my son but I don't want to put anybody at risk that gets in his way [when he is unwell and violent]. And I don't want to live like that [being frightened of son when he is violent]. (P11, multiple carer)

When participants were unsuccessful in gaining access to see doctors personally, they wrote letters to establish lines of communication with these doctors. While the participants were not altogether happy with the outcome of this strategy, they believed that at least the letters provided them with some information and understanding:

He [psychiatrist] does not like to lose the confidentiality with that person so he is not real keen to talk to other people [carers]. And so we [parents] gave up on trying to talk to him because he didn't want to. We write him letters because he said we could write to him, so we write him letters. We really don't get terribly
good answers back [participant laughs] but we do get some sort of correspondence. We never do it behind June’s [daughter] back. We don’t ever do anything behind her back. However, we do feel that we do things for her. We are there to watch out for her and we don’t think that anyone does as much for her as we do. (P16)

In **taking control**, participants began to recognise that if they wanted help from health professionals they would have to take the lead and initiate the contact. Using an assertive communication style the following participant rang health professionals (case manager) caring for her son whenever she wanted to discuss any issue related to her son’s care. She found it helpful to talk over specific problems with health professionals which were difficult for her to manage on her own. This successful strategy increased the participant’s feelings of control and facilitated her experience of seeking **balance**:

I ring them [case managers] up. I talk things [problems related to caring for son] through with them. ... I don’t think those things are ever going to be clear to anybody but just to be able to say "well maybe that fits into that one or that one or both categories". It is a form of justification. (P9)

Another participant used a similar assertive communication style and contacted health professionals as soon as she noticed any deterioration in her son’s condition. She viewed this early contact as very important in keeping her son well and in her movement towards seeking **balance** in her life:

Now at this stage of the illness I have to get help when I need it. Josh [son] is a very gentle boy. He always has been, very kind, gentle and loving. Already he has given me a bunch of flowers for Mother’s Day [interview conducted three weeks before Mother’s Day]. But his character changes [when he becomes ill] he starts to get argumentative with me and says, "stay away, I can do it. I don’t want you here". That is out of character with him so when that happens I know that he had not taken his medication. I contact his nurse straight away. (P13, multiple carer)

The following participant also used an assertive communication style when contacting health professionals. The participant claimed that this communication style usually got her the help she required:

Well I find sometimes you just have to be forthright with them [health professionals]. I find sometimes unless the person is totally crazy [very unwell] you don’t always get first priority and especially if you haven’t had a lot of help [are not well known to the service]. But I just find that generally speaking they are helpful. (P14)

The mobility of health professionals was a condition that influenced participants’ experience of **being consumed** and had made participants’ ability to communicate with health
professionals more difficult. In seeking balance, participants realised the mobility of health professionals would be an ongoing problem. In responding to this, participants began to become proactive in their interactions with each new health professional they encountered. Using an assertive communication style, participants began to request that certain aspects of the affected family member’s care was documented in their case notes, particularly issues to do with medication: "I said to the new doctor I have it written in her [mother’s] notes ‘do not take her off her medication’. I know there are benefits sometimes but for her it’s just not worth it" (P1, child/adult carer). In addition, participants negotiated their role and the role that the new case manager caring for the affected family member was going to assume.

Participants believed it was important that the roles were clearly defined so that the carer did not try to do the case manager’s job and visa versa. Likewise, Fox (1997) reported that while consumers, families, and professionals shared common goals, the approach of obtaining these goals differed in application.

The following participant in this study demonstrated how she was taking control and learning to obtain the results she required from her interactions with health professionals. She was proactive and used an assertive communication style when she needed to initiate communication with the health professionals caring for her son. At times she was also confrontational in her communication with health professionals:

Unfortunately the way things are now, people [health professionals] move around. Aaron’s first case manager got a better job. The one he has got now, I don’t think had dealt with carers and client relationships in that three way process before. I am pretty pushy and I have had a lot of practice now, so I am kind of forcing the issue. I have called meetings with the case manager when I have a problem. I say, “I need a meeting to talk to you”. The present case manager and I, it might have been a communication problem [participant laughs], but I ended up calling a meeting because I didn’t understand what was going on, not from a treatment point of view. I said, “you are supposed to be teaching kids [their clients] to integrate back into society, but you are not. That is what I expected of you. Why aren’t you doing it? Why aren’t you trying to get him into courses anymore, his other case manager was [because this is a relatively new case manager]? Why aren’t you doing any of these other things with him? You haven’t seen him for six weeks, why is that? I don’t understand” … So we sat down and talked about it for a couple of hours and we realised that we were both doing the same things. We didn’t have to cross over we could divide the jobs up. So it is working out a lot better, so you need to talk to them. What Sarah [case manager] and I are trying to do now is wear two separate hats. … As a carer you want to do all of it. You want to be the case manager, not necessarily that you want to, but you try to and you shouldn’t. By doing that, you may be missing out on some of the things the case manager can’t do. Day-to-day things, small problems, such as, “this is how you choose between two things, you need to weigh up the pros and cons”. So you do it, you know “do you know how to cook fried chicken? Come and I will show you how
to make it", little things that make life individual. Case managers don't have the time or the emotional input, to do that. I think that you need to understand what those two relationships are and the responsibilities of those relationships so you don't step in and try to be the case manager. If you are having a medication problem that is the case manager's problem, not mine. It empowers you and gives you the strength and the courage to keep going because you are doing it right. It is like being a first time mum and you think, "what the hell do I do?" (P9)

In taking control participants became assertive when they felt that health professionals were not listening to them. One participant told health professionals that her son was unwell, but her son had been allowed to leave the hospital following an assessment of his condition. He ran away and was not located for three days. He was found in a multi-storey building in the city and when he was located he was extremely unwell and psychotic. He was immediately returned to the hospital where he had been assessed three days earlier. The participant described her interaction with the doctors treating her son following the incident. She threatened the health professionals with legal action for what she believed to be negligent care of her son when he was unwell. She explained that the doctors needed to hear what she had to say to them. The participant's communication strategy demonstrated her increasing feelings of control. She stated that in future she wanted and expected to be told everything about what was happening to her son. This process was helpful in restoring self-identity and in the participant's movement towards seeking balance in her life:

I let them [doctors] have it [reprimanded the doctors]. I won't repeat what I said. I said, "you guys [doctors] are negligent". I said, "if my son had of jumped from that building I would have sued you to the hilt". I said, "you were negligent". I said, "he is sick and you allowed him to slip through your fingers". They [psychiatrists] said, "our registrar [junior doctor] is assessing Josh" [son]. I said, "Oh is he really, how very nice, how very kind of you to do that". My husband said to me, "Oh be quiet". I said, "No, they [doctors] need to hear this". Anyway the registrar spent about two minutes with Josh and said, "your son is completely psychotic". I said, "Oh! does that mean that you are going to send him home or is he going to be hospitalised?" He said, "I am making arrangements for him to be hospitalised immediately". I said, "thank you". I said, "thank you guys [psychiatrists] for nothing" and looked at the other three. I addressed everything to the registrar "how long is he going to be in hospital? What is the treatment? What is the testing?" I wanted to know and I expected to be told everything. (P13)

Another participant recounted the use of an assertive communication style when interacting with health professionals during a crisis situation. The participant's daughter had been self-harming for several days. When her daughter was finally taken to hospital, the psychiatrist was hesitant to admit her. The participant refused to accept any further
responsibility for her daughter. Feeling in control of the situation the participant told the psychiatrist that if he could not admit her daughter he would have to find somewhere else for her to go. Following this interaction, the psychiatrist calmed down and her daughter was hospitalised:

It was seven at night and he [psychiatrist] said, "she is not the [type of] person we usually take" [usually treat]. He said, "if she did not have her suitcase we would not really take her in". He did not want to discuss it with me. Well I said, "you can see the state that I am in [participant was very upset]. I am refusing to take responsibility for her. If you refuse to accept her here then you are responsible to find a place for her". He calmed down and he did turn around a bit. From my point of view they should be professional enough to sit and hear my point of view. (P12)

The following participant provided an insight into how effective an assertive communication style was when health professionals failed to respond to her claims that her husband was unwell. The participant explained that if she did not receive the help required, she would continue contacting them until this was the case. She used this approach, as it was successful in getting the help she needed:

If they [health professionals] don't listen to me I usually give them what for [reprimand them]. I just let them know that I am not going to put up with it [not having support when husband is unwell]. I will make some waves [cause problems] and so I usually tell them that I am not going to put up with any nonsense. I annoy them [keep contacting them] until they do listen to me. I say to them "we are a normal functioning family and sometimes we need some help to stay as a normal functioning family". So I basically put the hard word on them and tell them they had better help us or else. That is an approach that I very often find I have to use and I don't like having to use that. I will create problems for them. I really make life as difficult as I can for them. I don't always ask for help, but if I need the help, if I can see and recognise that we are in a time of need, they do have to be there to help us, and support us. (P14)

Some participants, while finding it hard to tell the affected family member they could no longer live at home, recognised that it was important in seeking balance to have some space from the affected person. Therefore, by using an assertive communication style participants insisted on adhering to their own plan of management and made it clear they would not have the affected family member living with them under any circumstances:

Periods of probably the best time that we have had, was when we were really advised to tell Pauline [daughter] to get out of home and into a flat. Telling her to look after herself instead of depending on us was one of the hardest things I ever had to do [parents had been advised by health professionals to do this]. Then when she had been in [hospital] and she couldn't stay there any longer they wanted to send her home. I said, "I am not having her home, I can't" [as it caused the participant too much distress]. They [health professionals] said "well where is she going to go?". I said,
"you find a place for her; you're tipping her out [discharging her], so you find a place for her". So they sent her to * [another hospital]. (P2)

These findings of interactions between carers and health professionals are reflected by those of Rose (1998) who reported that families responded intensely to incidents in which they felt judged or challenged by psychiatrists. Similarly, Winefield et al (1998) found that carers began to take control during their interactions with health professionals. One participant in the Winefield et al's study of determinants of psychological distress in relatives stated: "I'm amazed at myself, how far I've come in self confidence" (p. 108).

To sum up, participants developed strategies that were successful in helping them to take control of their interactions with health professionals. Participants who were assertive found that this communication style increased their chances of gaining access to health professionals. They also became proactive and began to initiate contacts with health professionals to clearly define their role as a carer. Participants used the contact with health professionals to clarify their caring role and the role the health professional would assume. Participants also felt they were being listened to by health professionals and this was important to participants' ability to seek balance in their lives. Participants felt in control of what was happening to them as a result of these new strategies that allowed them more access to and communication with health professionals.

6.3.1.3: Developing strategies to "play health professionals' bluff"

Participants also developed strategies to "play health professionals' bluff". Many participants explained there was pressure, sometimes immense pressure, placed on them by health professionals to take their family member home following periods of hospitalisation. This occurred even when the affected family member had not been living with the participant prior to being hospitalised. However, participants began to realise they were a vital link to maintaining their family member in the community and this recognition helped them in taking control. Therefore, participants stood their ground and refused to take the family member home, as one participant described:

I am learning. I have learnt to play their [health professionals] bluff. If you will be there and be responsible that is what they want. If you are not strong enough; you have to say, "no". I have learnt to do that. But I guess it is when you are at your weakest and when you need support you can't fight back so well. You think about it after it but when you are at your most vulnerable you don't have the strength. When Robyn
[daughter] was admitted to hospital they wanted me to take her home. I have learned now through trial and error and a lot of hard times, I refused to do that. (P12)

Participants believed that health professionals made assumptions about their caring role in relation to the affected family member. In taking control, participants corrected these assumptions but were concerned that the affected family member was often hurt during this process. This made participants frustrated and angry:

The assumption is from everybody [health professionals] who has not had a lot of contact with us [due to the mobility of health professionals], from the medical profession, that I will be taking Aaron [son] home. I have to continually point out, usually in front of Aaron, that Aaron can't stay with us [live at home]. This hurts him, to be constantly rejected by your parents and I find that very insensitive [of health professionals to continue to make the assumption the participant will take son home]. It is destructive because they will say it in front of him. He becomes invisible. They [health professionals] irritate me. It is not just hurtful but it is very frustrating and it makes me angry. (P9)

Many participants had difficulty in accessing support during emergency situations. It was a condition that influenced participants' experience of being consumed. In taking control, participants focused on developing strategies that would increase their future chances of gaining the support they required. In being proactive some participants' compiled lists of doctors they knew would be helpful during a crisis: "I have a list of them [general practitioners to contact during emergencies]. I find female doctors more understanding" (P17). Similarly another participant explained: "It is quite obvious [how to get help when you need it from PET] if you are experienced" (P8). Another participant described how she "played health professionals' bluff" by being assertive and threatening to withdraw her caring commitment to her son. This proved to be an effective strategy in getting help when she needed it:

The third time Michael [son] was admitted to hospital he was quite aggressive towards me. I had to go to the public phone box and ring [the hospital] and I was quite upset. I said, "if you don't do something I am going away [move away from son] and I am not going to care for him anymore". They did admit him that night because I threatened to withdraw my services of caring for him. (P17)

Participants became aware that they were a very important link in the provision of community mental health care to the affected family member. This awareness was helpful to participants and allowed them to set limits with health professionals so as not to be placed under pressure when they were feeling most vulnerable. This realisation was helpful in
restoring self-identity and helping participants move towards seeking balance in their lives. Participants also realised that when they were dissatisfied with the level of care being given to the affected family member they could initiate changes to that care by using people who had authority within the health care system. In restoring self-identity, participants used new communication strategies and spoke with or wrote to authority figures, for example, members of hospital management team, nursing executives, psychiatrists, lawyers, politicians, or members of the media. These people had the ability to question and change things in the health care system and, hence, help participants in seeking balance in their lives. The following two examples of participants using people in authority to bring about change for both themselves and for their family member are presented. One participant was caring for her husband who had dementia (with aggression and agitation). She was very concerned regarding his care when he was hospitalised. She was particularly upset about his toileting routine and staff’s reluctance to ambulate her husband:

They [nursing staff] did not change Larry [husband] sufficiently. You see he was still ambulant and he was walking around the garden. He was not lying in bed where the whole of the pad [incontinence] could be soaked up. He had this great clog, a urine saturated lump [where the pad had not been changed frequently and the urine had accumulated in one spot] dragging him down and he was weak. When I arrived and saw him for the first time in hospital I said to my son “we must get him walking, he has got to get up and walking”. We walked him in the garden every day. And he would drag himself, he was drugged up to the hilt [heavily medicated] but he knew he had to go [for a walk]. My son is strong thank goodness and he would take most of the weight. I don’t know what the nurses were saying but I did get the impression not only there [hospital] but in the nursing home he went to [after hospital] the idea was to get them down [keep them in bed or sitting in a chair] not to have them walking. (P25)

The participant began to seek out and use people in authority at the hospital to bring about the changes she wanted for her husband. She requested a meeting with the senior nurse on the ward and the Director of Nursing at the hospital. This meeting resulted in her husband being routinely taken to the toilet and his incontinence pad being changed more frequently:

I had done all the hard work with the nurses. They [nurses] used to say to me [when participant arrived to visit husband] following the meeting, “Oh we have got him changed for you [made sure husband was dry]”. I signed a paper to say that I would stay with him in the toilet at night [as participant wanted husband to continue to go to the toilet as long as he could] but they would not come immediately [if she required assistance]. ... But you just had to accept that. It helped sometimes, he would go [to the toilet] and that made him and me feel good. (P25)
Another participant recalled how she was left feeling very distressed following a crisis situation with her daughter late at night. When she contacted the psychiatric service managing her daughter she was not given the support she required. Angry at the response she received during the crisis, she decided to write to people in authority in hope of preventing a recurrence in the future. She wrote a letter to the psychiatrist in charge of the hospital requesting a meeting to discuss why she had been left without support to manage her daughter during a crisis:

I thought I have got to handle this differently [how she felt about how she had been let down by health professionals during an emergency situation]. I have got to write a letter. I have got to document something [what happened and why she was angry at the lack of support], so I did. My youngest son helped me. He said, "mum, you have got to state this and state that and they have got to reply to your questions". I asked for a meeting you know to ask how this came about [lack of support during an emergency situation]. I addressed it [the letter] to the Director of Psychiatric Services at * [hospital]. I personally delivered the letter and his [Director's] secretary said "look you can't give it to him but I will see he gets it". Well it was about 48 hours before he got that letter. You see they treat you like you get into the system and they just sort of shut you out. So when he did get my letter he rang up and said he would arrange a meeting with the consultant and the community nurse. So I felt much better, I did achieve something. (P5)

In summary, participants used new communication strategies during their interactions with health professionals. These interactions focused on planning and preparing themselves for their interactions with health professionals, the use of an assertive communication style, communicating in writing with people in authority, using people who possessed more power than themselves to bring about changes within the health care system, "playing health professionals bluff", and being proactive in interactions with health professionals. These strategies assisted participants in taking control as four of the six conditions influencing participants' experience of being consumed were influenced by their interactions with health professionals. In addition, these new strategies allowed participants to control many of the outcomes of their communication with health professionals. This in turn led to participants restoring self-identity and further movement towards seeking balance in their lives.

6.3.4.2: Acquiring the tricks of the trade

An "in vivo" code, acquiring the tricks of the trade, was the second component of taking control. Strauss (1987, p. 33) claimed that "in vivo" codes are taken from informants in the substantive field of inquiry. Acquiring the tricks of the trade was summarised in the
following comments: "there are tricks of the trade [caregiving] you learn" (P7); "you learn little tricks of the trade as you go along" (P8). Acquiring the tricks of the trade meant that participants acquired special skills that enabled them to be more effective as carers thus assisting in *restoring self-identity* and balance in their lives. Participants acquired special skills through their reading; from talking to other carers and support people, from watching how health professionals managed the affected family member, by using techniques that were successful in other areas of their lives, and through the use of trial and error approaches they believed would be effective with their family member. The specialised skills acquired by carers allowed them to, for example, assess and determine whether the affected family member’s behaviour was improving or deteriorating, initiate early intervention from health professionals to keep the affected family member’s condition stabilised, and decrease and manage their stress arising from caring for their family member. Participants learnt special skills that helped them to assist the affected family member in leading as normal a life as possible:

In the beginning as carers we went through the learning processes. You learn to cope with the stresses. We learnt little tricks like putting a sign ‘please lock me’ on the door to trigger Sky’s [sister-in-law] memory when she is unwell [family member runs out of the house and leaves the door open]. Everybody forgets to lock up, so there were things like that we learnt to do. (P8)

Other participants acquired special skills that helped them to communicate more effectively with the affected family member. They learnt not to argue or to get upset with them, as these responses were pointless and did not achieve anything:

In the beginning I didn’t want to argue with her [daughter] but I didn’t know if I was doing the right thing or not. That is how I coped [argued back] with it on a particular day. You see at that particular time [early on in the caregiving experience] we didn’t really know any strategies or anything. Now I know not to argue, I know that it is pointless to argue. It was pointless arguing then too, but I had not learnt then. (P10)

Jeon and Madjar (1998), Mannion (1996), and Rose (1998) also found that participants used trial and error learning, based on their personal experiences, to manage the affected family member’s abnormal behaviours. According to Rose, "they [participants] described patterns of learning by trial and error and coming to accept through experience how to respond in a way that helped [manage the affected family member’s abnormal behaviours]" (p. 144). Furthermore, Hardwick (2001) claimed "carers develop effective strategies for
working with consumers and these need to be acknowledged for the benefit of the consumer
and the well being of the family" (p. 31).

Participants in this study found their acquired special skills were particularly helpful
in assessing the affected family member’s mental state, in managing crisis situations, in
setting limits with the affected family member, in acknowledging improvement in the
affected family member, and in issues surrounding the family member’s prescribed
medication (See Figure 7).

6.3.4.2.1: Assessing the affected family member’s mental state

Participants began to recognise specific behaviours that indicated the family member
was becoming unwell. These special skills were helpful to participants as the skills allowed
them to more effectively manage the situation: "When Michael [son] is sick he eats toast and
vegemite [a vegetable yeast spread]" (P17); "Aaron [son] comes to me and says 'mum I think
you may have to think about this but the trees are people again'" [son has a delusion that
when he is unwell the intelligence of a person is measured by their root system, like a tree]
(P9); "When John [son] is becoming sick he can not trust reality [due to his obsessional
thoughts]" (P3); "Patrick [son] sees and hears things that other people don’t [auditory
hallucinations]" (P22, multiple carer); "I can tell by the tone of Jill’s [daughter] voice whether
she is low, high, or normal [manic or depressed]" (P10). One participant acquired special
skills that allowed her to assess her daughter’s mental state over the telephone:

I just ring her once a week [at that time the participant’s daughter had moved
interstate with her boyfriend]. She doesn’t say a lot on the phone. Sometimes she
sounds quite flat and other times she sounds quite bright. I know they [flat and bright]
can be signs [of mania or depression] but they are not excessive [at the moment] and
it appears to be balanced [daughter appears alright]. (P18)

Another participant summarised her ability to assess and talk to her husband when he
was becoming unwell. She believed the trust between them was vital to the success of this
process. When she noticed a change in his behaviour, she tried to get help for him to ensure
that his mental state was promptly reviewed:

I have been married to Harry for over eight years. I am becoming more aware of him
when he is getting unwell. When he is cycling [husband has a by-polar disorder] and
he becomes manic I know it is happening. I will give you a bit of an example. Harry
writes a lot when he is unwell. He usually writes to the paper [newspaper] and wants
to read the paper and watch the TV [television], especially the news. He starts getting
a little bit grandiosed and he begins to think that he is a little bit more important than
he would normally think he is. ... If I see he is getting unwell, I usually try to put some supports in place. I might contact the clinic [the psychiatric clinic that husband goes to] and get the community nurse to come and see him. I might talk to him [husband] but if he is not able to listen to me [because he is too unwell], I will just go ahead and do that [contact the clinic] myself. I say "Harry is getting a little bit unwell and could you let the psychiatrist know. I am his wife and I can probably see it a bit better than they [the community nurses] can". (P14)

Other participants described how, when the affected family member was suicidal, there was a need to observe them more closely and unobtrusively than other times: "I could not go out there [to the garden shed. Her husband was out there and he was very depressed]. I was scared that if I did he would get suspicious. I did not want him to realise how much I was aware of what he was doing [he was very suicidal and participant was watching him unobtrusively]" (P24). Similarly another participant gave this description of managing his wife’s suicidal behaviours, describing how he assessed her sleep patterns and the amount of medication she took, and unobtrusively watched her:

Yesterday, Rose [wife] was very bad. She was popping pills all day trying to keep calm. I am just keeping a close eye on her at the moment. She is having problems sleeping and once that happens she goes down hill. During some of her particularly bad times I have had to keep an eye on medication, obviously with her having six overdose attempts. She knows that you are [unobtrusively watching her]. ... I have to keep track of her medication. I have had to be there at the house 24 hours a day as she said she would probably do something to herself. (P7)

Participants recounted that the special skills they acquired enabled them to assess the affected family member’s behaviour and to determine if they were beginning to have a relapse of their illness. This allowed participants to seek help for the affected family member at an early stage and, in the majority of cases, prevented a crisis from occurring. The acquired special skills were helpful in allowing participants to more effectively care for the affected family member and to keep the family member mentally healthy.

6.3.4.2.2: Managing crisis situations

Dealing with crisis situations in the past had left participants with feelings of being overwhelmed by what was happening to them. The acquired "tricks of the trade" were important to participants in restoring self-identity as they enabled more effective management of the affected family member's behaviour during crisis situations. As a result, participants did not experience further feelings of being overwhelmed and their overall experience of
*being consumed* was lessened. The following participant described the skills that she had learnt that increased her ability to care for her sons when they were unwell:

I tend to immediately go into very low mode [become very quiet and non-threatening], gentle, soft speaking, slow speaking. I am not afraid to comfort them if they need it. I have had Josh [son] sleep in my bed with me, if that's what it takes [to manage the situation]. I don't care what anybody says. (P13, multiple carer)

Participants also learnt tricks of the trade which were helpful in their interactions with health professionals, particularly during emergency situations:

What people [carers] can learn is they do have rights. They should not wait to be asked to be invited in [to appointments with health professionals] as that may never happen. But they do have a right to go in. Obviously confidentiality is something that has got to be taken into account but I think more and more people [carers] have to say "I am coming in". The only problem is if the person who is ill doesn't want them in and then that is it, end of story. However, in most cases that is not the case. So there are tricks of the trade. You shouldn't have to wait to find these things out [tricks of the trade]; it [support from health professionals] should be given to you. (P7)

Learning the "tricks of the trade" also assisted participants to assess, limit, and manage violence in their family member. One strategy used by participants was to outline their standard of acceptable behaviour to the affected family member: "John [son] had got his fist [hand] this close to me [very close to participant's face]. I said, 'if you ever touch me I'll charge you with assault'. I said, 'you will take the consequences what ever that is'. He knows I mean it." (P3). Another participant recounted managing her daughter's aggression. In some cases this included making a plan for other family members:

I have learnt some very good strangle holds [ways of restraining daughter when she is aggressive]. With Jan [daughter] I usually sit on her. We [family] have a 'Jan escape plan'. The kids [other children] know that if I call [to enact the escape plan], how to react. Patrick [son] can also be violent when he is psychotic but his [aggression] is controlled. The children know when Jan is violent they have to go out onto the street and wait there until I tell them to come back. (P22, multiple carer)

Participants' newly acquired skills were also used, for example, to determine whether it was safe to bring the affected family member home from hospital for a visit. These skills helped not only to protect participants during the trip home but also to protect other family members and people who may have contact with the affected family member, as one participant recounted:

There are times when I have brought Peter [son] home [from hospital] and he hasn't been home more than half an hour and I have had to take him back to * [hospital]. Even though I have sat in the car [at the hospital] for a while talking to him
[participant learnt to do this to assess his mental state before taking him home]. I do not let him know that I am assessing [unobtrusively] his ability to want to go out and letting him have time to say "No I can't go today". He used to say "I don't want to hurt you mum, I am frightened I will". So then I visited him instead of bringing him home until he got past that phase. There is no sense in putting myself at risk. I have got other children and I have got other things to do and that would not accomplish anything. So there has been times when I have had to drive him straight back [to hospital] in the car. I have been told by staff at the hospital "why don't you send him by taxi". But the taxi driver is somebody's husband or father and I don't think they should be put in that position. If they have somebody who could be violent they may hit. I don't think it is the right thing to do, I don't think it is fair. So I always take him back. Sometimes I don't say anything [while driving son back to hospital]. I have got to be very, very careful. I have always got him there [back to the hospital]. (P11, multiple carer)

Other participants' acquired "tricks of the trade" that allowed them to assess against whom and when the affected family member would be violent. These acquired skills provided participants the confidence to intervene when the affected family member was being aggressive towards other members of the family:

One day when Josh [son] had just been committed [under the Mental Health Act as a compulsory patient] the ambulance and the police had come to get him. He had threatened Moses [husband] and pushed him. They were in the kitchen and he had a knife in his hands. I sensed that he would not do anything. He did not have it in him. However, he did have the knife in his hand and his father up against the stove. I stepped in between them and said "Josh, give me the knife. You don't want to do that. It is going to be alright". He gave me the knife and laughed. (P13)

Participants administered medication to the affected family member during crisis situations: "It was one o'clock in the morning. We were trying to slip her [daughter who was unwell] a sleeping tablet the doctor said she should have" (P12). Another participant was unable to get her son admitted to hospital despite the fact that he was very psychotic. To manage him in the home environment, she sedated her son:

We took Josh [son] home [son was very unwell, but participant could not get him admitted to hospital] and I doped him up that night [sedated him]. I thought "you are going to sleep". His tongue was all white, he had not slept, his feet were puffed up and he was filthy dirty. He was filthy, so we cleaned him up. He slept, we [parents] drugged him so the poor little devil did. (P13)

Another participant gave a similar account of managing her son when he was very psychotic. She gave him more medication that he was normally prescribed because he was very unwell and he had not slept for five nights and days:

He [son] hadn't slept for five nights and days. He was still going [very psychotic and unwell]. I gave him two sleeping tablets and some Largactil [a major tranquilliser]. I
tell you, I might have just as well given him water. It didn’t affect him at all, it didn’t touch him one little bit [make him sleepy]. It’s the only time I have ever given him more medicine than prescribed, but I had to, he was very bad. (P11, multiple carer)

Similar to the findings of this study, Doornbos (1996) found that managing conflict was an area in which families of the mentally ill demonstrated evidence of healthy functioning. Families were able to effectively manage their family member’s violence and incorporate that management strategy into their family life.

In summary, participants acquired "tricks of the trade" that allowed them to manage the affected family member during crisis situations. This helped participants in taking control and, therefore, assisted in their movement towards seeking balance in their lives.

6.3.4.2.3: Setting limits

Participants, in acquiring the tricks of the trade, began to set limits (establishing rules, acceptable practices, restrictions, and boundaries) with the affected family member. Setting limits assisted participants to make their caregiving commitment proportionate to other areas of their lives and, hence, influenced their experience of seeking balance. One participant realised that she was being manipulated by her daughter and she needed to set clear limits with her. This was helpful for the participant in restoring self-identity, as she was able to focus on her own life and well being rather than that of her daughter:

There were other things too that taught me that passive is powerful too because May could manipulate me. The other thing I found out was playing games. For instance, she would not go to school. She was a school refuser, she would not go to school she would run away. She loathed school and this is one of the reasons I got so engaged with her. I started to set limits with her. (P15)

Some participants attended courses and lectures that helped them to acquire skills. The courses allowed participants to recognise that they needed to set limits and to take time out for themselves in order to be able to continue to care for their family member:

I did a cognitive behavioural course and that was really helpful. I put down all of the things that were a problem for me. I learnt from that that you have got to set some limits with Rose [wife], which I had not done. If I thought she needed me I was there at a cost to myself. You know now I have set limits like I have got to go out, if you need me call me. I have set limits it works much better. (P7)

Another participant set limits as she believed her daughter was using her to care for her grand-daughter. She realised that she could not continue to make the commitment at the level expected by her daughter:
We [parents] felt used [by daughter]. We have learnt to put some boundaries on that because it was burning us up [wearing us out]. We were taking Casey [grand daughter] home and when we were getting close to her home I said, "we will be at mummy's house soon". She said "No, No". I saw the panic in that tiny child that really distressed us. We went in and Rachel [daughter] was stoned on marijuana. There was nothing we could do about it. We could have turned around and said "we are taking Casey home". However, I knew at the time we could not do that [continue to take responsibility of caring for grandchild]. (P21)

Setting limits meant that participants had to provide structure and consistency in the home environment. Achieving this meant that sometimes participants had to confront the affected family member about their behaviour:

There are times when Sky [sister-in-law] won’t wash and care for herself. Yet she was saying she wanted to go for an interview for this job. We [participant and his wife] said "Sky if you want to go for an interview for this job, it is okay if you want to live in the bush, as a mine prospector. Then it doesn’t really matter if you have a shower everyday. But if you go for an interview in an office we suggest you go and get your butt [self] in the shower". Things like that, so you have to reinforce things like that everyday. But you soon learn, you soon learn. If you have the medication calibrated properly she was fine. All she needed was a bit of training and a bit of structure. (P8)

Another aspect of limit setting was resolving the financial problems of the affected family member. Financial issues were a concern to participants, particularly when the affected family member accumulated significant debt. In seeking balance, many participants began to develop skills that helped them to better manage their family member's financial problems and the impact of these problems of their lives:

We [parents] knew that Jill [daughter] had a key [credit] card. ... As she got further and further into financial trouble I said to her "I think you should give me your key card". I wasn’t allowed to take it off her, I wasn’t allowed to close her bank account. I wasn’t allowed to touch any of her money because I thought she is just wasting it. She was borrowing off people and making numerous telephone calls [when she was unwell]. We had to lock the phone because of her. We told people "don't lend her money". However, a lot of people didn’t take any notice. So I said one day "why don’t you give us the key card". She gave it to me and of course her Social Security money [invalid pension] was going into her bank account. So in that way we were able to get a hold of her financial problems and gradually get her things together. Even when I had her key card she had a way of getting money [from relatives and friends]. Fortunately I had the key card for a long time and we were able to control her financial situation fairly well and helped her get back on her feet. (P10)

Another participant, who had her son living with her, set limits telling him that she expected him to contribute to the household financially. The participant believed he wasted his money, and accountability was an important process in helping him manage his finances:
I used to demand nominal board from John [son] when he lived with me. I said, "these are the bills, these are the overheads, these are the rates, you are living in this house". So I went around on pension day [son lived in the other side of duplex style house] with a receipt book. (P3)

Mannion (1996) also reported the use of limit setting by carers. One participant from Mannion's study of resilience and burden in spouses of people with mental illness stated, "setting limits greatly helped our relationship" (p. 19). To sum up, setting limits was important to the process of taking control and restoring self-identity as participants in this study began to realise they could only do so much for the affected family member and they needed to take time for themselves. This led to a more balanced life for participants.

6.3.4.2.4: Acknowledging improvement in the affected family member

Participants also acquired skills that helped them to acknowledge improvement in the affected family member. Acknowledging improvement was helpful for participants as they felt satisfaction that they were doing things that were advantageous for the affected family member. One participant read his wife's [affected family member] notes as it helped him to assess improvement in her condition:

"I don't like reliving the past, but every now and then I will go and read Rose's [wife] notes [she wrote down how she was feeling]. I don't know why, but I do. It just makes me more aware of what a terrible time we have had and how much better it is now" (P7).

Other participants kept their journals, which they read from time to time. This was useful to them in measuring differences in the affected family member over a period of time:

I have found if I look back [in journal] two months and think, "what was she like two months ago compared to now"? Most of the time I can see an improvement. But not week by week you can not see it. By writing down how she is week by week I can see the change. ... I could see that she was improving. I have since picked the book up a few months back and it was horrific reading. However, it just makes you realise the difference [daughter is much better]. It is like bringing a child up, like bringing up a little baby. You are looking for things all of the time. When the child takes the first step, for them to say their first word and that is what we were like with Jill [daughter]. You were waiting for her to sort of be more responsible with the telephone [not making so many calls], waiting for her to stop jabbering, waiting for her to be able to relax. (P10)

Journals allowed participants to reflect on how bad things had been and how much better they currently were:
I keep a journal and I have found that it is a really good thing when I start to feel I am getting nowhere. When I feel that nothing has changed, he is still psychotic he is on this medication, etc. I will get it out and read it. Then I will say, "well he is nothing like that anymore". It just acts as a little mental spur. I say, "hang on, just remember, go back and have a look and remember just how bad it was before I say it is not working now". (P9)

Noticing and acknowledging improvement was an important aspect of participants' ability to seek balance in their lives. Journaling was a particularly important strategy used by participants to acknowledge improvement in the affected family member.

6.3.4.2.5: Issues surrounding the affected family member's prescribed medication

Finally, in acquiring the "tricks of the trade", participants acquired skills that helped them to evaluate the care provided to the affected family member by health professionals, and, in particular the use of prescribed medications. In taking control, some participants began to question the effects the prescribed medication was having on their family member. One participant reported that she noticed her daughter was being given too much medication and as a result had become jaundiced: "I knew she was becoming unwell again because over the weekend she became yellow [jaundiced]. ... She was overdosed on medication you see. I had to send her to the doctor" (P18). Participants were also hopeful the medication would improve the affected family member's long term quality of life: "Hopefully with this new pill [drug] regime we won't get that up and down thing [relapses] where she is well and then she is sick. That is so terrible" (P6). Several participants who were multiple carers highlighted the importance of medication. One of the participants had been caring for her sons for the past 25 years. The length of time spent caring had facilitated an examination of the changing approaches regarding how people who have a mental disorder are treated. One of the greatest changes for her was when her son commenced a new drug treatment, prompting a change in his long-standing behaviour patterns:

Peter went on Clozapine [a newer anti-psychotic drug] four years ago in January. It changed his life. He really doesn't do anything different, but he is just happier and more outgoing. I always liken it to windows. He can look out and I can look in. Before you used to look and there was nothing, he was so ill and thought disordered. In two or three weeks you could see the difference, he has not looked back. ... There wasn't so much of a negative outlook. He wasn't suicidal all the time, he is just more open and more interested in life. (P11, multiple carer)
However, other participants believed the dosage of medication prescribed to their family member was too large and as a result the person was too sedated. One participant explained that his sister-in-law could be maintained on a lower dose of medication and this would greatly improve her quality of life:

Sky [sister-in-law] has got to have a life and medical castration [the use of medication] is not going to give that life to her. ... Doctors at * [hospital] are hell bent on medication [use a lot of medication]. As far as we [carers] are concerned it is not a whole lot better than if she starved herself to death. I mean if you can see what I mean in the long term. ... We believe she is being clamped down a bit too hard chemically [too much medication]. We are not qualified people [health professionals] but as we believe we could stabilise her [keep her well] with a lot less side effects, we think that maybe it [the current medication level] is not the optimal level of treatment. Maybe she has to go back to oral [family member is on depot or injection medication] to some of the new medications that can give her a better quality of life. The ones [medications] that can stop the mood swings without sort of clamping her down [keeping her sedated]. That is what we are experiencing at the moment. I am sort of working on that. (P8)

Other participants questioned why the affected family member’s medication regime was suddenly stopped. This meant that the person received no ongoing care and participants were left with little support:

Michael [son] was discharged early from hospital. When people like Michael are on community treatment order (CTO), I wish they [health professionals] would wean them down on the levels of medication. Instead they just stopped it. They know his history, he has been into hospital three times and his behaviour is quite bizarre. That is what I wished had of happened, but it didn’t. ... Now his CTO has expired. He says he is not getting into trouble but he has not been taking any medication and he has been isolating himself [participant observed that son may becoming unwell again]. (P17)

Hatfield et al (1996) also reported that medication was an important issue for carers. These authors found that carers described their family member’s prescribed medication as a tangible aid that decreased the person's abnormal behaviour allowing them to live a more productive life. Two multiple-carers in this study highlighted the improvement in both of their sons since they began new anti-psychotic medications. These drugs had decreased the severity of negative symptoms and, therefore, their sons experienced increased motivation and interest in life. This had increased both participants’ movement towards seeking balance in their lives as it became easier to relate to their sons and to get them involved in everyday life. Similarly, Greenberg et al (1997a) found that appropriate treatment reduced the affected family member’s symptoms enhancing their capacity to function independently. As a result,
carers experienced lower levels of distress because of the improvement in the affected family member’s condition.

To sum up, acquiring the tricks of the trade meant that participants acquired special skills that helped them to better manage their caregiving role and make the role more proportionate to other areas of their lives. These skills included the ability to assess the mental state of the affected family member, special skills that helped participants to better manage crisis situations, learning to set limits with the family member, strategies to acknowledge improvement in the affected family member, and managing issues surrounding the affected family member’s prescribed medication.

6.3.5: Summary

The second phase of the BSPP, seeking balance, was entitled restoring self-identity. The phase had three aspects: participants continued use of coping responses, regaining self-control, and taking control. Participants used their established coping responses to help manage their feelings associated with the newly acquired knowledge that the affected family member had a mental disorder. The second aspect of this phase was called regaining self-control. Participants began to regain self-confidence as they were freed of the guilt resulting from the belief they had caused the affected family member’s abnormal behaviour. They began to review the past and to prepare for the future. This process allowed them to think differently about themselves and about their future caregiving commitment to the affected family member.

The final aspect of this phase was called taking control. Participants acquired special skills that enabled them to care for the affected family member more effectively. In addition, they developed new communication strategies, for example, reflection and assertiveness to use during their interactions with health professionals to ensure improved outcomes from those interactions. This was important as "communication with health professionals", the "mobility of health professionals", "the quality and type of professional services provided", and "health professionals' management strategies" were all conditions that influenced participants’ experience of being consumed. Many participants had experienced lowered levels of self-esteem and self-worth as a result of their previous interactions with health professionals and these new strategies helped them to more successfully manage the outcomes of any future interactions.
This phase of the core process saw participants attain some degree of mastery over their caregiving role and, therefore, movement towards balance in their lives. Other researchers have previously identified the importance of people developing mastery over taxing life situations. According to Noh and Turner (1987), "mastery refers to the degree of confidence the individual has in his/her ability to help themselves and to manage outcomes of both expected and unexpected circumstances" (p. 265). In his classic work, Caplan (1981) described mastery as something that:

Mobilizes [sic] the individual’s internal and external resources and develops new capabilities in him that lead to his changing his environment or his relation to it, so that it reduces the threat or finds alternative sources of satisfaction for what is lost. (p. 413)

When participants in this study obtained a degree of mastery over their caregiving role they moved to the last phase of the BSPP, entitled reaching out to make a difference. It is important to note, that some participants were not yet engaged in phase three of the BSPP at the time of being interviewed for this study. Participants’ progression through the phases of seeking balance was related to their experience of seeking balance and the conditions that influenced that experience. The final phase of the core process will now be presented.
6.4: PHASE THREE: REACHING OUT TO MAKE A DIFFERENCE

6.4.1: Introduction

The third and final phase of the core process, seeking balance, was entitled reaching out to make a difference. When participants entered this phase, their experience of being consumed had lessened due to the use of successful coping responses and by increased knowledge and understanding about mental disorders achieved in the first two phases. Participants had restored self-identity by reviewing the past and planning for the future. Furthermore, participants began taking control over what was happening by their use of new communication strategies and the acquisition of special skills to help them to care more effectively for their family member. Upon entering the third phase of the core process participants spoke of having developed some degree of mastery over their caregiving role. All of these factors were helpful to participants in their movement towards seeking balance in their lives.

Successful passage through the first two phases of the core process resulted in participants’ lives becoming more balanced and their caring role more proportionate to other aspects of their lives. When this occurred, participants explained they began to feel the need to help others who were just beginning their caregiving experience. They then entered the third phase of the core process that is reaching out to make a difference.

As mentioned earlier, not all participants had reached the final phase of the core process at the time of being interviewed for this study. Furthermore, participants’ successful passage through the first two phases was not related to the length of time they had been caring for the affected family member, but to their experience of seeking balance and to the conditions influencing that experience.

6.4.2: Reaching out to make a difference

As a result of their experience to date, participants felt confident to begin reaching out to make a difference to help other people who were experiencing feelings of being consumed as they began to care for the affected family member. Many participants joined the carer groups that had been helpful when they had first experienced being consumed. They also became involved in educating people working in community service areas, for example, participating in meetings with members of the police force, concerning their experience as a
carer. Participants began working directly with health professionals to institute policy and practice changes that would benefit both the carer and the affected family member. In addition, several participants became involved with policy and planning at a state and national level through membership to committees, review groups, and stakeholder groups. Some participants claimed that they took part in this study because they wanted to make a difference for other carers: "I want to help others so they don't have to experience what I experienced" (P24); "It is important to try to make a difference [bring about understanding and change]" (P19). One participant stated that while he did not like reliving the experience, he had participated in this study, as it was important to tell his story. He hoped that it would be helpful to others:

I don't like reliving it [the experience of being consumed]. I mean I am here now [being interviewed] reliving it with you. That is why it was difficult to start this morning [participant cried in the beginning of the interview]. I don't like to go back. I am trying to forget [the past], but I am here because I think it is helpful for other people. I prefer not to be here, but I think it has to be done. (P7)

Another participant admitted similar motivations as to why she had become a participant in this study. She believed that it was very important for health professionals to fully understand what carers told them, and for them to work with, and value carers:

This [trying to make things different for other people] is one of the reasons why I wanted to come forward [to participate in this study] because this has to be addressed. You [health professionals] have got to involve the family who are at the bloody coal-face [deal on a daily basis] with this person. They need reassurance that what they are doing is right. In addition, they need to be able to take on board what they are doing wrong and try to change it. To do this we have to know what it is [get feedback from health professionals]. (P15)

Some participants in reaching out to make a difference became actively involved in the carer support groups that had been helpful when they began their caregiving experience. Many participants had been consumed by inadequate support and by their lack of knowledge and understanding of mental disorders. Carer groups had met many of these needs and therefore had lessened participants' experience of being consumed. Hence, it became important for these participants to help others by passing on the knowledge and the understanding they had acquired: "It is important to pass your knowledge on to other carers" (P8); "I will keep going to the carer meetings forever. They helped me and I hope that I can do the same for someone else that comes along" (P10). In reaching out to make a difference participants tried to initiate procedures that allowed them to provide information and
education to people beginning to care for their family member right from their first contact with the health care system:

It [information and education] should be given to you. You shouldn’t have to search for it. You have generally got enough on your plate if someone is ill. What I want to do is to organise so that it [information and education] is given out automatically to the carer and to the family of the person who is ill. ... I mean I am now quite heavily involved in * [support group]. The reason for being involved is for that very reason. I want to help people understand there is support out there. You shouldn’t have to wait two and a half years to find out there is support there. ... They have a lot of share and care groups where people can come along and talk to each other. (P7)

Some participants regularly attended carer meetings, realising it was important for new carers to hear success stories (one participant’s daughter was now well and was living and working independently in the community). Carers agreed that success stories, where family members had recovered and were living productive lives in the community, were important as they provided other people with future hopes and expectations:

[On] Wednesday [when] we [parents] were up at the carer’s breakfast [monthly support group]. There were two new carers there and they started telling their story. Then the convener of the group said, "Oh what about you [participants]?". I said, "I feel a bit guilty mentioning our story because it is a good news story". All the others [carers] haven’t got good news stories. There were four [other] families there and they all had fairly sad stories. ... I feel quite guilty but they all say "No, No tell us, we need to know that people do get well". It does them good. ... I am glad in a way that I did [tell my story]. I never believed she [daughter] would get well. I could never visualise her [as being well] because she was somebody else [daughter was changed by the illness]. I am glad now that I can say that to people because I had no hope that she would be well. (P10)

Participants involved in support groups began to develop groups with a specific focus, for example, partners’ groups and groups for children who had a parent with a mental disorder. These specialised groups provided support for carers and other family members:

I go to that [carers group for partners] every month. It is one specifically set up for partners because they have different issues than other people, like parents. So that has been very good and I help facilitate that because we get a lot of new people coming in and me being one of the more experienced people, I help out. (P7)

Similarly, Chapman (1997) also reported the importance of experienced carers acting as role models for less experienced carers claiming, "those who have ‘made it’ become a role model and a source of hope to the newcomer" (p. 152). Camann (1996) further highlighted the importance of carers reaching out to help others, stating this was important as carers were often asked to:
... carry on caring without information, inclusion, financial support, or social support, and to do so without incentive, acknowledgment, or assistance. Individually the faces of the mentally ill, and their families, are seldom seen by policymakers but collectively their voices are loud and are being heard. (p. 483).

In *reaching out to make a difference*, some participants in this study began to speak with community organisations when they believed that it would make a difference for other carers. As the police had frequent contact with carers, one participant freely gave of her time to speak to new recruits in the police force. She believed that it was essential for them to understand about mental disorders from both the carer’s and the affected family member’s perspectives. She believed that in *reaching out to make a difference*, she could enact change that would be beneficial to other carers in times of crisis:

I talk at the Police Academy [to police recruits]. I asked Jill [daughter] first if she would mind [if participant did the talk]. Through * [support group] they [police] asked for carers to go over there [to the Police Academy]. She [daughter] was actually very happy and came with me once. I let her read the talk, before I gave the first talk. (P10)

Another participant spoke to school children about her experiences of being a carer. She tried to involve these children as much as possible in her talks:

I talk to children in the schools [about mental disorders and the family]. Their reactions are mixed, but mostly they are very understanding. A few of them have actually got some problems themselves, or their families have. They come and talk to you afterwards. A lot of them are really quite amazed at what you are saying. I try to bring them into it [the talk] as much as possible. They are pretty amazed that everyone can be involved in mental illness, that it involves a lot of people [one in five Australians are affected by mental illness]. (P16)

In *reaching out to make a difference* participants took every opportunity in their contact with health professionals to try to make them understand the experience of a carer.

Participants believed that health professionals had little understanding of what carers did on a daily basis:

I had a doctor at one of the meetings [first psychosis carers’ group]. She was actually the doctor representative at one of the [carer’s] meetings. She [doctor] asked me about being a carer. I said, "it is about having a son coming and asking if I can borrow some money. Or asking can you take me so and so, or I have got nothing to do and I am really bored so I will just hang out here [in participant’s home]". Sometimes it is "I have got no food, or can you sort this out". There is the constant barrage of wants and needs. She [doctor] turned around and she said "but isn’t that just being a mother?" [the participant laughed]. For me that kind of highlighted and underlined the misunderstanding about what a carer has to do, because at 22 years of age you expect that your son has some life of his own. You expect they can make some decisions on
their own. Even if they are living at home you don’t generally have to prop them up emotionally five hundred times per day. (P9)

Being a member of a carers’ group with health professionals also provided participants with an avenue in reaching out to make a difference. Group members had a chance to change things by gaining more control for future carers, as one participant described:

We [carers] are growing. We are learning and growing. I guess as the carer representative I try to work out what needs to be done to have those things in place for each other [other carers]. This gives me a sense of achievement. I want to make sure the things that happened to me don’t happen to someone else. All of this lack of control, I can at least help somebody else have more control. ... I think that it is a lack of understanding and people need to learn a lot more about mental illness so that if it ever comes to a situation where they have to deal with it as we did they have some knowledge to begin with. I know these things are starting to happen and I know they are doing talks at the high schools and things. (P9)

Other participants became involved in developing new programmes for carers. Some hospitals were in the process of initiating a program where carers would routinely be at hospitals to talk to, and support, new carers when the affected family member was admitted for the first time:

The inaugural parent counselling [service], you know a counselling service for parents who have children newly admitted at the hospital. We are just waiting for our rooms [at the hospital before the service started]. I think they do something like that [provide the same service to parents and families of people who are admitted] at * [another hospital in Perth] and they have a bank of people [carers willing to be on roster to provide support]. (P11, multiple carer)

Some participants were working with health professionals to establish guidelines detailing both the carer’s and the case manager’s role:

What we [case manager and participant] are trying to do is to sort out a standard for the relationship between the carer and the case manager. The carer and the client have a relationship and the client and the case manager have a relationship. They should be well documented this is what I have to do. (P9)

Similarly, Rose (1997) reported that participants in her study of perceptions of social support for carers wanted to know what case managers were going to do for their family member. One participant from Rose’s study explained, "[they did not] want it [caregiving] to absorb all our lives. Thus, the one to one relationship with a health care professional was expected to provide this support” (p. 20). Solomon et al (1998) asserted that when carers had "a broader understanding of how professionals interact in the mental health system, families
are better prepared to seek access to and assistance from the most appropriate sources" (p. 338). Furthermore, Birchwood et al (1992) found that collaboration enhanced the family’s feeling of control, confidence in the health system, and respect for mental health professionals. These authors claimed that family-professional collaborative models facilitated communication and the family’s sense of competence in dealing with the affected family member’s mental disorder.

Other participants in this study reported that they were members of committees established by the government. These committees reviewed a range of issues, for example, compensating carers and making sure they were valued as stakeholders in any developments in community mental health care:

I’m also getting involved in seeing that carers are properly recompensed financially and also they are valued. It is important they are not going to be used as a government service. You know once the Health Department had all of these people that were working and caring [when people were in large mental hospitals]. I am making sure that organisations like *support group aren’t just used to deliver these services, and that professional staff [health professionals] are not just using up all of the funds that are available. It must be filtering through to consumers and carers, so that is sort of a little hobbyhorse [a passion] of mine. (P5)

Several participants were involved with government working parties, assisting to write the amendments to the 1996 Western Australian Mental Health Act. This was being completed to ensure the Act was providing the best protection for their family members as well as for themselves:

I am being proactive now. I have been for two years working on a committee for the new mental health act [reviewing and recommending amendments to the Act introduced in 1996]. I am working with psychiatrists, lawyers and I’m sort of seeing the bigger picture now [a more global view]. I am working with the WAAMH [Western Australian Association of Mental Health] who are a wonderful crowd of people to try to make things better for others. (P5)

Lefley (1997) also reported that involvement in groups established to prepare or review government policies was helpful to consumers and carers and led to increased levels of satisfaction in these groups of people. Several participants in this study spoke of the personal satisfaction they gained from helping other people: "I ended up getting on the roster [at support group] and going there and helping new people who came in. It really helped me, it did" (P5). Another participant, a child/adult carer, demonstrated this clearly in her *reaching out to make a difference* experience. She was working with children at risk to help change
their experience from that which she had endured when she was a child, living with her mother who had severe depression:

I am doing a lot for children who are living with parents with mental illness. We have started this group for children living with parents who have a mental illness and the dilemmas of it because the children are at risk. ... I am at the stage now where it is important to me to try to make a difference in these children's lives. ... I want my kids to be able to talk to me about what they experienced [participant also has a mental illness], work through it and have children of their own. I don't want them to pass any unhealthy legacy down to their kids. The only way that will happen is if I come out and talk, which my mother never did. (P4 child/adult carer)

Another participant provided a different perspective of reaching out to make a difference. Early on in her caregiving experience she had been deeply touched by the work of Anne Deveson, an Australian celebrity whose son had schizophrenia. When she was unable to express her feelings, she felt Anne's work in the area of human rights was an accurate representation. Now that she was mentally stronger and had achieved more balance in her life, the participant knew she must become a role model for other carers who were not yet ready to speak out:

They [people] like Anne Deveson, I would hear those people standing up saying things that were in my heart but I didn't have the words for them. I just knew the things they espoused and believed in and were demanding were things that I realised was what was needed [to support carers]. So you know they [people like Anne Deveson] sustained me over the years and helped me stay with it [present advocacy work participant does].

When I asked this participant how reaching out to make a difference made her feel she replied:

I turned my negative feelings and experiences into bringing hope to others. It [advocacy work] empowers you and it empowers others. I got chosen to go to a "train the trainer" course to empower consumers and carers to take their place on committees and things like that. (P5)

Another participant gained a sense of self-worth, fulfilment, and value in her career choice. She believed that her personal experience was helpful to others:

I ended up working in psychiatry. I felt that I could relate to that area and that I would probably be able to help people and be a bit more understanding. ... It was therapeutic for me. ... I sometimes think it is a wrong reason for doing it. Then I think it gives you that extra bit of understanding, which probably helps especially for the families that you're working with. So you know it's kind of a precious understanding to have. I could not have had it; you can't get it unless you do a lot, you know, work for many years in the field, then you would understand. (P1 child/adult carer)
One participant explained how she talked to other women who had been in similar situations (participant also had a mental disorder) and this gave her a sense of self-fulfilment:

I love going down to Women's Health Care House and all of the young women talk to us about things, you know all their problems. It is good because we just listen and they have unloaded loads of stuff you know. Maybe some of them we can help make it better, you know mostly just talking to them, I love doing that. (P4 child/adult carer)

Another participant spoke of being ready to reach out and help others in similar situations because of what she had experienced:

Looking, reflecting back on it [caregiving experience] now, I understand a whole lot of stuff [things], you know we have been through it, we have done it. Like if other people around the neighbourhood or anywhere get in that situation [being consumed], you know, you can offer help to them. You are just more understanding to cues in your environment. (P1, child/adult carer)

Participants in reaching out to make a difference also tried to redress the stigma that both they and their family members had experienced. One participant, although she did not enjoy talking to school children, described how she believed that it was important for her to do so in order to remove stigma from the community:

It [talking to children in schools about mental disorders] does not make me feel good. I don't like it much but afterwards I feel good that I may have made some difference to the kids. You hope if they are in that situation they can find help. I would hate everyone else to be in that situation that I was in. The thing I am trying to do is to remove stigma. (P16)

6.4.3: Summary

To sum up, participants entered the final phase of the core process, reaching out to make a difference, when they had attained a degree of mastery over their caregiving commitment, which presented a significant movement towards achieving balance in their lives. At this time participants experienced a need to reach out and help others and began to help make it different for other carers. It was now important to them to prevent other people from having to experience feelings of being consumed. In reaching out to make a difference participants became actively involved in self-help groups, taking on advocacy roles, and teaching community groups, for example, school children and the police, about the experience of being a carer for a person with a mental disorder. Other participants hoped to change things for future generations, for example, their grandchildren: "I also realise that I
have three little granddaughters. I feel that what ever changes for the better could make a
difference to their lives. I don't know what is coming up for them, you know” (P5).

During the previous phase participants had begun to take control and they had attained
some degree of mastery over their caregiving role, and reaching out to make a difference
further increased participants’ level of self-esteem, self-equilibrium, and movement towards
seeking balance in their lives. The self-evaluation and appraisal of their caregiving situation
was helpful in resolving additional issues that had consumed them. For example, one
child/adult carer who participated in this study began to work with young children who had a
parent who was mentally ill. This work allowed the participant to share her experiences with
these children and to allow the children to talk about their experiences. Furthermore, it
allowed her to work through and resolve issues from her own childhood, which was helpful to
the participant in seeking balance in her life.

As well as the core process the data identified the presence of a sub-process of seeking
balance that was part of the substantive theory of seeking balance to overcome being
consumed. This sub-process was entitled trying to make sense of what was happening, and it
will now be presented.
6.5: SUB-PROCESS OF SEEKING BALANCE: TRYING TO MAKE SENSE OF WHAT WAS HAPPENING

6.5.1: Introduction

Data analysis identified that a sub-process called trying to make sense of what was happening was part of the substantive theory of seeking balance to overcome being consumed. The sub-process had three phases and each of the phases was interconnected with the corresponding phase of the core process (See Figure 6, page 198). In order to extract the scope of the meanings of the words “trying” and “sense” definitions of these words were examined to confirm a fit with the data. The Macquarie Concise Dictionary (2000, no pagination) defined “trying” as “to attempt to accomplish, ... to attempt to open”. The Macquarie Concise Dictionary (2000, no pagination) defined “sense” as “a sense of security, ... the moral sense, ... clear or sound mental faculties; sanity, ... mental discernment, realisation or recognition, ... a sense of duty, ... to become aware, ... to comprehend or understand”. Overall these themes mirrored what was happening in the data. Participants were trying to find meaning in what was happening to them. They were trying to regain their sense of security and stability in life, while trying to control their feelings of being consumed. Some participants continued to remain in situations that increased their feelings of being consumed, because of a sense of duty. Throughout all of this, participants continued to try to comprehend and understand what was happening to both themselves and the affected family member. In summary, the definitions were pertinent as participants attempted to find solutions, to find avenues that would provide answers to help them in trying to make sense of what was happening.

This sub-process of seeking balance consisted of three phases: “seeking knowledge and understanding”, “making sense” and “placing the experience into perspective”. Each phase of the sub-process, trying to make sense of what was happening will now be presented.

6.5.2: Phase one: Seeking knowledge and understanding

Phase one of the sub-process, trying to make sense of what was happening, occurred during the period of time prior to when the affected family member was diagnosed with a mental disorder and was called seeking knowledge and understanding. Simultaneously, participants were engaged in phase one of the core process, utilising personal strategies to reduce the problem of being consumed. When participants developed the recognition that
something was wrong with the affected family member they also developed a preoccupation with not knowing what was wrong. For some participants, this confusion lasted for several years. In trying to make sense of what was happening, some participants began to discuss their concerns about the affected family member’s abnormal behaviour with teachers, school psychologists, and counsellors. Other participants sought advice from health professionals: “I spent a lot of time talking to the school counsellor about Aaron. ... You hope that somebody else knows what is going on [with son] because you don’t” (P9). For some participants their search for answers, concerning their family member’s behaviour, began when the person was very young. One participant spoke to her daughter’s kindergarten teacher but was told there was no need for her to worry: “I talked to April’s [daughter’s] kindergarten teacher. She said ‘No, this is what we call a strong willed child. Go to the library and get a book on the strong willed child’. I never did” (P20). Generally, participants reported their early contacts with professionals did little to decrease their experience of being consumed by what was happening to both themselves and to their family member. Similarly, carers in Jeon and Madjar’s (1998) study claimed they too experienced a great deal of confusion, had no clear understanding of what was happening to the affected family member and were left to “flounder in the dark”: “It was dreadful because you knew nothing about the illness and you didn’t understand the illness. You are floundering, you’re always floundering in the dark ...” (p. 698).

In trying to make sense of what was happening participants in this study spoke of realising, long before the official diagnosis was made, that their family member could have a mental disorder: “I guess all the way along you wonder [if family member had a mental disorder]. You can see the potential, but all the way along you wonder. I was assured whenever I raised the question [recognition that something was wrong with son] with a professional that it [son’s behaviour] was okay” (P3). Several participants began to access information pertaining to mental disorders. These participants realised their increased knowledge and understanding of mental disorders may provide some answers for them: “Unless I came to understand mental illness there was no way I was going to be able to handle this [what was happening]. I wouldn’t know what I was dealing with” (P3).

For other participants, the search for knowledge and understanding was helpful in trying to make sense of what was happening as it confirmed their established beliefs that the affected family member could have a mental disorder. It helped participants to face the reality of the situation and to continue to search for a solution:
In the end I said, "it is not just me", I can't pretend that this is not happening. I can't just say, "well it's not that bad really", which is what I was doing. ... You cannot help if you are forever playing catch up and not getting ahead. I needed to understand what was going on ... The first book I read was Anne Deveson's book [about her personal journey of having a son who developed schizophrenia titled "Tell me I'm here"]. I read the first four pages and I thought, "that is Aaron [son] and I can't read this", and I cried. I closed the book and two days later I got it out and said, "I have to read it, I have to know". So I read a bit further and put it away again. Eventually I finished it. I think it took me two weeks to read the book but listening to the things she went through and comparing it to the things we were going through, was really important. (P9)

Journaling was used by several participants in trying to make sense of what was happening as it provided participants with an avenue to write down their thoughts and feelings. This helped participants to increase their knowledge and understanding of what was happening because it facilitated the process of reflection. Participants found journaling particularly useful when events became overwhelming for them, as they described: "I started to write a diary. It helped to get a lot off your chest. I didn't keep it regularly; I am not an organised person. When things became overwhelming or very important, I wrote them down" (P9); "Molly my sister said 'write down every day what she [daughter] is doing and how you are feeling and then read it once a week'" (P10). The following participant found it useful to read his wife's journal as he described in this extract from his interview. He found that it provided him with a greater knowledge and understanding of the problem and this in turn was useful to him in trying to make sense of what was happening:

I gained a lot from reading that stuff [notes that his wife had written]. I would just go and read the [note] pad that she had written things on. Then I would realise how she was feeling inside. It made me sad to go and read it, but it was helpful. (P7)

White and Epston (1990) also described journaling as a helpful strategy that allowed individuals to detail their experiences, thoughts, and feelings, providing a record that could be reviewed. These authors claimed the review process encouraged individuals to find new meanings, to examine their values, and to clarify relationships. Stuart and Laraia (1998) further supported the use of journaling, claiming that it encouraged a description of the individual's perceptions, encouraged comparisons, and hence, promoted specificity and problem analysis.

In summary, during the first phase of the sub-process, participants sought knowledge and understanding of the problem of being consumed. By this time, many participants explained that they believed the affected family member could have a mental disorder and
their increased knowledge and understanding about mental disorders strengthened this belief. Journaling was also described as important as it facilitated reflection and the development of new knowledge and understanding.

6.5.3: Phase Two: Making sense

Phase two of the sub-process was called making sense. When a diagnosis of a mental disorder was made on the affected family member many of the questions surrounding participants' recognition that something was wrong along with their preoccupation with not knowing what was wrong were resolved. Participants' newly acquired knowledge concerning the affected family member allowed them to re-evaluate many of the issues that had impacted on their experience of being consumed. This phase occurred simultaneously with phase two of the core process, that is, restoring self-identity. Some participants expressed that it was much easier for them to cope once they knew the affected family member had a mental disorder and the new knowledge was helpful in trying to make sense of what was happening. Several participants spoke of expressing relief when they were finally told about the affected family member's illness. It was a turning point as the following participant explained:

They [health professionals] don't like diagnosing people. They don't like labelling people. However, I think if you know what is wrong, you cope a lot better. Otherwise it is like working in the dark. In one way it was a relief when we finally found out what was wrong. It was a turning point and I then looked to the future. (P11, multiple carer)

Similarly, other researchers have found that carers were relieved when a diagnosis of mental disorder was finally made on the affected family member (Jones, 1997a; Karp & Watts-Roy, 1999). The diagnosis clarified a history of problems over many years and generated hope the affected family member would finally be cured. A participant from Karp and Watt-Roy's study of how caregivers assess their obligations gave an example of how carers felt when they were told of the diagnosis:

I'll tell you one of the best days of my life was when I got a phone call from the hospital telling me what they decided was wrong with him [husband] and they couldn't understand why I was so excited or happy. (p. 479)

As with participants in this study, other researchers have also reported that a diagnosis of mental disorder was viewed as a turning point. Yamashita's (1998) study of family coping found that after a long struggle, carers were able to begin to cope with their situation when they found out their relative had a mental disorder. The author claimed that carers were then
able to begin "differentiating the relative from the illness behaviour, trying to connect and relate to the relative, maintaining normalcy, getting on with their own lives and at the same time keeping in mind they were responsible for their relative's well being" (p. 521). Similarly, Denzin (1989b) claimed that human experiences are often characterised by moments of revelation, when after a period of chaos the problems associated with the experience suddenly become clear. In the case of illness, one such moment is when receiving a diagnosis. Karp and Watts-Roy (1999) elaborated further on what it meant to families to finally know what was wrong with their ill member:

Large numbers of people who are eventually deemed mentally ill go for months, even years, without an "official" diagnosis. ... The point at which a person's troublesome behaviour is transformed into a disease, via the pronouncements of medical experts, is typically a moment of epiphany for caregivers (and sometimes for patients). (p. 479)

When a diagnosis of mental disorder was made on the affected family member, participants in this study described the need to further educate themselves about mental disorders. In particular, increased education and understanding of the affected family member's illness, for example, schizophrenia or bipolar disorder, was of paramount importance. Participants reported their increased knowledge and understanding of mental disorders helped them to more effectively care for the affected family member: "You just want to cope with what you have got [the family member's problem]. You want to make it better and understand it" (P11, multiple carer); "I read as much as I can on it [schizophrenia]" (P17). Several participants made appointments with health professionals in attempts to gain increased knowledge and understanding of the affected family member's illness: "We made an appointment [with daughter's psychologist] without her [daughter]. We were going around the twist [not coping] ourselves. We needed information. ... He [psychologist] was very good, he would answer anything" (P10). The education provided participants with a better understanding of what was happening to the affected family member: "I understood these awful things [memory loss and aggression due to husband's dementia] were going to happen. The education gave me an insight" (P25). Similarly, participants in Wackerbarth, Streams and Smith's (2002) study on family caregivers to people with dementia reported the benefits of understanding about the illness on their caregiving role.

Phase two of the sub-process was closely inter-related with phase two of the core process i.e. restoring self-identity. The increased knowledge and understanding of mental disorders further assisted participants in reviewing the past and in preparing for the future
aspects of that phase. The knowledge and understanding was helpful to participants and facilitated them gaining some degree of mastery over their caregiving role. There is an abundance of literature supporting the importance of carers receiving information and education about the affected family member’s illness. Caregivers have a persistent and consistent need to understand their family member’s illness (Ascher-Svanum, Lafuze, Barrickman, Van Duesen & Fompa-Loy, 1997; Pfeiffer & Mostek, 1991), hoping the information learnt will provide them with practical management strategies (Mueser, Bellack, Wade, Sayers & Rosenthal, 1992) and a sense of predictability to more effectively manage difficult events and situations (Kinsella et al, 1996). Once it became clear the affected family member had a mental disorder, caregivers go through a period of active learning, with many of them attending formal education groups (Porter-Smith, 2000). Baxter and Diehl (1998) and Smith and Cochrane (1992) claimed that education and understanding about mental disorders were building blocks that provided carers with skills to develop mastery over their caregiving role while the information dispelled the carer’s fears of the unknown.

Fox (1997) also portrayed the importance of knowledge and understanding to family members in the following extract from her article “A consumer perspective on the family agenda”:

Last weekend, I asked one of my daughters (now 20 years old) what might have helped her when she was younger to understand what had happened to our family. Things would have been much easier, she said if some education about my mental disorders, the medication I had to take, and why I had to go into hospital had been available. (p. 252)

Participants in this study reported that support groups were helpful in making sense of what was happening to them:

* [support group] gave me an understanding [about mental disorders] and education. I read a lot of books. The other thing were the meetings, to find out that you weren’t the only one was a relief. It helped me to realise that I was not alone. ... There were others that were the same that was the important thing. (P2)

Participants’ level of resourcefulness in finding knowledge and understanding was also important to their experience of seeking balance. Some participants did their research by obtaining books and videos from the library or by attending carer support groups:

I have done a lot of research of my own. I have got books and videos out of the library. I have contacted carers groups. I just found I needed to have as much information as I could. ... The carers [first psychosis] group is set up with a strong
information bias. We [carers] all went in there [to the group] saying, "we want to learn, we want to understand". We want to be able to say, "well this is normal or what do I do if he drinks all of the time and won't stop?" (P9)

In short, during the second phase of the sub-process of seeking balance, participants acquired additional knowledge and understanding of mental disorders and in particular a greater understanding of the affected family member’s illness. The increased level of knowledge and understanding was important to effectively care for their family member. In addition, further knowledge and understanding of mental disorders was helpful to participants in their future interactions with health professionals. Making sense helped participants develop a sense of mastery and linked the sub-process with phase two of the core process. Hence, making sense further enhanced participants’ ability to restore their self-identity.

6.5.4: Phase three: Placing the experience into perspective

As participants gained some sense of mastery over their caregiving experience they experienced the need to reach out to help others. Participants then entered phase three of the core process of seeking balance, called reaching out to make a difference. At the same time participants also became engaged in phase three of the sub-process, trying to make sense of what was happening. This phase was entitled placing the experience into perspective. During this phase of the sub-process participants began to place their experience to date into perspective in order to move forward with their lives. At the time of being interviewed for this study, 16 of the 27 participants were engaged in the third phases of the BSPP of seeking balance.

In placing the experience into perspective participants spoke of the positive effect their caregiving experience had on their development as a person. Several participants explained that they believed they were now more understanding of people’s rights, more compassionate, and had learnt more about people, for example:

I have learnt a lot about people. I have a lot more understanding of rights and responsibilities, not just mine, but others too . . . I have learnt a lot about mental illness. I have learnt a lot about compassion. I have learnt not so much to judge other people’s lifestyle choices but to acknowledge they have the right to choose the way they live. This is not something I thought about before. I have a lot more patience and wisdom. (P9)
In *trying to make sense of what was happening* participants explained that they now had a greater knowledge and understanding of mental disorders and, consequently, viewed people who have a mental disorder differently than they had before:

I have learnt to be more compassionate and understanding. I have learnt that to be different is not abnormal. I have got a better understanding about mental disorders. I get quite angry when people call them [people who are mentally ill] nuts because they [people in society] don’t know what it [having a mental disorder] is like. (P17)

One participant claimed she used to be frightened of people who were mentally ill, as well as those people who abused alcohol. Her caregiving experience had taught her to be more understanding of people and to accept people as they are. This had given her more confidence in life in her interactions with people:

I used to be frightened of the mentally ill and drunks. All of a sudden we were thrown into the deep end [caring for daughter]. I feel I have learnt a lot and I have a lot of feeling. I think I have a lot of feeling and understanding. ... Actually I feel that I have learnt to accept people how they are. She [daughter] has taught me or her illness has taught me to accept people as they are, no matter what. (P10)

Participants in Kinsella et al’s (1996) study of coping skills, strengths, and needs as perceived by adult offspring and siblings of people who have a mental disorder also reported their caregiving experience had made them more compassionate, understanding, and non-judgemental people. These participants felt that as a result of their experience they were able to more easily tolerate differences in people. One participant from Kinsella et al’s study provided this insight: “I think it’s made me much more empathetic ... you can’t judge people quickly. ... I have a more open perspective on people and those who are suffering” (p. 29).

Marsh et al (1996) reported similar findings and claimed the experiences people encountered added to their personal resilience. These authors described resilience as:

The ability to rebound from adversity and prevail over the circumstances in our lives. ... "When a family experiences something like this [mental disorders], it makes for very compassionate people - people of substance". (p. 4)

In *placing the experience into perspective* participants in this study reflected on the positive contribution the affected family member had made to their lives. *In trying to make sense of what was happening*, one participant who was caring for her two adult children, who were now around thirty years of age, expressed positive perceptions of her experience due to her continued close relationship with them. This support and companionship helped the participant to cope with other aspects of her life:
I keep Peter [son] happy, I don't blame him if he drops things but I don't clean up after him. I expect him to be a part of the household. I expect him to straighten up his bed and help with the dishes. We go out together, that can be a little bit of a problem because I am much older than him. He doesn't go out by himself any more. So we go for walks and we go out to visit his sister. We get videos and we go swimming. There are lots of things that he doesn't do that he could do. He just loves to come home [son comes home twice a week, the remaining time he lives in a hostel] and I love to have him home. (P11, multiple carer)

The same participant provided this description of the importance to her life of regular contact with her daughter who also had a mental disorder:

Hannah [daughter] used to ring up and talk to me [when she was unwell]. She used to ring up and talk to me a lot. That was alright because I was a sounding board for her. She is busy doing other things at the moment so she doesn't [call participant]. That is a very good thing for her, not a good thing for me, but a good thing for her. (P11, multiple carer)

A participant in Marsh et al's (1996) study provided another description regarding the positive contributions made to the family by the ill member:

As a family we have learned to include the son with mental illness in all our gatherings - without high expectations yet with gratitude for his courage and fortitude. He is important to all of us! He gives us balance. His illness puts other things into perspective. ... In some ways it has brought out the best in each of us. (p. 10)

Greenberg, Greenley and Benedict (1994) also reported that caring for a family member with a mental disorder had many positive rewards for carers. The authors reported that caregivers found it was helpful and therapeutic to recognise their relative's contribution to family life and they appreciated the chance to talk about the contribution made by the affected family member. Participants in Greenberg et al's study described several types of tasks in which the affected family member participated, for example, helping with meal preparation, household chores and shopping, and providing companionship. Similarly, Lim, Luna, Cronwell, Phillips, Russell and Torres de Ardon (1996) and Tuck, et al (1997) reported participants in their studies spoke of positive aspects of their caregiving. These authors claimed that, among certain cultures, caregiving was a source of pride and status ensuring the carer's spiritual development. Furthermore, Bulger, Wandersman and Goldman (1993) and Reinhard and Horwitz (1995) found the personal gratification experienced by caregivers mediated their level of caregiver distress.

Another positive aspect identified by participants in this study was the satisfaction they experienced when the affected family member's condition improved. As well as being
positive reinforcement, the affected family member’s improvement helped participants to achieve balance in their lives as the affected family member was able to function more independently: “The emotional rewards you get from making progress or seeing happiness in the person you are caring for is great” (P8); “She [daughter] is still improving, she is still getting better. It is just amazing and so rewarding for us” (P10). Similarly another participant gave this description of the positive rewards she received from caring for her sister:

We [sister and participant] are really good together. You know we don’t mind shopping together, it is really weird. I make her cups of tea and Helen [sister] loves the garden; she has done my garden just beautifully. She is starting to do out the front here [of the house] as well. I don’t like gardening, I cook and do the washing. I said that I would take on that role [when they started living together] because I prefer to do that. (P4 child/adult carer)

Participants in Marsh et al’s (1996) study of the family experience of mental illness also spoke of the personal gratification at seeing improvement in the affected family member:

... imagine seeing a beloved son regain his ability to smile, to laugh at a joke, to be socially acceptable to others. To see him regarded once more with affection by his siblings. To see him able to live independently once more, with a part-time job and the pride of being more like others. And to feel we have helped this process. (p. 9)

In placing the experience into perspective several participants suggested that their experience had been relatively trouble free when compared to other people, as the following participant explained:

I really can’t complain because my passage through the system [health care services] has really been relatively trouble free. Things that have cropped up that I haven’t liked or understood or had a grievance with have generally been resolved one way or another. And what hasn’t been resolved I am trying my best to change [through participant’s advocacy work]. (P9)

Another participant, in evaluating the impact of her caregiving experience, believed she had coped reasonably well and she could still find things in life that brought her pleasure and satisfaction. These helped her to find balance in her life and to increased her ability to cope with caring for her daughter:

I think taken all round over a lifetime it [caring] hasn’t got me down. I am feeling a bit flat at present but I am not usually like this. I am always thankful that I don’t have mental illness and that I don’t even have a depression that goes on and on. I have the blues occasionally but essentially there are things in life that bring me pleasure. I can see that I am really quite an optimistic person you know and so I have got that to be thankful for. (P5)
In trying to make sense of what was happening another participant explained that it was a good thing that her four children had disabilities as she did not think she could manage with a "normal" child. Her positive outlook on life was beneficial to her overall appraisal of her caregiving experience:

I do as much study as I can externally. I am studying social work. I have two close girlfriends. I see it as a good thing that all my children have disabilities [four children have either a mental or intellectual disability] because I think it would be more difficult to have one kid [child] who had a disability. I know no different. I would find it very difficult to have an average child. Life is there and you just get on with it. (P22, multiple carer)

In placing the experience into perspective the daily caregiving commitment to the affected family member was important. The caregiving obligation hindered several participants' ability to move outside the home or to find employment. Another participant had to constantly observe his wife as she was forgetful and was a danger to herself if left alone: "One problem I have is that if I do find work I have to take her [wife] with me" (P23). In contrast, other participants found their day-to-day obligation was not so restrictive and therefore their ability to seek balance in their lives was improved:

Zoe [daughter] can cook, she can do her own laundry and she keeps her own room clean. You know I don't have to do any of that for her like some people have to do. I can leave the house and leave her at home for hours and that's fine. I wouldn't like to get a full-time job though because I think she needs the company and the support. (P6)

In summary, the third phase of the sub-process of seeking balance was called placing the experience into perspective. During this phase, in trying to make sense of what was happening, participants reflected on the positive contributions the affected family member's illness had made to their lives. Many participants explained that they believed they were more tolerant, compassionate, and understanding people as a result of their experience.

6.5.5: Summary of the sub-process of seeking balance

The data identified that a three-phase sub-process of seeking balance was present. The sub-process, trying to make sense of what was happening, ran parallel to the core process of seeking balance and was inter-related with each corresponding phase of the core process. During the first phase of the sub-process participants tried to seek knowledge and understanding. They spoke to health professionals, teachers, and school psychologists or counsellors about their concerns. During this phase many participants came to the realisation
that the affected family member could have a mental disorder and they began to seek
knowledge and understanding about mental disorders. Participants also used the technique of
journaling, as it was useful in encouraging reflection and facilitating participants' ability to
make sense of what was happening.

Phase two of the sub-process was entitled making sense. Several participants spoke of
entry to this phase as a turning point in their experience of being consumed. Participants now
knew that their family member had a mental disorder and they began to seek knowledge and
understanding of their family member's specific disorder. They acquired this knowledge and
understanding from a variety of sources. The increased knowledge and understanding
acquired during this phase helped participants in making sense of what was happening and
allowed participants to develop mastery over their caregiving experience. The last phase of
the sub-process was called placing the experience of caregiving into perspective. In trying to
make sense of what was happening participants began to evaluate what they had been through
and see positive outcomes for themselves. Some participants spoke of being more
compassionate, tolerant, and accepting people; other participants saw positive aspects in their
lives resulting from their caregiving experience. This positive evaluation of their experience
further enhanced participants' ability in reaching out to make a difference and demonstrated
the inter-relations between the third phases of the core process and sub-process. At the time
of being interviewed for this study 16 participants were engaged in the third phases of the
BSPP of seeking balance. Participants' entry into the final phases was not dependent on the
length of their caregiving experience but on their experience of seeking balance and the
conditions influencing that process. In summary, the sub-process, trying to make sense of
what was happening was part of the BSPP of seeking balance. It ran parallel to and was inter-
related with each corresponding phase of the core process.

6.6: Summary of the basic psychological process of seeking balance

The core process of seeking balance consisted of three phases. In addition, a three-
phase sub-process entitled, trying to make sense of what was happening completed the
substantive theory of seeking balance to overcome being consumed. The first phase of the
core process, utilising personal strategies to reduce the problem of being consumed, occurred
predominantly in the time prior to when the affected family member was diagnosed with a
mental disorder. During this phase, participants used their established coping responses to
help them manage their experience of being consumed. Participants also used trial and error
approaches to try to find a solution to their experience of being consumed. Participants were simultaneously engaged in the first phase of the sub-process, entitled seeking knowledge and understanding. Participants sought advice from health professionals, teachers, and school counsellors and psychologists. Many of the participants believed by this stage that their family member could have a mental disorder, and so they began to acquire knowledge on mental disorders.

When a diagnosis of mental disorder was made on the affected family member, the majority of participants engaged in the second phase of the core process. This phase was entitled restoring self-identity. It consisted of three aspects. Participants continued to use their established coping mechanisms that had been successful for them in the past when faced with stressful situations. In addition, participants began to regain self control. This was achieved by reviewing the experience they had been through in the context of their newly acquired knowledge the affected family member had a mental disorder. Furthermore, participants began preparing for the future and, therefore, in regaining self-control began to make adjustments to their lives. The final aspect of phase two was called taking control. This aspect also assisted participants to more effectively communicate with health professionals. They also acquired "tricks of the trade" that helped them in their caregiving role. Simultaneously, participants were engaged in the second phase of the sub-process of trying to make sense of what was happening. This phase was called making sense and during this phase participants sought specific knowledge and understanding of their family member's mental disorder. As a result participants developed some degree of mastery over their understanding of the affected family member's illness and this facilitated their movement towards seeking balance in their lives.

When participants had successfully mastered phase two of the core process they moved to the final phase, reaching out to make a difference. During this phase participants felt the need to make a difference to other people, particularly new carers. They became advocates and joined groups to help these people. This gave participants a sense of self-worth, fulfilment, and value and was helpful to them in seeking balance in their lives. Phase three of the sub-process of trying to make sense of what was happening saw participants placing the experience into perspective. Hence, participants began to speak of positive outcomes of their experience and to explain that as a result of their experience they were now more compassionate, tolerant, and understanding people.
As mentioned earlier not all participants had entered the final phase of the core process and sub-process of seeking balance. Their engagement in phase three was not determined by the length of their caregiving experience but by their experience of seeking balance and the conditions influencing that experience. The data identified four conditions that influenced participants' experience of seeking balance. These conditions will be described in chapter seven.
CHAPTER 7

CONDITIONS INFLUENCING BASIC SOCIAL PSYCHOLOGICAL PROCESS: SEEKING BALANCE

7.1: Introduction

This chapter describes four conditions that influenced participants’ experience of seeking balance and these conditions were present throughout all phases of the core and subprocesses. They were "participants’ prior exposure to, knowledge of, or experience with mental disorders", "participants’ level of social support", "participants’ perceived level of well being", and "availability and support of health professionals" (See Figure 8). Each of these four conditions will now be presented.

7.2: Participants’ prior exposure to, knowledge of, or experience with mental disorders

The first condition identified as influencing participants’ experience of seeking balance was participants’ prior exposure to, knowledge of, or experience with mental disorders. The data revealed that the 19 participants had no prior exposure to, knowledge of, or experience with mental disorders before they developed the recognition that something was wrong with the affected family member. Participants’ lack of prior exposure to, knowledge of, or experience with mental disorders increased their feelings of being consumed, as they did not understand what was happening. The following description, provided by one participant, was representative of most participants’ experiences: "I guess I was still hoping it was something he [son] would outgrow. I had no experience at all with mental illness" (P3).

Eight of the 27 participants in this study reported that they had some prior exposure to, knowledge of, or experience with mental disorders and believed this prior experience was helpful in their movement towards seeking balance. For these eight participants, prior exposure to, knowledge of, or experience with mental disorders occurred either as a result of their occupation, from personal experience of having a mental disorder, because there was a history of a mental disorder in their family of origin, or because they were a multiple carer and they were already caring for another ill family member. As a result of their prior exposure to, knowledge of, or experience with mental disorders, several of these eight participants had previously accessed the mental health care system or had experience in interacting with health
CONDITIONS INFLUENCING THE BASIC SOCIAL PSYCHOLOGICAL PROCESS OF SEEKING BALANCE

1. Participants' prior exposure to knowledge of, or experience with mental disorders
2. Participants' level of social support
3. Participants' level of well-being
4. Availability and support of health professionals

FIGURE 8: CONDITIONS INFLUENCING THE BASIC SOCIAL PSYCHOLOGICAL PROCESS: SEEKING BALANCE
professionals. In addition, these participants had experience in interacting with people who had a mental disorder. Participants who were multiple carers had previously engaged in the experience of seeking balance and spoke about how this prior exposure positively influenced their current experience.

Some of these eight participants, as a result of their occupation, were familiar with medical terminology and had previous experience of working with mental health consumers. The following participant explained that because of her occupation she immediately diagnosed her son's abnormal behaviour as schizophrenia:

I am well versed with medical things I have to be because of my work. I am switched on I guess and I know my son [first son to develop a mental disorder]. ... He said, "there were some people at the petrol station that were going to kill me". I thought straight away don't be so silly just brush that aside. But I was a bit clued up [knowledgeable] so I did not brush that aside altogether. ... Then he came into the kitchen and said "mum there is a rattlesnake under my bed". I said, "Oh Josh, no, son, there can't be". He said, "there is, look at my legs". He pulled up his trousers and all his legs had been scratched to pieces. I said, "I will come with you, there is no rattlesnake under your bed". He said, "No! No don't go out there, he was in the corner he will get you". I said, "come with me I will go out and check but I know there is no snake under your bed". So he was like a scared petrified person watching me look under the bed. I said "there is nothing there Josh". But of course in his mind there was. Straight away I knew he had schizophrenia. ... I knew straight away I needed to get help for him. (P13, multiple carer)

The two participants who had personal experience of a mental disorder (depression and anorexia during adolescence) believed that their own illness allowed them to readily identify with the affected family member. These participants explained that because they knew what it felt like to be ill they could relate and understand the experience of the affected family member: "I had anorexia in 1982. It was only a personal experience but that helped. I had an experience of how it felt" (P24). "I knew a little bit about depression because I used to have chronic depression so I had read up on it and knew quite a bit about it. That experience was very helpful to me" (P7).

In addition, some (of the eight) participants had a family history of a mental disorder. Several of those participants believed their previous experience helped them. The following participant's mother and brother both had schizophrenia, so she had been exposed to the impact of a mental disorder from a very young age. She had attended self-help groups during her formative years and she had read and acquired some knowledge and understanding about mental disorders. In addition, she had acquired many of the "tricks of the trade" associated
with the caregiving experience. This prior experience was helpful to her when she married a man who had a bipolar disorder:

My mum, she was basically institutionalised [with a mental disorder] for most of her life. I didn’t intend marrying someone with a mental illness; if anything I tried to steer away [participant’s husband has a mental disorder]. I had enough in my upbringing. But I went to ARAFMI [Association for the Relatives and Friends of the Mentally Ill] and I found it helped me to come to terms with the mental illness in my family. ... I was blaming my mum you know for it. I went to ARAFMI and learnt and understood a lot more about mental illness. My brother also had, by that stage, developed schizophrenia, as it was a slow onset for him. So going along to the support group and talking and sharing really helped me to understand mental illness. ... It has been helpful in my relationship with Harry [husband]. (P14)

Conversely, other participants who had a history of a mental disorder in their family of origin reported that their prior exposure was not helpful to them. This was because these participants were very young when they were previously exposed to the impact of a mental disorder and they, therefore, did not understand the experience. In addition, families often hid mental illness in their family member and hence young children growing up in these families did not always know their relative was ill. However, while these participants did not recognise the signs in the affected family member, other members of their family did, as the following participant explained:

My father was also a manic-depressive and he committed suicide. It [seeing her grand-daughter ill] was a bit hard on my mother. She [participant’s mother] said, "I know what is the matter with her [grand-daughter]. I recognise the symptoms". My sister had them [mental disorder] as well. She said, "she is just like it [her husband and daughter]" and [she] was horrified to see it. I did not remember what my father was like, it happened too long ago. (P16)

Finally, two participants who were multiple carers stated their prior exposure to, knowledge of, or experience with mental disorders was helpful in their recognition that a second member of their family also had a mental disorder. One multiple-carer described how she recognised that another one of her sons was becoming ill: "it [seeing the warning signs] was hard for us [parents] because we had already been through it [another son had schizophrenia] and we were looking for it as well" (P13, multiple carer). Another multiple-carer provided a similar description when she noticed that her daughter was becoming unwell after she delivered her first child. Her son had already been diagnosed with schizophrenia and the participant found that her prior experience was helpful in her early recognition that something was also wrong with her daughter:
She [daughter] had her first baby. I left her all day and went out [to the maternity hospital] in the evening. She hadn’t been to sleep. You know she had a long labour and she hadn’t had any sleep for three days. I saw her the next day ... and Hannah [daughter] was showing definite signs of being sick [having a mental disorder]. She was saying that she did not want anyone to touch the baby, quite abnormal things really. ... I went and had a word with the staff. I said to Ben [daughter’s husband] “she should have been to sleep she is having too many visitors”. ... But he didn’t listen and I had a talk to the staff and they said “we will watch her carefully and give her a sleeping tablet tonight”. (P11, multiple carer)

In summary, those participants who had prior exposure to, knowledge of, or experience with mental disorders generally found that their previous experience was helpful to them. These participants had some knowledge and understanding of mental disorders and had developed skills that were helpful to them in managing the affected family member’s abnormal behaviours. Some of these participants had prior experience in accessing the mental health care system and in interacting with health professionals. Those participants who had personal experience with a mental disorder believed that they could empathise with the affected family member. Participants found their prior exposure to, knowledge of, or experience with mental disorders was helpful during all phases of the core and sub-process and facilitated their movement towards seeking balance in their lives.

7.3: Participants’ level of social support

The second condition identified as influencing the core and sub-process of seeking balance was participants’ level of social support. The importance of social support as a buffer against stressful life situations was identified many years ago by Caplan (1981) who asserted "empirical researchers confirm that exposure to high stress by individuals receiving adequate support does not increase the risk of mental or physical illness" (p. 413). Caplan’s findings have been supported by other researchers (Atkinson, Atkinson, Smith, Bem & Hilgard, 1990; Jubb & Shanley, 2002; Neufield & Harrison, 1995; Noh & Turner, 1987, Porter-Smith, 2001; Rose, 1997, Toseland et al, 1990). In this study, participants obtained support from key family members, from neighbours and friends, and from their association with different community organisations. Furthermore, some participants found the personal support they received from the affected family member influenced their experience of seeking balance.
7.3.1: Support provided by key family members

The personal support provided to participants by their spouse and/or mother/mother-in-law emerged from the data as a key factor influencing participants’ experience of seeking balance. This support was provided in several ways. Participants explained that their mother/mother-in-law provided support by helping them with household tasks. In addition, the participant’s mother/mother-in-law often had a close relationship with the affected family member and, therefore, spent a considerable amount of time with the ill person. This close relationship allowed the participant to regularly distance themselves from caregiving responsibilities and to pursue their personal goals. In addition, the mother/mother-in-law helped other members of the family, further lightening the participant’s responsibilities and freeing up participant’s time. A participant from Kinsella et al’s (1996) study of siblings of people with mental illness echoed this situation: "I had a really supportive grandmother, a really loving grandmother. ... I'd spend a month with her every summer, and it would really sort of renew me" (p. 26).

Participants in this study reported that the key support person was also available to personally support them and to provide, for example, financial or emotional advice and help: "My mother is extremely helpful and supportive. She moved [bought a house] closer to me, to be there for me" (P18); "My mother and father are there for me" (P22, multiple carer); "My mother tries very hard to have a relationship with Michael [son]. She is very supportive" (P17); "My mother is a very wise lady and she spent a lot of time with Aaron [son] working at getting him help" (P9); "My mother-in-law is very good. God help Josh [son] when she goes [dies]. She is 91 [years old]. He visits her every day. All my sons are extremely close to her. She has been a life-line for them and helpful to me (P13, multiple carer).

Other participants recounted the value of the personal support given to them by their spouse. These participants believed that without their spouse’s support, they would not have been able to continue to care for the affected family member: "I probably wouldn't be here today if I had not had that [husband’s] support" (P10). Participants believed they had grown closer to their spouse as a result of their experience, and their spouse was now more supportive and tolerant of them: "I think we are very close, we are very supportive of each other. We are a lot more tolerant of each other" (P2). Participants also found they could rely on their partners and this was important to them in seeking balance in their lives: "We have each other you know my husband and I and the family. We have a very harmonious family life" (P6). Another participant's husband supported her by being physically and emotionally
strong. There were times when she was strong and he was weak and visa versa and, therefore, they supported each other with their strength:

My husband was always there for me. When I was weak he was strong. When he was weak I would be strong. We needed each other. ... Ralph [husband], you know he was terrific. I have seen some marriages torn apart under this kind of stress. With us [husband and wife] it brought us closer together. (P15)

Previous research has identified that social support is crucial to carers of people with a mental disorder (Henderson, 1980; Mohr, 2000; Norbeck, Chafetz, Skodol Wilson & Weiss 1991) and the support has been identified as a major factor in lightening the burden associated with the caregiving role (Baxter & Diehl, 1998; Harvey, 2001). Furthermore, McNaughton, Patterson, Smith and Grant (1995) claimed that support is very important to carers, even if the support serves only to strengthen the carers’ existing coping mechanisms.

In this study, the data revealed that one participant, a single parent, did not have any key supports. At the time of being interviewed for this study, the participant was consumed by what was happening to her and to her affected family member. However, the participant felt that she should not look to her immediate family to provide her with support:

Being a single parent, you have to be everything. ... He [ex-husband] could not have coped with it [daughter’s illness]. Having two kids was enough [for ex-husband]; some support! I think it is wrong to look to the immediate family for support there should be someone [outside the family] who can come out and look at it [the problem] refreshed. (P20)

Pfeiffer and Mostek (1991) also identified that carers experiencing the most emotional stress were women acting without support from other family members. Similarly, Carpentier, Lesage, Goulet, Lalonde and Renaud (1992) reported that not all carers had the same level of resources available to them, claiming many carers were disadvantaged, for example, by poverty, poor housing, unemployment, and/or marital disharmony. These authors found that carers who were single women were particularly at risk and required more professional support, as they were less prompt to gather information on their own.

In summary, the level of personal support participants received from their spouse and/or mother/mother-in-law was a key factor in their movement towards seeking balance in their lives. The physical and emotional support provided by these key people was helpful to participants in managing what was happening to themselves and to the affected family member. These family members spent time with the affected family member, allowing participants to regularly distance themselves from the affected family member. The support
also allowed participants to meet their other life commitments and goals. The support provided participants with a valuable avenue to talk about problems they were experiencing.

7.3.2: Level of social support provided by friends and neighbours

Participants reported that the social support provided to them by their friends helped them in seeking balance. Participants explained that their friends were readily available when they required help and this promoted a sense of strength and security for them. Participants also believed that they could talk to their friends about personal issues and this was helpful: "Some friends couldn’t do enough to help. They said ‘anytime you want to talk, feel free to come and tell me all about it’. It was good and I needed that, I still do. I still talk" (P9);
"Friends helped by listening and offering support. ... It was the offers of help like can I help? If you need my help ring up, that was good" (P18); "Friends have been very good" (P16).
Friends that listened and did not criticise were particularly valued, as the following participant explained: "One of my friends she was the most helpful because she is the sort of person who will listen and accept and never criticise" (P10). Other participants felt that their friends were more helpful and supportive than members of their family: "They [friends] were just accepting. I think in lots of ways friends were more supportive than my sisters" (P5); "Two close friends were very helpful" (P13, multiple carer). Another participant found his friends were available to talk things over with and that was really helpful:

We have got a couple who are our closest friends. They were very supportive but I didn’t want to burden them too much because they had some problems of their own. ... We were still able to talk about things and they were the ones that really helped me the most, if it wasn’t for them. There really wasn’t anyone else because a lot of people didn’t understand. (P7)

Other participants found that friends who had similar life experiences were extremely supportive and helpful. These friends could relate to the participant’s experience and their advice was particularly helpful as it was based on personal experience:

I have a friend whose son has suffered a head injury a couple of years ago. She travelled a little bit of the road and she walks with me, as my sister would say. You need someone to walk with you at times. (P12)

Data analysis identified that a participant who had no key support people also lacked the social support of friends. Therefore, this participant had no one to share her experiences with, no one to give her support and/or advice, and no one to be there for her when she needed help:
Well I shed friends over the years I just shed them on purpose. Not so much actively push them away but I could not cope, it was too much of a disruption. When the kids were little we had people drop in all the time. It was a distraction from staying on top of what is going on, you turn your head [socialising with friends] and my, the shit had hit the fan [the affected family member would destroy things]. In addition, the sort of comments that you get about environment versus heredity [participant felt she was blamed for her daughter’s illness by her friends]. I never made an attempt to have contact with other parents [having similar problems]. I kept from getting involved. (P20)

Several participants spoke of the social support provided to them by their neighbours. These participants, unlike others in this study, did not experience any stigma from their neighbours. In particular, these participants found young people, who were their neighbours, to be tolerant and supportive of the affected family member. Participants explained that these young people were willing to help them and were readily available when they were needed. This support was helpful to participants as these neighbours also interacted with the affected family member and, therefore, facilitated the family member’s integration into the larger community: "I find that young kids and teenagers tend to take it [knowing neighbour has a mental disorder] very well. It is the older people that generally do not take it so well" (P16); "I had a very good neighbour across the road but they didn’t come and do my work for me or anything. They were just there" (P11, multiple carer); "We lived in a professional area and the people were very good [accepting of husband’s illness]" (P25).

Another participant had not experienced any stigma from friends or neighbours and consequently believed that some people may perceive, rather than directly experience, stigma. He described his neighbours as very supportive and willing to help him. He lived in a middle-class, mostly professional area and believed that this may have been a factor in the level of tolerance and acceptance he and his affected family member experienced:

Oh the neighbours are good, very supportive: When Sky [sister-in-law] went missing they kept an eye out and told us where she was. Yes, generally, I think people believe there is more of a stigma involved [than there is in reality]. Maybe it is the area [suburb] we are [live] in. Maybe there is more of a perceived stigma [by the affected person and/or the family] about mental illness than there actually is. (P8)

Similarly, Vannicelli, Washburn and Sheff (1980) found that religion and social class were two demographic variables that influenced people’s attitude towards people who have a mental disorder. However, for some participants in this study, experiencing stigma from friends and neighbours was a reality that posed a sustained threat to self-equilibrium (as described in 4.3.3.2: Grief and loss of “normal” family life). In seeking balance, one
participant preferred to tell people that the affected family member had a mental disability rather than a mental illness. She found that telling her neighbours that her daughter had a mental disability was more acceptable to them and she believed this strategy produced more desirable outcomes for her daughter and for herself. She explained that it allowed her daughter to be more readily accepted by people she brought into the home:

My friends, people who don't know Zoe [daughter] talk to her for four or five minutes and they work out there is something wrong. The information just doesn't go in, she doesn't talk and her face is not as animated; it is obvious. I tell people she has a mental disability. I don't tell them that she has a mental illness. As soon as you use the word illness, they think "that it is germs or they think she is crazy because mental illness is another word for crazy". Whereas if I tell them she has a mental disability they go "Oh really!". Then they kind of expect that she is not going to be quite right. That works a lot better. In fact I really would like to see them change that [the word mental illness]. That is not say mental illness anymore because it is not an illness. It isn't caused by germs or if it was caused by a virus which they now think that it may be because we have got the genetics of it, the virus might have been there when she was in the womb. (P6)

Karp and Watts-Roy (1999) also reported that relationships between carers and neighbours were often more positive when neighbours viewed the affected family member's illness as biological in origin. This perception of the cause of the illness resulted in the carer being largely absolved from the assumption they may have in some way caused the problem in the family member.

In summary, the social support given by friends and neighbours especially young people was helpful to some participants, with the support being highly valued by them. Friends who had similar experiences or who listened and never criticised were identified as particularly helpful to participants and their support and availability, influenced participants' movement towards seeking balance in their lives. However, not all participants experienced support from neighbours and friends, and this negatively influenced participants' experience of seeking balance in their lives.

7.3.3: Social support provided by community organisations

Carer associations were another source of support for participants. The following participant spoke of the support provided to both himself and other members of his family by community organisations such as ARAFMI: "It was only when I came to ARAFMI and I had support for myself that I realised they could support the kids [children] too. They have a youth service too" (P7). The congeniality and support provided by these community groups
helped participants realise that other carers had been able to move forward in seeking balance in their lives. This knowledge provided participants with hope that they also could achieve this in their own lives: "ARAFMI [carer’s group] became my surrogate family. It is very, very special" (P3); "I did go to a group [carers’ group] and that was good. I met a lot of people and I felt that I was not alone" (P17). Another participant provided this account of the support she received from attending ARAFMI:

ARAFMI made me realise that I wasn’t alone. ... Every carer should be put onto ARAFMI straight away as soon as it [family member is diagnosed with a mental disorder] happens. If I had ARAFMI to ring up when I was really distressed it would have been good. ... They tell you to do a lot of research. (P6)

Participants explained that listening to other people’s life stories helped them to reflect on their experiences and to look at their situation differently:

I did [go to ARAFMI] on a couple of occasions Dianne. I just found that you go down there and they just talk over your problems again. It makes you think and look at things differently. It was comforting to know that you are not the only one going through it, that you are not alone. (P13)

Participants also received education on mental disorders when they attended community support groups and this information was helpful. Participants found the newsletters produced by these community organisations containing segments written by other carers particularly valuable:

ARAFMI have carer’s writing in their newsletters. They have the consumer or client themselves writing in. They have a library, a resource library, where you can borrow books. There are pamphlets on all the illnesses and what is happening in mental health from the Government. They tell you how to be proactive about getting services and that type of thing. They have all the consumer information you need to do with the mental health area. (P1, child/adult carer)

Other researchers have previously identified the importance of support groups. These researchers have found that carers feel supported when they meet other carers (Rose, 1998) and are able to share their caregiving experiences (Chapman, 1997; Hatfield, 1997). Furthermore, carers frequently use support because of the lack of formal mental health services for them (Porter-Smith, 2001; Liberman, 1986).

Several participants in this study told how they only found out about carer organisations in the community by chance: "It was not until last year that I found out about the carer’s association. I did not feel like I needed it. However, I do now, I feel like I want to reach out now and they have been very helpful" (P23). However, not all participants in this
study found that carer groups provided them with valuable ongoing support. The following participant believed that support groups were most useful to new carers and were not helpful to her:

I found support groups are most useful for those who had recently found their child diagnosed. They are at the beginning of this long road. I have now been on this road for years and years and ended up being the supporter rather than the supported. I was so much further along than them [new carers]... They [carers] have these coffee sessions where everyone sits around and bitches [explain how bad things are]. I thought this is not my idea of a cure. I am not needing to share. (P20)

In summary, the support provided by community organisations was helpful to many participants in this study, as well as other members of their family. Participants found the personal experience of other carers was particularly useful to them in seeking balance in their lives.

7.3.4: Relationship with the affected family member

The last aspect of social support that influenced participants' experience of seeking balance was their relationship with the affected family member. Those participants who had a good relationship with the affected family member found this helpful when seeking balance. Many of these participants believed that their relationship with the affected family member was stronger as a result of the experience they had both been through: "I can talk to Zoe [daughter] and help her make sense of things" (P6); "It [wife’s depression] has made us stronger in our relationship" (P7). One participant explained that she had become her son’s main anchor, as she was an ongoing stable factor in his life:

I am Aaron’s anchor. He keeps coming back to me. I am the one he has to talk to. He keeps saying I am the only one that hasn’t given up on him. He uses me like a sounding board. Things like "Is this real? Do you see this?". So I guess that he dumps a lot of his emotional baggage on me. I sort it out and give it back sorted. It is like doing the washing. (P9)

Another participant provided a similar picture of her relationship with her daughter. The participant explained that her daughter spent a lot of time just talking with her:

I tend to be the person who worries about June [daughter]. Everyone else does not seem to worry too much. I am there for her all of the time. She tends to ring me and talk to me. Lately it is someone she can talk to and be an ordinary person. She likes to have a cup of tea with me and talk to me. I don’t know really what I am she just likes to talk to me. (P16)
Finally, a good relationship with the affected family member was helpful to participants in seeking balance in their lives as it helped to develop trust between them. This trust enabled participants to encourage their family member, when they were ill, to seek treatment from health professionals, to follow the planned treatment routines, and to discuss problems they were having. The relationship between participants and the affected family member helped to keep the family member well and helped the person’s integration into the community. This integration was beneficial to participants as it allowed them to make their caregiving role proportionate to other areas of their lives:

We [daughter and participant] came to an agreement that we would talk about it, when she goes a bit high [manic]. However when she gets high she doesn’t really want to and she knows what is going to happen. We just want to make sure that she does not get really bad and can be maintained on a CTO [community treatment orders] and that she does not have to go to hospital. So we encourage her to seek treatment early, our relationship with her helps. (P16)

When another participant observed that her husband was becoming unwell, she was able to discuss her observations with him because he trusted her. This made it much easier for the participant to encourage her husband to seek help when he required it:

I think when things start getting out of hand [husband is becoming unwell] Harry [husband] can see things and I can talk to him. He will usually recognise things as well. We have been married so long and I have stuck it out with him, I have stood by him, he has built that trust in me. So now he can sort of recognise there is a little bit of sense in what I am saying. He is also building trust in the psychiatrist now and so he is actually building a little bit more in himself also. He trusts me and he is trusting professionals more. (P14)

Greenberg, Kim and Greenley (1997b) also found the carer’s relationship with the affected family member a factor in the level of burden carers experienced. Similarly, Baxter and Diehl (1998) reported that a good relationship between the carer and affected family member influenced the course of the affected family member’s illness. In summary, participants’ level of social support was a condition that influenced their experience of seeking balance. Participants particularly valued the support given to them by their spouse, mother, and/or mother-in-law. The support given by friends, neighbours, and community organisations was also important to participants. Finally, participants valued a good relationship with the affected family member.
7.4: Participants’ perceived level of well being

Participants’ perceived level of well being was the third condition identified as influencing their experience of seeking balance. In the context of this study, participants’ perceived level of well being was defined as a general measure of their mental and physical health at any given time, their psychological morbidity, and/or their level of life strain or distress. These measures were not directly attributed to the presence of the affected family member, but to the participants’ overall life situation. To demonstrate the importance of participants’ perceived level of well being to their experience of seeking balance, two participants who represented opposing ends on a theoretical well being continuum were identified from the data. The first participant, who demonstrated a high level of well being, had a husband who was diagnosed with a bipolar disorder. The participant and her husband had been married for eight years and they had four children all below seven years of age. The participant’s mother and brother both had schizophrenia. Therefore, the participant had experience with, and prior knowledge of, mental disorders before she began caring for her husband. In her interview with me (husband was present throughout the interview) this participant explained that she had a busy life, spent quality time with her family, played an active life in her community, was very religious, had a variety of avenues of support available to her, possessed effective established coping skills, and had good supportive friends. The participant acknowledged that her family unit was very successful and she claimed that her friends often had more problems in life than she did. The data indicated that the participant’s perceived level of well being had a direct influence on her movement towards seeking balance. At the time of being interviewed the participant was entering the third phase of the process of seeking balance. She was reaching out to help other people who were experiencing problems because she had attained a degree of mastery and control over her caregiving experience:

I didn’t get married until I was 36 and I have had enough time on my own. I prefer to do things as a family. ... We are also involved in many people’s lives. This may sound a bit ridiculous but I actually find that our friends quite often now have more problems than us. So we are often involved in people’s lives that are struggling, you know. You know when people find that you are coping so well they sort of start sharing their problems with you, you can’t help it. There are different times when we have different people that come into our lives that we help. (P14)

The second participant, at the opposite end of the theoretical well being continuum, was identified as having major changes in her mental and physical health, psychological
morbidity, and/or level of life strain or distress. At the time of being interviewed the participant had chosen not to have daily contact with her daughter (affected family member) who for the past few months had lived in a hostel. The participant lived with her son. She was socially isolated, unemployed, divorced, financially challenged, and had several major health problems (depression and diabetes). The participant expressed a negative view of her future and she could not see how her life was going to change. This extract from the interview with the participant demonstrated that she was still clearly experiencing feelings of being consumed by what had happened to her:

I could go out now if I wanted to, I can go anywhere, anytime. However, I don’t have anything I want to do. I have all the freedom in the world. I used to crave for this and now that I have it, where would I want to go? ... I have got to find some goal or desire in life. I have got to get a job. ... It got to the point where I would go to bed at night and pray that I don’t wake up in the morning. "Let me die quietly in my sleep, I don’t want to keep on living, let me go quietly, I don’t want to go on living, this is a punishment, let me out. I don’t care if there is another life or nothingness, I don’t care, I have had it". ... Now I just, it feels like it is too late. I do not have the energy anymore it is too late. I don’t care, I don’t care, [the phrase the participant said to help her cope] I don’t care has worked I don’t care. ... I discovered two months ago that I had diabetes and I have probably had it for a couple of years. One of the things that diabetes causes is lethargy and it has an effect on your mood. It could have contributed to my mental lassitude. Just feeling so weary with life. Maybe as my medication gets it under control, that will change. It has added a whole new spin to the game. You know all these feelings that I have been attributing to that [daughter’s behaviour] may be due to this [diabetes]. (P20)

The early research surrounding the origin and effects of stress completed by Noh and Turner (1987) found that socially induced stress, such as that experienced by participant 20, impacted significantly on an individual’s perceived level of well being. These authors claim that socially induced stress can result from either the occurrence of discrete events or from the presence of continuous problems as described by participant 20. Pearl and Schooler as early as 1987 (cited in Noh & Turner, 1987) referred to these continuous problems as life strains. According to Pearl and Schooler "events do not necessarily impact on people directly, but may, instead, exert their effects through a wider context of life strains" (p.264). Hence, eventful experiences tend to be stressful for the individual because they intensify existing distress or create new distress. Around the same time, work by Paykel (1978) supported Pearl and Schooler’s claims while emphasising the relevance of life strain to an individual’s level of vulnerability. The author claimed, "the event must be regarded as interacting with the host of other factors in determining whether the outcome is an illness, and which specific
illness. It is not merely the event but the soil on which it falls" (1978, p. 251). More recently, Greenberg et al (1997a) in their study of carers, identified that stressful factors other than those resulting from the affected family member’s illness, for example, the death of a family member, being unemployed outside the home, being unmarried, poor physical health, and being a women place the carer at risk of experiencing distress. In support of the findings of this study these authors also found these life stressors (or carer’s perceived level of well being) may have a stronger relationship to psychological distress in carers than the more frequently referred to indicators of objective and subjective burden. Therefore, these authors assert that by only focusing on stressors associated with the affected family member’s mental disorder, researchers fail to capture the full-range of stressors that influence the psychological well being of caregivers.

The remaining participants in this study described events in their lives that placed them between participants 14 and 20 on the theoretical well being continuum. The death of family members was one life issue that affected several participants’ perceived level of well being because it lessened their ability to cope with other issues occurring in their lives. One participant spoke of her distress when her father died. However, she had a very supportive husband who encouraged her to stay with her mother and grieve the loss of her father while he cared for their daughter (affected family member). When she was ready she joined her husband and daughter in the country and re-established her caregiving role: "I had lost my father. I stayed here [in Perth] a couple of weeks with mum and then I felt that it was time I went down [to the country] and joined Craig [husband] and Jill [daughter who was unwell]" (P10).

Other participants had family members who were experiencing health and/or other personal problems and these problems also impacted on participants’ perceived level of well being. Although the following participants husband was very supportive to both her and her son, he had several serious health problems. His failing health meant that he was no longer able to provide the participant with the level of support he had previously given. As such, her well being was affected by her concern for his well being:

James [husband] has been in hospital six times in the last sixteen months with different things. He has cancer of the prostrate and he goes in [to hospital] tomorrow for bi-lateral hernia [reduction]. He has something to do [wrong] with his bladder also I am not sure what that is. (P3)
Another participant explained that she was distressed because her husband had both physical and financial problems, all of which impacted on both her and her affected family member’s level of well being. These problems were an ongoing worry for the participant. Furthermore, her youngest daughter was in her final years of high school, a notoriously stressful time for most families:

My husband had a lot of financial trouble and I thought that his business was going to collapse. It was a constant worry for us. Then he got gall bladder trouble and he had a gall bladder operation. ... My second daughter who is now 17 years of age was in Year 11, it was a very stressful time for everyone [second last year of high school]. (P6)

Events such as separation, the divorce process, or other life changes also influenced participants’ perceived level of well being. For some participants, the divorce process was particularly distressing and consuming of their time, energy, finances, and emotions. In turn, this impacted on their ability to cope with other aspects of their lives: "To get our divorce, it was so difficult. Lawyers say you have got to have it all checked. It was getting that I didn’t want any of it [money from the settlement of the divorce]. It is just awful" (P18); "I am just starting out on a new life after 33 years of marriage" (P12). For another participant, the separation from her partner caused her financial, as well as personal, distress and this impacted on her level of well being:

I said "you [partner] have finished putting me, and my son down". So I walked out of that relationship with not a penny to my name. I eventually made him buy me out [participant’s share of the house]. My sister said "don’t be so silly that is your life savings. That is what you and Peter [previous husband] had together. You are not letting him have that". So of course when you go into a relationship you never get back what you fully put in but that is over and done with now, that time of life. It was just another impact. (P13, multiple carer)

Another life event that affected some participants’ perceived level of well being was when emotional, relationship, or behavioural problems developed in other family members as a result of growing up with the affected family member. Participants then began to worry about other family members and as a result some old feelings of guilt and self-blame were rekindled: "The older boy [participant’s other son] he has had therapy and he still is having it. ... His marriage of five years broke up last year" (P11, multiple carer). Another participant gave this account of how her other daughter developed emotional problems as a result of her childhood experiences of growing up with a sister with a mental disorder:
Natalie [other daughter] needed counselling. She sort of rushed into marriage and had a baby. He was a nice young man she married but it did not work out. He now lives overseas he is an engineer. That poor lass, [girl] had to grow up the hard way. (P15)

In summary, two participants who represented opposing ends of the well being continuum were identified from the data. The remaining participants experienced perceived levels of well being that placed them between these two participants on the continuum. Life events that caused distress in participants were: the death of a relative, other family member’s physical or financial problems, divorce and separation, and mental health, relationship, or behavioural problems in other members of the family. These life events impacted on the participants’ perceived level of well being, on their ability to cope and, therefore, affected participants’ movement towards seeking balance in their lives.

7.5: Availability and support of health professionals

The data identified the availability and support of health professionals as the fourth and final condition influencing participants’ movement towards seeking balance in their lives. Four of the six conditions that had influenced participants’ experience of being consumed were related to their interactions with health professionals. These conditions were: communication with health professionals, mobility of health professionals, health professionals’ management strategies, and the type and quality of emergency services provided. In seeking balance, participants developed strategies to 1) influence the outcomes of their communication with health professionals, 2) lessen the effect on them associated with the mobility of health professionals, 3) manage the impact of management strategies health professionals used, and 4) better manage crisis or emergency situations involving the affected family member.

Some participants reported that they had excellent availability and support of health professionals, and this person was usually the affected family member’s case manager. The following participant spoke of the importance of her relationship with her two sons’ case manager:

Lance [son] has been under the care of a community carer who is also looking after Josh [other son]. He is a fabulous guy. He has been the case manager for five or six years, he is fabulous. He and Lance click [get on very well] and they are very close. He listens to me, he is very, very good. (P13, multiple carer)
Two multiple carers reported that the availability and support of health professionals had improved since the time when the two participants first began to care for the affected family members approximately 20 years ago: "The attitude to carers being part of the person with the illness’ life is changing and that is a good thing. That has changed even in the last two to three years. That is a lot more helpful to us as carers" (P11, multiple carer). The other multiple carer explained that she believed health professionals now involved the carer in what was happening and they did not discard carers as had been her previous experience. The availability and support of health professionals helped the participant in her movement towards balance in her life:

They [health professionals] tend now to involve the person who is closest to the patient. Before they tended to put you down, push you aside. What you had to say was not important. Now that seems to be much better. In fact when Lance [second son to develop a mental disorder] got sick, it was the first time a doctor has ever said to me “what do you think is wrong with your son?” (P13, multiple carer)

Similarly Grella and Gusky (1989), Hatfield et al, (1996); and Rose (1998) highlighted the importance of case managers or primary nurses to carers. These authors reported that these key health professionals contributed more to carers’ level of satisfaction than any other service provided by the formal mental health system. Participants in Rose’s (1998) study of professional family interactions described that family members felt particularly supported when the primary nurse took time to discuss the meaning of the affected family member’s abnormal behaviours and provided the carer with information on medication issues.

The importance of the availability and support of health professionals to carers when the affected family member was hospitalised was highlighted by a participant from Jeon and Madjar’s (1998) study on caregivers to people who have a chronic mental illness:

There was a very good nursing sister ... who was excellent with him and with me. She just said, "Well, just keep coming, just letting him know that you’re there". Then she said, "I know, it’s hard for now, turning his back on you, walking away when you go to hospital" ... "But," she said to me, "just keep coming because he needs to know that you, you’re still there, even though he doesn’t want to see you, he’s very hurt and angry". (p. 703)

While some participants in this study described the level of availability and support provided by health professionals was helpful to them in seeking balance, the majority of participants did not hold this view. A large number of participants voiced concern regarding the lack of availability and support of health professionals when participants first
experienced *being consumed*, thus inhibiting the process of *seeking balance*. This was during the time when their family member's behaviour first became pronounced and when the recognition that *something was wrong* first developed. These participants were particularly critical of the *availability and support of health professionals*, for example, school counsellors and/or psychologists. Participants believed that these professionals did not recognise and/or acknowledge the severity of the affected family member's abnormal behaviour or the impact on participants. These participants claimed that this group of health professionals used flippant comments about the affected family member, which affected participants' experience of *seeking balance*. Several participants were advised by this group of health professionals to take the affected family member out of school and place them in the workforce as a solution to the problem. When a diagnosis of mental disorder was finally made on the affected family member, participants were relieved that they had not followed the advice given to them by these professionals:

Well relief was the first thing we felt [regarding daughter's diagnosis]. Somebody had finally realised that something was wrong. We had been trying to get help from counsellors at June's school for so long. We were relieved that finally June [daughter] would get some attention and the help she needed. We also knew that we had not been silly for thinking there was more than just adolescence. (P16)

Another participant had a similar experience and commented on the lack of support given to her by health professionals working at her son's school. She was particularly concerned that other teenagers with similar problems were not being adequately assessed and supported by the educational system. In addition, the participant believed that health professionals working in schools were not supportive to parents and this affected her experience of *seeking balance*:

The things I would change if I could, would be with the high school. They [teachers, school counsellors] had no idea what I was talking about [that she believed her son could have a mental disorder]. They had no idea that Aaron [son] was totally submerged in Dungeons and Dragons to the point where he didn't tell what was Dungeons and Dragons and what was day-to-day reality. The fact that he was withdrawn and those sorts of things, it should have raised some flags [awareness in professionals that something was wrong]. If I had of known what I now know, it would have raised some flags with me. I hate to think there are other sixteen-year-olds out there who may need help and aren't getting it. (P9)

Participants explained that throughout the caregiving experience their perception of the *availability and support of health professionals* was influenced by various health professional's communication style. Some participants recounted health professionals using a
very condescending communication style which was not engaging or supportive. These participants explained that education of health professionals was urgently needed to address how health professionals spoke to and supported carers:

I think it [education of health professionals] needs to be an ongoing thing and updated. ... In general, the nursing staff seem fairly understanding. I wouldn’t say sympathetic and I have had to deal with a few that are quite condescending. The surest way to get on his [son’s] wrong side is to talk to him like a baby. A few [health professionals] have been known to do that "you just sit down there and don’t worry about it. We will take care of it for you, be a good boy". (P9)

Another participant gave a similar account of health professionals using a condescending communication style with her:

This psychiatrist when I was walking out he said, "you have done a good job and it is a hard job". I felt he was condescending and he put me down. It was the wrong time to say that to me. It was like a procedure he had to follow. It didn’t mean anything. (P12)

Budd and Hughes (1997) and Mound, Gyulay, Khan and Goering (1991) found that carers’ perceived level of support from health professionals was influenced by the personal qualities displayed by the health professional. These authors reported that carers felt very supported when health professionals used communication styles that demonstrated warmth and empathy, sensitivity, patience, and creativity. Similarly, Kruijver, Kerksstra, Bensing and van de Wiel (2000), in their study of nurses’ communication styles with simulated cancer patients, identified the importance to patients of health professionals using supportive and engaging communication styles.

Participants in this study also explained that they perceived health professionals as being unsupportive because they made assumptions about the participant’s capacity to understand treatment issues. Because of these assumptions, health professionals did not inform participants about what was happening:

The assumption [by health professionals] is that you either will or won’t understand what they are trying to tell you. I think that medical staff work on the assumption that carer’s become so emotionally involved they can’t have things explained to them. ... When they are continually not talking, you tend to collect a lot of incorrect information. (P9)

A participant from Rose’s (1997) study on caregivers’ perceptions of social support gave a similar account regarding the assumptions health professionals make about carers: "psychiatrists have difficulty believing a layman could understand what they are doing" (p. 20). According to Cason and Manchershaw (1992), providing information and support to
carers should be an integral part of community mental health care as research has shown that when this support is present the level of caregiver burden decreases significantly (Greenberg et al, 1997a; Hardwick, 2001; Rose, 1997). Furthermore, Mohr (2000) claimed that as families of people with a serious mental illness play a key role in sustaining gains made in therapy, it is crucial that carers be supported and involved in treatment programs. However, despite the theoretical and practical rationales for family inclusion in treatment, participants in Mohr’s study of professional attitudes in the clinical setting reported that, in reality, they were not involved: "I [mother] had no rights. ... I never saw a treatment plan. ... No one would talk to me. No one had time to. [This last sentence was said with sarcasm.]" (p. 602).

In this study, participants explained the required availability and support of health professionals took many forms. Throughout the caregiving experience, participants were looking for different types of availability and support from health professionals. The following participant wanted health professionals to help her to develop better coping strategies. Furthermore, she wanted one identified health professional that she could contact:

I am looking for different answers at different times. It would be useful to talk to somebody [a health professional]. If I had to put a title on that person it would be possibly a social worker or a psychologist. I don’t know exactly what they are because I have never had to deal in this arena before. Somebody that could teach me better coping strategies for myself because when I am down, I can’t help Aaron [son]. Quite often, it [when participant is down] will also bring him [son] down. So I have to be strong otherwise I take both of us [down] and sometimes you can’t be strong. There are times when I feel I need to talk to somebody about those things. How do I hold myself up? Should I have to deal with this problem? Am I just being silly or is this the start of something else? It is that need for reassurance and acceptance. (P9)

Participants also sought emotional support and counselling from health professionals: "Some counselling for the carer would be good. If maybe it is someone who is just sitting and letting you talk, like you are doing now [during interview for data collection]" (P13, multiple carer). Morris and Thomas (2001) found that carers also wanted services for themselves. Participants in their study of carers of cancer patients "expressed their own need to have someone to talk to, some counselling, or a meeting separate from the patient in which they could discuss the implications of the illness" (p. 94). Not knowing who might provide this support was another problem identified by participants in Morris and Thomas' study: "When it comes to the emotional side, if you did need help you wouldn’t know where to go, I wouldn’t know where to go. I mean there’s counselling, ... but how do you access them." (p. 94).
Participants in this study spoke of requiring support from health professionals in the form of education to provide them with a greater understanding of what was happening to the affected family member: "There is a fine line between what you are trying to achieve [as a carer] and you always have to be conscious all of the time. Having support from professionals is essential in managing these dilemmas" (P8).

Greenberg et al (1997a) found that while carers had a pressing need for education and understanding of the affected family member’s illness, health professionals often failed to provide the level of education and understanding carers required. Solomon et al (1998) found that caregivers wanted more education and understanding of how to cope with illness behaviours such as behaviour management, medication monitoring and how to talk to other family members about their relative’s illness. Harvey (2001) questioned whether the formal support currently provided by health professionals actually benefited carers, as the support provided through current carer education programs was conceptually rooted in educating families about the notion of expressed emotion, and consequently, was focused on patient rather than carer outcomes.

Participants in this study spoke of support from health professionals in the form of recognition of their caregiving role. This recognition was particularly important to participants’ experience of seeking balance, as the following participant described: "It would be very helpful if someone [health professional] said 'you are doing a good job' instead of this very clinical 'yes, well now I have done that and that'" (P21). Similarly Norbeck, et al (1991) and Rose (1997) found that caregivers needed affirmation that they were doing a good job and that they felt valued by mental health professionals.

While participants in this study had developed strategies that facilitated access to the affected family member’s doctor, they explained that the available consultation time was so limited that very little progress was usually achieved. In reality, appointments with the doctor did not include time for giving support to carers although providing support was spoken of by doctors as an important part of a multi-modal (physical, psychological, and behavioural) approach to service delivery. One participant described that while her daughter’s doctor advocated a multi-modal approach, he only provided limited access to patients and never offered her any support. She was concerned by the apparent hypocrisy in doctors presenting papers espousing the importance of providing multi-modal approaches, yet not providing practical applications of these models:
In those five or ten minutes [appointment with specialist doctor] I would try to, with notes, get across how bad things were. I would just give them the highlights about how dreadful things were. Yet on hearing this, what we were going through, they would write us a script and say "goodbye". How can these doctors do this? They must know our situation. They must know our needs. They must know the attention deficit disorder (ADD) world in Perth. They must know organisations that have anything to do with ADD. They must know the services that are provided. Why don’t they help us? Why don’t they tell us where to go for help? It is the same thing, getting rid of you, processing you. These are the top doctors in Perth. They go to seminars and talk about the multi-modal approach, yet they never use the multi-modal approach. At the seminar they would criticise the doctor who saw you for ten minutes every few months and gave you a script, yet they do the same thing. (P20)

Participants also spoke of health professionals not understanding what participants had to cope with on a daily basis. Participants explained that they felt unsupported by health professionals when they were distressed as a result of other life issues, for example, disputes with neighbours. One participant had been embroiled in an ongoing, sometimes explosive, dispute with a neighbour for several years. The psychiatrist treating her husband, who had depression, continually blamed the participant for making her husband’s condition worse through her continuing her quest for compensation against her neighbour. The psychiatrist regularly demanded the participant cease the legal action against the neighbour. For the participant this was very distressing as she was financially dependent on the outcome of the court case:

I felt that he [psychiatrist treating husband] blamed me [for husband’s depression] because we have had an ongoing problem with the neighbour next door since we built our house. This is an ongoing dispute [over a vacant block between the two houses] and it gets us down. ... The doctor says I have got to forget about it. He blamed me that it was my fault and that Barry [husband] was worried about me. That was the hard part [caused the most distress]. ... I can not give this up [court case] as we would lose a lot of money. I was upset the doctor could not see what I see. I was upset that he could not see it from my point of view. (P24)

In summary, the availability and support of health professionals was a condition that influenced the basic social psychological process seeking balance. Some participants had very supportive health professionals, however, the majority of participants reported that health professionals displayed little knowledge and understanding of the experience of being a carer, and this limited the value of support provided.
7.6: Summary

Four conditions were identified as influencing participants' experience of seeking balance, and the first condition was participants' prior exposure to, knowledge of or experience with mental disorders. Eight participants who had this experience believed this was helpful to them and facilitated their movement towards seeking balance. The second condition was participants' level of social support. Support was accessed in many ways: from key family members, from neighbours and friends and from community organisations. In addition, participants' relationship with the affected family member was also important to their experience of seeking balance. The third condition was participants' perceived level of well being, that is, participants' perceived mental and physical health, their psychological morbidity, and/or their level of life strain or distress. The fourth condition was the availability of and support from health professionals. This was particularly important to participants in the movement towards seeking balance in their lives as four of the six conditions that had influenced participants' experience of being consumed were related to their interactions with health professionals.

In examining how these four conditions influenced participants' experience of seeking balance, it is important to recognise that at the time of being interviewed not all participants had reached the final phase of the core and sub-process, seeking balance. A further comparison between participant 14 and participant 20 is provided to demonstrate this point. Participant 14 had moved to phase three of the core and sub-process and was experiencing a degree of balance in her life that allowed her caregiving role to be proportionate to other areas of her life. When examining how the four conditions influenced her experience of seeking balance, the data revealed that she had high perceived level of well being, she possessed prior knowledge and understanding of mental disorders and she had many avenues of support available to her in her daily life. She had a strong relationship with her husband (the affected family member). In addition, she had learnt skills that were helpful to her in accessing professional help when she required it. In contrast, participant 20, on the other end of the continuum, was still experiencing feelings of being consumed. This participant was "multi-disadvantaged", she was divorced, unemployed, financially challenged, socially isolated, with limited support, and she had several health problems. She had no prior exposure to, knowledge of, or experience with mental disorders and felt unsupported by health professionals. In addition, she had what she described as "carer burnout". The impact of the four influencing conditions on this participant's ability to seek balance in her life meant that,
at the time of being interviewed for this study, she was still in phases one of the core and sub-process of seeking balance and unable to advance further in the process.

The substantive theory of seeking balance to overcome being consumed presented in the last four chapters of this thesis will now be further discussed in relation to pertinent scientific literature in part four of this thesis.
PART FOUR

DISCUSSION AND CONCLUSION

CHAPTER 8
THE SUBSTANTIVE THEORY OF SEEING BALANCE TO
OVERCOME BEING CONSUMED

CHAPTER 9
IMPLICATIONS AND CONCLUSION
CHAPTER 8

THE SUBSTANTIVE THEORY OF
SEEKING BALANCE TO OVERCOME BEING CONSUMED

8.1: Introduction

The final objective of this study is to present the substantive theory of seeking balance to overcome being consumed and place the substantive theory in the context of relevant scientific literature. Although pertinent literature findings have been presented throughout the results section of this thesis, this chapter further addresses that research objective. Major theories and research findings pertaining to the substantive theory will then be detailed. These include Grad and Sainsbury’s (1963) burden of care, Lazarus and Folkman’s (1984) theory of stress and coping (1966), Caplan’s (1981) mastery of stress theory, Egan’s (1990) skilled helper model, and several recent studies on caregiving. Finally, a discussion on professional caring, family caring, and working collaboratively with carers will be presented.

8.2: The substantive theory of seeking balance to overcome being consumed

An assumption underlying grounded theory methodology is that participants experiencing the phenomenon being studied share a basic social psychological problem or a central issue of concern. The shared problem may not be articulated as such by participants but the problem is addressed through their engagement in a basic social psychological process. The substantive theory of seeking balance to overcome being consumed involved a process entitled seeking balance that participants engaged in to manage a problem of being consumed. Participants’ movement through the phases of the basic social psychological process was not related to the length of their caregiving experience but to their experience of seeking balance and the conditions influencing that experience.

The first stage of the two-stage problem of being consumed was entitled disruption of established lifestyle. This stage began for participants when the affected family member’s abnormal behaviours first became pronounced, and continued until the person was diagnosed with having a mental disorder. When the affected family member was finally diagnosed with a mental disorder, participants entered the second (and final) stage of the basic social psychological problem, called sustained threat to self-equilibrium. Prior to becoming a primary carer, the majority of participants had no prior knowledge of, exposure
to, or experience with mental disorders. As a result, participants were unprepared for the caregiving role and experienced feelings of *being consumed* by what was happening to them.

Participants’ experience of *being consumed* began when the affected family member’s abnormal behaviour became pronounced and participants’ developed the recognition that *something was wrong* with them. Participants noticed warning signs in the affected family member along with an increasing disturbance to the family’s established pattern of life. The recognition that *something was wrong* led to participants’ preoccupation with not knowing what was wrong. Some participants experienced feelings of self-blame and believed that they were responsible for the disturbing change in the affected family member’s behaviour. Other participants began to question whether the affected family member had a mental disorder. The affected family member’s escalating abnormal behaviour along with participants’ ongoing enroilment in crisis situations was at times overwhelming for them.

When the affected family member was diagnosed with a mental disorder most participants’ expressed relief that at last they knew what was wrong. However, participants now had to make a commitment to care for the family member, possibly, on a long-term basis. In addition, participants experienced feelings of grief and loss for their own as well as their family member’s future life goals and dreams. Moreover, participants recounted a personal cost of caring for their family member.

Participants’ lives were changed as a result of their commitment to care. Until they developed the recognition that *something was wrong* with the affected family member, their perspective on life was influenced by their experiences up to that time. This included their aspirations, life goals, and dreams that they held for others, as well as for themselves. For most participants their life was, to a large degree, in balance and they lived each day with a reasonable sense of continuity and equilibrium.

Participants’ commitment to care for their family member impacted on their social life and on their ability to bring friends into their home. Furthermore, participants experienced stigma by association from friends and neighbours and this further increased their feelings of *being consumed*. Participants were no longer free to pursue their own life goals and dreams and their own needs now took second place to those of the affected family member. It was evident from the data that caring for a person with a mental disorder left participants with the experience of *being consumed*. 
Six conditions were identified as influencing participants’ experience of being consumed. The level of support provided by family members, friends, neighbours, support groups in the community, and from health professionals was one condition. Participants’ prior exposure to, knowledge of, or experience with mental disorders was another condition with only eight of the 27 participants having a prior knowledge of, exposure to, or experience with mental disorders. These eight participants found this helpful as they had previously sought help from mental health professionals and they had acquired some understanding of the treatment of mental disorders.

Participants’ communication with health professionals was the third condition influencing the experience of being consumed. While some participants reported that their communication with health professionals was helpful, the majority of participants spoke of it increasing their experience of being consumed. The mobility of health professionals was another condition that impacted on every aspect of participants’ lives. Participants had to continuously re-negotiate aspects of their caregiving role with each new health professional. The type and quality of emergency services was the next condition that influenced participants’ experience of being consumed. Some emergency services, for example, the police, were viewed as helpful. However, other emergency psychiatric services sometimes failed to provide the level of service participants expected and required and participants spoke of being left alone to care for the affected family member during times of crisis.

The last condition influencing participants’ experience of being consumed was health professionals’ management strategies. One of these strategies, health professionals’ application of the principles of patient confidentiality, was the management strategy reported by participants as most impacting on their experience of being consumed. Participants were refused access to health professionals treating the affected family member and were frequently not provided with information regarding the affected family member’s illness. This occurred even when participants perceived themselves as being “at risk” from the affected family member’s behaviours.

In an attempt to neutralise the experience of being consumed participants' engaged in a basic social psychological process entitled seeking balance. Seeking balance referred to a perceived or imagined view regarding participants’ future life. For participants, the process of seeking balance allowed them to search for, obtain, and try to maintain a state whereby their self-equilibrium, mental steadiness, and other aspects of their lives were increasingly more balanced, harmonious, and calm. In seeking balance, participants made adjustments that
resulted in their caregiving commitment to the affected family member being perceived as more proportional to other areas of their lives. As participants made adjustments to their lives they again experienced the freedom to pursue their own life goals and dreams.

The basic social psychological process of seeking balance was a three-phase process and these phases were: using personal strategies to reduce the problem of being consumed, restoring self-identity, and reaching out to make a difference. In addition, the data identified a sub-process of seeking balance called “trying to make sense of what was happening”. This sub-process also consisted of three phases and each of these phases was inter-related to the corresponding phase of the core process. The three phases of the sub-process were: seeking knowledge and understanding, making sense, and placing the experience into perspective.

The first phases of the core process and the sub-process occurred predominantly during the time when the affected family member’s abnormal behaviour first began to become pronounced. When participants developed the recognition that something was wrong with the affected family member they also became preoccupied with not knowing what was wrong. In an attempt to reduce their experience of being consumed, participants began utilising personal strategies to reduce the problem of being consumed. Participants used their established coping responses that had been helpful in the past when they had been faced with stressful situations. Furthermore, they began to use different trial and error approaches in the hope of finding a solution to their experience of being consumed. Several participants believed that they were in some way responsible for the affected family member’s behaviour and so they initiated trial and error approaches, for example, changing their established parenting style or seeking professional help for themselves. During the first phase of the sub-process, trying to make sense of what was happening, participants began to seek education and understanding about mental disorders. Several participants suspected that the affected family member had a mental disorder long before the diagnosis was made, and these participants began accessing information that would provide them with some knowledge and understanding about mental disorders.

The majority of participants, on discovering that the affected family member had a mental disorder, became engaged in the second phases of the core process and sub-process. The second phase of the core process was called restoring self-identity. In this phase, participants employed the further use of established coping responses in their movement towards seeking balance in their lives. These coping strategies were now employed to help participants to manage their emotional response to the affected family member’s illness. The
second aspect of this phase was called *regaining self-control* and participants began to review many of the issues that had increased their experience of *being consumed*, for example, feelings of guilt and/or self-blame. This review or introspection assisted participants to regain self-control as it facilitated resolution of many of the issues that had consumed them. In *regaining self-control*, participants’ perception of their own and the affected family member’s future were also re-evaluated. Participants began to step-back from always being there for the affected family member and this helped them to *regain self-control*.

The final aspect of this phase was called *taking control*. During this time, participants sought to strengthen and maintain their movement towards *seeking balance* in their lives by acquiring special skills that enabled them to care for the affected family member more effectively. In addition, they developed new strategies that provided them with a sense of mastery over their caregiving experience. The new strategies helped participants to more effectively manage the outcomes of future interactions with health professionals. The second phase of the sub-process, was called *making sense*. During this phase, participants gained a further sense of mastery over their caregiving role by increasing their knowledge and understanding of the affected family member’s specific mental disorder.

Participants entered the final phase of the core process, *reaching out to make a difference*, when they had attained a degree of control and mastery over their caregiving commitment, and they had achieved significant movement towards *seeking balance* in their lives. When this occurred participants experienced a need to reach out and help others and they began to use their knowledge and understanding about mental disorders and their experience of caregiving to help make it different for new, inexperienced carers. They provided this help to new carers either directly within the group situation or indirectly, for example, helping new carers to gain insight. It became important for participants to prevent new carers from having to experience the problem of *being consumed*. Although during the second phase participants had gained more control and mastery over their caregiving role, *reaching out to make a difference* further increased their level of self-esteem, self-equilibrium, and movement towards balance in their lives. During the third phase of the sub-process of *seeking balance*, participants began to *place the experience into perspective*. In doing so participants’ spoke of the positive outcomes of their caregiving experience and of becoming more tolerant, understanding, and compassionate people as a result of what they had been through.
At the time of being interviewed for this study, 16 participants had reached the third phases, ten were in the second phases, and one participant was engaged in the first phases of the basic social psychological process of seeking balance. Participants’ passage through the phases of seeking balance was not related to the length of time that they had been caring for the affected family member, but to the experience of seeking balance and the conditions influencing the experience.

Four conditions were identified as influencing the experience of seeking balance and they were: participants’ prior knowledge and understanding of mental disorders, participants’ level of support, participants’ level of well-being, and the availability and support of health professionals. Participants who had a prior knowledge and understanding of mental disorders found this helpful in seeking balance in their lives. They had some understanding of what the affected family member was going through, some experience of interacting with health professionals, and some experience in accessing the health care system. Furthermore, participants who were multiple carers reported that their prior experience of caring for a person with a mental disorder was helpful to their experience of seeking balance when they commenced caring for a second affected family member.

Participants’ level of support was another condition influencing the experience of seeking balance. Those participants who reported receiving high quality support spoke of how valuable the support was to them. Participants particularly valued the support given to them by their spouse, mother, or mother-in-law. The next condition influencing participants’ experience of seeking balance was participants’ perceived level of well being. In this study, well being was defined as a general measure of participants’ level of mental and physical health at any given time, their psychological morbidity, and/or their level of life strain or distress. These perceived levels were not directly attributed to the presence of the affected family member, but to the participants’ overall life situation. Participants who reported the highest perceived levels of well being had more success in seeking balance in their lives. The last condition influencing the experience of seeking balance was the availability and support of health professionals. Participants who received high-quality support from health professionals were more successful in their movement through the phases of seeking balance (See Figure 9).

By engaging in the process of seeking balance most participants moved from a state of being consumed to one where they began to seek, obtain, and maintain a more balanced perspective on life. This perspective was one where participants perceived their caregiving
Figure 9: THE SUBSTANTIVE THEORY OF SEEKING BALANCE TO OVERCOME BEING CONSUMED
role as being more proportionate to other aspects of their life. Most participants were
successfully able to obtain and maintain this more balanced life perspective. However, one
participant was, at the time of being interviewed for this study, still in the first phase of the
core process and sub-process. She remained consumed by what was happening to her. The
participant had no significant available supports, she was a single parent, divorced, and
unemployed, and she had several severe health problems. These issues impacted on her
experience of seeking balance and were influential in prolonging her experience of being
consumed.

In summary, the substantive theory of seeking balance to overcome being consumed
saw participants move from a state of being consumed and at times overwhelmed by their
caregiving experiences to a position where participants regained a sense of balance in their
lives. In seeking balance participants again started to pursue their life goals and dreams and
their caregiving commitment to the affected family member became proportionate to other
areas of their lives. The substantive theory of seeking balance to overcome being consumed
will now be compared with existing research findings and theories.

8.3: Comparison of the substantive theory of seeking balance to overcome being
consumed with other research findings and theories

The following discussion relates to similarities between the substantive theory,
seeking balance to overcome being consumed, and other relevant research findings and
theories. A literature search revealed that there was no theory that was identical to the
substantive theory but there were several theories in the literature that reflect important
components of the substantive theory. Firstly the founding literature on the burden of
caregiving will be compared with the substantive theory. The substantive theory will then be
compared with several qualitative research studies in the literature on the caregiver’s
experience of caring for a person with a mental disorder and other enduring illnesses. In
of stress theory and Egan’s skilled helper model will be compared to the substantive theory.
Finally, a discussion on caring in nursing, family caring, and working collaboratively with
carers will be presented.
8.3.1: Comparison of the substantive theory with the founding literature on caregiving

The substantive theory of seeking balance to overcome being consumed will now be compared with the founding literature on caregiving to a person with a mental disorder. Clausen and Yarrow (1955a) in their classic two-year study on mental illness and the family first identified the stress experienced by families when one family member had a mental disorder. In 1963, Grad and Sainsbury completed a one-year study to identify the impact of caregiving on families (Grad & Sainsbury, 1963). The study focused on two areas: 1) the impact of the affected family member's abnormal behaviours on the family in the time prior to when a diagnosis of a mental disorder was made, and 2) a comparison of the burden experienced by families in a community care service versus a hospital service. Hoenig and Hamilton (1966) further differentiated between the subjective and objective level of burden experienced by family members. The subjective dimension of burden referred to the carer's perception of, and attitude towards, the experience, while the objective dimension of burden was related to the social and economic cost of caring to the carer. Today this distinction is still used with some consistency.

Grad and Sainsbury (1963) found that nearly two thirds of the 410 families in their study reported suffering hardship as a result of the affected family member's abnormal behaviours in the time before a diagnosis of a mental disorder was made. In 61 percent of families, this hardship was present for more than two years. In this study, participants reported similar findings during stage one of the problem of being consumed. This stage, disruption of established lifestyle, lasted many years for some participants and the hardship they experienced was conceptualised in the three aspects of this stage: the recognition that something was wrong, preoccupation with not knowing what was wrong and being overwhelmed.

Grad and Sainsbury reported that one fifth of participants in their study experienced excessive levels of anxiety and related the presence of symptoms such as insomnia, headaches, excessive irritability, and depression to carers' concerns about the affected family member. The affected family member's abnormal behaviours placed restrictions on the leisure and social life of the family and one quarter of participants had to stop working to care for the affected family member and this placed a burden on the family's economic status. More than a third of the 410 families in Grad and Sainsbury's study believed that other children in the family were affected by what was happening. Equally, these aspects were
highlighted by participants in this study and were concepts described in the second stage of the problem of *being consumed*, called *sustained threat to self-equilibrium*.

Grad and Sainsbury reported that families who had social or health problems were less able to cope with the experience of caregiving. Likewise, participants in this study described the importance of social support and their perceived level of well being on their experience of *seeking balance*. Grad and Sainsbury reported that the closer the relationship of the affected family member to the carer the greater burden the family experienced. Similarly in this study, some participants caring for their spouse spoke of *being overwhelmed* by their thoughts of letting their spouse commit suicide or of leaving their spouse. In addition, these participants spoke of the personal cost of the responsibility of being a carer, parent, and provider for the family.

Grad and Sainsbury (1963) identified affected family members' behaviours that caused families severe levels of burden as being: aggression, delusions, hallucinations, confusion, and the person’s inability to care for self (p. 545). These authors identified that the top ten reported behaviours that increased the level of caregiver burden (n=410) were: frequent complaints about bodily symptoms (38%); a danger to self (suicide or accident) (34%); inappropriate and demanding (34%); behaving badly or expressing peculiar ideas (27%); uncooperative and contrary (26%); constantly restless or over-talkative by day (23%), troublesome at night (21%); threatening the safety of others (12%); objectionable, rude, or embarrassing (8%); and causing trouble with neighbours (7%) (p. 544). Similarly, all of these behaviours were identified by participants in this study as factors impacting on their experience of *being consumed*. Many of the behaviours led to participants experiencing feelings of *being overwhelmed*, and at time, made participants question their ability to continue to be there for the affected family member.

Grad and Sainsbury identified a correlation between psychiatric diagnosis and the level of burden families experienced and these authors identified that the highest burden was associated with a family member who had a psychiatric diagnosis of an organic psychosis or a personality disorder. Equally, the difficulty of caring for people with a personality disorder was a problem identified by participants in this study and these participants reported experiencing feelings of *being overwhelmed* by their family members’ self-harming behaviours and by the lack of support offered by health professionals during times of crisis. Finally, Grad and Sainsbury found that the burden of care associated with community services or inpatient services was not significantly different after one month and admission to hospital.
did not necessarily reduce the family’s level of burden. Participants in this study also reported that when the affected family member returned home after being hospitalised nothing had changed.

While there were many similarities between the findings of Grad and Sainsbury’s 1963 study and this study the substantive theory of seeking balance to overcome being consumed also identified findings that were not documented by these early researchers. While the findings of this study identified the objective and subjective burden documented in the literature, this study also highlighted the personal rewards carers obtained from their caregiving experience. In addition, the findings of this study show that the outcomes of current health care plans and policies, along with the practices of some health professionals, further increased the physical, psychological, social, and economic costs experienced by carers. This finding is supported by Muhlbauer’s (2002) North American study of 26 carers, which found “the experience [of caring] has been substantially altered by recent social, political, economic, and technological changes” (p. 1076).

Current health care plans and policies placed an additional stress on participants in this study because these policies did not adequately address strategies for the early identification and treatment of people who were “at risk” of developing a mental disorder. As a result the majority of participants spent years searching for a solution or finding appropriate assistance for the affected family member. Professionals contacted during this time, for example, school counsellors, psychologists, or teachers, were not able to provide the level of support, intervention, or answers that participants required and this increased their experience of being consumed and added to the physical, psychological, social, and economic costs experienced by participants.

Current health care plans and policies have also resulted in the movement to briefer periods of hospitalisation and as a result participants were regularly left to manage the affected family member during an acute phase of their illness. The quality and type of emergency services available to support participants in this study were perceived as inadequate and participants were used as “safety nets”. This practice of using carers as “safety nets” placed carers “at risk” due to the affected family member’s behaviours and because of the lack of support available to them.

The findings of this study highlight that the practices of some health professionals further increase the distress experienced by carers. For example, participants in this study spoke of the exclusionary practices of health professionals and of not being listened to, or
valued. Many participants believed that their assessment of the affected family member’s mental state was valuable but this view was not held by health professionals. While current mental health policy espouses the concept of carers, consumers, and health professionals working together in a “partnership model”, in reality, participants were excluded from the “partnership”. Health professionals’ application of the principles of patient confidentiality resulted in participants being provided with very little information about the affected family member. Participants reported that while they respected the need for confidentiality in relation to the family member’s personal life, they believed that they should be routinely provided with information that impacted on their ability to care for their family member. This information should include education about the affected family member’s disorder, medications, and information and education that helped carers manage symptoms presenting in the affected family member, for example, auditory hallucinations, aggression and delusions.

Participants in this study also expressed many positive outcomes from their caregiving experience, for example, companionship, and a sense of purpose in their life. This aspect was not identified by early studies because these studies focused on the burden of caregiving, rather than the whole experience of caregiving.

In summary, while the burden of care previously identified in the literature was conceptualised by participants in this study, it was only one aspect of the caregiving experience. Furthermore, the physical, psychological, economic, and emotional cost of caring to participants was significantly increased by the outcomes of current health care policies and plans and by the practices of some health professionals. The findings of this study indicate that further research into the impact of these policies and practices is needed.

8.3.2 Comparison of substantive theory with other studies on caregiving

Since the founding studies on caregiver burden, many other researchers have continued to investigate the consequences of caring for a person with a mental disorder on families and carers. Many of these studies have used quantitative methodology and while the findings have added to the existing knowledge they have not captured the multi-dimensional experience of caregiving (Bland, 1998; Chapman, H, 1997; Doornbos, 1996; Fadden, et al, 1987b; Maurin and Barmann Boyd, 1990; Mueser, Webb, Pfeiffer, Gladis, Levinson, 1996; Porter-Smith, 2001; Vaddadi, Soosai, Gillear & Adlard, 1997; Winefield, Barlow & Harvey, 1998).
Research into the experience of caregiving remains important, as many families have had to increase their caregiving commitments to affected family members as a result of changes in mental health legislation, social policy, and technological advances. Several recent qualitative studies on caring will now be presented and compared with the substantive theory of seeking balance to overcome being consumed.

8.3.2.1: A comparison of the substantive theory of seeking balance to overcome being consumed with Muhlbaier’s (2002) study “Navigating the storm of mental illness: Phases in the family’s journey”

Muhlbaier’s (2002) qualitative study of 26 North American carers used semi-structured interviews within a framework of symbolic interaction through a paradigm of dramaturgical interviewing. Of all of the literature on caregiving reviewed for this study, Muhlbaier’s study most closely resembled this study for two reasons. Firstly, apart from the studies being conducted in different countries the demographics of participants in Muhlbaier’s study were similar to those of participants in this study. Furthermore, the family members being cared for in both studies covered a broad spectrum of mental disorders rather than one disorder, for example, schizophrenia which has been the focus of many previous studies on caregiving.

Secondly, Muhlbaier’s described a six phase sequential process that carers engaged in during their caregiving experience and these phases were: 1) developing an awareness, 2) crisis, 3) cycle of instability and recurrent crises, 4) movement towards stability, 5) continuum of stability, and 6) growth and advocacy. The content of the six phases were all identified in this study as important components of the substantive theory of seeking balance to overcome being consumed.

Muhlbaier’s first phase was similar to the first stage of the basic social psychological problem of being consumed. For participants in both studies this first part of the caregiving process varied in length and for some participants it lasted for many years. As with participants in this study, Muhlbaier found that carers in her study reported a “pattern of recognizing [sic] a problem, seeking assistance, and having concerns negated” (p. 1082). While participants in this study developed the recognition that something was wrong and became preoccupied with not knowing what was wrong, participants in Muhlbaier’s study also acknowledged knowing that something was wrong but not being able to define what was wrong. One mother from Muhlbaier’s study said, “We knew something was terribly wrong,
we didn’t have a name for it” (p. 1082). Participants in both studies tried to manage the affected family member’s abnormal behaviour until a crisis occurred. When a crisis happened, participants in Muhl Bauer’s study entered the second phase of the caregiving experience while participants in this study entered the third aspect of the problem, of being consumed, called being overwhelmed.

During crises participants in both studies noticed an exacerbation in the affected family member’s abnormal behaviour that was beyond their control and, therefore, participants in both studies sought help from health professionals. However, for both groups of participants the experience was made worse by the communication problems they experienced with health professionals. Health professionals did not listen to what participants were telling them and patient confidentiality laws were a major problem. One participant from Muhl Bauer’s study reported this communication with a social worker about his wife:

She [social worker] said “I cannot talk to you without a release of information from you wife”. Then she walked away and left me standing, embarrassed, in the hallway ... I’m still frustrated at not being able, at least, to express myself ... I had to pay a $28,000 hospital bill ... but nobody would talk to me. (p. 1083)

Crises for participants in both studies were traumatic and terrifying. Participants reported being involved in numerous crisis situations until, following one crisis, the affected family member was finally diagnosed with a mental disorder. Muhl Bauer’s third phase was similar to the second stage of this substantive theory, entitled sustained threat to self-equilibrium. During this time participants in both studies had to manage further crisis situations, experienced anger, grief and loss, and continued to voice dissatisfaction with mental health services and providers. Participants in both studies were also exposed to stigma as a result of their association with the affected family member.

In response to their experience of being consumed participants in this study engaged in the basic social psychological process of seeking balance and Muhl Bauer’s fourth and fifth phases were consistent with the second phase of the process of seeking balance. Participants in both studies began to regain control, to manage their feelings of guilt, to change their perceptions and expectations of the ill family member, and to attain some degree of mastery in managing the affected family member’s behaviour, particularly aggression. Participants also developed strategies to manage the outcomes of their interactions with health professionals. In addition, they continued to use behavioural-focused and emotion-focused coping responses to manage feelings associated with the caregiving experience. One
participant from Muhlbauser’s study also claimed spiritual and religious beliefs helped her:
“That [belief] helps my peace of mind” (p. 1086). Both groups of participants also spoke of the importance of social support. This support was provided by family, friends, and by carer support groups. One participant from Muhlbauser’s study stated:

It was helpful to listen to people that have the disease and had it under control. … I can’t emphasize [sic] enough, learning about [it] is so very helpful … don’t worry about where it came from, whether it is hereditary, in your family. Learn to accept it. Don’t be ashamed because it is nothing you did. (p. 1089)

Muhlbauser’s last phase was consistent with the third phase of the process of seeking balance, entitled reaching out to make a difference. Both groups of participants spoke about feeling empowered. Participants began to see positive outcomes of the experience and derived meaning, value, and personal growth as a result of what they had been through. Participants also reached out to make a difference, taking on advocacy roles and trying to make things different for other carers.

In summary, the findings of Muhlbauser’s study on caregiving closely resembled the findings of this study. Both groups of participants although from different countries were similar and the family members being cared for in both studies covered a broad spectrum of mental disorders. Furthermore, the caregiving experience of both groups had many similarities. Another important finding of both studies was that participants’ experience of caregiving was substantially affected by recent social, political, economic, and technological changes in the mental health care system. The consistency in findings between these two studies adds to the credibility and trustworthiness of the findings of this study, along with the transferability of the findings to carers in other countries.

8.3.2.2: A comparison of the substantive theory of seeking balance to overcome being consumed with Jeon and Madjar’s (1998) study “Caring for a family member with chronic mental illness”

Jeon and Madjar (1998) completed a phenomenological study on 14 Australian carers. Using two individual in-depth interviews each carer was asked to describe their experience of caring for a son, daughter, or parent affected by chronic mental illness. The findings of Jeon and Madjar’s study focused on two interrelated existential themes: temporality, or the experience of lived time, and rationality, or the experience of being with others. Descriptions of these two themes demonstrated similarities between Jeon and Madjar’s finding and the substantive theory of seeking balance to overcome being consumed.
The theme of temporality, or the experience of lived time, highlighted the subtle onset of a mental disorder and the protracted period of time before a diagnosis was made on the affected family member. During this time carers were confused and lived from day to day unable to make long term plans because of their commitment to the affected family member. Similarly, in this study during the first stage of the basic social psychological problem participants developed the recognition that something was wrong with the affected family member and became preoccupied with not knowing what was wrong. At times when participants were exposed to crisis situations they were overwhelmed with what was happening to them. Participants reported that they were “floundering in the dark”, and were left alone to figure out what was happening to their family member. Participants also reported using similar coping responses to those documented by Jeon and Madjar. These responses included making adjustments to family life and trying not to think too far into the future. Carers in Jeon and Madjar’s study took each day as it came and could not make any long-term plans. They used trial and error approaches to their caregiving and learned to differentiate between things they could change and those things that were beyond their control. They developed a degree of mastery over some of the affected family member’s frightening and unpredictable behaviours. Jeon and Madjar also identified the inadequate level of support and education provided to carers by health professionals as well as the impact of practices employed by health professionals on carers. The authors identified the ongoing grieving experienced by carers and the importance of social support, particularly from support and carer groups. Participants in this study also reported all of the above findings and these were components of the social psychological problem of being consumed.

Jeon and Madjar described that carers came to the point of realisation that in order to meet the needs of the affected family member they also had to attend to their own needs. This is similar to the basic social psychological process of seeking balance articulated by participants in this study. According to Jeon and Madjar “it involves a degree of passive letting go of those things that are not possible and an active struggle to achieve the possible and make the most of it” (p. 700).

The second theme identified by Jeon and Madjar was that of relationality, or the experience of being with others. This theme also had many similarities with concepts identified in the substantive theory of seeking balance to overcome being consumed. The authors described the impact of the family member’s illness on family life and on the ability to meet the needs of other family members. Jeon and Madjar also identified the positive,
compassionate, tolerant attributes of carers or their “generosity of spirit that was quite remarkable” (p. 701).

Similar to participants in this study, the carers in Jeon and Madjar’s study spoke of the impact on them of stigma by association. The authors also highlighted that “health professionals did little to bolster caregivers’ self-esteem and added to the feelings that they and their concerns were being swept under the carpet, made invisible, and ignored” (p. 702). Carers had to continually battle with health professionals to obtain help and they reported that they were not valued or supported by health professionals. Finally, carers in Jeon and Madjar’s study showed that when they were supported by health professionals the “interpersonal communication, often taken for granted before, could be a source of meaningful support that made all the difference to people struggling to cope with difficult situations” (p. 703). Equally, these were all concepts described by participants in this study with social support being identified as a condition influencing participants’ experience of seeking balance.

In summary, the findings of the Australian study completed by Jeon and Madjar had many similarities to the substantive theory of seeking balance to overcome being consumed. Of significance, Jeon and Madjar also described the increased psychological, social, economic, and physical costs to carers resulting from the outcomes of current Australian mental health policy. The findings of Jeon and Madjar’s study, although derived from different research methods, further add credibility to the findings of this study, demonstrating that the experiences described by participants in this study were not isolated to carers in Western Australia but resembled the experience of carers in other parts of Australia.

8.3.2.3 A comparison of the substantive theory of seeking balance to overcome being consumed with Tuck, du Mont, Evans and Shupe (1997) “The experience of caring for an adult child with schizophrenia”

The findings of Tuck, du Mont, Evans and Shupe’s (1997) phenomenological study of nine American primary carers also described similarities with the substantive theory of seeking balance to overcome being consumed. For participants in Tuck et al’s study the caregiving experience was clearly demarcated into the period of time before and after the family member was diagnosed with a mental disorder. Likewise in this study, stage one of the basic social problem of being consumed was predominately the period of time before diagnosis, while stage two of the problem of being consumed occurred after the family
member was diagnosed with a mental disorder. Similarly, participants in both studies were confused about what was happening during the time prior to when a diagnosis of a mental disorder was made on the affected family member. Participants lacked knowledge and were unable to differentiate between what was adolescent behaviour and what was illness behaviour. Participants in both studies described their desperate search for help. However, they found that the professionals they sought help from appeared not to understand what was wrong with the affected family members. One participant from Tuck et al’s study claimed, “He [son] had been under a psychologist, supposedly one of the best, and um, why this confused thinking and poor judgment was not evident to the psychologist, I’ll never know” (p. 121). Similarly, in both studies participants reported the recognition that something was wrong with the affected family member. In Tuck et al’s study this was categorised as the theme of “seeking help” while in this study it was an aspect of the first stage of the basic social psychological problem of being consumed and was conceptualised as the recognition that something was wrong.

When a diagnosis of a mental disorder was made on the affected family member participants in both studies described similar experiences of relief when they finally knew what was wrong. In addition, both groups of participants expressed grief and the sense of loss that the affected family member would never be the same again. Participants described their day-to-day caregiving commitment to the affected family member along with the sacrifice of their own personal goals and dreams.

Participants in Tuck et al’s study described reaching a turning point where they needed to establish a balance in their lives. One participant from Tuck et al’s study explained: “The needs of the person with schizophrenia supersede the cherished goals and values of the caregiver, however the desire for a person’s identity persists. With time, the desire for a separate life becomes more focal” (p. 123). Participants in this study also spoke of the importance of restoring self-identity and it was conceptualised as the second phase of the basic social psychological process of seeking balance. In addition, participants in both studies described the importance of understanding what was wrong with the affected family member and it was conceptualised by Tuck et al as the theme of “knowing” and by participants in this study as the sub-process of seeking balance, called trying to make sense of what was happening. A participant from Tuck et al’s study claimed: “I have had to learn and read every book I could get my hands on” (p.123).
Similarly, participants in Tuck et al’s study reported frustrating interactions with professionals in the health care system. According to these authors, because of the time it took to diagnose the affected family member’s disorder, the family’s faith in the ability of identified experts to diagnose and treat a person with schizophrenia was eroded. This was a view also held by participants in this study and was conceptualised as the first phase of *seeking balance*, entitled *utilising personal strategies to reduce the experience of being consumed*. Furthermore, health professionals’ interpretations of the principles of patient confidentiality impacted heavily on participants in both studies. According to Tuck et al: “Issues about patient confidentiality must be dealt with in a way which recognizes [sic] the family’s role in caring …” (p. 124).

In summary, many of the themes identified in Tuck et al’s study were identified in this study. The similarities of problems experienced by carers in these two studies is important and adds to the trustworthiness of the data of this study and demonstrates similar experiences of carers universally.

### 8.3.2.4: A comparison of the substantive theory of *seeking balance* to overcome being *consumed* with Karp and Watts-Roy (1999) “Bearing responsibility: how caregivers to the mentally ill assess their obligations”

Karp and Watts-Roy’s (1999) study of 50 American carers used a grounded theory framework for the analysis of data and the four main emergent themes were presented from a heuristic framework. These authors’ findings had similarities to the substantive theory of *seeking balance* to overcome being *consumed*. Karp and Watts-Roy identified four main themes to explain the “social tango” (p. 473) existing between caregivers and family members. They were: 1) hoping and learning; 2) revising expectations; 3) assessing responsibility, and 4) preserving oneself. These themes mirrored many of the findings of this study and the similarities will now be presented.

Karp and Watts-Roy’s theme of “hoping and learning” encompassed carers lack of knowledge and understanding of mental illness, their long and lonely search to find an answer to the family member’s abnormal behaviours, the relief when they eventually found out that the affected family member had a mental disorder, and their desire to gain knowledge and understanding about the disorder. Similarly in this study, these concepts were clearly identified by participants and were major components of the substantive theory of *seeking balance* to overcome being *consumed*. The authors’ second theme, “revising expectations”,
was similar to aspects described in the second phase of the process of seeking balance, “reviewing the past” and “preparing for the future”. These aspects involved participants’ reviewing what they had been through and planning for the future. The third theme, “assessing responsibility”, encompassed concepts that were similar to those described by participants in this study and conceptualised as regaining self-control and taking control components of the second phase of the process of seeking balance. The fourth theme, “preserving oneself”, was where carers in Karp and Watts-Roy’s study described the need to find a balance in their lives that led to the “maintenance of their own well-being” (p. 472). This theme was consistent with aspects of the social psychological processes described in this study and conceptualised as the core process of seeking balance.

Karp and Watts-Roy avoided “traditional” descriptors of caregiver burden and according to these authors, to talk about caregiver burden was to suggest that, “the notion of a singular caregiving role implies a consistency and uniformity of experience that does not adequately address the contextual factors that shape caregiving” (p. 488). Therefore, studies that focus on caregiver burden do not take into account, for example, the positive outcomes of the caregiving experience on carers that were identified by participants in both Karp and Watts-Roy’s study and this study. In summary, Karp and Watts-Roy’s finding further add to the trustworthiness of the findings of this study, particularly the extensive similarities in the social psychological process engaged in by participants to overcome problems they encounter as a result of their caregiving experience.


The final study on caregiving to be compared with this substantive theory is a grounded theory study involving 20 English carers of people with HIV and AIDS. The study was included because it used grounded theory methodology and because of the similarities identified between the carers of people with HIV and AIDS and participants in this study. The carers in Carlisle’s (2000) study spoke about making sure that their caregiving responsibility did not take over their lives and of the need to find a balance. According to Carlisle “even when severe HIV-related illnesses were being confronted, it was important to find time when HIV was not the centre around which everything else revolved” (p. 754). The
need to find balance appeared to be as strong for carers of people with HIV and AIDS as it was for carers in this study. This may have occurred because of the similarities in issues faced by carers of people with HIV and AIDS and carers of people who have a mental disorder, for example, the stigma by association experienced by these carers and the cycle of the caregiving that reveal periods of remission and normalcy followed by periods of crises.

Another important finding of Carlisle’s study was the need for carers of people with HIV and AIDS to reach out to other people. In a similar mode, participants in this study during the third phase of the process of seeking balance experienced the same need and the process in both groups of carers was similar. Carers reached out to help new carers and became actively involved in educating the general population and other target groups about the experience of being a carer. Participants became involved in advocacy work and in reducing the stigma associated with HIV, AIDS, and mental disorders. In reaching out to help others, participants in both studies evaluated their experience to date and as a result believed that they were now better people. There was a sense of pride and achievement that these carers were making a difference in the lives of other people. For participants in both studies the finding of meaning in their caregiving experience was a powerful way in which to redress the balance of the costs of caregiving with personal rewards (Carlisle, 2000), and demonstrated that dealing with suffering and/or death can provide people with a deeper meaning of life. Many of the caregivers in both studies expressed positive aspects that caregiving had brought to their lives and this finding may suggest that caregivers not only found meaning in their lives but also found meaning in the quality of their relationship with the affected family member. According to Carlisle “one picture that emerges from this study is that there is a change in the value system for carers, and this triggers the growth towards a new way of living” (p. 762).

In summary, there were many similarities between the findings of Carlisle’s study and the substantive theory of seeking balance to overcome being consumed. These similarities also confirm the transferability of findings of this study to the experiences of carers of people with other enduring illnesses.

8.3.4: Lazarus and Folkman’s theory of stress and coping

A major feature of the substantive theory of seeking balance to overcome being consumed was participants’ use of their established coping responses. Participants employed
these coping responses, which had been successful for them in the past, to protect themselves from the feelings evoked by their experience of being consumed.

Coping responses refer to specific efforts, both behavioural and psychological, that people employ to master, tolerate, reduce, or minimise stressful events occurring in their lives. A theory of stress and coping was first proposed by Lazarus (1966) and further refined by Lazarus and Folkman (1984). Lazarus and Folkman’s stress and coping theory provided a framework to understand how people reacted when confronted with a wide variety of threats and challenges. Understanding concepts related to stress and coping is important for health professionals to enable them to assist consumers and their families to cope with stress more effectively.

Two coping responses that successfully help people to manage stressful situations have been identified: problem (behavioural)-focused responses that aim to actively do something to alleviate the stressor and emotion-focused responses which involve efforts to regulate the emotional consequences of stressful or potentially stressful events on the individual (Taylor, 1999). Whether people choose to use problem (behavioural)-focused or emotion-focused responses is in part determined by their personal style. However, active coping strategies whether they are behavioural or emotional are reputed to be more effective ways of coping with stressful events than avoidant coping responses (Holahan & Moos, 1987).

Some participants in this study described the use of denial, an unconscious avoidant coping response; however, most participants spoke of using problem (behavioural)-focused and/or emotion-focused responses. These active coping responses described by participants included a variety of intrapersonal, interpersonal, and social responses, for example, personal achievements at work or outside of the home, setting and achieving personal goals, physical exercise, religion, maintaining an optimistic mindset, and the use of humour.

When participants became aware that the affected family member had a mental disorder they continued to utilise their established coping responses. However, participants’ coping responses were now also employed to help them manage their caregiving commitment to their family member. In doing so, participants made purposeful adjustments to their daily routines. Furthermore, they began to accept that certain things were beyond their control and to accept the reality of their life situation. In addition, participants began to set goals for themselves and to use problem (behavioural)-focused and/or emotion-focused responses, for
example, religion, physical exercise, and/or work to help them to achieve balance in their lives.

When coping with stressful events, a person's level of self-efficacy is important to how a person feels, thinks, or acts. According to Schwarzer (2000), people with high levels of self-efficacy are able to perform more challenging tasks, set themselves higher goals and, in terms of thinking, a strong sense of competence facilitates cognitive processes. More specifically, in relation to this study, stress was related to the meaning the person attached to the situation, for example, caregiving was viewed as either a challenge or as a threat. In seeking balance, through the use of coping responses participants' self-identity was restored and participants' level of self-efficacy increased. As a result, participants felt the need to reach out to help people who had just commenced their caregiving experience to prevent those people from experiencing the problem of being consumed.

Through the use of both problem-focused and/or emotion-focused responses participants were able to reframe or change their perspective of their experience to date. In seeking balance participants reframed many of their established life goals, beliefs, and dreams. In addition, they expressed that as a result of their experience they were now more compassionate, understanding, and accepting of people. In summary, Lazarus and Folkman's theory of stress and coping reflected aspects of the substantive theory of seeking balance to overcome being consumed. As participants became engaged in each phase of the process of seeking balance, they utilised their established problem-focused and/or emotion-focused responses to enable them to move forward in seeking balance in their lives.

8.3.5: Caplan’s theory of mastery

Caplan's (1981) work on mastery of stress reflected several aspects of the substantive theory of seeking balance to overcome being consumed. Caplan reported that stressful life events increased an individual's vulnerability to develop a physical or psychological illness. However, Caplan found that vulnerability to illness decreased if a person had high quality social support, as social support helped a person to manage the impact of stressful life events.

Caplan described mastery behaviour as a response aimed at 1) reducing to tolerable limits the physiological and psychological manifestations of emotional arousal to stressful life events, and 2) the mobilisation of the individual’s internal and external resources to reduce the impact of the event on them. According to Caplan, to obtain mastery over the stressful event, a person must successfully use both components of mastery behaviour.
In this study, the second phases of the core process and sub-process of seeking balance were important to participants' successful development of mastery over their experience of being consumed. These phases called restoring self-identity and making sense were comprised of responses to reduce the physiological and psychological manifestations of emotional arousal caused by the experience of being consumed along with the mobilisation of participants' internal and external resources.

Regaining self-control was the second aspect of restoring self-identity and was a largely cognitive process that allowed participants to re-evaluate many issues that had influenced their experience of being consumed, for example, beliefs that they had caused the affected family member's abnormal behaviours. Participants began to make adjustments to their life, for example, lessening their commitment of always being there for the affected family member. These adjustments were helpful to participants in their movement towards seeking balance and in making their caregiving commitment proportionate to other areas of their lives.

The third aspect of restoring self-identity was called taking control, and participants' acquired skills that helped them to improve their care to the affected family member. Participants learnt new communication strategies to use during their interactions with health professionals. The use of these newly found skills provided participants with increased feelings of control and mastery over their lives. Phase two of the sub-process was called making sense and when a diagnosis of a mental disorder was made on the affected family member participants' newly acquired knowledge concerning the affected family member allowed them to re-evaluate many of the issues that had impacted on their experience of being consumed.

Two of the four conditions influencing participants' experience of seeking balance were related to social support. This social support was provided by key family members, friends and neighbours, and by health professionals. A third condition influencing participants' experience of seeking balance was participants' perceived level of well being. Those participants who reported having high-quality social support were more successful in seeking balance in their lives.

In concluding, many of the components of Caplan's mastery of stress were applicable to the substantive theory of seeking balance to overcome being consumed. Participants described the mobilisation of their internal and external resources to reduce the impact of
being consumed and in seeking balance in their lives. Participants also identified the importance of high quality support on their experience of seeking balance.

8.3.6: Substantive theory of seeking balance to overcome being consumed compared with the Egan’s (1990) “The skilled helper: A systematic approach to effective helping”

Participants in this study sought contact with health professionals when they encountered problem situations that they were unable to manage alone. Participants anticipated that this contact would provide them with avenues to manage, solve, or transcend their experience of being consumed. For some participants, their interactions with health professionals were viewed as helpful. These interactions assisted them to move towards seeking balance in their lives by helping them to more successfully manage problems they were experiencing. However, the majority of participants in this study reported that their interactions with health professionals were not helpful and served to increase their experience of being consumed. These participants reported that this occurred because health professionals failed to provide them with the level of information and education they required. Participants also claimed that the exclusionary practices used by health professionals left them feeling powerless, and health professionals failed to listen to what participants told them about the affected family member, therefore, participants felt unvalued and unsupported. Participants believed that their experience of being consumed was also influenced by casual, unhelpful, and often hurtful remarks made by health professionals about the affected family members, which left participants perceiving that they had no one to turn to for help or advice.

Fisch, Weakland, and Segal (1985) suggested that the most important indicator of successful interactions between health professionals and clients is “the client’s statement that he or she is reasonably or completely content with the outcomes of treatment” (p. 122-123). This indicator also has relevance when measuring the outcomes of collaborative interactions between health professionals and carers. In order to ensure carers’ continued willingness to care for affected family members, primary carers must be content with and value the service provided to them by health professionals.

Egan’s (1990) problem-management and opportunity-development model described in his book “The skilled helper: A systematic approach to effective helping” is a model of collaboration and one that health professionals could use in their interactions with carers to
facilitate engaging and supportive communication. Egan’s model is a helping approach that focuses on teaching health professionals to assist people facing problems of living by developing unused resources and opportunities in those people. The model outlines the communication skills that are needed to effectively interact with people and how to involve and work with people collaboratively in managing problems.

Egan’s reference to the importance of effective communication skills to the success of helping is particularly important in relation to the findings of this study. According to Egan “helping, at its best, is a deeply human venture” (p. 57). Egan emphasised the importance of health professionals utilising a communication style that facilitated engagement and collaboration with those being helped. In humanising the helping experience, Egan highlighted the importance of the “beliefs, assumptions, values, norms, and standards that serve as the philosophical and moral foundations of helping” (p. 60). Furthermore, Egan claimed that health professionals must evaluate the beliefs, values, and norms that govern their interactions with clients and their families as values are not just ideals but are used by health professionals as criteria for making decisions.

The values displayed by health professionals in this study conveyed to participants the message that they were not valued and that their assessment of the affected family member were not respected and this served to create a rift between themselves and carers. During their interactions with carers health professionals failed to demonstrate the important values inherent in the helping process, for example, respect, understanding, tolerance, or assisting carers to utilise their own resources to manage problems.

In summary, some participants in this study reported that their interactions with health professionals assisted their movement towards seeking balance in their lives. This reinforces the power of effective communication and collaboration in helping people to manage problems in their lives. However, the majority of participants in this study reported that the communication style used by health professionals did not foster the collaborative approach advocated in mental health policy documents, and these participants reported that the communication with health professionals served to increase their experience of being consumed. As a result of this finding, health professionals need to re-evaluate their communication with carers of people who have a mental disorder. Egan’s “the skilled-helper: A systematic approach to effective helping” may provide health professionals with a framework that facilitates more successful outcomes.
8.3.7: The dimensions of caring

Within the context of this study the researcher believed it was important to discuss the dimensions of caring and their relationship to the substantive theory of seeking balance to overcome being consumed. Three dimensions will be presented and they are: caring in nursing, family caring, and working collaboratively with carers.

8.3.7.1: Caring in nursing

Caring is central to nursing theory and practice and it has been described in numerous ways (Cloyes, 2002). Caring has frequently been posed as a concept that comprises nursing’s specialised knowledge (Benner & Wrubel, 1989; Leininger, 1988) and nurses have theorised caring in clinical, psychological, instrumental, humanistic, existential, phenomenological, and discursive terms (Cloyes, 2002). Morse, Bottorff, Neander and Solberg (1991) in a review of the caring in nursing literature identified five universal conceptualisations of caring: caring as a human trait, caring as a moral imperative, caring as an affect, caring as an interpersonal interaction and caring as a therapeutic intervention.

It is widely acknowledged that Watson (1985) has made a significant contribution to the development of nursing knowledge on caring and the theorist has attempted to conceptualise the nature of caring. Watson claimed that there is a philosophical and spiritual basis that places emphasis on the interpersonal conceptualisation of caring (Lapsley, 1999). Watson’s original ten curative factors have been further developed by the nurse theorist and have now evolved into what Watson terms the clinical caritas process (Watson, 2000). Irurita (2000; 1996), an Australian nurse theorist has added to the knowledge on caring from both patient and nurse perspectives. The author’s “Preserving integrity: A theory of nursing” encompassed the basic social psychological problem of “patient vulnerability” and the basic social psychological process entitled “preserving integrity”. According to Irurita (1999) “vulnerability meant being susceptible to physical and/or emotional hurt, harm, or injury; defenceless or weak in relation to self-protection, open to assault” (p. 11). Patients’ perception of caring in Irurita’s study encompassed two levels: firm-hand (technical competence) and soft-hand care. Soft hand care was identified as nurses’ use of humanistic behaviours, for example, the use of touch, taking time to listen and do little extra things. Conversely, rough hand care was when the nurse was impatient, threatening, bullied patients or treated patients as objects or “slabs of meat” (p.13) and represented non-caring behaviour.
The philosophical perspective of nursing has changed little over the last century and the relationship between the nurse and the client remains the focus of nursing. However, the purpose of nursing has changed within the context of time and societal expectations (Lapsley, 1999). Many theorists believe that the preservation of caring in nursing, that is, the humanistic and interpersonal process of nursing, is increasingly being threatened by the technological, medical specialised health care system (Watson, 2002). According to Watson, nursing has "medicalised and clinicalised the human experience and nursing needs to go back and recapture it soul.... Nursing needs to shift from the medical to the human dimension" (2002, no pagination). This shift from the human to the medical dimension has occurred because in acute care situations nurses need to "fix" problems quickly as a result of patient acuity levels and work pressures. However, this model has not allowed nurses to understand, or capture, the human experience that is essential to caring. According to Watson "nurses hold another person’s life in their hands" and "one person’s level or concept of humanity reflects on another" (Watson, 2002, no pagination). Therefore, nurses need to make a "conscious, intentional reflection on their practice and this makes the difference between night and day [in understanding the client’s experience]" (Watson, 2002, no pagination).

Both Watson and Irurita place emphasis on the importance of the humanistic side of nursing. Watson (2002) referred to "the nurse as the environment" (no pagination) and Irurita referred to the nurse’s use of soft hand care in addition to technical competence. When patients are admitted to hospital they lack information and understanding of and control over what is happening to them and, therefore, their level of vulnerability is increased. If nurses understand the patient’s experience and, as Watson stated, "used their imagination to see what it is like from the other side" (no pagination), the patient’s integrity or well being is maintained. The work of Watson (1985) and Irurita (2000; 1999) reflect important components of caring that are central to the substantive theory of seeking balance to overcome being consumed.

In this study, participants’ experience of being consumed was increased because nurses and other health professionals failed to understand the human experience of being a carer. Participants in this study were treated like “a nobody”, not listened to, put down, not given any information about what was happening to the affected family member, left feeling powerless, and traumatised by seeing their family member hospitalised. Furthermore, their experience of being consumed was further increased by the uncaring attitudes and responses displayed by health professionals.
Patients in Irurita’s study engaged in a basic social psychological process called “preserving integrity” which had many similarities to the basic social psychological process of seeking balance. Participants in both studies reduced their problem of “vulnerability” or of being consumed by regaining self-control and developing strategies to reducing threats to their personal integrity. However, a condition influencing participants’ ability to restore their integrity or to seek balance was health professionals’ use of humanistic values when they communicated with clients and carers.

Understanding the human experience from the client or carer’s perspective and the use of humanistic values are central to caring in the theories outlined in this section of the thesis. Morse et al (1991) also highlighted the importance of health professionals understanding the human experience:

If caring is really the “essence of nursing” then it must be demonstrated and not simply proclaimed. If caring is the “central, dominant, and unifying feature of nursing”, then it must be relevant to practice and to the patient and not merely an internalized [sic] feeling on the part of the nurse. (p. 119)

In summary, Watson’s (1985) “theory of human caring” and Irurita’s (2000) “preserving integrity: a theory of nursing” have many similarities to the substantive theory of seeking balance to overcome being consumed. The findings demonstrate that in order to provide clients and carers with high quality care nurses need to go “beyond evidence-based practice, they need to also reflect on the importance of value based practice” (Watson, 2002, no pagination).

8.3.7.2: Family caring

Many public policies and ideologies support the notion of a shared sense of obligation that family members will care for each other and these ideologies are often thought to reflect the rightful role of the family in the scheme of nature (Karp and Watts-Roy, 1999). However, Finch (1989), in a study on family practices, concluded that in reality “[the family] does not operate to the kind of fixed rules that caring is ‘naturally’ a part of the family relationship” (p. 240). Family caregiving is not simply an entity and it reflects itself through behaviour, feeling, and emotion (Kellett & Mannion, 1999).

It has been argued that the quantitative emphasis of the body of knowledge on family caregiving has constrained the ability to understand the multidimensional experience of family caregiving (Kellett, 1996; Kellet, 1997). However, irrespective of our current level of
understanding, family caregiving is increasingly becoming a reality in an economic climate of reduced public spending on health and welfare services. According to Lee (2001) family caregiving has been disguised by the “rhetoric of community care” (p. 394) and although some researchers have demonstrated that families obtain satisfaction and a sense of self-worth from caregiving (Cohen, Gold, Shulman & Zuccher, 1994; O’Connor, Pollitt, Roth, Brook & Reiss, 1990) families also experience a considerable burden (McKinlay, Crawford & Tennstedt, 1995). King, Collins, and Liken (1995) in their study of values and the use of community services identified four main themes as to why families make a commitment to care for an affected family member. The themes were that: 1) families are obligated to care, 2) families are owners of their difficulties, 3) families should protect vulnerable members, and 4) families are self-reliant units. One or more of these themes may account for a particular family's ongoing commitment to care even when the personal cost is considerable.

In assessing the impact of caring on families, it is important to discuss the issue of gender. Of the 27 carers who participated in this study 22 were women and, therefore, in understanding the experience of caregiving it is also important to question the ideologically based assumption that it is natural for women to want to care (Lee, 2001). While it is middle-aged women who are most likely to provide family care (Orbell, 1996), these women often have reduced social and economic power and are a particularly vulnerable group. In this study, a participant who was still in phase one of the basic social psychological process of seeking balance and was consumed by her experience was a middle-aged woman with limited social and economic support who had placed the needs of her affected family member above her own. According to Lee (2001):

these women may also be more likely than younger women to have internalized [sic] the concepts underlying traditional gender roles, accepting that women have a “natural” responsibility to care for family members, and that women should always place their families’ needs before their own. (p. 394)

Further research needs to be conducted to fully understand the impact of the societal expectation that women will care for sick family members. Currently, middle-aged women in society undertake the majority of caring obligations within families and these women are already one of the most vulnerable groups in society.

The theory of normalisation developed by Clarke (1999) provides further information as to why families care for a sick family member. Clarke used both quantitative and qualitative methodologies in her study on family caregiving for people with dementia.
Clarke’s theory of normalisation consisted of three aspects: normalising, interfacing, and interacting. The aspect of normalising explained why families care: the concept of reciprocity in the relationship, families are obligated to care, and the belief that home care is the best care for the affected family member.

The aspect of interfacing was the amount of professional involvement in the caregiving process, and this service may at times benefit one person at the expense of the other. The aspect of interacting was the relationship between the client, carer, and professional. While families in Clarke’s study made a commitment to the affected family member they believed that the medicalisation of dementia stripped people of their human rights and that health professionals devalued the dementing client as a person. Similar to the findings of this study, participants in Clarke’s study experienced problems working with health professionals. Participants in Clarke’s study found that while they travelled along the path of normalising their family member’s experience, health professionals’ care was often dictated by the family member’s prognosis and failed to understand dementia from the family perspective.

Leggatt (2000), in a paper “Families in limbo”, identified that families of people with a mental disorder cared for the affected family member out of obligation because of an expectation placed upon them by health professionals. However, Leggat found that while health professionals expected families to care for their ill members “at present, family members are generally seen as not entitled to ‘rights’” (p. 1). Leggat spoke of the importance of family members being provided with education and understanding about mental disorders claiming, “mental health professionals have a ‘duty of care’. It is in the best interests of the patient to inform and support their family carers” (p. 2). Both Leggat’s findings and the findings of this study found that while health professionals do not involve or inform caregivers about the family member’s illness or management, there is an expectation placed on families by health professionals to take responsibility for the affected family member.

Pejler (2001), in a Swedish study, used a phenomenological hermeneutic approach to examine eight parents’ experience of caring for their adult son or daughter who had a severe mental disorder. Pejler also found that health professionals held an expectation that parents would care for the affected family member. While the expectation to care was placed on parents, they received vague and evasive information from health professionals and were blamed and excluded from the treatment of the affected family member. Pejler reported that the view of families as pathogenic may still exist and this may be a possible explanation as to
why many health professionals still exclude family members from involvement in treatment. Pejlert found that most conflict arising between health professionals and family members was about power and health professionals’ attitude of knowing the client better, along with their willingness to cooperate, were interpreted by families as a threat. Furthermore, Pejlert claimed that the relationship between health professionals and carers also affected the severity of the stigma experienced by family members, as health professionals’ attitudes towards them awakened unresolved feelings of guilt. Therefore, Pejlert suggested, “it is vitally important to find ways of avoiding the uncomfortable relationship that often occurs between the family and mental health professionals. … if the goal is to involve them [families] in care and ease their burden” (p. 202).

Kellett and Mannion (1999) completed a phenomenological study of the caregiving experiences of seven family carers to older relatives. Six themes emerged from the data and they were: sense of family life past, sense of change, sense of engaged involvement, sense of worth, sense of concern, and sense of continuity. These themes were similar to those identified by other researchers and were based on the concepts of reciprocity in the relationship, families are obligated to care, the belief that home care is the best care for the affected family member, and the positive outcomes of providing care. Kellett and Mannion urged health professionals to recognise that caring provides significance and meaning to the lives of many carers and to work collaboratively with them. By acknowledging the importance of the human experience of caring, nurses can increase their awareness and respect for carers and recognise differences in how carers define their role. According to Kellett and Mannion “ultimately it is nurses’ ability to understand the experience of caring, meaning in caring, that determines family carers’ perception of professional involvement as supportive or intrusive” (p. 702).

Brown and Stetz (1999) used grounded theory methodology to analyse the findings of a study on 26 caregivers to people with AIDS and advanced cancer. The authors also reported that their family’s willingness to care was based on the sense of obligation and reciprocity, the relationship with the ill person, what the ill person would allow to occur, and what the caregiver was willing to give. Brown and Stetz suggested that in order to support family care changes to health policy and clinical practice were necessary. The authors claimed, “even though an individual person has the disease, whole families experience the illness. Health care …. should include family caregivers throughout the entire illness experience. Such a health care system does not currently exist” (p. 195). These findings were
also identified by participants in this study and further demonstrate similarities of experiences of carers of people with different types of enduring illnesses.

In evaluating the level of reciprocity that carers experience it is also important to examine reciprocity in spousal relationships. While social support is acknowledged as important to carers it is often concluded that when a spouse becomes a caregiver to their partner they lose a primary source of support (Fergus, Gray, Fitch, Labrecque & Phillips, 2002). This conclusion assumes that when a person develops an illness they can no longer provide a supportive function in life. While several participants in this study caring for a spouse did report feelings of being consumed and at times overwhelmed by the experience, one participant caring for her husband was very dependent on his support. Therefore, while the support offered by a spouse to their partner may be different for each carer, the fact that a spouse is unwell does not mean that support between a couple does not exist, nor does it mean that the support is any less critical to the carer’s level of functioning. When the ill family member is acknowledged as an active agent in the support process, reciprocity occurs in the relationship. Fergus et al (2002) found that the perception of social support between spouses was of greater consequence for the psychological well being of female caregivers and this may be linked to societal expectations associated with gender roles.

In the context of caring for a family member who has a mental disorder, caregivers must also reconcile obligation and love for the family member with the emotions of fear, bewilderment, loneliness*, exhaustion, depression, frustration, guilt, resentment, anger, and even hate (Chambers, Ryan & Connor, 2001; Karp & Tanarugsachock, 2000). These emotions change throughout different phases of the caregiving process and one of the main problems of caring for a person with a mental disorder is the volume and volatility of emotions experienced by both the caregiver and the affected family member. Caregivers are continually trying to make sense of their obligations and to manage their feelings and emotions. In this study this was conceptualised as being overwhelmed and as a sustained threat to self-equilibrium.

Karp and Tanarugsachock (2000) identified four interpretive junctures in the social trajectories of caregiving to people who have a mental disorder. Before diagnosis family members are bewildered and do not know how to react emotionally or behaviourally. When they learn that the family member has a mental disorder, kinder emotions of sympathy and empathy surface. As family members become aware of the long-term commitment they will make to caring, concern recedes and frustration, anger, and resentment surface. Finally,
caregivers conclude that the person’s illness is beyond their control, and such recognition may liberate them by legitimating their withdrawal from caring without experiencing guilt.

Participants in this study described similar emotions and social trajectories in their caregiving experience. However, in this study, all participants had made a commitment to care for the affected family member, and when they recognised that aspects of the person’s disorder were beyond their control they had engaged in the basic social process of seeking balance.

In summary, family caring is the lived experience of caring for someone who is vulnerable due to age, health, or circumstances. The caregiving experience may express affection but it also brings with it burden, worry and an array of emotions (van Manen, 2002). Most studies demonstrate that families care because of obligation and reciprocity in relationships. Karp and Tanarugsachok (2000) found that to genuinely care for another person presumes an effort to empathise with that person and to try to view the world from their perspective.

Whatever the reason why families care for an affected family member, most carers provide care with limited help, support, or recognition of their contribution. The experiences of carers across a variety of enduring illnesses demonstrate many similarities, and community care depends on the goodwill and health of families who make the commitment to the affected family member (Walker & Dewar, 2000). Unless health professionals understand and begin to value the role that families play in caring, this valuable resource may not be sustained, to the detriment of the affected family member. The challenge to mental health professionals and policy makers is to understand the problems identified in this substantive theory of seeking balance to overcome being consumed and other supporting literature and to find ways to implement changes that foster collaborative supportive approaches to working with families.

8.3.7.3: Working collaboratively with carers

Globally, during the last few decades, a central theme of government health policies has been to encourage health service providers to change the way they relate to people who use these services. These government policies advocate that consumers should be more readily involved in decision-making processes and, in many situations, this involvement also include carers (Hazleton, 1999; Walker & Dewar, 2001).

Most government policies aim to facilitate the development of health services that are more accountable to consumers, and where consumers and their carers are provided with a
greater levels of involvement and support (Mental Health Council of Australia, 2001) as high quality social support has been identified as a major influence on the level of stress people experience (Chambers, Ryan & Connor, 2001). However, it appears that these policies have not been implemented at the service level because those with the power to implement change are not usually the ones who develop the ideas for change (Walker & Dewar, 2000).

Participants in this study valued the support from and collaboration with health professionals. It made participants feel involved in the decisions being made about the affected family member’s present and future care. However, for the majority of participants in this study, high quality support from and collaboration with health professionals did not materialise and this finding was consistent with those of Walker and Dewar (2001).

Walker and Dewar (2001) reported that health professionals affirmed that the quality of care that the affected family member received both in and outside hospital improved if the carer was involved in the decision making process. However, when examining how health professionals work with carers, two factors appear to be significant. Firstly, health professionals are often constrained by their willingness or by their ability to involve carers. Secondly, carers have an unequal distribution of power when negotiating an active role in their family member’s care because the health care environment is alien to them and weighted in favour of health service providers (Walker & Dewar, 2001).

Health professionals were constrained in their ability to involved carers because of acuity and staffing levels in health services. These high acuity and low staffing levels lead to decreased staff morale which left health professionals not feeling valued. According to Allen (2000) “empowering the clients and their carers can only be accomplished, if nurses are themselves empowered” (p. 151).

Casey (1995) found that the nature and level of carer involvement was also depended on the practice of each health professional. In addition, health services failed to provide clinicians with best practice standards for the involvement of carers. Therefore, carers’ involvement was subject to the health professionals’ perception of how and when they should be involved. Furthermore, Allen (2000) reported that health professionals do not involve carers because of previous negative interactions with them. Allen claimed that carers sometimes directed their anger and frustration towards health professionals and this resulted in health professionals stereotyping carers as guilt-ridden and emotionally vulnerable. The anger directed towards health professionals left them experiencing considerable levels of
anxiety and stress, which made them defensive towards further encounters with carers (Walker & Dewar, 2001).

For the majority of carers the health care service is alien to them. They are unsure of what contribution or role they may play in the affected family member’s care or what opportunities are available to them. What constitutes a satisfactory level of involvement may differ between carers and most carers, when defining their level of involvement, were reliant on the guidance of nurses. However, it appears that nurses currently do not have clear ideas regarding carers’ level of involvement in the care of the affected family member. Walker and Dewar (2001) claimed as:

there are no agreed objectives for carer involvement, there is no basis on which it can be evaluated either by carers themselves or by nursing staff and management. Such evaluation provides opportunities for practice and service development as well as for assuring the quality of care. (p. 336)

Chambers, Ryan and Connor (2001) described areas where nurses could work collaboratively with carers and these were: providing support, providing education and understanding about the affected family member’s mental disorder, dealing with family issues, for example, conflict, increasing family dysfunction, improving carers’ coping skills, improved communication with carers, information on how to access community services, dealing with carers’ emotions, involving the carer in long-term planning, and helping carers to adapt and change their caregiving role over time. These areas provide a framework for collaborative involvement, which in turn can further increase the carer’s level of self-efficacy and self-confidence; and furthermore, these areas were identified by participants in this study as being important to their experience of seeking balance.

In summary, collaboration between health professionals and carers is advocated in most policy documents pertaining to the treatment and care of people who have a mental disorder. However, in clinical practice the objectives outlined in these policy documents are left to individual health professionals to implement. Currently, there are two main factors preventing health professionals from actively involving carers. These factors are: 1) the willingness and the ability of the health professional to involve the carer, and 2) carers’ unequal distribution of power within the health system to enable them to negotiate an active role in their family member’s care. Until these factors are resolved at a practice level the “partnership model” outlined in the Australian National Mental Health Strategy will be little more than an objective in a government policy document.
8.3.8: Summary

This chapter began with a presentation of the substantive theory of seeking balance to overcome being consumed. Following this, the discussion focused on comparing the substantive theory of seeking balance to overcome being consumed with other pertinent theories and research. The literature presented highlighted similarities to the findings of this study and the presented literature adds to the credibility, trustworthiness, and transferability of the substantive theory of seeking balance to overcome being consumed. The experiences of carers to people with a mental disorder appear to be universal and similarities are also present across a range of other enduring illnesses, and therefore, the findings of this study are equally useful to carers of people with other enduring illnesses. While this study has many similarities to the literature reviewed in this chapter, the substantive theory of seeking balance to overcome being consumed is unique in the very detailed outline of specific components of the caregiving experience that are consuming for carers. In addition the theory provides a framework for health professionals, policy makers, carers, and other stakeholder groups to prevent new carers from being consumed and to facilitate new carers’ movement towards seeking balance in their lives. The substantive theory captures the multi-dimensional experience of caregiving that has not been documented in some of the literature on caregiving. The findings show the burden experienced by carers but the findings also highlight the positive outcomes carers attribute to the caregiving role. In addition, the substantive theory demonstrates the need to review current health care policies particularly the “partnership model” of care to prevent a further increase in the social, economic, physical, and psychological costs to carers. Chapter nine presents the concluding statements of this thesis along with implications and recommendations based on the findings of this study.
CHAPTER 9

IMPLICATIONS AND CONCLUDING STATEMENT

9.1: Introduction and Overview

The substantive theory of seeking balance to overcome being consumed provides carers, consumers, health professionals, governments, and policy makers with an insight into the unique experience of being a primary carer of a person with a mental disorder. The experience of being a primary carer goes far beyond that of any professional caregiving experience (Jeon & Madjar, 1988). The findings of this study show that caring for a person with a mental disorder has social, physical, psychological, and economic costs to carers. Furthermore, the costs appear to be significantly increased by current government mental health plans and policies, and by practices employed by some health professionals.

With the expansion of community mental health care, many more families will be required to make a commitment to care for an ill family member. The “partnership model”, outlined in the Australian Second National Mental Health Plan (Australian Health Minister, 1998) encouraged collaboration between carers, consumers, and health professionals.

However, in reality, it appears that this model has limited clinical application. To prevent a further increase in the social, physical, psychological, and economic costs to carers, governments, policy makers, and health professionals must understand and acknowledge the human experiences that are outcomes of current mental health care policies and service provision (Jeon & Madjar, 1998). The findings of this study suggest that:

1. Policy makers and health professionals do not understand the extent of the current social, physical, psychological, and economic costs placed on primary carers.
2. In reality the “partnership model” outlined in the Australian National Mental Health Strategy has limited clinical application.
3. Primary carers’ knowledge, skills, and caregiving expertise are currently not acknowledged, valued, or facilitated by health professionals.
4. A lack of emergency services for people with a mental disorder results in carers regularly being left alone to manage an acutely ill family member. As a result, carers experience high levels of stress, fear, anxiety, and feelings of being overwhelmed by what is happening. Furthermore, carers regularly appear to be placed “at risk” because
of the ill family members’ paranoid and/or violent behaviours and by the lack of professional support during times of crisis.

5. Health professionals’ application of the principles of patient confidentiality also appear to place carers “at risk” because carers do not understand the affected family member’s illness and/or treatment plan and are left to “flounder in the dark”.

6. The experience of caregiving has long-term consequences on the life and health of the family that as yet may not be fully understood by governments, health professionals, and policy makers.

This chapter will outline implications based on the findings of this study and detail the need for further research into the primary carer’s experience of caring for a person with a mental disorder. Finally, the concluding statement of this thesis is presented.

9.2: Implications of the findings

In the concluding chapter of this thesis the clinical applications of the substantive theory of seeking balance to overcome being consumed are presented. The clinical applications are described in terms of: 1) initiatives needed to help carers of people with mental disorders, and 2) the enhanced delivery of formal mental health care services. Each of these two implications will now be presented.

9.2.1: Initiatives needed to help carers of people with mental disorders

The first implication of the findings of this study is described and presented in terms of initiatives needed to help carers of people with mental disorders. It is suggested that these initiatives target six main areas: 1) the general population; 2) health professionals; 3) the management strategies used by health professionals in relation to carers; 4) education of general practitioners and front-line professionals; 5) media personnel, and 6) providing carers with programs that supply them with knowledge and understanding about mental disorders, emotional support, and tangible aid. Each of these initiatives will now be presented.

9.2.1.1: Initiatives directed towards the general population

The majority of participants in this study were unprepared to care for their ill family member because they lacked knowledge and understanding about mental disorders. Moreover, participants experienced feelings of being consumed and at times overwhelmed by
what was happening to them. Therefore, there is a need for increased education and understanding in the general population regarding the causes, presentation, and treatment of mental disorders. This increased level of education and understanding would help people to more readily recognise a mental disorder in a family member or friend. It would also reduce the experience of *being consumed* for those people who, in the future, go on to become a carer to a person who has a mental disorder.

Increasing the general population’s education and understanding of mental disorders and current treatment methods is an approach supported by other researchers, for example, those studying chronic illnesses such as cancer and dementia. These researchers have reported that such an approach enabled those affected by the condition, and their carers, to cope with the experience more successfully (Brodaty et al, 1990; Shaw, Wilson & O’Brien, 1994).

The increased education and understanding in the general population about mental disorders may also decrease the stigma experienced by people who have a mental disorder, their carers, and their families. Stigma is acknowledged globally as one of the major problems to the success of community mental health care (Sartorius, 1998) and it prevents a person from being fully accepted by society (Bruton, 1997). To help reduce the level of stigma, the general population should receive information on the benefits of early diagnosis and treatment of mental disorders. This is important as the fear of rejection, and the resulting stigma, currently prevents many people who have a mental disorder from seeking help.

Other researchers and community organisations support the need for a greater awareness in the general population about the impact of stigma on people who have a mental disorder and their families (American National Mental Health Association, 1998; Dunn, 1999; World Federation for Mental Health, 1999). These researchers found that many people who require treatment do not seek help because of the stigma associated with mental disorders. In Australia, the Australian Bureau of Statistics’ (1997) study, *The National Survey of Mental Health and Well-being*, reported almost one in five Australians over the age of 18 years met the criteria for a mental disorder at some time during the year prior to the survey. However, the Second Australian National Mental Health Report (1998), for example, found that only 38 percent of the people identified in the above survey as experiencing symptoms of a disorder had accessed a health service.

It is recommended that strategies to reduce stigma directed towards mental health consumers and their families should also target children, as negative attitudes towards people with a mental disorder are not exclusive to the adult population. Children learn from
a very early age to view psychiatric problems as failures of character, and people who admit to having these problems are looked down upon by their peers. Many governments are now developing programs for use in schools to help children understand and manage mental health and illness issues. One such program, "MindMatters", an Australian Government initiative, is providing information about mental disorders to school children throughout Australia (Commonwealth Department of Health and Aged Care, 2000). "MindMatters" emphasises mental health promotion and suicide prevention and aims to enhance the development of school environments where young people feel safe, valued, engaged, and purposeful. The expansion of such programmes in schools should be encouraged.

Social support was an important condition identified as influencing participants' experience of seeking balance, and ongoing education to address stigma in our society is vital for increasing the level of community support to carers. While most research currently supports the notion that the key to eliminating stigma towards people who have a mental disorder is education, understanding, and compassion, new ideas may also be required. Some researchers believe exposure to people with a mental disorder may be vital in reducing stigma (Lawrie, Parsons & Patrick, 1996, Rabkin, 1974). Wahl (1989) agreed with this view, claiming one of the most powerful factors in changing stereotypes is seeing and interacting with people, in the stereotyped category, who do not fit general expectations. Therefore, people with a mental disorder who are successfully living in the community, for example a successful articulate businessman, may have a much greater role on changing stereotypes than any information provided by mental health professionals or government organisations.

The general population should also be provided with information regarding current government policies, plans, and philosophies in relation to the delivery of modern mental health care. The information should portray the importance of people with a mental disorder being able to live, work, and be treated in their local community and provide guidelines suggesting how members of the general population can understand the role of carers and help and support neighbours, friends, or relatives who are caring for a family member with a mental disorder.

In summary, a multi-faceted collaborative approach by government departments is required to facilitate the implementation of policies that could alter the general population's knowledge and understanding about mental disorders and current treatment methods. Finally, the initiatives could facilitate the early recognition and treatment of mental disorders in
society, providing better outcomes and quality of life for consumers of mental health care, their carers, and other family members.

9.2.1.2: Initiatives directed towards health professionals

Initiatives directed towards health professionals could also reduce carers' experiences of being consumed. One such initiative is ongoing education and this should focus on the importance of health professionals using an engaging and supportive communication style in their interactions with carers. Participants in this study explained that when health professionals used an engaging and supportive communication style it increased the likelihood of successful collaboration between the two groups. The importance of using an engaging and supportive communication style has long been identified in the literature as influencing patient care outcomes (Budd & Hughes, 1997; Egan, 1990; Irurita, 1996b; Kruijver, et al, 2000; Mould et al, 1991; Reid-Ponte, 1992; Suominen, et al, 1995). According to Egan (1990): "If the collaboration between helpers and clients is successful, clients learn in very practical ways. They have more 'degrees of freedom' in their lives as they open up options and take advantage of them" (p. 6). Egan’s comments are equally pertinent in regard to health professionals’ collaboration with carers. For example, respectful communication styles that facilitate the use of strengths, resources, and expertise of both the carer and the health profession should be vigorously promoted at the service level. Furthermore, health professionals should be encouraged to use reflective practice models as a means of evaluating the impact of their actions on health care outcomes.

The disparity in the level of knowledge and understanding about mental disorders between carers and health professionals along with the uncaring attitudes and responses displayed by some health professionals increased participants' experience of being consumed. Therefore, there is a need for the improved education of health professionals in regard to their awareness of the experience of being a carer for a person with a mental disorder. This could assist health professionals to better relate to carers and to more effectively understand their needs and experiences of being a carer. Deakin Health Services, Australia (1999) previously identified this need in a report on the education and training of mental health professionals funded by the Australian National Mental Health Strategy. The report stated that the:

future training structures and processes [for mental health professionals] must cohere around the two guiding principles:
- mental health professionals need to learn about and value the lived experience of consumers and carers
mental health professionals should recognise and value the healing potential in relationships between consumers and service providers and carers and service providers.

Each discipline needs to develop a new body of knowledge around the "lived experience of consumers and carers. (p. 1)

The above mentioned report, on the education and training of mental health professionals, further recommended that a deep dialogue, in the form of workshops, occur between health professionals, consumers, and carers as a means of enhancing health professionals' understanding of the experience of being a carer for a person with a mental disorder. This thesis, and any subsequent published articles, will also provide an insightful account of the experience of being a carer of a person with a mental disorder. These finding may be useful to carers, health professionals, policy makers, and other stakeholder groups.

**9.2.1.3: Initiatives to assist carers and other family members**

As revealed by the findings of this study, carers and other family members could benefit from initiatives to better prepare them for their caregiving experience. These initiatives should aim to provide carers with knowledge, understanding, and information about mental disorders, as well as ongoing emotional support, and the provision of tangible aid.

Participants' feelings of *being consumed* were increased by their lack of knowledge, understanding, and information about mental disorders. As previously stated, the general populations' improved education and understanding regarding mental illness could in the future lessen new carers' experiences of *being consumed*. In addition, health professionals should routinely provide carers with information about the family member's illness.

Traditionally, information programs provided to family members have focused on promoting better outcomes for consumers and have not been aimed at promoting the well being of carers. Such programs have focused on educating family members, for example, on using communication patterns that are low in expressed emotion and critical comments (Miklowitz, Goldstein, Nuechterlein, Snyder & Mintz, 1988). More recently, information programs provided by health professionals have begun to focus on developing carers' coping and problem solving skills. These programs provide a social focus that promote networking between families, foster practical and emotional support networks, and develop social understanding about mental disorders (Porter-Smith, 2001). Governments and health service providers should encourage the development of more of these social-focused programs. The
development of social-focused programs is supported by Simpson (1999) who reported that
carers wanted health professionals to provide them with informative education regarding the
affected family member's illness, management strategies, and knowledge and side effects of
the family member's medication.

Governments and health professionals should also support the development of
education programmes for new carers by experienced carers. One such programme is "The
Bridges Journey of Hope Program" (Baxter and Diehl, 1998). "The Bridges Journey of Hope
Program" is a twelve week programme facilitated by experienced carers which provides new
carers with information and education, for example, on subjects like mood disorders,
medication, rehabilitation, showing empathy towards their loved ones, developing
communication and problems solving skills, self care for family members, and effective
advocacy. Programmes such as "The Bridges Journey of Hope Program" should be useful in
lessening participants' experience of being consumed, as participants appreciate that other
people are undergoing similar experiences to themselves. These programs have been valuable
to carers in helping them to more effectively manage their caregiving experiences and to
resolve feelings of grief and self-blame.

Carers and other family members should also receive structured ongoing emotional
support from health professionals. This has been supported by other researchers who claim
the uniqueness of each carer, their caregiving situation, and their assets and strengths must be
acknowledged by health professionals and emotional support should focus on facilitating the
carer's strengths rather than the affected family member's illness and pathology (Doornbos,
1996). The provision of ongoing emotional support that acknowledges the uniqueness of each
carer is crucial to decrease carers' experience of being consumed and health professionals
should focus on areas that are most distressing for carers in their daily lives (Rose, 1998).

Carers are regularly exposed to crisis situations, some of which involve managing aggression.
Therefore, carers and other family members may benefit from education and training that
ensures their physical and emotional safety within their own home. In agreement with this
Parker (1993) suggested that if the affected family member's illness has an aggressive
component, carers should be encouraged to have a "safe room" in their home with a solid
door, a dead bolt, and a telephone with relevant telephone numbers readily available. The
provision of emotional support is very important during emergency situations and health
professionals also need to provide this support to carers after the emergency has been
resolved.
The third area of initiatives for carers and other family members needs to be in the form of the provision of tangible aid, for example, preparing carers to participate in groups to facilitate change at all level of the mental health care system. As participants in this study moved through the phases of the basic social psychological process of seeking balance, their need to reach out to make a difference for other carers should be supported by governments and health professionals. In Western Australia, one such form of tangible aid to carers has enabled them to develop a "Carer issue paper". This paper links the issues of carers to the core and basic elements of a mental health service. The paper outlines the principles necessary to meet the minimum requirements of the National Standards for Mental Health Services in Australia and is considered by carer groups to be essential in documenting carer participation in the mental health care system (Hardwick, 2001). Carers also require tangible aid in the form of financial remuneration to develop carers' collaborative and advocacy skills in order to progress the "partnership model" outlined under the Australian National Mental Health Strategy.

Carers also require education on how to access, for example, respite care and/or avenues for obtaining financial assistance that is essential if carers are to make ongoing commitments to care for family members. This is supported by Hardwick (2001), who reported that carers spent, on average, 104 hours per week caring and "on call" for an affected family member. According to Hill (2000) it is estimated that the 2.3 million Australians carers of people who are frail, ill, or have disabilities, save the Australian government $16 billion each year. Furthermore, Hughes (cited in Hill, 2000) claimed "we'll have a fairer system when carers don't have to give up work, employers offer paid carer leave, and community services are adequate to assist families" (p. 23).

In summary, initiatives for carers and other family members should focus on providing informative education, emotional support, and tangible aid. These initiatives would be beneficial in preparing people to more successfully care for a family member who has a mental disorder.

9.2.1.4: Initiatives to assist general practitioners and other front-line professionals

There is a need for the improved preparation of general practitioners and other front-line professionals, for example, teachers, psychologists, and school counsellors. When participants experienced a disruption of established lifestyle during the first stage of the
problem of being consumed, many of them contacted front-line professionals for help. Similarly, during the first phase of the sub-process, trying to make sense of what was happening, participants again sought contact with this group of professionals. However, for the majority of participants, these contacts did little to lessen their experience of being consumed. Some professionals encouraged the affected family member to leave school as a solution to the problem. This advice left participants feeling unsupported and perceiving these front-line professionals as lacking in knowledge and understanding of their situation.

These front-line professionals would benefit from education on the prodromal behaviours linked to the development of mental disorders in order to help them to more accurately assess and manage people who may be "at risk". Whilst the difficulty of prospectively predicting a mental disorder is acknowledged, prodromal indicators, when used appropriately, could facilitate the early diagnosis and treatment of young people with mental disorders. This improved preparation of general practitioners and other front-line professionals should include raising the awareness of the importance of listening to parents and providing them with appropriate support, informative education, and advice in response to their expressed concerns about the affected family member's abnormal behaviours. The employment of mental health nurses in the education system could also assist this process and facilitate the early recognition and treatment of people displaying "at risk" behaviours.

Finally, ongoing education and support from specialist mental health professionals should be routinely available to front-line professionals. Increased collaboration between these groups of professionals could reduce carers' experience of being consumed and promote the early diagnosis and treatment of people who have mental disorders.

9.2.1.5: Initiatives directed towards media personnel

As the media is a major avenue for communication, increased knowledge and understanding of mental disorders and current treatment methods by media personnel could be beneficial in preparing people to more successfully cope with caring for a family member who has a mental disorder. Current research suggests that the media plays a pivotal role in the stigmatisation of mental disorders and, therefore, could also play a role in the destigmatisation process (Philo, 1996; Smellie, 1999). Participants in this study commented on the relationship between the roles the media played and the promotion of negative perceptions held by the general community. Smellie (1999) agreed, stating that where mental disorders are concerned, the media is "sensationalist, distorted, uninterested in policy and
only concerned with the bizarre and tragic. It uses the language of madness casually, incorrectly, and sometimes vituperatively, thus deepening stigma against those who are mentally ill" (p. 23). Media portrayals of people who have a mental disorder are often inaccurate and most likely appear when tragedy has occurred. If coverage of mental disorders is sympathetic, the article is usually found on the back pages of the paper or advertising in health columns (Heginbotham, 1998).

Several participants in this study felt stigmatised by their neighbours and friends because these people lacked knowledge and understanding of mental disorders and believed that the participant’s affected family member could be violent. This stigma increased participants’ experience of being consumed by what was happening to them. The general population’s belief that mental disorders and violence are linked is further supported when the media portrays the two as being inseparable. As a result, the media focuses on the pain inflicted by people who have a mental disorder rather than the pain they personally experience. Ferriman (2000) claimed that in most media reports people who have a mental disorder were portrayed as ‘dangerous time bombs’. Hazelton (1997) and Cull (2000) found that the media constantly linked people who have a mental disorder with violent, difficult, and/or offensive behaviours. Robbins (1996) concurred, indicating a National Institute of Mental Health Survey found that 83 percent of people surveyed in their study believed people who have a mental disorder were dangerous. Similarly, William and Taylor (1995) reviewed the media’s representation of mental health consumers documented in 83 newspapers between 1991-1993 and reported that two main themes emerged: the stereotypical view that people who have a mental disorder are violent and unpredictable, and the negative portrayal of the closing of mental institutions.

Fear of people who have a mental disorder appears to be a common reaction, one that Scheff, as early as 1966, claimed was regularly reinforced by the selective, melodramatic reports in the media of virtually every violent incident involving a psychiatric patient (Scheff, 1966). Moreover, public unfamiliarity with mental disorders and their selective exposure to people who have a mental disorder reinforces rather than corrects this misinformation or the stereotyped views. Lawrie et al (1996) contended that maintaining local relevance in regard to information was an important pre-requisite for successful education of media personnel. Media kits are a recent Australian government innovative way of educating media personnel. The aim of the media kit is to encourage media personnel to report and portray suicide and mental disorders in a way that is least likely to cause harm,
induce copycat behaviour, or contribute to the stigma experienced by people who have a mental disorder (Commonwealth Department of Health and Aged Care, 2002). The use of these kits should encourage more informed, responsible reporting by media personnel.

In summary, the media is a highly effective medium in the passage of information to the general community and could be successfully used by governments to effectively improve the preparation of the general population's understanding of mental disorders. In turn, this would reduce the primary carer's experience of being consumed and facilitate their movement towards seeking balance in their lives.

9.2.2: The enhanced delivery of formal mental health care services

The second implication based on the findings of this study is the enhanced delivery of formal mental health care services and it encompassed four main areas: the implementation of a workable "partnership model" that involves carers at all levels of policy planning and service delivery, health professionals' application of the principles of patient confidentiality, the provision of an effective and supportive emergency psychiatric service, and reviewing health professionals management strategies.

9.2.2.1: The implementation of a workable "partnership model" that involves carers at all levels of policy planning and service delivery

The need for health professionals, consumers, and carers to work collaboratively has been highlighted by many researchers and governments (Health Department of Western Australia Policy Document on Carer/Consumer Participation, 1999; Marshall & Solomon, 2000; Mental Health Promotion & Prevention National Action Plan, 1999; Noh & Turner, 1987; Peternelji-Taylor & Hartley, 1993; Pfeiffer & Mostek, 1991). The philosophy of collaboration between health professionals, consumers, and carers is embedded in the current Australian National Mental Health Strategy and is referred to as the "partnership model". The importance of this collaborative model is highlighted in the Australian National Mental Health Report (1996), which states:

The involvement of consumers and carers in service delivery and planning embodies a core philosophy of the national mental health policy. The [Australian National Mental Health] Strategy advocates consumer and carer participation to empower and inform consumers, carers and the community, to destigmatising mental disorders and ultimately improve mental health outcomes for consumers. (p. 88)
The findings of this study suggest that, in reality, the collaborative model outlined in the Australian National Mental Health Strategy has not been routinely implemented at a service level. The disparity in the level of knowledge and understanding between participants and health professionals in this study, along with the uncaring attitudes and responses of health professionals towards carers, suggest that health professionals do not value carers. The findings also suggest that health professionals do not view carers as partners in the process of caring for people who have a mental disorder. The "partnership" problem, between health professionals and carers, is further exacerbated by health professionals’ application of the principles of patient confidentiality that excludes carers from being given information about the ill family member’s mental disorder and treatment strategies.

It is recommended that a collaborative solution to the “partnership model” be identified and implemented to reduce the psychological, social, physical, and economic costs of caring to carers. Service providers need to facilitate opportunities for consumers and carers to have input into a "partnership model" at all levels of policy-making and service provision. The recent development of carer and consumer advisory groups at a national, State and Territory level in Australia and the establishment of the National Mental Health Peak Council should assist in this process. The use of reflective and supervised practice models will further expedite the acceptance and use of collaborative models of practice by health professionals. These models would allow health professionals to embrace, discuss, evaluate, and refine the "partnership model" in collaboration with carers and to facilitate the use of a workable collaborative model at a service level. In reality, at a service level, the “partnership model” is collaboration between case managers, consumers, and carers (Mound, Gyulay, Khan & Goering, 1991). More information regarding the impact of case management on carers should be obtained, particularly regarding the level of carer satisfaction with the service provided.

Finally, ongoing education of health professionals about current national mental health policies as well as education on the philosophy governing the delivery of mental health care in Australia may be beneficial in reducing carers’ experience of being consumed. The education should cover the Australian Government’s plan and policy in relation to community mental health care.

9.2.2.2: Health professionals’ application of the principles of patient confidentiality

Health professionals’ application of the principles of patient confidentiality impacted on all aspects of the caregiving experience and prevented participants from being provided
with information regarding the affected family member. As a result many participants believed that at times their safety was placed “at risk”. Participants reported that they were often left to “flounder in the dark” without being provided with an appropriate level of information. Furthermore, participants believed that issues related to patient confidentiality impacted on their day-to-day caregiving commitment and influenced their relationship with health professionals and with their family member.

In order to provide quality mental health care, health professionals require education on patient confidentiality laws in relation to carers. Fitch (1994) claimed that, while health professionals have a requirement to maintain confidentiality, in practice this is not a clear-cut issue. Marshall and Solomon (2000) found there was confusion amongst health professionals concerning what constitutes confidential information and what information should be freely given to carers. As a result of this confusion, carers were often deprived of all information regarding their family member’s illness and this lack of knowledge and understanding by carers is not accordant with the "partnership model". Therefore, health professionals urgently require education on the principles of patient confidentiality and as Szmukler (1999) highlighted: "In this era of community care we expect much from informal carers but this has not been balanced yet by mapping out our duties towards them" (p. 337). In addition, Szmukler (1999) suggested that a lot is achieved when health professionals, carers, and consumers use an ethically sensitive approach to family engagement at the outset of treatment. This ethically sensitive approach involves spelling out, through the process of obtaining informed consent from the patient, the basis on which family involvement will proceed.

Szmukler (1999) also claimed that in the application of the principles of patient confidentiality, health professionals might need to reframe the carer’s relationship with the patient to one of not only being a family member but also being a carer. This reframing should encourage health professionals to provide carers with the rights intrinsically provided to all carers whether or not they are family.

Finally, Szmukler suggested that health professionals need to review patient confidentiality laws from the perspective of the family being viewed as a "unit of treatment" and as such carers contribute so much to the care of the ill family member. According to this author it is just and right that carers should be given certain information that they need to know, particularly information that ensures their ongoing commitment to care as well as their safety (Szmukler, 1999). However, the moral obligation to maintain or breach confidentiality
in such situations has been widely debated since the “Tarasoff case” was considered by the California Supreme Court in 1974 and 1976. In that case a patient, Prosenjit Paddor, confided in his psychologist that he intended to kill his ex-girlfriend, Tatiana Tarasoff. His psychologist, Dr Moore, informed the University of California campus police but did not warn Tatiana. Paddor murdered Tatiana and her parents sued for negligence. The court found Dr Moore and the University of California liable for negligence for failure to follow a legal duty to breach confidentiality – a decision broadened in a re-hearing of the case in 1976 (Tarasoff v Regents of the University of California 551 P2d 334, 1976). In practice this case must be relied upon with caution, as the application of this principle has not been considered in Australian courts. It should also be noted that in the United States of America the principle has not been followed in almost half of presenting cases (Kerridge, Lowe & Mc Phee, 1998).

The development of procedural definitions and guidelines related to health professionals’ application of the principles of patient confidentiality at a national and service level would be beneficial in preparing people to more successfully care for a family member who has a mental disorder. Recent legislation in England, and in some States in Australia, suggest that carers’ interests are beginning to be recognised. However, participants in this study struggled to obtain adequate information about their ill family member in the face of misunderstanding regarding legal restrictions and bureaucratic management policies.

9.2.2.3: The provision of an effective and supportive emergency psychiatric service

The findings of this study show there is a need for an improved emergency psychiatric service. Crises were particularly stressful for participants and many participants experienced feelings of being overwhelmed during crises; and the government needs to provide an emergency psychiatric service that meets the needs of both consumers and carers. Carers need to be routinely informed of procedures to follow when they require help in a crisis situation. The emergency service offered by governments during a psychiatric emergency should be analogous to calling an ambulance for a heart attack victim (Parker, 1993) and the government should provide this equality in service.

Psychiatric emergency services need to be available to carers irrespective of the affected family member’s psychiatric diagnosis or history. In this study, the needs of participants caring for a family member with a personality disorder were not met in several crisis situations. This group of carers were repeatedly used as "safety nets" by emergency services and they were left to care for their ill family member without support. It is
recommended that staff from emergency services receive education regarding the experience of being a carer of a person who has a personality disorder. This would enable health professionals to appreciate the similarity in levels of distress experienced by carers during emergency situations irrespective of their family members psychiatric diagnosis. This education is particularly important as Winston (2000) found that 15 percent of psychiatric inpatients had a borderline personality disorder.

Participants in this study recounted examples of being passed from one community service to another during times of crisis. It is recommended that community support services should be adequately staffed so as not to portray the image that they are not interested in the carer’s problems or convey the message that they are trying to get rid of the carer as quickly as possible. Community support personnel need education on the importance of using engaging and supportive communication styles to health care outcomes for people who have a mental disorder and their families.

The majority of participants in this study expressed gratitude regarding the support given to them by members of the Western Australian police force. The model of training used by the police force, over the last decade, appears very successful and this program may be applicable for use in other community emergency support training programmes. Based on the findings of this study it is suggested that the Psychiatric Emergency Team (PET) provide similar educational programs to their staff. The findings of this study show that carers require and expect support and debriefing from staff from PET following PET’s involvement in an emergency situation. As such, governments should increase funding to PET to allow this process to occur routinely. When people who have a mental disorder are removed from their homes during crisis situations, community mental health staff should debrief the carer and provide them with information regarding relevant contact people at the hospital where their family member has been taken. The community mental health professional or case manager should maintain regular contact with the carer throughout the affected family member’s period of hospitalisation. This contact would allay carers’ anxiety, providing them with essential information, education, and the promotion of a “partnership model” of mental health care.

9.2.2.4: Reviewing health professionals’ management strategies

Throughout this study participants spoke of how the management strategies used by health professionals increased their experience of being consumed. These management
strategies encompassed three main areas: the trend towards briefer periods of hospitalisation; the mobility of health professionals and the treatment choices made by psychiatrists. In providing an enhanced delivery of formal mental health services governments, policy makers, and health professionals need to review the outcomes of these strategies on the social, psychological, physical, and economic costs of caring to carers.

The trend towards briefer periods of hospitalisation increased participants’ experience of being consumed as the demand on inpatient beds meant that the family members had to be very ill before they gained access to inpatient services. As the family member’s illness had to fully develop before inpatient care was provided, the person’s recovery was often protracted. Participants also spoke of negative outcomes of hospitalisation, claiming that when the family member returned home their condition had not changed. In fact, when they returned home the situation may be worse as the ill family member was often resentful of the carer who may have initiated the request for inpatient care. Finally, brief periods of hospitalisation meant that the family member returned home before their medication was stabilised and their behaviour was socially appropriate. This placed additional strain on all members of the family and the success of the family’s integration in the community.

The mobility of health professionals also impacted on carers who had to continually interact with different health professionals and, therefore, repeat the process of establishing rapport. Each health professional had a different style, and carers had to continually manage the impact of that style on their caregiving experience. As a result carers had to continually re-negotiate their caregiving role. Furthermore, participants reported that new health professionals regularly changed the family member’s medication and this management strategy also impacted on carers and family life.

Participants in this study explained that psychiatrists used different methods in treating mental disorders. While this was commended, participants voiced concern about the general population’s knowledge of treatment choices available as the lack of knowledge led to carers and families experiencing an increased level of distress. Participant believed that psychiatrists, when making a diagnosis of a mental disorder on a person, should inform the person about all of the treatment options available to treat the diagnosed disorder and then a collaborative treatment plan should be developed.

In summary, further investigation is required to measure the impact of health professionals’ management strategies on carers. Increased collaboration between carers,
consumers, and health professionals is needed to fully understand and address the impact of these strategies on carers, consumers, and families.

9.3: Implications for the profession of mental health nursing

Mental health nursing standards advocate the inclusion of families in the treatment setting. Zeeman, Chapman, Wynaden, McGowan, Lewis, and Austin (2002) claimed that community mental health nurses worked with the most acutely ill clients and the major components of their workloads were managing psychotic clients in the home environment, crisis intervention, defusing situations in the community, and providing support to carers. However, participants in this study reported that they felt excluded from, rather than involved in, their ill family member’s care. In view of this finding, further evaluation and examination of the community mental health nurses’ (CMHN) role with both consumers and carers needs to be completed, as currently, there appears to be reasons why mental health nurses do not routinely actively involve carers. Firstly, mental health nurses are often constrained by their willingness or by their ability to involve carers. Secondly, carers have an unequal distribution of power when negotiating an active role in their family member’s care because the health care environment is alien to them and weighted in favour of the community mental health nurse (Walker & Dewar, 2001).

Mental health nurses need to identify the constraints, for example, client acuity and staffing levels, that decrease their ability to involve carers in their ill family member’s care, as well as their own value system regarding carer involvement. Therefore, undergraduate nursing curricula and ongoing education programs need to promote the importance of nurses understanding the unique experience of being a carer. In addition, nurses in education and clinical practice need to develop best practice standards that provide nurses with a framework of practice to use with carers throughout all aspects of the caregiving experience. Once developed, the best practice standards need to be implemented at a service level by mental health nurses with each carer. In addition, carers need to be invited to become actively involved in the education of undergraduate nurses and education at the service level. This collaboration would further increase an appreciation of the strengths of each partner and foster further collaboration between the two groups.

CMHNs are major stakeholders and key personnel in meeting the objectives of the Australian National Mental Health Strategy, providing the vital link between the formal and informal mental health care system. Mental health nurses are often designated as case
managers and as such have extensive contact with carers on a regular basis (Paternelj-Taylor & Hartley, 1993, Powers, 1991). In addition, CMHNs play an important liaison role in the community and this liaison role is important in educating the general population and in decreasing the stigma associated with mental disorders.

CMHNs need to be encouraged to develop outcome measures that ensure carer collaboration and satisfaction with the services they provide. By working collaboratively with carers and other professional groups, CMHNs could enact interventions such as education, advocacy, and providing support, particularly during times of crisis (Paternelj-Taylor & Hartley 1993; Zeeman, et al, 2002). Moreover, collaboration should further enhance the development of best practice models of community mental health nursing and increase the quality of life for people who have a mental disorder as well as their carers.

9.4: Further research

The findings of this study reveal the complexity and diversity of experiences of the primary carer of a person with a mental disorder. The substantive theory of seeking balance to overcome being consumed details the basic social psychological problem experienced by carers and the process carers engage in to manage this problem. While this substantive theory adds to the existing literature, to fully understand the phenomenon of caregiving to a person with a mental disorder, further research is needed. This research needs to focus on the conditions identified in this study as influencing participants' experience of being consumed and their movement towards seeking balance in their lives. This research should focus on how health professionals and policy makers can further reduce carers' psychological, physical, social and economic costs of caring. This research should be completed in a variety of social, geographical, and cultural contexts to ensure all aspects of the phenomena identified in this study are addressed.

It is recommended that further research be completed to evaluate the implementation of the "partnership model" outlined in the Australian National Mental Health Strategy. This research is crucial, as while the philosophy behind the concept of the "partnership model" is to be commended, in reality, the implementation of the model appears limited. Problems with the implementation of the "partnerships model" appears to be compounded by the communications styles employed by some health professionals, as well as health professionals' interpretations of patient confidentiality laws. Therefore, further research in these two areas is recommended.
Further research is needed to evaluate the effectiveness of education programs currently implemented in schools, the general community, and for health professionals in preparing a society to be able to interact and work with people who have a mental disorder. This research should also focus on changing attitudes of the general population towards people who have a mental disorder. More research is needed to understand societal expectations that women will care for sick family members. Finally, future research should also focus on the positive aspects of caregiving and the impact on high quality support on the experience of caregiving.

9.5: Concluding Statement

This study was aimed at gaining empirical evidence on the social and psychological experience of being a primary carer for a person with a mental disorder in the Western Australian community. Using grounded theory methodology, a basic social psychological problem and a basic social psychological process were identified. Although not articulated as such by all participants, data analysis revealed that all participants in this study experienced the problem and engaged in the process.

Participants experienced feelings of being consumed when they noticed a disruption to their established lifestyle and they developed recognition that something was wrong with the affected family member. The recognition that something was wrong led to their preoccupation with not knowing what was wrong. In addition, at times when participants were involved in emergency situations they became overwhelmed by what was happening. Participants’ experience of being consumed prevented them from meeting their established life goals and dreams. When the affected family member was diagnosed with a mental disorder, participants experienced a sustained threat to self-equilibrium as a result of their experience of caregiving.

Seeking balance was a process that participants engaged in to ensure that the caregiving commitment to the affected family member became proportionate to other areas of their lives. The experience of seeking balance consisted of a three-phase core process and a three-phase sub-process. Phase one of the core and sub-process occurred predominately in the time before the affected family member was diagnosed with a mental disorder and participants engaged in the remaining two phases after they knew what was wrong with their affected family member. As the participants elaborated on their experience of being a primary carer for a person with a mental disorder, many spoke of the experience changing their lives.
These participants explained how their experience of seeking balance had forced reflection on other important areas of their lives. Several participants believed that they were now "a better person" as a result of their caregiving experience. These participants felt they had become more compassionate, accepting, and tolerant of other people.

The research findings detail the substantive theory of seeking balance to overcome being consumed and the conditions that influenced the experience. The substantive theory will be of value to carers of people who have a mental disorder, mental health professionals, health, and government policy planners. The findings can be used in a variety of ways to facilitate carers' movement from being consumed through the process of seeking balance.

In conclusion, as the researcher conducting this study, I am not a primary carer of a person with a mental disorder. However, if at some time in the future I did become a primary carer the findings of this study would be helpful to me in seeking balance. The substantive theory of seeking balance to overcome being consumed would provide me with an understanding of how people in similar situations managed their experience of being consumed and engaged in the process of seeking balance. Like many of the participants in this study, I would hope that my experience would also make me more compassionate, accepting, and tolerant of other people. I would hope that as a result of my experience I would become a better person.

In closing, it has been a privilege to journey with the participants in this study through their experience of being consumed and their engagement in the process of seeking balance. As a health professional, I now have a deeper understanding of the experience of being a primary carer of a person with a mental disorder. I believe that my journey through each participant's experience has sensitised me to the problems faced by carers, made me more respectful of their knowledge, understanding, and expertise in assessing and managing their ill family member, made me more willing to promote collaborative models of care, and made me committed to ongoing work with carers. The journey I have taken has shown me the inner strength that people possess when faced with extraordinary situations, as well as their ability to accept and move forward in their lives while extracting positive outcomes from consuming circumstances. I, too, have grown, professionally and personally, as a result of this experience.
REFERENCES


References


Commonwealth Department of Health and Aged Care: National Mental Health Strategy.


*Health Department of Western Australia Policy Document on Consumer/Caregiver Participation* (1999). Perth, Western Australia: Mental Health Division/Health Department of Western Australia Publication.


Morse, J. (1999a). Qualitative methods: The state of the art. *Qualitative Health Research, 9*(3), 393-406.

Morse, J. (1999b). Qualitative generalizability. *Qualitative Health Research, 9*(1), 5-6.


Porter-Smith, N. (2001). Carers’ of relatives with schizophrenia or a first episode of psychosis: Coping strategies, level of burden, social network and the reported level of
symptomatic disturbance. Connect: Mental Health Matters in Western Australia, 6(2), 29.


Van Manen, M. (2002). Care-as-worry, or “don’t worry, be happy”. *Qualitative Health Research, 12*(2), 262-278.


Principles for the protection of persons with mental illness and the improvement of mental health care

Adopted by General Assembly resolution 46/119 of 17 December 1991

APPENDIX A

Application

These Principles shall be applied without discrimination of any kind such as on grounds of disability, race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, legal or social status, age, property or birth.

Definitions

In these Principles:

"Counsel" means a legal or other qualified representative;

"Independent authority" means a competent and independent authority prescribed by domestic law;

"Mental health care" includes analysis and diagnosis of a person's mental condition, and treatment, care and rehabilitation for a mental illness or suspected mental illness;

"Mental health facility" means any establishment, or any unit of an establishment, which as its primary function provides mental health care;

"Mental health practitioner" means a medical doctor, clinical psychologist, nurse, social worker or other appropriately trained and qualified person with specific skills relevant to mental health care;

"Patient" means a person receiving mental health care and includes all persons who are admitted to a mental health facility;

"Personal representative" means a person charged by law with the duty of representing a patient's interests in any specified respect or of exercising specified rights on the patient's behalf, and includes the parent or legal guardian of a minor unless otherwise provided by domestic law;

The review body" means the body established in accordance with Principle 17 to review the involuntary admission or retention of a patient in a mental health facility.

General limitation clause

The exercise of the rights set forth in these Principles may be subject only to such limitations as are prescribed by law and are necessary to protect the health or safety of the person concerned or of others, or otherwise to protect public safety, order, health or morals.
The exercise of the rights set forth in these Principles may be subject only to such limitations as are prescribed by law and are necessary to protect the health or safety of the person concerned or of others, or otherwise to protect public safety, order, health or morals or the fundamental rights and freedoms of others.

**Principle 1**

**Fundamental freedoms and basic rights**

1. All persons have the right to the best available mental health care, which shall be part of the health and social care system.

2. All persons with a mental illness, or who are being treated as such persons, shall be treated with humanity and respect for the inherent dignity of the human person.

3. All persons with a mental illness, or who are being treated as such persons, have the right to protection from economic, sexual and other forms of exploitation, physical or other abuse and degrading treatment.

4. There shall be no discrimination on the grounds of mental illness. "Discrimination" means any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights. Special measures solely to protect the rights, or secure the advancement, of persons with mental illness shall not be deemed to be discriminatory. Discrimination does not include any distinction, exclusion or preference undertaken in accordance with the provisions of these Principles and necessary to protect the human rights of a person with a mental illness or of other individuals.

5. Every person with a mental illness shall have the right to exercise all civil, political, economic, social and cultural rights as recognized in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, and in other relevant instruments, such as the Declaration on the Rights of Disabled Persons and the Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment.

6. Any decision that, by reason of his or her mental illness, a person lacks legal capacity, and any decision that, in consequence of such incapacity, a personal representative shall be appointed, shall be made only after a fair hearing by an independent and impartial tribunal established by domestic law. The person whose capacity is at issue shall be entitled to be represented by a counsel. If the person whose capacity is at issue does not himself or herself secure such representation, it shall be made available without payment by that person to the extent that he or she does not have sufficient means to pay for it. The counsel shall not in the same proceedings represent a mental health facility or its personnel and shall not also represent a member of the family of the person whose capacity is at issue unless the tribunal is satisfied that there is no conflict of interest. Decisions regarding capacity and the need for a personal representative shall be reviewed at reasonable intervals prescribed by domestic law. The person whose capacity is at issue, his or her personal representative, if any, and any other interested person shall have the right to appeal to a higher court against any such decision.

7. Where a court or other competent tribunal finds that a person with mental illness is unable to manage his or her own affairs, measures shall be taken, so far as is necessary and
appropriate to that person's condition, to ensure the protection of his or her interest.

Principle 2

Protection of minors

Special care should be given within the purposes of these Principles and within the context of domestic law relating to the protection of minors to protect the rights of minors, including, if necessary, the appointment of a personal representative other than a family member.

Principle 3

Life in the community

Every person with a mental illness shall have the right to live and work, as far as possible, in the community.

Principle 4

Determination of mental illness

1. A determination that a person has a mental illness shall be made in accordance with internationally accepted medical standards.

2. A determination of mental illness shall never be made on the basis of political, economic or social status, or membership of a cultural, racial or religious group, or any other reason not directly relevant to mental health status.

3. Family or professional conflict, or non-conformity with moral, social, cultural or political values or religious beliefs prevailing in a person's community, shall never be a determining factor in diagnosing mental illness.

4. A background of past treatment or hospitalization as a patient shall not of itself justify any present or future determination of mental illness.

5. No person or authority shall classify a person as having, or otherwise indicate that a person has, a mental illness except for purposes directly relating to mental illness or the consequences of mental illness.

Principle 5

Medical examination

No person shall be compelled to undergo medical examination with a view to determining whether or not he or she has a mental illness except in accordance with a procedure authorized by domestic law.

Principle 6
Confidentiality

The right of confidentiality of information concerning all persons to whom these Principles apply shall be respected.

Principle 7

Role of community and culture

1. Every patient shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives.

2. Where treatment takes place in a mental health facility, a patient shall have the right, whenever possible, to be treated near his or her home or the home of his or her relatives or friends and shall have the right to return to the community as soon as possible.

3. Every patient shall have the right to treatment suited to his or her cultural background.

Principle 8

Standards of care

1. Every patient shall have the right to receive such health and social care as is appropriate to his or her health needs, and is entitled to care and treatment in accordance with the same standards as other ill persons.

2. Every patient shall be protected from harm, including unjustified medication, abuse by other patients, staff or others or other acts causing mental distress or physical discomfort.

Principle 9

Treatment

1. Every patient shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the patient’s health needs and the need to protect the physical safety of others.

2. The treatment and care of every patient shall be based on an individually prescribed plan, discussed with the patient, reviewed regularly, revised as necessary and provided by qualified professional staff.

3. Mental health care shall always be provided in accordance with applicable standards of ethics for mental health practitioners, including internationally accepted standards such as the Principles of Medical Ethics adopted by the United Nations General Assembly. Mental health knowledge and skills shall never be abused.

4. The treatment of every patient shall be directed towards preserving and enhancing personal autonomy.
Principle 10

Medication

1. Medication shall meet the best health needs of the patient, shall be given to a patient only for therapeutic or diagnostic purposes and shall never be administered as a punishment or for the convenience of others. Subject to the provisions of paragraph 15 of Principle 11, mental health practitioners shall only administer medication of known or demonstrated efficacy.

2. All medication shall be prescribed by a mental health practitioner authorized by law and shall be recorded in the patient's records.

Principle 11

Consent to treatment

1. No treatment shall be given to a patient without his or her informed consent, except as provided for in paragraphs 6, 7, 8, 13 and 15 below.

2. Informed consent is consent obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient on:

   (a) The diagnostic assessment;

   (b) The purpose, method, Likely duration and expected benefit of the proposed treatment;

   (c) Alternative modes of treatment, including those less intrusive; and

   (d) Possible pain or discomfort, risks and side-effects of the proposed treatment.

3. A patient may request the presence of a person or persons of the patient's choosing during the procedure for granting consent.

4. A patient has the right to refuse or stop treatment, except as provided for in paragraphs 6, 7, 8, 13 and 15 below. The consequences of refusing or stopping treatment must be explained to the patient.

5. A patient shall never be invited or induced to waive the right to informed consent. If the patient should seek to do so, it shall be explained to the patient that the treatment cannot be given without informed consent.

6. Except as provided in paragraphs 7, 8, 12, 13, 14 and 15 below, a proposed plan of treatment may be given to a patient without a patient's informed consent if the following conditions are satisfied:

   (a) The patient is, at the relevant time, held as an involuntary patient;

   (b) An independent authority, having in its possession all relevant information, including the
information specified in paragraph 2 above, is satisfied that, at the relevant time, the patient lacks the capacity to give or withhold informed consent to the proposed plan of treatment or, if domestic legislation so provides, that, having regard to the patient's own safety or the safety of others, the patient unreasonably withholds such consent; and

(c) The independent authority is satisfied that the proposed plan of treatment is in the best interest of the patient's health needs.

7. Paragraph 6 above does not apply to a patient with a personal representative empowered by law to consent to treatment for the patient; but, except as provided in paragraphs 12, 13, 14 and 15 below, treatment may be given to such a patient without his or her informed consent if the personal representative, having been given the information described in paragraph 2 above, consents on the patient's behalf.

8. Except as provided in paragraphs 12, 13, 14 and 15 below, treatment may also be given to any patient without the patient's informed consent if a qualified mental health practitioner authorized by law determines that it is urgently necessary in order to prevent immediate or imminent harm to the patient or to other persons. Such treatment shall not be prolonged beyond the period that is strictly necessary for this purpose.

9. Where any treatment is authorized without the patient's informed consent, every effort shall nevertheless be made to inform the patient about the nature of the treatment and any possible alternatives and to involve the patient as far as practicable in the development of the treatment plan.

10. All treatment shall be immediately recorded in the patient's medical records, with an indication of whether involuntary or voluntary.

11. Physical restraint or involuntary seclusion of a patient shall not be employed except in accordance with the officially approved procedures of the mental health facility and only when it is the only means available to prevent immediate or imminent harm to the patient or others. It shall not be prolonged beyond the period which is strictly necessary for this purpose. All instances of physical restraint or involuntary seclusion, the reasons for them and their nature and extent shall be recorded in the patient's medical record. A patient who is restrained or secluded shall be kept under humane conditions and be under the care and close and regular supervision of qualified members of the staff. A personal representative, if any and if relevant, shall be given prompt notice of any physical restraint or involuntary seclusion of the patient.

12. Sterilization shall never be carried out as a treatment for mental illness.

13. A major medical or surgical procedure may be carried out on a person with mental illness only where it is permitted by domestic law, where it is considered that it would best serve the health needs of the patient and where the patient gives informed consent, except that, where the patient is unable to give informed consent, the procedure shall be authorized only after independent review.

14. Psychosurgery and other intrusive and irreversible treatments for mental illness shall never be carried out on a patient who is an involuntary patient in a mental health facility and, to the extent that domestic law permits them to be carried out, they may be carried out on any other patient only where the patient has given informed consent and an independent external body
has satisfied itself that there is genuine informed consent and that the treatment best serves the health needs of the patient.

15. Clinical trials and experimental treatment shall never be carried out on any patient without informed consent, except that a patient who is unable to give informed consent may be admitted to a clinical trial or given experimental treatment, but only with the approval of a competent, independent review body specifically constituted for this purpose.

16. In the cases specified in paragraphs 6, 7, 8, 13, 14 and 15 above, the patient or his or her personal representative, or any interested person, shall have the right to appeal to a judicial or other independent authority concerning any treatment given to him or her.

Principle 12

Notice of rights

1. A patient in a mental health facility shall be informed as soon as possible after admission, in a form and a language which the patient understands, of all his or her rights in accordance with these Principles and under domestic law, which information shall include an explanation of those rights and how to exercise them.

2. If and for so long as a patient is unable to understand such information, the rights of the patient shall be communicated to the personal representative, if any and if appropriate, and to the person or persons best able to represent the patient's interests and willing to do so.

3. A patient who has the necessary capacity has the right to nominate a person who should be informed on his or her behalf, as well as a person to represent his or her interests to the authorities of the facility.

Principle 13

Rights and conditions in mental health facilities

1. Every patient in a mental health facility shall, in particular, have the right to full respect for his or her:

(a) Recognition everywhere as a person before the law;

(b) Privacy;

(c) Freedom of communication, which includes freedom to communicate with other persons in the facility; freedom to send and receive uncensored private communications; freedom to receive, in private, visits from a counsel or personal representative and, at all reasonable times, from other visitors; and freedom of access to postal and telephone services and to newspapers, radio and television;

(d) Freedom of religion or belief.

2. The environment and living conditions in mental health facilities shall be as close as possible to those of the normal life of persons of similar age and in particular shall include:

(a) Facilities for recreational and leisure activities;

(b) Facilities for education;

(c) Facilities to purchase or receive items for daily living, recreation and communication;

(d) Facilities, and encouragement to use such facilities, for a patient’s engagement in active occupation suited to his or her social and cultural background, and for appropriate vocational rehabilitation measures to promote reintegration in the community. These measures should include vocational guidance, vocational training and placement services to enable patients to secure or retain employment in the community.

3. In no circumstances shall a patient be subject to forced labour. Within the limits compatible with the needs of the patient and with the requirements of institutional administration, a patient shall be able to choose the type of work he or she wishes to perform.

4. The labour of a patient in a mental health facility shall not be exploited. Every such patient shall have the right to receive the same remuneration for any work which he or she does as would, according to domestic law or custom, be paid for such work to a non-patient. Every such patient shall, in any event, have the right to receive a fair share of any remuneration which is paid to the mental health facility for his or her work.

Principle 14

Resources for mental health facilities

1. A mental health facility shall have access to the same level of resources as any other health establishment, and in particular:

(a) Qualified medical and other appropriate professional staff in sufficient numbers and with adequate space to provide each patient with privacy and a programme of appropriate and active therapy;

(b) Diagnostic and therapeutic equipment for the patient;

(c) Appropriate professional care; and

(d) Adequate, regular and comprehensive treatment, including supplies of medication.

2. Every mental health facility shall be inspected by the competent authorities with sufficient frequency to ensure that the conditions, treatment and care of patients comply with these Principles.

Principle 15

Admission principles

1. Where a person needs treatment in a mental health facility, every effort shall be made to avoid involuntary admission.
2. Access to a mental health facility shall be administered in the same way as access to any other facility for any other illness.

3. Every patient not admitted involuntarily shall have the right to leave the mental health facility at any time unless the criteria for his or her retention as an involuntary patient, as set forth in Principle 16, apply, and he or she shall be informed of that right.

Principle 16

Involuntary admission

1. A person may (a) be admitted involuntarily to a mental health facility as a patient; or (b) having already been admitted voluntarily as a patient, be retained as an involuntary patient in the mental health facility if, and only if, a qualified mental health practitioner authorized by law for that purpose determines, in accordance with Principle 4, that person has a mental illness and considers:

(a) That, because of that mental illness, there is a serious likelihood of immediate or imminent harm to that person or to other persons; or

(b) That, in the case of a person whose mental illness is severe and whose judgment is impaired, failure to admit or retain that person is likely to lead to a serious deterioration in his or her condition or will prevent the giving of appropriate treatment that can only be given by admission to a mental health facility in accordance with the principle of the least restrictive alternative.

In the case referred to in subparagraph (b), a second such mental health practitioner, independent of the first, should be consulted where possible. If such consultation takes place, the involuntary admission or retention may not take place unless the second mental health practitioner concurs.

2. Involuntary admission or retention shall initially be for a short period as specified by domestic law for observation and preliminary treatment pending review of the admission or retention by the review body. The grounds of the admission shall be communicated to the patient without delay and the fact of the admission and the grounds for it shall also be communicated promptly and in detail to the review body, to the patient's personal representative, if any, and, unless the patient objects, to the patient's family.

3. A mental health facility may receive involuntarily admitted patients only if the facility has been designated to do so by a competent authority prescribed by domestic law.

Principle 17

Review body

1. The review body shall be a judicial or other independent and impartial body established by domestic law and functioning in accordance with procedures laid down by domestic law. It shall, in formulating its decisions, have the assistance of one or more qualified and independent mental health practitioners and take their advice into account.
2. The review body's initial review, as required by paragraph 2 of Principle 16, of a decision to admit or retain a person as an involuntary patient shall take place as soon as possible after that decision and shall be conducted in accordance with simple and expeditious procedures as specified by domestic law.

3. The review body shall periodically review the cases of involuntary patients at reasonable intervals as specified by domestic law.

4. An involuntary patient may apply to the review body for release or voluntary status, at reasonable intervals as specified by domestic law.

5. At each review, the review body shall consider whether the criteria for involuntary admission set out in paragraph 1 of Principle 16 are still satisfied, and, if not, the patient shall be discharged as an involuntary patient.

6. If at any time the mental health practitioner responsible for the case is satisfied that the conditions for the retention of a person as an involuntary patient are no longer satisfied, he or she shall order the discharge of that person as such a patient.

7. A patient or his personal representative or any interested person shall have the right to appeal to a higher court against a decision that the patient be admitted to, or be retained in, a mental health facility.

**Principle 18**

**Procedural safeguards**

1. The patient shall be entitled to choose and appoint a counsel to represent the patient as such, including representation in any complaint procedure or appeal. If the patient does not secure such services, a counsel shall be made available without payment by the patient to the extent that the patient lacks sufficient means to pay.

2. The patient shall also be entitled to the assistance, if necessary, of the services of an interpreter. Where such services are necessary and the patient does not secure them, they shall be made available without payment by the patient to the extent that the patient lacks sufficient means to pay.

3. The patient and the patient's counsel may request and produce at any hearing an independent mental health report and any other reports and oral, written and other evidence that are relevant and admissible.

4. Copies of the patient's records and any reports and documents to be submitted shall be given to the patient and to the patient's counsel, except in special cases where it is determined that a specific disclosure to the patient would cause serious harm to the patient's health or put at risk the safety of others. As domestic law may provide, any document not given to the patient should, when this can be done in confidence, be given to the patient's personal representative and counsel. When any part of a document is withheld from a patient, the patient or the patient's counsel, if any, shall receive notice of the withholding and the reasons for it and shall be subject to judicial review.

5. The patient and the patient's personal representative and counsel shall be entitled to attend, participate and be heard personally in any hearing.

6. If the patient or the patient's personal representative or counsel requests that a particular person be present at a hearing, that person shall be admitted unless it is determined that the person's presence could cause serious harm to the patient's health or put at risk the safety of others.

7. Any decision whether the hearing or any part of it shall be in public or in private and may be publicly reported shall give full consideration to the patient's own wishes, to the need to respect the privacy of the patient and of other persons and to the need to prevent serious harm to the patient's health or to avoid putting at risk the safety of others.

8. The decision arising out of the hearing and the reasons for it shall be expressed in writing. Copies shall be given to the patient and his or her personal representative and counsel. In deciding whether the decision shall be published in whole or in part, full consideration shall be given to the patient's own wishes, to the need to respect his or her privacy and that of other persons, to the public interest in the open administration of justice and to the need to prevent serious harm to the patient's health or to avoid putting at risk the safety of others.

_Principle 19_

_Access to information_

1. A patient (which term in this Principle includes a former patient) shall be entitled to have access to the information concerning the patient in his or her health and personal records maintained by a mental health facility. This right may be subject to restrictions in order to prevent serious harm to the patient's health and avoid putting at risk the safety of others. As domestic law may provide, any such information not given to the patient should, when this can be done in confidence, be given to the patient's personal representative and counsel. When any of the information is withheld from a patient, the patient or the patient's counsel, if any, shall receive notice of the withholding and the reasons for it and it shall be subject to judicial review.

2. Any written comments by the patient or the patient's personal representative or counsel shall, on request, be inserted in the patient's file.

_Principle 20_

_Criminal offenders_

1. This Principle applies to persons serving sentences of imprisonment for criminal offences, or who are otherwise detained in the course of criminal proceedings or investigations against them, and who are determined to have a mental illness or who it is believed may have such an illness.

2. All such persons should receive the best available mental health care as provided in Principle 1. These Principles shall apply to them to the fullest extent possible, with only such limited modifications and exceptions as are necessary in the circumstances. No such modifications and exceptions shall prejudice the persons' rights under the instruments noted in

paragraph 5 of Principle 1.

3. Domestic law may authorize a court or other competent authority, acting on the basis of competent and independent medical advice, to order that such persons be admitted to a mental health facility.

4. Treatment of persons determined to have a mental illness shall in all circumstances be consistent with Principle 11.

*Principle 21*

*Complaints*

Every patient and former patient shall have the right to make a complaint through procedures as specified by domestic law.

*Principle 22*

*Monitoring and remedies*

States shall ensure that appropriate mechanisms are in force to promote compliance with these Principles, for the inspection of mental health facilities, for the submission, investigation and resolution of complaints and for the institution of appropriate disciplinary or judicial proceedings for professional misconduct or violation of the rights of a patient.

*Principle 23*

*Implementation*

1. States should implement these Principles through appropriate legislative, judicial, administrative, educational and other measures, which they shall review periodically.

2. States shall make these Principles widely known by appropriate and active means.

*Principle 24*

*Scope of principles relating to mental health facilities*

These Principles apply to all persons who are admitted to a mental health facility.

*Principle 25*

*Saving of existing rights*

There shall be no restriction upon or derogation from any existing rights of patients, including rights recognized in applicable international or domestic law, on the pretext that these Principles do not recognize such rights or that they recognize them to a lesser extent.
APPENDIX B

DIAGNOSTIC AND STATISTICAL MANUAL OF THE
AMERICAN PSYCHIATRIC ASSOCIATION
CLASSIFICATION OF DISORDERS
(DSM IV)

Reprinted with permission from the Diagnostic and Statistical Manual of Mental Disorders, Fourth

The DSM IV is comprised of a multi axial assessment system. The five axes included in the
DSM IV multiaxial classification system
Axis I Clinical disorders, other conditions that may be a focus of clinical
attention
Axis II Personality disorders, mental retardation
Axis III General medical conditions
Axis IV Psychosocial and environmental problems
Axis V Global assessment of functioning

The use of the multiaxial system facilitates comprehensive and systematic evaluation with
attention to the various mental disorders and general medical conditions, psychosocial and
environmental problems, and the level of functioning that might be overlooked if the focus
were on assessing a single presenting problem.

SCHIZOPHRENIA

DSM IV DIAGNOSTIC CRITERIA FOR SCHIZOPHRENIA

Diagnosis of schizophrenia is based on six criteria:

A. Characteristic symptoms: Two (or more) of the following, each present for a significant
portion of the time during a one month period (or less if successfully treated):
1. delusions
2. hallucinations
3. disorganised speech
4. grossly disorganised or catatonic behaviour
5. negative symptom, i.e., affective flattening, alogia, or avolition.

B. Social or occupational dysfunction for a significant portion of the time since the onset of
the disturbance, one or more major areas of functioning, such as work, interpersonal
relations, or self care are markedly below the level achieved prior to the onset (or when
the onset is in childhood or adolescence, failure to achieve expected level of interpersonal,
academic, or occupational achievement).

C. Duration: Continuous signs of the disturbance persist for at least six months. This six
month period must include at least one month of symptoms (or less if successfully
treated) that meet Criterion I i.e., active-phase symptoms) and may include periods of
prodromal or residual symptoms. During these prodromal or residual periods, the signs of
the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. Schizoaffective and Mood disorder exclusion: Schizoaffective Disorder and Mood Disorder with Psychotic features have been ruled out because either (1) no Major Depressive, Manic, or Mixed Episodes have occurred concurrently with the active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms their total duration has been brief relative to the duration of the active and residual periods.

E. Substance/ general medical condition exclusion: The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

F. Relationship to a Pervasive Development Disorder. If there is a history of Autistic Disorder or another Pervasive Development Disorder, the additional diagnosis of Schizophrenia is only made if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

Schizophrenic Subtypes

Paranoid type: (295.30)
A type of Schizophrenia in which the following criteria are met:

A. Preoccupation with one or more delusions or frequent auditory hallucinations.

B. None of the following is prominent: disorganised speech, disorganised or catatonic behaviour, or flat or inappropriate affect.

Disorganised type: (295.10)
A type of Schizophrenia in which the following criteria are met:

A. All of the following are prominent:
   1. disorganised speech
   2. disorganised behaviour
   3. flat or inappropriate affect

B. The criteria are not met for Catatonic Type.

Catatonic Type: (295.20)
A type of Schizophrenia in which the clinical picture is dominated by at least two of the following:
   1. motor immobility as evidenced by catalepsy (including waxy flexibility) or stupor
   2. excessive motor activity (that is apparently purposeless and not influenced by external stimuli)
   3. extreme negativism (an apparently motiveless resistance to all instructions or maintenance of a rigid posture against attempts to be moved) or mutism.
4. Peculiarities of voluntary movement as evidenced by posturing (voluntary assumption of inappropriate or bizarre postures), stereotyped movements, prominent mannerisms, or prominent grimacing.
5. echolalia or echopraxia.

Undifferentiated Type (295.90)
A type of Schizophrenia in which symptoms that meet Criterion A are present but the criteria are not met for the Paranoid, Disorganised, or Catatonic Type.

Residual Type (295.60)
A type of Schizophrenia in which the following criteria are met

A. Absence of prominent delusions, hallucinations, disorganised speech, and grossly disorganised or catatonic behaviour.
B. There is continuing evidence of the disturbance, as indicated by the presence of negative symptoms or two or more symptoms listed in Criterion A for Schizophrenia, present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

Schizophréniform Disorder (295.40)

A. Criteria A, D and E of Schizophrenia are met
B. An episode of the disorder (including prodromal, active, and residual phases) lasts at least one month but less than six months. (When the diagnosis must be made without waiting for recovery, it should be qualified as "Provisional").

Specify if:
Without good prognostic features
With good prognostic features: as evidenced by two (or more) of the following:
1. onset of prominent psychotic symptoms within four weeks from the first noticeable change in usual behaviour or functioning.
2. confusion or perplexity at the height of the psychotic episode
3. good premorbid social and occupational functioning
4. absence of blunted or flat affect.

Schizoaffective Disorder (295.70)

A. An uninterrupted period of illness during which, at some time, there is either a Major Depressive Episode, a Manic Episode, or a Mixed Episode concurrent with symptoms that meet Criterion A for Schizophrenia. Note: The Major Depressive Episode must include Criterion A1: depressed mood.
B. During the same period of illness, there have been delusions or hallucinations for at least two weeks in the absence of prominent mood symptoms.
C. Symptoms that meet criteria for a mood episode are present for a substantial portion of the total duration of the active and residual periods of the illness.
D. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

Specify type:
- **Bipolar type**: if the disturbance includes a Manic or a Mixed Episode (or a Manic or a Mixed Episode and Major Depressive Episodes)
- **Depressive type**: if the disturbance only includes Major Depressive Episodes

**MOOD DISORDERS**

1. **DEPRESSIVE DISORDERS**
   - **Major Depressive Disorder**

**THE DSMIV DIAGNOSTIC CRITERIA FOR MAJOR DEPRESSIVE DISORDER**

A. Five (or more) of the following symptoms have been present during the same 2 week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

1. **Depressed mood for most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: In children and adolescents, can be irritable mood.**
2. **Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day.**
3. **Significant weight loss when not dieting or weight gain, or decrease or increase in appetite nearly every day. Note: In children, consider failure to make expected weight gains.**
4. **Insomnia or hypersomnia nearly every day.**
5. **Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).**
6. **Fatigue or loss of energy nearly every day.**
7. **Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).**
8. **Diminished ability to think or concentrate, or indecisiveness, nearly every day.**
9. **Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.**

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. The symptoms are not due to the direct physiological effects of a substance or a general medical condition.

D. The symptoms are not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than two months or are characterised by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.
Dysthymic Disorder

DSMIV DIAGNOSTIC CRITERIA FOR DYSTHYMIC DISORDER

A. Depressed mood for most of the day, for more days than not, as indicated either by subjective account or observation by others, for at least two years. Note: In children and adolescents, mood can be irritable and duration must be at least one year.

B. Presence, while depressed, of two (or more) of the following:
   1. Poor appetite or overeating
   2. Insomnia or hypersomnia
   3. Low energy or fatigue
   4. Low self-esteem
   5. Poor concentration or difficulty making decisions
   6. Feelings of hopelessness

C. During the two-year period (one year for children or adolescents) of the disturbance, the person has never been without the symptoms in Criteria A and B for more than 2 months at a time.

D. No major Depressive Episode has been present during the first two years of the disturbance (one year for children and adolescents); or Major Depressive Disorder, In partial Remission.

E. There has never been a Manic Episode, a Mixed Episode, or a Hypomanic Episode and criteria have never been met for Cyclothymic Disorder.

F. The symptoms are not due to the direct physiological effects of a substance or a general medical condition.

G. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Depressive Disorder Not Otherwise Specified

Depressive disorder Not Otherwise Specified includes disorders with depressive features that do not meet the criteria of other depressive disorders. Examples include, premenstrual dysphoric disorder, a minor depressive disorder, and postpsychotic depressive disorder of schizophrenia.

2. BIPOLAR DISORDERS:

DSMIV DIAGNOSTIC CRITERIA FOR MANIC AND HYPOMANIC EPISODES

Manic episode
A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood, lasting at least one week (or any duration if hospitalisation is necessary).
B. During the period of mood disturbance, three (or more) of the following symptoms have persisted (four if the mood is only irritable) and have been present to a significant degree:

1. Inflated self-esteem or grandiosity
2. Decreased need for sleep (e.g., feels rested after only three hours of sleep).
3. More talkative than usual or pressure to keep talking.
4. Flight of ideas or subjective experience that thoughts are racing
5. Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli)
6. Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation
7. Excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)

C. The symptoms do not meet criteria for Mixed Episode

D. The mood disturbance is sufficiently severe to cause marked impairment in occupational functioning or in usual social activities or relationships with others, or to necessitate hospitalisation to prevent harm to self or others, or there are psychotic features.

E. The symptoms are not due to the direct physiological effects of a substance or a general medical condition.

Hypomanic episode

A. A distinct period of persistently elevated, expansive, or irritable mood, lasting at least four days, that is clearly different from the usual nondepressed mood.

B. Same mood disturbances as in Manic Episode occur.

C. The episode is associated with an unequivocal change in functioning that is uncharacteristic of the person.

D. The episode is not severe enough to cause marked impairment in social or occupational functioning, or to necessitate hospitalisation, and there are no psychotic features.

E. The symptoms are not due to the direct physiological effects of a substance or a general medical condition.

Bipolar 1 Disorder

DSM IV DIAGNOSTIC CRITERIA FOR BIPOLAR 1 DISORDER VARIANTS

BIPOLAR 1 DISORDER, SINGLE MANIC EPISODE

A. Presence of only one Manic Episode and no past Major Depressive Episodes

BIPOLAR 1 DISORDER, MOST RECENT EPISODE HYPOMANIC

A. Currently (or most recently) in a Hypomanic Episode
B. There has previously been at least one Manic Episode or Mixed Episode
C. The mood symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

**BIPOLAR I DISORDER, MOST RECENT EPISODE MANIC**
A. Currently (or most recently) in a Manic Episode
B. There has previously been at least one Major Depressive Episode, Manic Episode, or Mixed Episode.

**BIPOLAR I DISORDER, MOST RECENT EPISODE DEPRESSED**
A. Currently (or most recently) in a Major Depressive Episode
B. There has previously been at least one Manic Episode or Mixed Episode.

**BIPOLAR I DISORDER, MOST RECENT EPISODE DEPRESSED**
A. Currently (or most recently) in a Major Depressive Episode.
B. There has previously been at least one Manic Episode or Mixed Episode.

Note: For all Bipolar Disorders, the Manic Episode is not better accounted for by Schizoaffective Disorder and is not superimposed on Schizophrenia, Schizoaffective Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

**Bipolar II disorder**

**DSMIV CRITERIA FOR BIPOLAR II DISORDER**
A. Presence (or history) of one or more major Depressive Episodes
B. Presence (or history) of at least one Hypomanic Episode
C. There has never been a Manic Episode or a Mixed Episode
D. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

**Cyclothymic Disorder**

**DSMIV DIAGNOSTIC CRITERIA FOR CYCLOTHYMIC DISORDER**
A. For at least two years, the presence of numerous periods of hypomanic symptoms and numerous periods with depressive symptoms that do not meet criteria for a Major Depressive Episode. Note: In children and adolescents, the duration must be at least one year.
B. During the above two year period (one year in children and adolescents), the person has not been without the symptoms in Criterion A for more than two months at a time.
C. No Major Depressive Episode, Manic Episode, or Mixed Episode has been present during the first two years of the disturbance.
D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).

E. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

**Bipolar Disorder Not Otherwise Specified**

Bipolar Disorder Not Otherwise Specified includes disorders with bipolar features that do not meet the criteria for any specific bipolar disorder. Examples are a rapid alteration (over days) of depressive and manic behaviour that does not meet the criteria for major depression or manic episodes or recurrent hypomanic episodes without depression.

**ANXIETY DISORDERS**

**Obsessive Compulsive Disorder**

**DSMIV Diagnostic Criteria for Obsessive-Compulsive Disorder**

A. Either obsessions or compulsions: 
   *Obsessions as defined by (1), (2), (3), and (4):*
   1. Recurrent and persistent thoughts, impulses, or images that are experienced, at some time during the disturbance, as intrusive and inappropriate and that cause marked anxiety or distress.
   2. The thoughts, impulses, or images are not simply excessive worries about real-life problems.
   3. The person attempts to ignore or suppress such thoughts, impulses, or images, or to neutralise them with some other thought or action.
   4. The person recognises that the obsessed thoughts, impulses, or images are a product of his or her own mind (not imposed from without as in thought insertion).

   *Compulsions as defined by (1) and (2):*
   1. Repetitive behaviours, (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly.
   2. The behaviours or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however these behaviours or mental acts either are not connected in a realistic way with what they are designed to neutralise or prevent or are clearly excessive.

B. At some point during the course of the disorder, the person has recognised that the obsessions or compulsions are excessive or unreasonable. Note: This does not apply to children.
C. The obsessions or compulsions cause marked distress, are time consuming (take more than 1 hour a day), or significantly interfere with the person's normal routine, occupational (or academic) functioning, or usual social activities or relationships.

D. If another Axis I disorder is present, the content of the obsession or compulsions is not restricted to it (e.g., preoccupation with food in the presence of an Eating Disorder, hair pulling in the presence of Trichotillomania; concern with appearance in the presence of Body Dysmorphic Disorder; preoccupation with drugs in the presence of a Substance use Disorder; preoccupation with having a serious illness in the presence of Hypochondriasis; preoccupation with sexual urges or fantasies in the presence of a Paraphilia; or guilty ruminations in the presence of Major Depressive Disorder).

E. The disturbance is not due to the direct physiological effects of substance (e.g., a drug of abuse, a medication) or a general medical condition.

PERSONALITY DISORDERS

All personality disorders are coded on Axis II of the DSM IV.

DSM IV GENERAL DIAGNOSTIC CRITERIA FOR A PERSONALITY DISORDER

A. An enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture. This pattern is manifested in two (or more) of the following areas:
   1. cognition (i.e., ways of perceiving and interpreting self, other people, and events)
   2. affectivity (i.e., the range, intensity, lability, and appropriateness of emotional response)
   3. interpersonal functioning
   4. impulse control

B. The enduring pattern is inflexible and pervasive across a broad range of personal and social situations.

C. The enduring pattern leads to clinically significant distress or impairment in social, occupational, or other important areas of functioning.

D. The pattern is stable and of long duration and its onset can be traced back at least to adolescents or early adulthood.

E. The enduring pattern is not better accounted for as a manifestation or consequence of another mental disorder.

F. The enduring pattern is not due to the direct physiological effect of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., head trauma).

Cluster B Personality Disorders

Boderline Personality Disorder
DSMIV DIAGNOSTIC CRITERIA FOR BORDERLINE PERSONALITY DISORDER

A pervasive pattern of instability of interpersonal relationships, self image, and affects, and marked impulsivity beginning by early childhood and present in a variety of contexts, as indicated by five (or more) of the following:

1. Frantic efforts to avoid real or imagined abandonment. Note: Do not include suicidal or self-mutilating behaviour covered by Criterion 5.
2. A pattern of unstable and intense interpersonal relationships characterised by alternating between extremes of idealisation and devaluation
3. Identity disturbance: markedly and persistently unstable self-image or sense of self.
4. Impulsivity in at least two areas that are potentially self-damaging (e.g. spending, sex, substance abuse, reckless driving, binge eating).
5. Recurrent suicidal behaviour, gestures, or threats, or self mutilating behaviour.
6. Affective instability due to a marked reactivity of mood (e.g. Intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days)
7. Chronic feelings of emptiness
8. Inappropriate, intense anger or difficulty controlling anger (e.g. frequent displays of temper, constant anger, recurrent physical fights)
9. Transient, stress related paranoid ideation or severe dissociative symptoms.

ATTENTION DEFICIT/HYPERACTIVITY DISORDER

DSMIV DIAGNOSTIC CRITERIA FOR ATTENTION DEFICIT/HYPERACTIVITY DISORDER

A. Either (1) or (2):
1. Six (or more) of the following symptoms of inattention have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level.

Inattention
a) Often fails to give close attention to details or makes careless mistakes in school work, work or other activities
b) Often has difficulty sustaining attention in tasks or play activities
c) Often does not seem to listen when spoken to directly
d) Often does not follow through on instructions and fails to finish school work, chores, or duties in the workplace (not due to oppositional behaviour or fail to understand instructions)
e) Often has difficulty organising tasks and activities
f) Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as school work or homework)
g) Often loses things necessary for tasks or activities (e.g. toys, school assignments, pencils, books, or toys)
h) Is often easily distracted by extraneous stimuli
i) Is often forgetful in daily activities

2. Six (or more) of the following symptoms of hyperactivity-impulsivity have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level.

Hyperactivity
a) often fidgets with hands or feet or squirms in seat
b) often leaves seat in classroom or in other situations in which remaining seated is expected
c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
d) often has difficulty playing or engaging in leisure activities quietly
e) is often "on the go" or often acts as if "driven by a motor"
f) often talks excessively

**Impulsivity**

(g) often blurts out answers before questions have been completed
(h) often has difficulty awaiting turn
(i) often interrupts or intrudes on others (e.g., butts into conversations or games)

B. Some hyperactive-impulsive or inattentive symptoms that cause impairment were present before the age of seven years.

C. Some impairment from the symptoms is present in two or more settings (e.g., at school [or work] and at home).

D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic disorder and are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Code based on type

**314.01 Attention Deficit/Hyperactivity Disorder, Combined type:** if both Criteria A1 and A2 are met for the past six months

**314.00 Attention Deficit/Hyperactivity Disorder, Predominantly Inattentive Type:** If Criterion A1 is met but Criterion A2 is not met for the past six months

**314.01 Attention Deficit/Hyperactivity Disorder, Predominantly Hyperactive Impulsive Type:** if Criterion A2 is met but Criterion A1 is not met for the past six months.

Coding note: For individuals (especially adolescents and adults) who currently have symptoms that no longer meet full criteria, "In Partial Remission" should be specified.

**314.9 Attention Deficit/Hyperactivity Disorder Not Otherwise Specified**
This category is for disorders with prominent symptoms of inattention or hyperactivity-impulsivity that do not meet criteria for Attention-Deficit/Hyperactivity Disorder.

**DEMENTIA**

**DSMIV CRITERIA FOR DEMENTIA**

*Dementia of the Alzheimer’s Type*
A. The development of multiple cognitive deficits manifested by both
1. memory impairment (impaired ability to learn new information or to recall previously learned information)
2. one (or more) of the following cognitive disturbances:
   a) aphasia (language disturbance)
   b) apraxia (impaired ability to carry out motor activities despite intact motor function).
   c) Agnosia (failure to recognise or identify objects despite intact sensory function)
   d) disturbance in executive functioning (i.e., planning, organising, sequencing, abstracting).

B. The cognitive deficits in Criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline form a previous level of functioning.

C. The course is characterised by gradual onset and continuing cognitive decline

D. The cognitive deficits in Criteria A1 and A2 are not due to any of the following:
   1. other central nervous system conditions that cause progressive deficits in memory and cognition (e.g., cerebrovascular disease, Parkinson’s disease, Huntington’s disease, subdural haematoma, normal-pressure hydrocephalus, brain tumour)
   2. systemic conditions that are known to cause dementia (e.g. hypothyroidism, vitamin B12 or folate deficiency, niacin deficiency, hypercalcaemia, neurosyphilis, HIV infection)
   3. substance-induced conditions

E. The deficits do not occur exclusively during the course of a delirium.

F. The disturbance is not better accounted for by another Axis I disorder (e.g. Major Depressive Disorder, Schizophrenia)

Code based on type of onset and predominant features:
**With Early Onset**: if onset is at age 65 years or below
290.11 **With Delirium**: if delirium is superimposed on dementia
290.12 **With Delusions**: if delusions are the predominant feature
290.13 **With Depressed Mood**: if depressed mood (including presentation that meet full symptom criteria for a Major Depressive Episode) is the predominant feature. A separate diagnosis of Mood Disorder Due to a General Medical Condition is not given.
290.10 **Uncomplicated**: if none of the above predominates in the current clinical condition

**With Late Onset**: if onset is after 65 years
290.3 **With Delirium**: if delirium is superimposed on dementia
290.20 **With Delusions**: if delusions are the predominant feature
290.21 **With Depressed Mood**: if depressed mood (including presentation that meet full symptom criteria for a Major Depressive Episode) is the predominant feature. A separate diagnosis of Mood Disorder Due to a General Medical Condition is not given.
290.0 **Uncomplicated**: if none of the above predominates in the current clinical condition

Specify if (can be applied to any of the above subtypes):
**With behavioural disturbances**: if there is a clinically significant behavioural disturbance (e.g., wandering)
Coding note: Also code 331.0 Alzheimer’s disease on Axis III.
Re: Copyright permission

Dear Sir/Madam,

My name is Dianne Wynaden and I am a PhD student at Curtin University of Technology in Perth Western Australia. I am completing my thesis on "The primary carer's experience of caring for a person with mental disorder". It is a qualitative study using Grounded theory methodology.

In writing my methodology chapter I must include the criteria for the types of carers in my study. They are people caring for a person with Schizophrenia, Mood disorders, Anxiety Disorders, dementia and Childhood psychiatric disorders. I need to include a description of each of these disorders as an Appendix in my thesis. I would like to use the DSMIV diagnostic criteria and therefore, I am writing to seek permission to include these criteria as an appendix in my thesis. My estimated date of submission is June 2002.

Yours Sincerely

Dianne Wynaden
64 Farnley Street
Mt Lawley
Western Australia 6050
Australia
email: wynadend@nursing.curtin.edu.au
APPENDIX C

November 1, 2000

Dianne Wynaden
64 Farley Street
Mt. Lawley, Western Australia 6050
AUSTRALIA

Dear Ms. Wynaden,

I am responding to your 10/12/2000 request to reprint the diagnostic criteria for Schizophrenia, Mood Disorders, Anxiety Disorders, Dementia, and Childhood Psychiatric Disorders from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. This information will be used as an appendix in your thesis “The Primary Carer’s Experience of Caring for a Person with Mental Illness.”

Permission is granted under the following conditions:

- Permission is nonexclusive and limited to the single use specified in your letter;
- Use is limited to English language only;
- Permission must be requested for subsequent uses (including subsequent editions, revisions, and all electronic uses);
- Payment received of the administrative fee of no charge

In all instances, the source and copyright status of the reprinted material must appear with the reproduced text. The following notice should be used:


The correct bibliographic citation for DSM-IV is as follows:


Sincerely,

Ronald E. McMillen
Director of Publications

1400 K Street, N.W., Washington, DC 20005 • (202) 682-6268 • FAX (202) 682-6341
London Office • 3 Henrietta Street • Covent Garden • London, England WC2E 8LU
APPENDIX D

Chairperson
Carers Association of Western Australia
2 Selby Street
Shenton Park, WA 6008

Dear Sir/Madam,

My name is Dianne Wynaden and I am enrolled in the Doctor of Philosophy at the School of Nursing, Curtin University of Technology. The purpose of my study is to describe the experience of caring for a person with a mental disorder in the Western Australian community. I hope that the information obtained from this study will facilitate better collaboration between consumers, carers, and health professionals.

I am writing to you to ask if you could pass this letter on to your members. I wish to invite them to participate in the study on caregiving. Information about their experiences of caregiving will be obtained through an interview lasting approximately 60-90 minutes. The interview will be tape-recorded and subsequently transcribed and analysed. Participation in this study is voluntary and participants can withdraw at any time without penalty.

During the interview, participants may decline to answer any question and they may ask me to cease the interview or turn off the tape recorder at any time. At no time will any participant be identified with the information they have given me in any reports or articles written concerning the outcomes of the study to protect their confidentiality. Data and tapes will be kept in a locked cupboard. Tapes will be erased at the end of the study and data will be destroyed five years after the completion of the study. I will be the only person involved in the study that will know the participant's name.

I am interested in interviewing carers who:
• are over eighteen years of age
• do not have a mental or physical condition that affects their ability to understand the researcher or to express their perceptions concerning their experience of caregiving
• speak English well enough to be interviewed (to avoid the use of interpreters)
• live in the Perth metropolitan area.
• are the primary carer
• are carers to people who have been diagnosed with a major mental disorder (Schizophrenia, Mood Disorders, Anxiety Disorders).

I will report my findings to all participants. I will also be happy to do a presentation at the end of the study to the members of the Carers Association of Western Australia.

If members of your association are interested in participating in this study or they would like to find out more information about the study they can contact me on (08) 92662203 (work) or 0412691477 (mobile).

Thank you very much for taking the time to read this letter.

Dianne Wynaden
APPENDIX E

Curtin University of Technology
School of Nursing and Midwifery
Department of Postgraduate Studies

INFORMATION SHEET

Thesis Title: A grounded theory study of the primary carer’s experience of caring for a person with a mental disorder in the Western Australian community

My name is Dianne Wynaden, and I am a student in the Doctor of Philosophy at the School of Nursing, Curtin University of Technology. The purpose of my study is to describe the experience of caring for a person with a mental disorder in the Western Australian community. I hope that the information obtained during this study will facilitate better collaboration between consumers, carers, and health professionals.

I wish to invite you to participate in this study on caregiving. Information about your experience of caregiving will be obtained through an interview lasting approximately 60-90 minutes. The interview will be tape-recorded, transcribed, and analysed. When this process is completed I may need to make a further appointment with you to discuss or clarify issues.

Your participation in this study is voluntary and you can withdraw at any time without penalty. If you sign this consent form you are consenting to:

1. Be interviewed by myself at a mutually agreed place regarding your experiences of caring for a family member who has a mental disorder.
2. Have the interview tape recorded.
3. Be re-interviewed to clarify any issues arising from the first interview.

During the interview, you may decline to answer any question and you may ask me to cease the interview or turn off the tape recorder at any time. At no time will you be able to be identified by the information you have given me and any reports or articles written concerning the outcomes of the study will protect your confidentiality. Code numbers will be given to each interview and I will be the only person involved in the study who knows your name.

The information obtained during the interview (including the tape) will be stored in a locked cupboard during the study period. At the completion of the study the tapes will be erased. All transcribed interviews will be stored in the locked cupboard for five years after the completion of the study and then destroyed. I will be the only person involved in the study who knows your name.

When the interview has been transcribed I am happy for you to read it. I will report the findings of the study to all participants. I will also be happy to do a presentation at the end of the study to the mental health organisation you belong to.

If you have any questions or require any further information concerning this study, please do not hesitate to contact me on (08) 92662203 (work) or 0412691477 (mobile). If you prefer, you may contact my supervisor Associate Professor Vera Irurita on (08) 92662191 (work).

Thank you very much for taking the time to read this information sheet.

Dianne Wynaden
APPENDIX F

THE ASSOCIATION FOR THE RELATIVES AND FRIENDS OF THE MENTALLY ILL (ARAFMI)

ARAFMI is a non-government family support organisation that aims to provide education, counselling, support, information, social interaction and advocacy for families, carers and people who have been affected by psychiatric disability.

ARAFMI was formed to meet the needs of local carers to meet regularly and exchange ideas on how to cope with caring for relatives suffering psychiatric conditions. The group provides education on mental illness and its management, also coping skills, suicide prevention, support during loss and grief counselling and gives information about other services and how to access them. A family support worker is available for individual contact.

THE MENTAL ILLNESS FELLOWSHIP OF AUSTRALIA (FORMERLY SCHIZOPHRENIA FELLOWSHIP OF WESTERN AUSTRALIA)

The Mental Illness Fellowship of Australia was established to carry out the successful work of the state and territory bodies to ensure that mental illness and in particular, schizophrenia, receives adequate attention in both policy and legislation. It has the largest membership base of any single mental health organisation in Australia. Each state and territory has a properly incorporated body with a duly elected management committee. Combined, these organisations have between fourteen and fifteen thousand members, many of whom are family or corporate members and therefore represent many more people than the membership number.

THE WESTERN AUSTRALIAN ASSOCIATION OF MENTAL HEALTH (WAAMH)

WAAMH is the peak mental health representative body in Western Australia for non-government not for profit agencies that operate for the benefit of people affected by mental disorders. WAAMH represents the perspectives and interests of the sector to relevant government and community bodies through consultation with member agencies and representations to relevant government, community bodies, and members of parliament. Members contribute to policy development to improve the quality of life for people affected by a mental disorder and carry out systematic advocacy in the interest of people affected by mental disorders. It has an active development sector that identifies training needs and assists
policy development of standards, benchmarks, and protocols. WAAMH has over 500 individual members and 70 public, private and non-government member organisations throughout Western Australia. WAAMH coordinates and facilitates the annual National Mental Health Week in Western Australia (www.waamh.org.au).

THE CARERS ASSOCIATION OF WESTERN AUSTRALIA INC

The Carers Association of Western Australia Inc. is a non-profit community based organisation and registered charity dedicated to improving the lives of the estimated 2000,000 family carers living in Western Australia. The Carers Association of WA Inc. is the peak body recognised both state and federally for carers. The Carers Association of WA Inc works in active partnerships with carers, person with care and support needs, health professionals, service providers, government and the wider community to improve the quality of life of carers.
APPENDIX G

Thesis Title: A grounded theory study of the primary carer's experience of caring for a person with a mental disorder in the Western Australian community

SEMI STRUCTURED INTERVIEW GUIDE

The semi-structured interview format will be used in this study. The researcher will meet with the participant approximately 15 minutes before the interview begins. During this time the researcher will establish rapport with the participant and explain the purpose of the study. The benefits of participating in the study for the carer will also be discussed during this time. The researcher will inform the participant that they will be informed of the outcomes of the study, and that the researcher is happy to conduct a presentation for any carer group the participant belongs to in order to present the findings of the study.

The interview will commence by asking the participant the following two questions:

Question 1
Tell me about the things you do to care for ....................

Question 2
Tell me about your experience of caring for ....................... over the last week.

The future direction of the interview will be centred on the responses obtained from Questions 1 and 2. However the following prompts will be reflected in subsequent questions used in the interview to ensure that the objectives of the study are met.

Themes:
1. The length of time the participant has been caring for the mentally ill person.
2. How they became a carer?
3. What they enjoy most about their carer role.
4. What they enjoy least about their carer role.
5. What changes they would like to make to their caregiving role?
6. What effect does the caregiving role have on them?
7. What effect does the caregiving role have on family life?
8. Their experience of contact with health professionals.
9. Changes in treatment /management of .......... during the time they have been caregiving.
10. How they feel their role of being a carer is viewed within the community.
11. Do they experience any stigma associated with their caring role?
12. What worries them most regarding their caregiving role?

The Demographic Information Sheet will be filled in by the researcher with the participant prior to the tape recorder being turned off.

Following the interview the researcher will undertake a 'debriefing' period with the participant to ensure that they are not experiencing any distress from the interview. All participants will be given a card with the name of a counselling service that the researcher has arranged to be available to see any of the participants who may require counselling as a result of issues that may have arisen from the interview.
To: Ms Dianne Wynaden, c/- Associate Professor Vera Irufita, Nursing and Midwifery
From: Max Page, Executive Officer, Human Research Ethics Committee
Subject: PROTOCOL APPROVAL – EXTENSION HR 122/99
Date: 21 June 2002
Copy

The Human Research Ethics Committee acknowledges receipt of your Form B progress report for the project *A grounded theory study of the primary carer's experience of caring for a person with a mental illness in the Western Australian community*.

Extended approval for this project is for the year to 13/Jul/2003.

Your approval number remains HR 122/99. Please quote this number in any further correspondence regarding this project.

Thank you.

Maxwell Page
Executive Officer
Human Research Ethics Committee

*Anna Leech*
APPENDIX I

Curtin University of Technology
School of Nursing and Midwifery
Department of Postgraduate Studies

INFORMED CONSENT FORM

Thesis Title: A grounded theory study of the primary carer's experience of caring for a person with a mental disorder in the Western Australian community

I........................................................................................................................................................................... have read the information sheet accompanying this informed consent form relating to the study on caregiving. I understand that by signing this consent form I am agreeing to be interviewed by Dianne Wynaden, to have that interview tape-recorded and to be re-interviewed if necessary. I understand that I may cease the interview and withdraw from the study at any time with no penalty. I have been given a copy of this consent form. I understand that if I have any questions or concerns I can contact Dianne on (08) 92662203 (work) or 0412691477 (mobile) or her supervisor Associate Professor Vera Irurita (08) 92662191 to discuss these.

Signed....................................................................................Participant

Signed ....................................................................................Researcher

Date: ........................................}