Ambiguous loss associated with mental ill health: How is it perceived, experienced and managed by those affected?

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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. I also certify that to the best of my knowledge this thesis does not contain any material previously written or published by another person without due reference being made to this fact in the text.

The University of Western Australia’s (2011) Harvard referencing style has been used in this thesis.

Signed: Kanthi V. Perera

Date:
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Abstract

The impairments associated with mental ill health present those affected and their significant-others with losses that are uncertain, incomplete and lack resolution. The ambiguity of mental ill health is confusing not only for those living intimately with it but also for those around them. Ambiguous loss associated with mental ill health has gone unrecognised by health professionals. Instead, often the grief that accompanies ambiguous loss has been seen as pathological, resulting in healthy expression of grief being seriously inhibited. Such inhibition has created a barrier to grieving and has the potential for breakdown of family relationships. Parallel stories of the experience of complicated grief for people affected by mental ill health and their significant-others are rare in the literature. The journey of grieving for family members is not necessarily synchronised and, the nuances of a complex dynamic process of complicated grief can therefore be further exacerbated. The aim of this study was to attain a critical understanding of ambiguous loss associated with mental ill health and gather research-based evidence of parallel stories of the experience of loss and uncertainties associated with mental ill health, and develop substantive theory about how a group of people living in West Australia affected by mental ill health manage the ambiguities associated.

The study was underpinned by the interpretive paradigm of symbolic interactionism and used a combination of constructivist grounded theory methods, transcendental realism methods and a collective case study design to develop substantive theory. The study was also guided by the middle range theory of Ambiguous Loss developed by Boss (1999, 2006). Fifteen in-depth interviews with seven families from diverse backgrounds were conducted. It was also a three-dimensional view of consumers, their significant-others and significant-others who had developed symptoms of mental ill health and considered themselves as consumers at the time of the study. Through a combination of open, focused, axial and pattern coding and data display through matrices I merged findings to make assertions. Metaphors helped me collapse data into the larger context without locking out multiple avenues for analysis and place patterns noted in the data.

Reverberating losses emerged as the major theme of losses coming under the ‘rubric’ of four sub-themes of losing self, losing family ties, losing connectedness and losing functionality. Two themes of spinning in a whirlpool and being adrift at sea emerged as additional stressors associated with mental ill health which taxed the capacity of people to adapt to crises and complicated the grieving process. In order to manage these ambiguities participants engaged in the basic social process (BSP) of navigating the winds and tides of ambiguity to stay afloat. The
BSP was a circular model of managing, where those affected moved through the tension of a complex phenomenon over time that required moving between courses of steering choppy waters and negotiating to smooth the voyage depending on the context and intervening conditions. The course of steering through choppy waters included consulting maps and charts, resisting the surge, seeking a safe harbour, avoiding crosswinds and going with the flow. The course of negotiating to smooth the voyage included building rapport, taking the helm and trying a different tack, developing the spirit of an adventurer, sailing to parts unknown and knowing current location, facing the storm and adjusting your sails, and determining which way the winds are blowing and the state of the tides. The three groups took one or more courses of action concurrently but also at times oscillating with actions of other courses. In this way, participants strove to bring coherence to their lives by negotiating back and forth between individual resources and resources in the environment around them that impact one on the other in endless and unpredictable combinations.

The process captured in the metaphor of navigating the winds and tides of ambiguity to stay afloat provides a new perspective on how people manage the uncertainties of mental ill health and extends Boss’s theory of ambiguous loss to a new and unstudied population.

The results of the study would be valuable for consumers, their significant-others and health professionals in the mental health sector and has implications for clinical practice, capacity building in health promotion, prevention of ill health, breakdown of family relationships and education of health professionals.
# Definitions and Acronyms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Ambiguous loss</td>
<td>Ambiguous loss is a specific, relatively rare type of loss that is inherently ambiguous because of some situational features that make it impossible for families to obtain factual information surrounding the event of loss (Boss 1999, p. 517; 2002, 2006; Carroll, Olson &amp; Buckmiller 2007)</td>
</tr>
<tr>
<td>Mental ill health (MIH)</td>
<td>A wide spectrum of problems that interfere with a person’s cognitive, social and emotional abilities.</td>
</tr>
<tr>
<td>CoMHWA</td>
<td>Consumers of Mental Health WA (Inc.) (Consumers of Mental Health WA). A community-based, not for profit mental health consumer organisation in Western Australian which is run by consumers.</td>
</tr>
<tr>
<td>Consumer</td>
<td>Any person who has been diagnosed with a mental illness, or a person who identifies as such, who may or may not be accessing mental health services. As far back as 1995, the word ‘consumer’ has been used because it has been chosen by people who seek help from mental health services in order to deal with problems they are experiencing in their lives (Dulwich Centre Newsletter 1995, No.4).</td>
</tr>
<tr>
<td>Eco-map</td>
<td>A diagrammatic tool to understand an individual or family in the life space (Hartman 1978)</td>
</tr>
<tr>
<td>Family boundary ambiguity</td>
<td>A state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system (Boss &amp; Greenberg 1984).</td>
</tr>
<tr>
<td>Genogram</td>
<td>A diagrammatic tool to chart intergenerational family history (Hartman 1978).</td>
</tr>
<tr>
<td>Grief</td>
<td>A word used to describe natural but complex responses when facing a loss.</td>
</tr>
<tr>
<td>Loss</td>
<td>The reduction in a person’s resources, whether personal, material, or symbolic, to which the person was emotionally attached (Harvey &amp; Weber 1998, p. 320)</td>
</tr>
<tr>
<td>Psychological family</td>
<td>An active and affective bond that helps people live with loss and trauma in the present (Boss 2006, p. 26).</td>
</tr>
<tr>
<td>Recovery</td>
<td>A personal process, as opposed to clinical recovery (asymptomatic/cure) or social recovery (functionality/rehabilitation focused only) paradigm (Consumers of Mental Health WA).</td>
</tr>
<tr>
<td>Significant-other</td>
<td>Family in the broadest possible sense as that group of persons with whom one shares a bond of connection by virtue of blood, marriage, adoption or a bond of commitment (Patterson &amp; Garwick 1994).</td>
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Chapter 1: Introduction

“You’re constantly living on the edge of a precipice. You don’t really know what’s down there in the murky depths. You’ve fallen off the top many times, and you’re scared stiff. Each time it’s different, so you never get used to it”.

(Human Rights and Equal Opportunity Commission 1993, p. 443)

1.1 Introduction

This thesis is a study of ambiguous loss associated with mental ill health. Using a qualitative case study approach guided by ambiguous loss theory (Boss 1999; 2006) and underpinned by the interpretative paradigm of symbolic interactionism, I explored the experiences of a sample of people who have experienced mental ill health (MIH) and their significant-others to study their perceptions of ambiguous loss and how they manage the ambiguity associated with MIH. For the purpose of this study, mental ill health is used throughout this dissertation to mean a wide spectrum of problems that interfere with a person’s cognitive, social and emotional abilities.

1.2 Rationale for this Research

We face many losses in our lifetime: death of a person we care for, illness, disability, divorce and separation, loss of hope, faith, expectations and dreams. Death is the loss many of us think of when we hear the word grief. Death is usually met with expressions of grief as family, friends and colleagues come together as a community to comfort each other and mourn the loss of a loved one. Such validation of sorrow helps the healing process. Every culture has rites and rituals to aid in the healing process and in the expression of emotions when faced with death. Hopefully in time, participation in rites and rituals helps the journey of loss, paving the way towards resolution and closure. Death is a physical absence but what if loss is not as clear-cut as death, such as when a person disappears and they or their remains are never found – what is referred as ambiguous loss where grief must be endured day after day without any validation or support from those around us?

Ambiguous loss theory is a relatively new concept and thus many professionals are still untrained in it. Although ambiguous loss theory has been applied to the uncertainty associated with a physical disappearance and uncertainty of return, it seems it can be extended to mental ill health as well; the difference is that with physical disappearance there is physical absence with psychological uncertainty, whereas with a person with mental ill health there is physical presence with psychological absence and uncertainty of return. As a social worker working in mental
health services for many years, I am acutely aware of the gap in knowledge and practice of working with people experiencing ambiguous loss and the need to address this gap. The following scenarios are examples:

- What if a young client just reaching adolescence or young adulthood full of promise and hope becomes mentally unwell, where symptoms are serious and they are unsure if the typical milestones of finishing school, keeping pace with their peers, having a job or holding down a job is going to be possible? (Loss of certainty about future)
- What if the illness itself is poorly understood and they may be receiving differing diagnoses? (Loss of clear diagnosis)
- What if they are shuttling back and forth between getting better, which encourages them to get their hopes up, and then later getting unwell again and thus having hopes dashed repeatedly? (Loss of certainty about health)
- What if coping itself becomes problematic when side effects of medication lead to secondary health problems such as metabolic syndrome and sleep disorder? (Loss of clarification about coping)
- What if none of their friends or family knows how to approach them and provide emotional support? (Loss of validation)
- What if they, because of the seriousness of the illness, are forced to remain always dependent on their parents or siblings, both emotionally and financially? (Loss of certainty of roles and tasks in life)
- What if services depend on parents and siblings to support the individual emotionally and financially and provide shelter, but information is denied them because of confidentiality and they are seen as intrusive or enmeshed when information is requested, or neglectful and disengaged if they remain in the background? (Loss of clarification of family roles and tasks)

These scenarios describe losses that lack clarification and validation because they lead to ambiguity. The impairments associated with mental illness present those affected and their families with losses that are uncertain, incomplete and lack resolution. In my clinical practice I see that such ambiguity results in unresolved grief, leading to complications such as depression, anxiety and difficulties in relationships.
1.3 Contextual Background

In June 1990, the Federal Human Rights Commissioner of Australia formally announced an inquiry into the human rights and fundamental freedoms of persons who are, or have been, or are alleged to be, affected by mental illness, having due regard to the rights of their families and members of the general community. The Inquiry considered evidence from 456 witnesses during its formal hearings. Despite the many stories of loss, grief and continuing bereavement documented in the Commissioner’s Report published in 1993, there is a significant gap in the literature in Australia and internationally addressing this aspect of care in clinical practice and policy development. Although the major aspect of clinical care in mental health services relates to those who are psychologically distressed and their significant-others, there is minimal intellectual or practical emphasis on the many ways people feel reduced and grieve for experiences of loss not connected to death.

In the Report above, a parent says:

It is an ongoing trauma, you lose your son during the illness but … you can’t sort of grieve and [then] think you’ve got your life back again. Every time he goes into hospital, we grieve all over again. (Human Rights and Equal Opportunity Commission 1993, p. 469) (Traumatic loss)

A father of a 19 year-old describes the psychological absence of his son:

Try to imagine our shock when, at the age of 18, our son develops symptoms of a mental illness. Try to imagine the grief that struck our family when this wonderful, active person with so much ability and potential for a good life was “crippled” mentally. (p. 469) (Physical presence with psychological absence)

A sibling says:

My little sister became steadily worse which caused divisions within our family. Dad could not see the things which Mum noticed my sister was saying … By New Year’s Eve I thought our whole family was going crazy. Tiny problems would turn into loud arguments, everyone was on edge. Any time there was peace [my sister] was sure to end it. (Human Rights and Equal Opportunity Commission 1993, p. 472) (Relational conflict)

A consumer describes the personal experience of MIH:

Anything I had done, any achievements, hopes or aspirations were as if I had never existed, because I was no longer part of the mainstream. I had gone. (Human Rights and Equal Opportunity Commission 1993, p. 443) (Loss of validity)

Personal accounts in international literature indicate that ambiguous loss and the subsequent family boundary ambiguity may be a factor leading to family breakdown and social isolation of people with mental illness.
A consumer (Fox 2009, p. 430) says:

For a person suffering with schizophrenia or any other mental illness, there is what I would call a protocol for dealing with family activities. When there was a family function to which I was invited (I was invited to some events but not others), people seemed embarrassed or unsure how to speak with me. I was unsure how to act at these functions … (Family boundary ambiguity, as a consequence of ambiguous loss)

A significant-other (Wasow 2000, p. 134) as a mother identifies this gap in knowledge specifically with serious MI and grieving. She says:

Grieving about a relative with mental illness is a special subcategory because it involves a family member, it involves chronic loss and it involves the brain. She says it is a special kind of grief because changes in the brain affect human capacity in many respects, so that communication with the person affected becomes difficult, causing confusion when interacting with someone who looks the same as he or she did before the illness, but in many ways is not. This is an ambiguous loss because of the combination of physical presence and psychological absence.

Another significant-other, a father of a son with schizophrenia, says:

For a long time, when I looked into his eyes I felt that there was no one there. This is one of those manifestations that are difficult for the observer, let alone the person with the illness, to put into words. Some of the expressions that came into my mind were these: “He has become a shell of a person, there is no one there, he has lost his self, he looks different, his face has changed, he’s a lost soul.” (Willick 1994, p. 9)

The father describes the feelings as a terrible sense of loss, an ongoing feeling of grief, and a chronic state of mourning, which he calls, ‘mourning without end’. This is an ambiguous loss because there is physical presence but psychological absence, and it is grief without closure.

Despite the frequency of these subjective experiences of ambiguous loss, complicated and unresolved grief, its significance in the practice of mental health services has received minimal emphasis. In the interest of diagnostic fairness, guidelines for assessment and response to treatment, the arguments raised by (Boss 2012; Wakefield 2013; Cooper 2013) are worthy of consideration and researchers and health care professionals need to rethink the concept of complicated and prolonged grief as only in personal pathology, and instead consider the complex dynamics of stressors in the environment that lead to the development of characteristics of complicated and prolonged grief, as well as considering whether these characteristics should be considered a distinct condition or merely a variant of some other condition.
Having read all available literature in the field of grief and loss associated with MIH, in 2005 I applied for, and was granted, an award for an international study tour from the Winston Churchill Memorial Trust of Australia to study innovative programs of loss and grief. During this tour I studied and observed many different programs set up in Canada and the USA. Of particular interest was how ambiguous loss theory was applied by various organisations in New York to help families of victims to cope with unresolved grief when bodies were not found following the attack on the Twin Towers on September 11. Since my return, I have conceptualised my observations of the complicated and unresolved grief for both consumers and their significant-others in the mental health practice setting through the “lens” of ambiguous loss theory, and realised the need for empirical research in this particular setting.

Boss (1999; 2002, 2006) made a vital contribution to family stress theory with her introduction of the construct of ambiguous loss. She developed this construct by studying the experience of loss in the context of an additional stressor – ambiguity, to describe a loss where there is no validation or clarification of the loss. The word ‘ambiguous’ in the term ‘ambiguous loss’ refers to an objective feature of the situation, not a subjective feature grounded in family perceptions (Boss 2004; Carroll, Olson & Buckmiller 2007). This study will be guided by a middle-range theory put forward by Boss - Ambiguous Loss Theory (Boss 1977a; Fravel & Boss 1992; Boss 1999; 2004; 2006; 2010, 2012; 2013). She described two types. Type one occurs when there is physical absence and psychological presence, situations when a loved one is physically missing or bodily gone but whose presence persists in the minds of those left behind. Boss calls this Leaving without Goodbye (Boss 1999, pp. 26-44). In type two there is physical presence and psychological absence, situations when the person one cares about is psychologically absent or inaccessible. Boss calls this situation Goodbye without Leaving (Boss 1999, pp. 45-60). Ambiguous loss is a relational disorder and not a psychic dysfunction. It is the result of an externally caused stressor. Individual and relational symptoms may result, such as depression, anxiety, conflict and somatisation; however, the cause is the ambiguity. Using qualitative methodology this study investigates losses associated with the dichotomy of psychological absence or inaccessibility with physical presence for those affected by MIH and their significant-others, which corresponds to type two of Boss’s description of ambiguous loss.

The scope and depth of a theory increases as the concepts of the theory are studied in different situations, times and settings. In April 2007, a special issue of Family Relations, an official publication of the National Council on Family Relations, published a series of papers illustrating how a new generation of scientists and practitioners applies ambiguous loss theory to understand
previously unstudied situations and populations (Boss 2007). These articles encouraged me to take up the challenge of finding out if it can be extended to mental ill health as well.

1.4 A Historical Development

Several articles pertaining to the loss and/or grief associated with MIH are cited in literature: Miller et al. (1990); Appelo et al. (1993); Atkinson (1994); MacGregor (1994); Willick (1994); Solomon and Draine (1996); Doornbos (1997); Baxter and Diehl (1998); Bland (1998); Davis and Schultz (1998); Farina (2000); Wasow (2000); Lafond (2002); Jones (2004); Stein et al. (2005); Henderson (2011); Wittmann and Keshavan (2007); Hinshaw (2008); Mauritz and van Meijel (2009). Stein and Wemmerus (2001), using a life course perspective, examined personal accounts of adults with schizophrenia, and their parents and well-siblings from six families and found that family members and those experiencing mental ill health grieved for subjective losses related to symptoms as well as psychosocial losses due to changes in functioning and lack of access to valued social roles.

Kristoffersen et al. (2000), studying the experience of siblings, identified mixed feelings of grief, hope, anger, guilt and shame interrupted by four interrelated factors: ambiguous loss, the fluctuating nature of schizophrenia, an inner prohibition of feelings and the tendency of others to invalidate the feelings. In their study they say that the core of the experience of loss among the subjects ‘lies in the paradoxical experience of losing a loved one whom one physically has not lost’ (Kristoffersen et al. 2000, p. 25). They name this experience ‘ambiguous loss’, and say that the experience interrupted the feelings in a decisive way and is also reflected in the other themes with which their study is concerned such as the fluctuating nature of the ill health, an inner prohibition against grieving over and missing someone who both is and is not present, and lack of validation by the community.

1.5 Need for this Study

None of the studies above has been investigated through the lens of ambiguous loss theory and its account of subsequent boundary ambiguity for the consumer and his/her family. Although the theme ‘ambiguous loss’ formed the background for the understanding of other themes of loss in the study of Kristoffersen et al. (2000), it was a study of one-dimensional perceptions of siblings only. Parallel stories of the experience of loss that exists for the person with the MIH and their significant-others are rare in the literature. This study is unique because it offers a parallel story about grief without closure, and thus complicated and chronic grief.
1.6 Purpose of the Study

The purpose of my study is to attain a critical understanding of ambiguous loss associated with MIH and to gather research-based evidence in the particular domain of mental health services. Traditional theories of loss and grief do not address the complicated grief that I observe in my clinical practice. In my search for more inclusive theories in the published literature, my intuition that there were ambiguities associated with MIH led me to Boss’s theory of ambiguous loss.

This study fills a gap in knowledge, builds on Boss’s research, and adds to existing research on loss and grief associated with MIH and thus complicated grief. By doing so, this study will offer a substantial and original contribution to knowledge in the area of mental health. It also raises questions for clinical practice and future research.

1.7 Bridging the Gap Between Research and Practice Through Tacit Knowledge

To develop research that is clinically relevant practitioner-researchers have an important role to play in bridging the gap between research and practice. Substance use and misuse among people with mental ill health was not studied until practitioners raised the issue (Yanos & Ziedonis 2006, p. 250). The tacit knowledge that I have developed over the years through personal experience, working in mental health settings, investigating a similar subject towards a Master of Social Work degree, and the knowledge gained through the Winston Churchill Memorial Trust international study tour assisted me to craft a study to answer the two research questions. The direct practice exposure that I have of the real-world issues for consumers and their significant-others in Western Australia gave me insights and inspired me to undertake research on ambiguous loss associated with MIH.

Tacit knowledge is difficult to articulate adequately by verbal means. In this study, I define tacit knowledge as intuition which I have gathered through the many years of practice in mental health services with extensive personal contact and interaction with those who have lived experience of MIH. Through this interaction I have built trust that helped understand uncertainties associated with MIH.

Lincoln and Guba (1985, p. 198) write that it is essential that in naturalistic inquiry the researcher as a human instrument be permitted to use the tacit knowledge they possess at full strength and in most explicit fashion. Not doing so, they write, reduces the value of the inquiry because as human beings we build upon tacit knowledge as much as propositional knowledge. They also
say that such tacit knowledge has been the base on which many insights and hypotheses are eventually developed in propositional form and shared with others at the conclusion of the study.

The case study strategy also assists readers to build on their tacit knowledge. For example, through my practice experience I am aware of the lack of validation of mental ill health in Australian government organisations as recently highlighted in the report, Invisible Care (Ilsley August 2013). This report was prepared as a result of many carers, carer organisations and practitioners raising concerns that the assessment tool used to determine eligibility for social and health-related payment and services by Centrelink (the Australian Government’s Department of Human Services) does not take into account many of the most important types of care provided by those caring for a person with mental illness, namely assistance with practical matters, social support, accommodation, board and social participation. Significant-others have cited several factors that impede their access to payments – design of the questionnaire that determines eligibility and difficulties arising from caring for a person with a fluctuating health condition are some of these factors. The report also cited the risk of homelessness that people with MIH experience when family relationships break down. Although the report was prepared from interviews with a sample of the population of the State of Victoria, many of the examples are relevant to the West Australian context. In my clinical practice I recognised this lack of validation for family members and raised my concerns with Carers WA. At a meeting with Carers WA in 2011 I contributed examples where family members’ application for carers’ allowances had been declined by Centrelink. These examples were similar to where a participant of the survey by Carers Victoria said:

I can be with her for fifteen hours nonstop. If I provided her with physical care that might take thirty minutes … And [then] I might get Carer Allowance. People just don’t get it. It makes me angry. (Ilsley August 2013)

In this thesis I argue that perception, psychological in origin, is influenced by individuals and families. However, the example above suggests that perception is also mediated by the larger context in which a stress event occurs (Boss 2002, p. 150). The lack of validation of the care provided by significant-others for their relative with MIH, as well as stigma, demonstrate how the context external to the family, in this case the Australian context, affects the family’s perception and therefore influences the management of stress.

Freedman and Combs (1996), offering a postmodernist perspective, write that realities are organised and maintained through stories. People make sense of their lives through stories and construct personal narratives in relation to the cultural narrative they are born into. From this point of view, understanding the influence of the dominant stories of their culture is important.
Research that contributes to decreasing discrimination and prejudice assists legislators and policy makers in changing legislation that has detrimental effect on people with MIH.

Boss (2002) writes that the cultural context is a major part of the external context. In the situation above, the government provides the canons and rules to which the community reacts and by which they define the stress of MIH. Boss (2002) also writes that such uncertainty in turn fosters ambiguity and thus high stress. In such cases, the external culture has the potential to influence a family’s internal context by denying the loss and creating a barrier to grieving. Being involved in direct clinical practice, practitioners have clear evidence of such barriers to managing stress. As a practitioner, I am concerned about such issues of discrimination. If the stress is to be eased for families, health practitioners need to be involved in the social context and social consequences of MIH by making support services more accessible and responsive to the specific needs of families, and advocate for change in this larger arena. Such practice bridges the gap between research, clinical practice and issues of social justice through advocacy.

1.8 The Self of the Researcher

Values can and do influence inquiry in many ways. Clough and Nutbrown (2002) write that social research is persuasive, purposive, positional and political. This study has given me the opportunity to investigate an area of interest from a particular perspective and follow a clinical hunch I have had for many years about the nebulous nature of MIH and how the experience of grief becomes even more complex when the loss is inherently uncertain.

I migrated to Australia in 1978 having left behind important supportive networks such as family and friends in Sri Lanka. This was an ambiguous loss because, although they were physically absent, their psychological presence was strong until I made new supportive networks in my new country. My husband had less success in making new supportive networks and experienced long periods of depression complicated by alcohol misuse. The relationship broke down and we eventually divorced. I completed a Bachelor of Social Work degree in 1993 and started working in the mental health sector soon after, where I heard many stories of loss and grief from consumers and their family members but there was very little knowledge or training available for me to help them with the relentless stories I heard. In 2003 I completed a project towards a Master of Social Work, investigating the relationship between intensity of grief and coping patterns of parents of individuals affected by psychotic disorder. It was a quantitative study for which I used the Mental Illness Version of the Texas Inventory of Grief (MIV-TIG) developed by Miller et al. (1990). The research findings suggested that there was measurable grief in a cross-section of parents of individuals with psychotic disorders in Western Australia, with many
similarities to studies done internationally. The findings of the study were very valuable, however I realised I needed more useful theory to guide me to effectively understand, assess and intervene in the issues of loss that arose in my clinical practice. Boss’s theory and practice resonated with many of the aspects of loss and grief that I have experienced as a migrant, as a significant-other of a person affected by mental ill health and also seen in my clinical practice over the years. Therefore, the need to research ambiguous loss associated with MIH grew from the context in which I have experienced ambiguous loss, and studied and worked as a social worker in mental health services in Metropolitan Mental Health Services of Western Australia, a medical system that is often trained to focus on the individual whereas the disciplinary background of social work emphasises the importance of working with family systems of interaction.

From a social justice perspective, I have observed that there are no forms of socially prescribed and formalised help and sympathy from society for people with MIH and their families. An example being that there are no volunteer run card or flower shops with “get well” wishes in hospitals treating people with MIH when compared to hospitals treating people for physical illnesses. The propositional, practical and experiential knowledge that I have gained throughout my studies and work have all contributed to initiating and conducting this study.

The study was undertaken with the hope that the findings will help me make a difference in my clinical practice of working with families experiencing MIH, influence the attitudes and perceptions of my colleagues and the community around me, and bring about change in mental health policy.

1.9 Significance of the Study

In order to locate my study in the present time, I undertook an extensive search of published research studies using the concept of ambiguous loss theory. There was only one study that identified ambiguous loss associated with MIH (Kristoffersen et al. 2000) in relation to the experience of siblings of people with schizophrenia. A special issue of Family Relations in 2007 published many papers illustrating how a new generation of scientists and practitioners applied ambiguous loss theory to understand previously unstudied situations and populations. These papers applied ambiguous loss and boundary ambiguity theory to a range of situations including military deployment, chronically ill or profoundly disabled children, unmarried fathers-to-be, lesbian and gay families and ageing couples. Boss (2007, pp. 106-107) identified seven assumptions at the core of the varied collection of papers. In the seventh of her list of assumptions she writes, “It is assumed that a phenomenon can exist even if it cannot be measured. Even if ambiguous loss is not quantifiable, it exists phenomenologically”. She suggests that a second generation of researchers use qualitative methods to assess ambiguous
loss. This study on ambiguous loss associated with MIH follows from the assumption that ambiguous loss exists phenomenologically, and sheds light on the phenomenon of ambiguous loss in a previously unstudied population. The research also has potential for transfer into clinical practice.

1.10 Statement of the Problem

Boss (2006) raised the possibility of ambiguous loss associated with MIH. Ambiguity causes stress leading to feelings of helplessness, hopelessness and anxiety in individuals. In a typology of stressors, Boss (2002, 2006) identifies ambiguous loss as the most unmanageable and traumatising loss. It is complicated grief with no resolution which has the potential for relational conflict. The concept of ‘complicated grief’ derives from bereavement theory. Different definitions and criteria have been adopted by researchers and health professionals to try and describe the concept more precisely, for both scientific and clinical purposes; however, Stroebe, Schut and van den Bout (2013, p. 3) write that:

In general terms, complicated grief can be understood as something like a ‘derailing’ of the normal, usually painful process of adapting to the loss of a significant person.

To date there has not been any research that I am aware of, into prolonged and complicated grief and how it relates to grief of MIH. Although the editors of the above publication consider complicated grief to be the most contemporary topic of concern for researchers and health care professionals, there were no references to complicated grief resulting from relational disorders such as losses that remain ambiguous and without closure. Complicated and prolonged grief, if not recognised, has the potential to threaten health, mental wellbeing and resilience as well as family relationships.

For practitioners who encounter such issues, Robert K. Merton (1957; 1968), a distinguished American sociologist (Scott & Marshall 2009), advocated the use of middle-range theories. Middle-range theorising is an approach to research that begins from specific local-level issues, where practitioners question what type of processes they have encountered and how they can explain the underlying dynamics. Middle-range theory is principally used in sociology to guide empirical inquiry (Merton 1968) and will be discussed further in the Methodology section of this thesis. Although middle-range theory was developed by Merton, a sociologist, since its first development middle-range theorising has become inherently multidisciplinary, and enables practitioners to work on research relevant to urgent practical problems (Green & Schweber 2008).
My study is guided by the middle-range theory of Ambiguous Loss put forward by Boss (1999; 2006).

1.11 Research Questions

The first research question is: How is loss perceived by those affected by MIH? A sub-question is: How do participants experience the additional stressor of ambiguity associated with MIH? The second research question is: How do people manage the ambiguity associated with MIH?

1.12 Aims of the Study

Using qualitative methodology, this study aims to undertake a collective case study of perceptions of loss associated with MIH within a family context, analysing the experiences through the lens of ambiguous loss theory. As multiple social realities surround the issue which I wish to study, and the identification of these multiple realities is an aim of the study, it further supports the argument that the study lends itself to a qualitative inquiry. Identifying ways that people manage ambiguity associated with mental ill health has the potential to add value to the study, as coping or managing processes involve both a family’s external context such as the family’s history, culture, economics, developmental state and constitutional state as well as the family’s internal context which includes such things as family values, beliefs, structure and function (Boss 2002). Qualitative case study is valued for its ability to capture complex actions, perceptions and interpretations. In this way, an aim of this study is to generate a substantive theory on how people manage the ambiguity associated with MIH and broaden our understanding of how people affected by mental ill health experience ambiguity related to the ill health, and make an original contribution to the literature. The findings also have the potential to inform clinical practice and policy formulation. In undertaking this study, my interest was in insight, discovery and interpretation rather than hypothesis testing (Merriam 2009).

1.13 Methodology

I use the theory of symbolic interactionism to understand how participants create a symbolic understanding or reality which is shaped by the shared meanings within the family, by the larger context of the world outside the family and by the interactions that occur both within and between the internal and external contexts (Fravel & Boss 1992, p. 127).

There are many approaches to the analysis of qualitative data. For this study, I chose a combination of Grounded Theory Methods (GTM) (Strauss & Corbin 1990) and Transcendental Realism Methods (TRM) from the framework of Miles and Huberman (1994), to generate theory.
on how those affected by MIH manage the associated ambiguity. These approaches are similar in logic (Punch 2005, p. 196) and were the most suitable for the purpose of my study. Grounded theory is essentially an inductive technique but some deduction is also necessary (Miles & Huberman 1994, pp. 16-23), thus I was guided by the ambiguous loss theory of Boss (1999; 2006) and the Theory of Sense of Coherence (Antonovsky 1979) to test emerging theoretical ideas (Punch 2005).

Gilgun (1992, pp. 29-30) writes that grounded theory approaches are more likely to generate pattern theory and are more compatible with ideas of diversity whereas hierarchical theory can lead to “norming” families and overriding individuality and diversity. There are numerous approaches to GTM. I used the approach of Strauss and Corbin (1990) advanced by Charmaz (2000), as it closely fits the symbolic interactionist perspective.

Case studies were the basis for the foundation work of family therapy and family sociology (Gilgun, Daly & Handel 1992; Handel 1991). As a form of research, case study is defined by interest in an individual case and of studying an issue or phenomenon within the case, not by the methods of inquiry used (Stake 2005; 2006). I chose a collective case study approach because this approach is useful to study issues in depth and to understand situations in context. Case studies that rely on qualitative methods help researchers gain an understanding of the subjective meanings that participants give to the issues being observed. Thickly described case studies taking multiple perceptions into account are also useful in understanding the influence of multilayered social systems on participants’ perceptions and actions (Gilgun 1994). As objects, events or situations can mean a variety of things to a variety of people in the family, Boss, Dahl and Kaplan (1996) write that multiple perceptions of the same event or situation are important to hear.

An aim of this study is to generate substantive theory on how people manage the ambiguity associated with mental ill health. Substantive theory evolves from the study of a phenomenon situated in one particular situational context, in contrast to formal theory which emerges from a study of a phenomenon examined under many different types of situations (Strauss & Corbin 1990).

1.14 Metaphors

There is an argument in postmodern thought that no language can be purely objective especially when evaluating phenomena within vastly different contexts. Thus it was imperative to find ways of gaining a critical understanding of each participant’s unique interpretation with diverse beliefs
and values, as well as eliciting varied examples of managing ambiguities of mental ill health and articulating complex social processes. However, conceptual relativism does not capture such unique experiences either. Goatly (2007) argues for experientialism as a middle course between objectivism and subjectivism because our infant bodily experiences, which are universal, are what we use as tools for thinking. He writes that through these universal bodily experiences a common metaphorical language has evolved. To this end, I developed a number of key conceptual metaphors to articulate the nuances of social processes when analysing how participants manage ambiguity. Goatly (2007, pp. 11-17) opines that metaphors are central to human thought and vital to our conceptualisation of abstract ideas, and that they do not occur randomly but fall into patterns. For example, in Western culture emotion is seen as liquid where grief=tears (liquid) or even “tears of happiness”. Miles and Huberman (1994, pp. 250-252) write that the richness and complexity of metaphors assist a researcher see new theoretical possibilities. In this study, metaphors helped me collapse data without locking out multiple avenues for analysis, and place patterns noted in the data into the larger context. Metaphors also helped as a decentring device by helping me step back and question what is going on and thus move up the abstraction ladder to an analytical level. Further, metaphors also helped me connect findings to theory. For example the “navigating” metaphor made me peruse the data to find out how participants “managed” to stay resilient despite the additional stressors of ambiguity. Navigating connotes managing and negotiating which is movement, whereas coping connotes enduring or “putting up with” and no movement. Discussion with supervisors, a collaborator and peers stimulated new and different ideas from several points of view. Using a metaphor of a marine theme, I was able to conceptualise activities within a context of overpowering emotions which were open-ended and ongoing.

Metaphors often give access to complexity/connotations unavailable in more literal language and thus assist a researcher to identify connotations in the way each individual and family perceives the situation they find themselves in. However there are times at which metaphors cannot capture nuances and might imply a more homogenous group dynamic than is likely the case. An example of this is the power differentials between consumers, family members and health professionals.

The methodology, procedures and techniques I use in the study come within the interpretive paradigm and are described in detail in Chapter 2 on Methodology.
1.15 Ethical Considerations

I made applications to the Human Research Ethics Committees of the University of Western Australia and the North and South Metropolitan Area Health Department of WA for approval to conduct the study. These committees were satisfied that the study protocol followed guidelines for protecting participants’ rights to confidentiality in conducting the study and also in the storage, access and disposal of data.

Before participating in the study participants were given an information sheet (Appendix 2) that contained: a description of the nature and the purpose of the study, what participation in the research would involve, how participants might address any concerns they might have as a consequence of the participation, potential benefits of the study and an assurance that participants could withdraw from the study at any time without prejudice. Participants were guaranteed confidentiality.

An agreement was obtained from family counsellors of the Association for Relatives and Friends of Mental Illness (ARAFMI) and key workers from mental health clinics that they would be available for support should participants experience increased grief reactions as a consequence of participation in the study. Family counsellors at this organisation and key workers from mental health clinics were provided with training on ambiguous loss theory prior to commencement of the study.

1.15.1 Data Storage, Access and Disposal

The tape recorder was stored in a locked filing cabinet in my home. The transcriptions, contact summary forms including field notes and memos were all filed on my desk top computer and laptop to ensure I had duplicates if one system failed. Names in these were replaced with numbers. Both desk top computer and laptop have password protection. All material will only be kept for a period of 5 years. Hard copies are kept of conceptual diagrams and matrices.

1.15.2 Participant Consent

I met with each consumer who volunteered to participate. I explained that participation required one or more of their significant-others to participate as well. I then met with each of the significant-others individually. All participants were given a copy of the Participant Information Sheet (Appendix 2) which explained the nature of the proposed project and what their participation would involve, addressing concerns that they may have as a consequence of their participation, the potential benefits to them and society, their right to withdraw from the study at
any time without prejudice and also their right to confidentiality. Interviews commenced when
signed participant consent forms were returned.

1.16 Summary

This introductory chapter presents a rationale for undertaking this study and writing the thesis,
and some common scenarios that I experience in my social work practice in mental health
services of Western Australia. It also presents definitions pertaining to ambiguous loss theory and
mental ill health, a contextual background, a historical account of the research and literature of
loss and grief associated with mental ill health. The chapter then presents the need for this study,
purpose of the study, self of the researcher, significance of the study, statement of the problem,
the two research questions, aims of the study, a brief description of methodology, use of
metaphors and ethical considerations.

The following chapter describes the methodology and methods in detail. In Chapter 3 I present
the analytic findings of Reverberating Losses and experiences of ambiguity associated with
MIH, Spinning in a Whirlpool and Being Adrift at Sea. In Chapter 4, I give a detailed
explanation of the Basic Social Psychological Process of Navigating the Winds and Tides of
Ambiguity to Stay Afloat. In Chapter 5, I compare findings of my study with ten other empirical
studies that use some form of qualitative method to study the perspectives of consumers or
significant-others about mental ill health. In Chapter 6, I compare findings of my study with
related bodies of theoretical literature. In Chapter 7, I conclude the thesis with a summary,
discussion, implications for future research and recommendations for clinical practice, capacity
building in health promotion, prevention of ill health and breakdown of relationships and health
professional education.
Chapter 2: Methodology and Method

2.1 Introduction

In this chapter, I present the methodology and methods I use to investigate the research questions: 1) How is loss perceived by those affected by MIH?, 1(a) How do people manage the ambiguity associated with mental ill health? and 2) How do people manage the ambiguity associated with MIH? The questions are investigated through a qualitative collective case study of seven families conceptualised within the interpretative research paradigm. Firstly, the chapter characterises a form of symbolic interaction methodology developed by Herbert Blumer (1900-1987) (Blumer 1969, 1972), which underpins the investigation of how participants experienced loss, the ambiguities inherent in mental ill health and how they managed this ambiguity. Secondly, the chapter provides details of the Grounded Theory Methods (GTM) of Strauss and Corbin (1990), advanced by Charmaz (1988, 1995, 2000), the Transcendental Realism Method (TRM) developed by Miles and Huberman (1994) and the case study design of Stake (1978; 1995, 2005; 2006; 2010) and the rationale for choosing these combinations of methods.

I adopt an interpretive approach and study phenomena within their context. I consider the importance of the subjective meaning that participants bring to their situation. In addition, by including family and/or significant-others of those experiencing mental ill health, I suggest that everyday activity involves a person interacting with other people rather than acting in isolation. Through this interaction, new meanings are formed. My interest is in exploring beyond perceptions taken for granted in my everyday practice as a social worker in the mental health service of Western Australia. I use qualitative methods for this inquiry as multiple social realities surround the issue which I wish to study, and the identification of these multiple realities is an aim of the study.

For ease of reading, the chapter is divided into thirteen sections. In the first section I present the Australian and West Australian context. In the second section I explain the methodology within the interpretive research paradigm which I use to conceptualise the study, and the rationale for selection of the particular approach of symbolic interactionism (Blumer 1969). In the third section I describe the Grounded Theory Method (GTM) (Strauss & Corbin 1990; Charmaz 2000), Transcendental Realism (Miles & Huberman 1994), use of literature in data analysis and the Qualitative Case Study design (Stake 1978; 1994, 1995, 2005; 2006; 2010). In the fourth section, I discuss middle-range theory construction and in the fifth I describe participant recruitment and selection. The sixth presents participant characteristics. The seventh presents field procedures. The eighth presents data analysis. In the ninth section I discuss diagrams, matrices and
theoretical memos. In the tenth section I discuss data management through use of Atlas.ti computer-aided qualitative data analysis software (Friese 2012). In the eleventh I discuss trustworthiness of findings. The twelfth section consists of a discussion on bracketing. The thirteenth section completes the chapter with a summary.

2.2 The Australian and West Australian (WA) Context

Although this study was at the collective, group and individual level of families, it stands in conditional relationship to the broader level of Australian Federal and Western Australian State Government policies and the mental health sectors of West Australia – the government, private and non-government, not-for-profit organisations. Throughout the period of study, I sourced documentary information through discussions with supervisors, colleagues, government reports, organisational policy documents, annual reports and newspaper articles to gain a broad understanding of the national and local context and the impact these have on participants’ lives.

Data collection for the project started at a time of change in mental health services in West Australia. Australia’s first Mental Health Commission was established in West Australia on 8th March 2010. The Commission focused on engagement with people with mental health problems and/or mental illness, their families and carers as genuine partners in advising and leading mental health development at individual, community and service system levels across Western Australia (Mental Health Commission 2011-2012), illustrating the increasingly understood importance of the lived experience. There was increased debate on the importance of the voice of the individual with mental ill health as well as their significant-others. The West Australian Association for Mental Health (WAAMH) is the peak mental health representative body for non-government, not-for-profit agencies. In May 2011, $1.6M was allocated to WAAMH to build capacity within the community sector that provides services for people living with mental ill health and they actively supported Consumers of Mental Health WA (CoMHWA) as the new consumer body where part of the funds were used to provide a mentoring service as the new organisation sought to establish itself (Western Australian Association for Mental Health 2011-12). With these changes the voice of people with mental ill health, as well as their significant-others and the community, was strengthened. Community educational forums also increased.

In Australia, terms such as dual diagnosis, co-morbidity or co-occurring disorder are used to describe the complexity of MIH among people who seek help for MIH as well as misuse of alcohol and other illicit substances. A report by Stokes (2012) found that these consumers often bounce between mental health and alcohol and other drug services because of limited capacity in each
service to provide the care and support they need. As part of the Council of Australian Governments (COAG) National Action Plan on Mental Health (2006-2011), a national project was set up to build the capacity of non-government drug and alcohol organisations to identify and treat this cohort of consumers. This project is known as the Improved Services Initiative (ISI). Since 2008, Palmerston Association Inc. (Palmerston Association Inc 2012) has been the lead agency for the Non-Residential ISI - Perth Co-occurring Disorders Capacity Building Project (PCDCBP). The project now represents a consortium of nine alcohol and other drug (AOD) agencies based in the Perth metropolitan area.

This study was conducted in the context of the above developments and as such Federal and State Government legislation was beginning to have an influence on families and the individuals in them at a micro level.

2.3 Methodology

Clough and Nutbrown (2002, p. 30) say that the twin terms of methodology are ontology and epistemology. Ontology is the theory of what exists and how it exists. Epistemology is a related theory of how we can come to know those things. The purpose of my study determined the methodology and method that I adopt, thus the methods chosen mediate between the research questions and the findings which the data from this study provide: firstly to understand how people affected by MIH and their significant-others perceive the losses associated with the ill health; secondly to understand how they experience the additional stressor of ambiguity associated with MIH; and thirdly to generate a substantive theory about how they manage ambiguity associated with the losses.

2.3.1 Symbolic Interaction Theory

Symbolic interactionism describes both a social theory and an approach to the study of human behaviour. This theory is based on three premises. The first is that human beings act towards things on the basis of the meanings that the things have for them; these meanings are central in their own right. The second is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows; this suggests that meanings are social products which arise in the process of interaction between people, and grow out of the ways in which other persons act towards the person with regard to the things. The third premise is that these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters Blumer (1969, p. 2). Participants in human interaction build up their respective lines of conduct by constant interpretation of each other’s ongoing lines
of action through the use of symbols, by interpretation or by ascertaining the meaning. In this way, individuals seek to ascertain the intention or direction of the acts of others. They then form and align their own action on the basis of such interpretation of the acts of others. A key feature of the theory is that human beings have a self and that they can act towards themselves as they might act towards others. Examples of these are getting angry with themselves, taking pride in themselves, setting goals for themselves and then planning what they are going to do (Blumer 1972; Prus 1996). Of importance to my study is the theory's interpretive approach of studying human lived experience. Within an interpretive approach, a researcher needs to:

a) Get out into the field, to understand what is going on;
b) Understand the importance of theory, grounded in reality, to the development of a discipline;
c) Understand that the nature of experience is continually evolving;
d) Understand the active role of persons in shaping the worlds they live in;
e) Adopt an emphasis on change and process, and the variability and complexity of life; and
f) Understand the interrelationships among conditions, meaning, and action.

(Strauss & Corbin 1990, pp. 24-25).

Symbolic interactionism as a distinct theoretical approach falls within one of two types of social psychology: 'psychological social psychology' and 'sociological social psychology', with the notion of 'perception' being central to 'psychological social psychology' and the notion of 'perspective' being central to 'sociological social psychology' (O'Donoghue 2007, pp. 29-30). I use psychological social psychology, which investigates perceptions of those affected by MIH. This symbolic interactionist methodology underpins the methods I use.

2.4 Method

2.4.1 Grounded Theory Method (GTM)

GTM is both a qualitative and quantitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon (Strauss & Corbin 1990). The qualitative methods of grounded theory emerged in the 1960s from the collaboration of Barney G. Glaser and Anselm L. Strauss (Glaser & Strauss 1967). With this approach, they developed clear sets of written guidelines for conducting qualitative research at a time when sophisticated quantitative methods were dominant. It was developed as a method for the study of complex social behaviour (Glaser & Strauss 1967). However Strauss later developed his own method of GTM with Corbin (Strauss & Corbin 1990).
I use the procedures and techniques of Strauss and Corbin (1990) which include open coding, axial coding, focused coding and pattern coding, drawing also from the constructivist grounded theory approach of Charmaz (2000). Charmaz (2000, p. 525) writes, ‘constructivists aim to include multiple voices, views and visions in their rendering of lived experience’. By so doing, researchers seek both respondents’ and researchers’ meanings to gain depth and understanding in their study. My study encompasses the constructivist paradigm which proposes that each individual mentally constructs the world of experience through cognitive processes (Andrews 2012). Within this paradigm, all truth is constructed by humans, situated within a particular time and social context. Knowledge is then created by the interaction of individuals within society. The constructivist approach resists the quest to capture a single reality instead, through attention to detail a researcher using a constructivist approach sensitises themselves to multiple realities and the multiple viewpoints within them (Charmaz 2000). By studying participants’ perceptions, I attempt to find what they define as real and where their definition of reality takes them.

I also use Charmaz’s (2000, p. 517) technique of memo writing which she describes as an intermediate step between coding and the first draft of the completed analysis. I use action codes in the memos and this together with data display helped me identify interrelated processes. For the purpose of this dissertation, I refer to the approaches of Strauss and Corbin (1990) and Charmaz (1988, 1995, 2000) as GTM.

2.4.2 Transcendental Realism Method (TRM)

Miles and Huberman (1994, p. 4) name their method of data analysis ‘transcendental realism’, explaining that social phenomena exist both in the mind and the objective world. Lawful and reasonably stable relationships are to be found among them through regularities and sequences that link them together. Constructs that underlie individual and social life are derived from the patterns of regularities and sequences. They assert that although most of these constructs are invisible to the human eye this does not make them invalid. The method of transcendental realism in data analysis is particularly useful in analysing the experiential knowing rather than just the tangible. According to TRM, human meanings and intentions are worked out within social institutions, structures, practices and conventions that exert strong influences over human activities because people construe them in common ways. Language, decisions, conflicts and hierarchies, all social phenomena, exist objectively in the world of which we may only be remotely aware. Through these influences, things that are believed become real. Such peculiarities of society and human relationship make a realist approach to understanding them more complex but
not impossible. Through the method advocated by these authors, I was able to gain an understanding of the complex social phenomenon of ambiguous loss associated with MIH.

Miles and Huberman (1994) locate their orientation to analysis within the interpretive paradigm and affirm the existence and importance of the subjective, the phenomenological, and the meaning-making at the centre of social life. Their aim in developing transcendental realism was to ‘register and “transcend” these processes by building theories to account for a real world that is both bounded and perceptually laden, and to test these theories in our various disciplines’ (Miles & Huberman 1994, p. 4). They define analysis as consisting of three concurrent flows of activity: data reduction, data display and conclusion drawing/verification. Data reduction refers to the process of selecting, focusing, simplifying, abstracting, and transforming the data that appear in transcriptions as well as field notes. Data display refers to compressed assembly of information such as matrices, graphs, charts and networks. Conclusion drawing/verification refers to noting regularities, patterns, explanations, possible configurations, causal flows and propositions (Miles & Huberman 1994, pp. 10-12).

TRM calls both for an explanatory structure as well as a grasp of a particular configuration through evidence to show that each entity or event is an instance of that explanation (Miles & Huberman 1994, p. 4).

Both GTM and TRM of data analysis come within the general term ‘analytic induction’. Punch (2005, p. 97) describes analytic induction as comparing incidents or cases, establishing similarities and differences in order to define categories and concepts. As such, focusing on evidence that challenges or disconfirms concepts and ideas is as important as focusing on similarities in defining categories and concepts. Both GTM and TRM share these common features. The transcendental aspect of ambiguous loss meant that no one method or theory can explain what is going on, hence I have combined the various methods and theories explained in this section.

### 2.4.3 The Use of Literature in Data Analysis

Literature is also important in data analysis. However, the use of literature differs in GTM from other research methods in that it is seen as further data to be fed into the analysis when theoretical directions have become clearer from the data generated from the study. However, as Punch (2005) asserts, although GTM is essentially an inductive technique, deduction will also often be necessary. Swanborn (2010) also states that even when using an exploratory approach, a researcher needs a theoretical foundation from which to begin. Miles and Huberman (1994, p. 61) support this assertion and suggest an alternative between a priori and inductive
approaches where the researcher creates a general accounting scheme for codes that is not content specific, but points to the general domains in which codes can be developed inductively.

I use this approach where I begin with a general accounting scheme for codes using a conceptual framework from the first research question: How is loss perceived by those affected by MIH? and the sub-question: How do participants experience the additional stressor of ambiguity associated with MIH?, and then reduce the breadth of the enquiry to give more concentrated attention to the emerging issues. For the second research question: How do participants manage the ambiguity associated with MIH? I looked for phrases used by participants repeatedly and line by line coding for 'interaction among participants', 'strategies used' and 'consequences'.

A wide variety of autobiographies were examined closely for similarities and differences. Concepts and categories that emerged from interviews and observations of my study were cross-checked against autobiographical accounts published by significant-others and consumers (Deveson 1992; McGrath 1984; Stakes 1985; Jamison 1997; Ruocchio 1991; Hinshaw 2008; Murphy 1997; Molta 1997; Fox 2009; Fox 2004; Willis 1982). Strauss and Corbin (1990, p. 55) write that such literature plays an essential role in grounded theory studies for supplementing usual interviews and observations.

My rationale for choosing the above methods is that they all come within the interpretative paradigm and sensitised me to multiple realities and the multiple viewpoints within them of participants who had a diagnosis of MIH, their significant-others as well as me, a researcher and practitioner. This approach assisted me in developing an understanding of meanings and perceptions that participants attribute to the situation and what constitutes MIH for that particular participant rather than just the name of the disorder.

In summary, I use a combination of methods drawn from GTM and TRM to conceptualise, identify and analyse data. My rationale for using these methods and theoretical positions is that I believe a family dealing with the ambiguous loss of MIH would be expected to create a symbolic understanding which is shaped by experiential knowledge and the shared meanings from within the family as well as the environment. This symbolic understanding or reality is further shaped through the interactions that occur both within and between the internal context of the family and external contexts outside the family.

I now describe the case study research design adopted. This method is particularly useful in taking into account the contexts of the issues of the research questions.
2.4.4 Qualitative Case Study in Social Inquiry

I chose a qualitative collective case study design described by Stake (2005); (Stake 1995, 1994; Stake 1978; Stake 2006; Stake 2010) comprising a series of fifteen in-depth interviews with seven families in order to understand the issues in depth, in their natural setting, recognising their complexity and context. The data obtained from the study is used to achieve a critical understanding of the social phenomena of ambiguous loss associated with MIH rather than assume representativeness.

I reviewed the literature of several authors’ interpretation of case study research (Gilgun 1994; Hancock & Algozzine 2006; Merriam 2009; Miles & Huberman 1994; Platt 1992; Punch 2005; Simons 2009; Stake 2005, 1995, 1994; Stake 1978; Stake 2006; Stake 2010; Yin 2009). Among these authors, opinions differ in the definitions of case study. Walcott (2009, p. 85), conceptualising qualitative approaches in research as a researcher climbing a ‘tree’ to get a view of what is going on, was surprised to discover that he had trouble finding a suitable place for the case study on the tree. He says the problem was not that the case study did not fit anywhere but that it seemed to fit everywhere.

For this study, I chose the definition of Stake (1995, 2005) who bases his approach to case study on a constructivist paradigm and identifies three kinds of case studies: (1) *Intrinsic* when the focus is on a particular case, (2) *Instrumental* when the focus is on understanding something (an issue) other than the case, (3) *Collective* when the focus is on understanding something other than the case from several cases rather than just one. This study is a *collective case study*. Each of the seven cases (families) is instrumental to learning about the *issue* — ambiguous loss associated with MIH. The issue is dominant and the study starts and ends with issues being dominant. In order to focus attention on complexity and context, Stake (2005) suggests using issues as a conceptual structure and issue questions as the primary research questions. ‘These issues are not simple and clean but intricately wired to political, social, historical and especially personal contexts’ (Stake 2005, p. 17).

The individual cases share a common characteristic and are categorically bound together by the phenomenon of ambiguous loss associated with MIH. Stake (2005, pp. 6-7) names this phenomenon of study ‘a quintain’ (pronounced kwin’ton). He adopts an uncommon word such as ‘quintain’ to facilitate dialogue. This ‘quintain’ acts as an ‘umbrella’ for the cases and the functions or conditions of which researchers might seek examples to study. My study has been designed to give attention to the ‘quintain’ and not individual cases. Single cases were studied for similarities and differences in order to understand the ‘quintain’.
My rationale for choosing a qualitative case study approach is because I want to capture complex, real-life events and processes within naturalistic settings and to ascertain the subjective meanings that families assign to loss associated with MIH. Further, from practice experience, I am aware that the issues of ambiguous loss associated with MIH are intricately linked to personal, political, social and historical contexts. The interaction of the unit of study with its context is a significant part of a qualitative case study investigation (Gilgun 1994). Both internal and external contexts are important to me as a social worker. Case studies are idiographic and generalising is analytic. Idiographic findings are particularly useful in practice issues to provide detail and gain an understanding of the environment in which practice is embedded (Gilgun 1994). Idiographic theory, as defined by O'Donoghue (2007), corresponds with substantive theory described by Strauss and Corbin (1990) in that both theories are designed to explain particular events or human actions within specific cultural contexts.

2.4.4.1 Particularisation

Stake (1995); Stake (2010) describes particularisation as attending to what is important about the cases at hand and coming to understand their activity within important circumstances and contexts. Stake explains that within every human activity, the reality of the personal experience and the reality of the group and societal relationships exist simultaneously. Although these two realities are recognisably different, they connect, overlap and merge. In this study I sought to understand both the unique and the collective.

In summary, I have used various combinations of methods and approaches to craft a study to suit the research questions and the peculiarities of the study.

2.5 Middle Range Theory Construction

In transcending the difficulties of reflecting on abstract grand theories of grief and the local issues encountered in the mental health practice field, I considered Ambiguous Loss Theory (Boss 2004, 1992, 2010; Boss 1999; Boss 2006; Boss 2012; Boss 1977a, 2013) as a middle-range theory as it was directly engaged with my concerns as a practitioner, involved investigation by multi-disciplinary researchers and practitioners (Boss 2007) and was context-driven. The concept of ‘middle-range theory’ was first advocated by Robert K. Merton (Bruce & Yearley 2006; Scott & Marshall 2009) as an approach to theory construction. Merton (Merton 1968, p. 39) described theories of the middle-range as:

Theories that lie between the minor but necessary working hypotheses that evolve in abundance during day-to-day research and the all-inclusive systematic efforts to
develop a unified theory that will explain all the observed uniformities of social behaviour, social organisation and social change.

Middle-range theorising also emphasises the interconnectivity between theory and practice. Green and Schweber (2008) argue that theories that are useful act as a boundary between researchers and communities of practitioners by employing concepts and explanations that directly engage with issues and practices in their local context. Thus my study is primarily guided by the Theory of Ambiguous Loss put forward by Boss (Boss 2004, 1992, 2010; Boss 1999; Boss 2006; Boss 2012; Boss 1977a, 2013).

2.6 Participant Recruitment and Selection

An advertisement (Appendix 1) was circulated through the newsletters of consumer organisations in WA and mental health clinics of metropolitan WA. Participants who were active consumers of the mental health clinic where I worked were excluded from the study to prevent a conflict of interest. Following interviews with eleven participants from five families and with no new information forthcoming, I found that I had reached data saturation. However I was keen to find out if my findings apply in a different set of consumers such as consumers with co-morbid substance use/misuse and mental ill health. Qualitative samples tend to be purposive and can evolve once fieldwork begins, which means that a researcher makes a judgement to seek information from participants who are likely to have the required information and are willing to share it to achieve the objectives of the study. Miles and Huberman (1994, p. 27) state that ‘observing one class of events invites comparison with another; and understanding one key relationship in the setting reveals facets to be studied in others’. They call this ‘conceptually-driven sequential sampling’. With this in mind, I sourced further participants by advertising in a non-government drug and alcohol project of WA for co-morbidity.

I assured participants of anonymity and confidentiality and that names and identifying information would be altered during the writing of the thesis, and emphasised that I would not discuss any of what they told me with their significant-others.

2.7 Participant Characteristics

The study called for men and women:

- diagnosed with mental ill health,
- who were in recovery,
- aged 18 to 60 years,
- able to communicate in English,
who were prepared to invite members of their family/significant-others (who were 18 years and over and also able to communicate in English) to participate with them in the research.

Four members and their significant-others from Consumers of Mental Health (WA), one consumer and significant-other from a local mental health clinic, and two consumers and their significant-others from the non-government alcohol and drug project volunteered to participate. In total, there were fifteen participants from seven families. As it was a voluntary study, I did not source different combinations of family relationships; however there were combinations of mothers and daughters, a mother and son, siblings, a married couple and a very close friend who was considered a significant-other. No fathers volunteered to participate. Men participating were two brothers, a son and a husband.

Table 1 – Comparison of Participant Profiles

<table>
<thead>
<tr>
<th>Participants</th>
<th>Relationship</th>
<th>Sex</th>
<th>Age group</th>
<th>Identifying as</th>
<th>Religion</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family A</td>
<td>Siblings</td>
<td>male</td>
<td>50-60</td>
<td>Sig.O/con</td>
<td>Anglican</td>
<td>Technical</td>
</tr>
<tr>
<td></td>
<td></td>
<td>female</td>
<td>60-70</td>
<td>Sig.O/con</td>
<td>Catholic</td>
<td>Secondary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>male</td>
<td>50-60</td>
<td>Sig.Other</td>
<td>No religion</td>
<td>Secondary</td>
</tr>
<tr>
<td>Family B</td>
<td>Wife &amp; husband</td>
<td>female</td>
<td>50-60</td>
<td>Sig.O/con</td>
<td>Catholic/spiritual</td>
<td>Tertiary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>male</td>
<td>60-70</td>
<td>Sig. Other</td>
<td>Spiritual</td>
<td>Tertiary</td>
</tr>
<tr>
<td>Family C</td>
<td>Son &amp; mother</td>
<td>male</td>
<td>20-30</td>
<td>Consumer</td>
<td>Catholic</td>
<td>Secondary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>female</td>
<td>50-60</td>
<td>Sig. other</td>
<td>Catholic</td>
<td>Secondary</td>
</tr>
<tr>
<td>Family D</td>
<td>Intentional family</td>
<td>female</td>
<td>50-60</td>
<td>Consumer</td>
<td>No religion</td>
<td>Tertiary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>female</td>
<td>60-70</td>
<td>Sig.O/con</td>
<td>Spiritual</td>
<td>Post-graduate</td>
</tr>
<tr>
<td>Family E</td>
<td>Siblings</td>
<td>female</td>
<td>50-60</td>
<td>Sig.O/con</td>
<td>Catholic</td>
<td>Tertiary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>female</td>
<td>50-60</td>
<td>Sig. other</td>
<td>Catholic</td>
<td>Tertiary</td>
</tr>
<tr>
<td>Family F</td>
<td>Daughter &amp; mother</td>
<td>female</td>
<td>30-40</td>
<td>Consumer</td>
<td>Catholic</td>
<td>Secondary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>female</td>
<td>50-60</td>
<td>Sig. other</td>
<td>Catholic</td>
<td>Secondary</td>
</tr>
<tr>
<td>Family G</td>
<td>Daughter &amp; mother</td>
<td>female</td>
<td>30-40</td>
<td>Consumer</td>
<td>Spiritual</td>
<td>Technical</td>
</tr>
<tr>
<td></td>
<td></td>
<td>female</td>
<td>60-70</td>
<td>Sig. other</td>
<td>Anglican</td>
<td>Secondary</td>
</tr>
</tbody>
</table>
2.8 Field Procedures

I had one in-depth face-to-face interview with each participant separately. Each interview lasted 2-3 hours. Interviewing participants separately meant that they were able to reveal their thoughts and feelings freely but the limitation was that I was not able to capture interactional data.

Using a method suggested by Miles and Huberman (1994, p. 61) which is part way between the priori and inductive approaches, I developed a conceptual framework with a general accounting scheme for codes. My choices of domains were based on the research questions, Boss’s ambiguous loss theory, and clinical hunches from 20 years of experience working in the mental health sector. To keep an open mind, I used this framework as an initial accounting scheme for codes that were not content specific but pointed to the general domains in which codes can be developed inductively. Within this framework, I intended to generate concepts grounded in data. Within these domains, my intention at the outset was to capture data from consumers as well as significant-others but maintain an open mind that some of these domains may not come up in the data and that I may discover new domains from emerging data.

Codes were divided into the following four general domains which were the basic units of study:

<table>
<thead>
<tr>
<th>Embedded unit of analysis 1</th>
<th>Embedded unit of analysis 2</th>
<th>Embedded unit of analysis 3</th>
<th>Embedded unit of analysis 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do people perceive loss? (Themes of loss)</td>
<td>How do people perceive uncertainties? (Themes of ambiguity as an additional stressor of loss)</td>
<td>How do participants perceive their relationships and social structure? (Uncertainties in perceptions of connectedness/sense of belonging)</td>
<td>How do participants manage losses and ambiguity? (Strategies, processes, activities)</td>
</tr>
</tbody>
</table>

I also developed a contact summary form as suggested by Miles and Huberman (1994, pp. 51-54) with demographic information, descriptive information needed for cross-case analysis, genograms and eco-maps to preserve the complexity inherent in the situation. In addition to the above, the contact summary form also included the main issues/themes that emerged from the
particular contact, summarised the information gathered, and included other salient, illuminating or important issues as well as new information to be gathered at the next field contact. The forms were also used as a guide for the next interview and to suggest new or revised domains, and prevented me from forcing data into the four domains of the initial accounting scheme and assisted me to consider emerging issues. The contact summary form was a single sheet about a particular interview with only the main points of the interview and my reflective remarks in dot points to be expanded in field notes. The genograms and eco-maps were drawn up whilst discussing how participants perceived their relationships and social structures. In addition to contact summary forms, field notes of each interview were compiled soon after and recorded my overall observations and expanded on the main points in the contact summary form.

Table 3 - Contact Summary Form

<table>
<thead>
<tr>
<th>ID</th>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
</tr>
<tr>
<td>Age</td>
<td>20-30</td>
</tr>
<tr>
<td>Religion</td>
<td>Anglican</td>
</tr>
<tr>
<td>Edu.</td>
<td>Primary</td>
</tr>
<tr>
<td>Relat.</td>
<td>father</td>
</tr>
<tr>
<td>Occup.</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
</tr>
<tr>
<td>Living</td>
<td>alone</td>
</tr>
<tr>
<td>Country Of birth</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
</tbody>
</table>

- Genogram/eco-map.
- What were the main themes or issues of this contact?
- What are the new hunches or speculations about this interview?
- What are the leads to follow up in next interview?

2.8.1 Interview Process

I used two formal questions: (1) ‘Tell me about the losses associated with your mental ill health?’ or to significant-others: ‘Tell me about your losses associated with the mental ill health of (name of consumer)?’ (2) ‘Tell me how you manage these losses?’ Although the questions were structured by the issue of the study, they were not asked in a structured way. Instead the interviews were conversational where I asked probing questions to clarify and refine the information and interpretation. As interviews progressed, I asked open-ended questions to elicit
data on the four domains of the conceptual framework but importantly focusing on emerging issues. Probing questions were asked when confusion or uncertainties about MIH, relationships or social structure emerged. However as a clinician with many years of experience in the mental health field, I was acutely aware that I needed to be tuned to the mood of those being interviewed and watch for verbal as well as non-verbal cues so as not to create further distress by recalling past events.

Genograms and eco-maps were introduced and explained to participants as the interview progressed. This took place as a collaborative discussion in the form of an interactive and reflexive relationship where I was able to ascertain the perceptions of the participants, of their family and wider social networks, the characteristics of these relationships while at the same time I had the opportunity to prompt the participants to consider areas that they may have forgotten. Making it a collaborative exercise ensured continuous validation checking.

2.8.2 Privacy and Confidentiality

I audio digital-recorded all interviews, using several strategies to maintain anonymity of participants. During taping, only the person’s first name was used. All tape-recorded interviews were transcribed by one secretary of the Department of Psychiatry and Clinical Neurosciences. She was informed of the importance of maintaining the confidentiality of the participants and the content of the data. Participants’ names were replaced with numbers in contact summary forms and when transcripts were saved on the computer. The computer has password protection. Original recordings were deleted.

2.8.3 Minimising Risk of Harm

Whilst conducting interviews, I checked out periodically with participants their comfort levels in discussing their personal experiences. On two occasions participants became very distressed when discussing deaths of significant-others. I offered to end the interview but both participants were keen to continue and said at the conclusion that it helped them to talk about their feelings. There was one occasion when my role as researcher and therapist was clearly at odds and I informed the participant that it was not possible for me simultaneously to be researcher and therapist. Information about available support was given.

2.8.4 Sampling: Bounding the Collection of Data

To ensure that the study remains reasonable in scope, placing boundaries is important (Stake 1995; 2006; Miles & Huberman 1994). Stake (1995) describes a case as a specific, complex, functioning thing and a bounded system. Vanderstoep and Johnston (2009, p. 209) write “a
family demonstrates the characteristics of a system by its (1) wholeness—it is an entity unto itself and distinct from other families; (2) interdependence—the actions of one member have a reverberating influence on other family members, (3) nonsummativity—the family is greater than the sum of its individual members because its rituals, traditions, intimacy, and history are greater than any individual member; and (4) equilibrium—the family creates habitual patterns of behaviour that, whether functional or dysfunctional, are difficult to change”. In my study, ‘family’ was considered in the broadest possible sense as from practice experiences I was aware that people with mental ill health may sometimes be marginalised from their biological families by virtue of their illness and may form new bonds of commitment. This situation emerged when one participant nominated a friend as a significant-other. I have named this family an ‘intentional family’ (Ahern & Bailey 1996).

The boundaries of the cases in this study are:

- Consumers aged between 18- 60 years who have experienced mental ill health
- Those who have recovered
- Significant-others as defined by consumers (aged 18 years and over)
- Interviewed in their home
- Interview data of consumers and their significant-others of ‘lived experience’ of losses and ambiguities in 12 month period from 1st May 2011 to 30th April 2012.

However, as the study commenced, I found that boundaries were not as solid as I had envisaged. Some consumers who volunteered to participate spoke of the losses associated with the mental ill health of a parent as well as of themselves when they developed symptoms. As qualitative methodology protocol allows design changes during data collection without jeopardising results in response to emerging issues, the data were assigned to three groups of participants—consumers, significant-others and significant-others/consumers.

2.9 Data Analysis

As in the GTM and TRM traditions, data collection and data analysis were not separated in time but were interactive processes. I kept a research diary in the ‘memo’ function of Atlasti software which contained daily or weekly research activities, ideas to follow and questions for supervisors. A ‘code memo’ was kept for the evolving coding scheme. Through constant comparison between and within codes I developed insights. The aim was to generate a substantive theory grounded in data. The visual diagrams of eco-maps and genograms used as
a research tool provided a rich context for analysis of participants’ perceptions of family history of MIH, losing family ties, identifying reciprocal relationships and sources of support and nurturance. The tools also helped in analysis of unique experiences.

2.9.1 Coding

Coding is the process of analysing data. I used four levels of coding: Open, Axial, Focused and Pattern coding. The conceptual framework in Table 2 with four domains of how participants perceive loss, how participants perceive uncertainties, how participants perceive their relationships and social structure and how participants manage losses and ambiguity was the initial guide in naming and categorising of phenomena through close examination of data (Strauss & Corbin 1990, p. 62). I did this through two basic analytic procedures: (a) making comparisons and (2) asking questions. In this way, I generated action codes and concepts from the data and in some instances used ‘in-vivo’ codes such as ‘walking on egg shells’, and ‘taking time-out’. To maintain consistency of a marine theme, these ‘in-vivo’ codes were later changed to ‘avoiding crosswinds’ and ‘seeking a safe harbour’. In the ‘comment on code’ section of the software I defined the code, described its properties, explained causes, demonstrated the conditions under which they operate and spelled out consequences (Charmaz 1988; Strauss & Corbin 1990). The software assisted in keeping an audit trail when codes were merged to develop categories or changed to maintain consistency of the theme. The meanings and intentions of research participants were queried and actions were observed. Strauss and Corbin (1990, p. 77) suggest basic questions such as Who? When? Where? What? How? How Much? Why? My training as a clinician in narrative therapy assisted this process of maintaining curiosity to ask questions and make comparisons. Information gathered from such questions led to the development of categories, properties and their dimensions. I developed concepts of interactional processes and consequences through circular questioning, and genograms and eco-maps in field notes — all techniques I learnt from family therapy training. The data, personal and professional knowledge and literature were all used for constant comparison. As suggested by Strauss and Corbin (1990), I compared my data with the literature to stimulate theoretical sensitivity.

2.9.1.1 Open Coding

I combined the methods of topic coding of Miles and Huberman (1994) and open coding of Strauss and Corbin (1990) as well as line-by-line coding of Charmaz (1995, 2000). The list of topics was from the four general domains (Table 2). I analysed transcripts line-by-line as well as sentences and paragraphs. As interviews progressed, I developed emerging codes by re-reading
interview transcripts and field notes of contrasting groups so that I was sensitising myself to what was different about them.

2.9.1.2 Axial Coding

Strauss and Corbin (1990, p. 96) defines axial coding as a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories. In axial coding, sub-categories are related to their categories through the paradigm model where sub-categories are linked to a category in a set of relationships taking into account causal conditions, phenomena, context, intervening conditions, action/interaction strategies and consequences. Although open, focused and axial coding are distinct analytic procedures, I was alternating between these three procedures in the initial stages of interviewing and analysing. By using the ‘word search’ function of Atlas.ti software, I looked for words such as ‘because’ or ‘since’ to find conditions and consequences. Important local factors were uncovered by this strategy of coding and the initial conceptual structure of the four general domains I brought to the study in Table 2 was continuously refined throughout the analysis. I will now describe the third and fourth levels of coding.

2.9.1.3 Focused Coding

I used codes that continually reappear and used them to sift through large amounts of data to be more selective and raise analysis to a conceptual level. By subsuming common themes and patterns in several codes, I created categories. Codes were kept active so that processes could be seen more readily (Charmaz 1995).

2.9.1.4 Pattern Coding

Miles and Huberman (1994, p. 69) define pattern codes as explanatory or inferential codes, ones that identify an emergent theme, configuration, or explanation. This process of moving up the abstraction ladder was done by clustering data, noting patterns, making metaphors, subsuming particulars into the general and factoring. Throughout this process I moved back and forth between first-level data and the evolving categories and sub-categories until new data from subsequent fieldwork did not add to the meaning of the general categories developed. I kept in mind the study’s conceptual framework and the research questions: (1) How is loss perceived by those affected? (1a) How do they experience the additional stressor of ambiguity associated with MIH? (2) How do people manage the ambiguity? Searching for rules, conditions and explanations helped construct assertions, and examining social networks and patterns of human
relationships helped me uncover evolving and more integrated processes grounded in local conditions. It also helped me lay the groundwork for cross-case analysis by surfacing common themes.

Attaching metaphorical gerunds helped me synthesize data and shift from facts to processes. As such, uncovering patterns and grouping the data accordingly gave specificity to the theory of the basic social process of navigating the winds and tides of ambiguity to stay afloat. Strauss and Corbin (1990, pp. 130-131) say that by pattern coding a researcher is able to say: Under these conditions (listing them) this happens; whereas under these conditions, this is what occurs. The common themes and directional processes that emerged from pattern coding laid the groundwork for cross-case analysis.

2.9.1.5 Conditional Matrix

Strauss and Corbin (1990) define a conditional matrix as an analytical aid which is useful for considering the wide range of conditions and consequences related to the phenomenon under study. A conditional matrix developed for this study is incorporated in the diagram of navigating the winds and tides of ambiguity to stay afloat with the outer box depicting the national level, the next level depicting the state level and the inner box depicting the individual and family context. For example, when participants spoke about the benefits of self-help groups or joining committees of consumer or carer groups or a local mental health clinic, funded through State or Federal Governments, I sourced policy documents to gain background information on this context and process and triangulate participants’ perspectives of this research area. This information was subsequently incorporated into the sailing to parts unknown and knowing current location sub-category to illustrate an intervening condition. During the period of study, I attended three educational forums where I met service providers, consumers and significant-others and one participant in my study (field notes 10th May 2011). The participant spoke of the benefits of such forums as information was shared with service providers as well as consumers and significant-others. When this perspective came up in a subsequent interview, I was more sensitive to it and when examining data during analytic sessions. The participants’ perspectives were triangulated into the data and subsequently incorporated into the taking the helm and trying a different tack sub-category.

Strauss and Corbin (1990, pp. 103-104) define intervening conditions as the broad and general conditions bearing upon a phenomenon. These conditions act to either facilitate or constrain the action/interactional strategies taken within a specific context but the authors say that it is up to the
analyst to identify which to apply and to weave into the analysis by showing how they facilitate or constrain action/interaction. Stake (2006, p. 3) supports this method and says that certain features of a case lie outside the system and help define the context or environment of the case, and that a researcher needs to consider many of these features and choose a few that can be studied thoroughly.

2.9.1.6 Genograms and Eco-maps

Genograms and eco-maps (Hartman 1978) were also used as analytical tools to identify participants' family structure and sources of support. These visual tools were also useful in asking probing questions and getting a fuller understanding of their contexts. A genogram charts intergenerational family history. An eco-map pictures the individual or family in the life space, the major systems that are a part of a person's life and the nature of the relationships with the various systems. Eco-maps were used to visualise the balance between participants' family and environment and their relationship with the external system, showing sources of nurturance, stimulation and support. Genograms and eco-maps used as research tools assisted me to understand the nature of complex transactions of multiple variables of human interactions in the real world. Visual models and metaphors both helped me move from a linear thought and language of human transactions to a more circular view. Through these research tools, it emerged that consumer and carer movements and religious organisations were significant sources of support for individual participants in this study but not necessarily for the entire family. Getting out into the field to interview people in their own homes enabled me to gain a greater understanding of the context and family structures – such as through discussions about photographs that were displayed in homes.

2.9.1.7 Merging Case Findings

Each case was treated as a comprehensive case in itself and contextual information that may have a bearing on the particular case was gathered. Following this, I merged case findings for a broader analysis of the whole group. A qualitative, inductive, collective case study seeks to build abstractions across cases (Stake 1995; 2006; 2010; Miles & Huberman 1994). Once some clear conceptual themes were discovered, I developed a conceptually clustered matrix (Appendix 3) with rows of cases and columns of conceptual themes arranged to bring together items that belonged to recurring themes and occurred less in other themes. By so doing, I was able to identify the dominant themes of the research questions (Stake 2006). The method of ‘factoring’ (Miles & Huberman 1994, pp. 256-257) helped me understand the underlying dynamics of an
oscillating factor in the basic social processes of navigating the winds and tides of ambiguity to stay afloat; that is, participants move between these processes when consulting maps and charts and determining which way the winds are blowing and the state of the tides when new information becomes available as well as when there is a relapse into ill health.

Looking for negative evidence and the meaning of outliers was also a technique that was useful for understanding the underlying themes and dynamics. For example, when I identified a unique case of a mother who experienced the death of one child before the onset of mental ill health in another, I explored the phenomenon of the study within its context. At this stage, to test the assertion of my study of reverberating losses, I looked for rival explanations by making comparisons and asking myself questions drawn from literature, professional experience and personal experience, thus linking theoretical sensitivity to theoretical sampling (Strauss & Corbin 1990; Charmaz 1988, 1995). As a further inductive technique, comparison of cases from a non-government drug and alcohol project was chosen for its theoretical relevance because as the study progressed certain concepts were repeatedly present or notably absent in the evolving theory. Through this process, I did not find any negative evidence.

2.9.1.8 Summary of Coding

Coding was a cyclical process of data reduction, data display and drawing assertions and verifying these assertions by a continuous move through transcription of interviews, field notes, writing memos, reading documents and literature as well as discussions with supervisors and colleagues. To move up the ladder of abstraction, I moved back and forth between data reduction, data display and drawing assertions, and verifying by noting regularities, patterns, explanations, possible configurations, causal flows and propositions. Through a combination of open, focused, axial and pattern coding and data display through matrices, I merged findings to make assertions.

2.10 Diagrams, Matrices and Theoretical Memos

Strauss and Corbin (1990, p. 197) define diagrams as visual representations of relationships between concepts. These diagrams evolved throughout the study, giving a logical relationship between categories and their sub-categories in terms of the conceptual framework of the study and the research questions. Matrices essentially involved crossing of two or more dimensions to see how they interact and helped expand the study to a more holistic case-oriented style of analysis (Miles & Huberman 1994, p. 239). This technique required me to think about my
research questions and what portions of the data were needed to answer them, and then focus and organise the data coherently to make as full an analysis as possible.

Data display through matrices, graphs, charts and networks was a particularly useful technique of analysis for my study. Guided by suggestions of Miles and Huberman (1994) and Stake (2005), I developed matrices combining or integrating case-oriented and variable-oriented approaches to gain more sophisticated descriptions and more powerful explanations of the data. For example, I used matrices for displaying a combination of variable-oriented and case-oriented methods for analysing. Themes that cut across cases reverberating losses and ambiguities associated with MIH were identified in a matrix (Appendix 3). The six cross-cutting themes, i.e. losing ‘self’, losing family ties, losing connectedness, losing functionality, spinning in a whirlpool and being adrift at sea, informed additional questions to be asked such as ‘How do participants manage the ambiguity?’ and ‘What kinds of strategies, networks and partnerships are supporting participants to manage ambiguity?’ From such questions, I developed processes of steering through choppy waters and negotiating to smooth the voyage. The cross-case analysis assisted me to identify key variables. Swanborn (2010, p. 115) says that the presentational techniques recommended by Miles and Huberman (1994) can be applied in the context of different kinds of research approaches. Being a ‘visual’ person the techniques of data display helped me to reduce complex information into selective and simplified configurations to tease out relationships and patterns spatially. In conclusion-drawing and verification, I make decisions about what things mean by noting regularities, patterns, explanations, possible configurations, causal flows and propositions. The three streams of data reduction, display and conclusion-drawing/verification are interwoven before, during and after data collection in parallel form in an interactive cyclical process. I was drawn to these presentational techniques advocated in TRM.

Memos are written records of analysis that tie together different pieces of data into a recognisable cluster illustrating when the data are instances of a general concept that may be related to the formulation of theory (Strauss & Corbin 1990; Miles & Huberman 1994; Charmaz 2000). By dating each stage of the analytic memo while coding, I was able to keep track of the evolution of key concepts thus moving from descriptive to analytic categories. The categories were more abstract than the original topic and yet explicated more underlying assumptions and processes (Charmaz 1988). Being a novice researcher, I preferred constructing short memos on diverse categories such as Perceptions of losses and Uncertainties of mental ill health. By gradually integrating these memos, I built up levels of abstraction as the theoretical understanding of the material expanded. I used participants’ quotes from transcripts so that I was able to preserve the
ideas that were developing in my mind and also to make comparisons. This helped me move from individual cases to identify patterns. Atlast.ti software allowed the memos to be linked to particular places in the interview transcripts, field notes and key concepts being discussed. An example of a memo is given below.
Table 4 – Memo: Being Adrift at Sea

<table>
<thead>
<tr>
<th>Memo</th>
<th>Being Adrift at Sea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiencing uncertainty (comes from outside of “self”)</td>
<td>Being adrift at sea in this case is an external stressor in that it comes from outside of “self”. One example being when the diagnosis given by a health professional is unclear as explained by F1: “And so he said use it like ADHD, and when I went back, he said it sounds like, not necessarily bipolar, but maybe just like a slight sort of mood disorder, or personality disorder”. This leaves the person with ill health and their significant-others confused with lack of clear information to form an opinion and start process of managing their ill health. This also leads to confusion in “making sense of their experience”. The consequence is perceptual differences within family members, feelings of alienation and questioning one’s reality as explained by C1: “I felt they didn’t understand what I was going through at the time and therefore I kind of - I guess there’s a whole alienation thing going, because they didn’t know what I was going through, I didn’t understand them. So the whole alienation thing … and just the communication skills, you know, like … so I guess the loss associated with mental illness with family, is that I would have liked to probably enjoy more good times with my family.” The perceptual differences and alienation leads to “loss of family ties” for this participant. Shared meaning in families and communities reduces ambiguity and uncertainty about a stressful event. Shared meaning also makes coordination of responses among family and community members possible and in turn contributes to stability in families and communities (Symbolic Interaction Theory). The example of shared meaning and coordination of responses to ill health was explained well by two families (Families C experienced cancer and F experienced diabetes in other family members). In both situations family members had shared meanings related to cancer and diabetes. As such they were able to coordinate the tasks of managing the illness and supporting each other but was unable to share a meaning with mental ill health. Is this related to lack of clear information or behaviour which results in changes in thought process and emotions of those with mental ill health? Participant G2 (a mother) said she had a lot of “what ifs” and questioned herself about her child’s upbringing and could she have done things differently. She knew something was “not quite right” but did not know what that was. Is this a result of lack of clarity about MIH? She chose to go in search of information. However although information is important and is powerful, the way mental health professionals present information to consumers and their significant-others is equally important. As explained by G1: “but when you’re told that you have a mental illness that’s a chemical imbalance, that you’re going to be on medication for the rest of your life, I think you get filled with a sense of hopelessness”. Presenting information this way of an illness that is poorly understood and may have many factors contributing to the onset is unhelpful and leaves a person “being adrift at sea” with emotions of hopelessness and perhaps demoralisation as both internal and external environments are unpredictable. How does one assess a stressor when there is paucity of information? This is in many ways similar to Antonovsky’s concept of ‘Sense of Coherence’ – “The concept of a sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one’s internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected” (Antonovsky 1979, p. 123).</td>
</tr>
<tr>
<td>Determining which way the winds are blowing and the state of the tides (consequence) Losing family ties</td>
<td></td>
</tr>
<tr>
<td>Spinning in a whirlpool</td>
<td></td>
</tr>
<tr>
<td>Taking the helm</td>
<td></td>
</tr>
<tr>
<td>Being adrift at sea (Feeling hopeless?Demoralising)</td>
<td></td>
</tr>
</tbody>
</table>

One participant who as a teenager was not given information about her mother’s ill health looked for signs to form an opinion to manage the stress associated. E2 said” If I smelt cooking when coming home from school, I knew my mother was having a good day”. This brings up another example of ambiguity/confusion related to mental ill health and to its cyclical nature. This is another example of leaving a person “being adrift at sea”.

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2.11 Data Management Through Atlas.ti

With assistance from a graduate education officer of the University’s Department of Research and Scholarship, and literature searches (Miles & Huberman 1994; Swanborn 2010), I chose the Atlas.ti 6.0 computer software program which is grounded in the tradition of symbolic-interactionism (Swanborn 2010). This program had many beneficial functions for my study where interview transcripts and contact summary forms could be entered in the database. I was able to code these documents on screen into separate words, phrases, lines, sentences and paragraphs through nesting or overlapping ‘chunks’, as well as recode data, combine data and subsume codes under more general codes. I was able to attach ‘source tags’ to efficiently retrieve chunks of data throughout the process of analysis to see where it came from, e.g. which interview and with whom, when etc. The program was suitable for the constant comparative method of data analysis where the coding scheme, although started with a priori, evolved as the analysis progressed. Whilst I started at a lower level of abstraction, the codes were gradually replaced by classifications and categories at a higher level of abstraction. It was also suitable for selective coding, where I was able to name a category that had a central position in the network of relations. In the code manager, I was able to see the complete list of codes, classifications and categories, colour-coded for ease of analysis. Such graphic displays helped in formulating propositions and conceptual structures that were grounded in the data. Within this database, I was also able to keep a research diary and memos on the process of analysis. All of these functions eased navigating through the database throughout the process of analysis (Friese 2012).

2.12 Trustworthiness of Findings

The concept of trustworthiness was introduced by Lincoln and Guba (1985) to evaluate the worth of a qualitative research study. According to the authors, trustworthiness involves establishing credibility, transferability, dependability and confirmability. I will now define each of these criteria and describe the techniques I used to address them.

2.12.1 Credibility

To establish confidence in the findings I used techniques of triangulation and peer debriefing. Triangulation involves using multiple data sources to gain a deeper understanding of the phenomenon of interest. By conducting interviews with consumers and their significant-others the same phenomenon was examined from more than one perspective. The transcribed
interviews were also triangulated against findings from observations in the field and document sources such as autobiographical literature. The autobiographical literature includes First Person Accounts from the *Schizophrenia Bulletin* (Stakes 1985; Murphy 1997; Molta 1997; Fox 2009; Willis 1982; McGrath 1984; Ruocchio 1991), first person accounts from other professional journals (Willick 1994; MacGregor 1994), *An unquiet mind* (Jamison 1997), *Tell me I am here* (Deveson 1992), *Breaking the silence* (Hinshaw 2008), *Secret squirrel business* (Middlemiss 2012). Documents relevant to the phenomenon of interest are a form of data triangulation which collects data from people with different perspectives (Merriam 2009, p. 216). Strauss and Corbin (1990) also believe that non-technical literature is an important source of information, which supplements data through interviews and observation. The autobiographical literature sourced was written by those affected by MIH as well as their significant-others. To establish further credibility, a ‘collaborator’ who was experienced in the field progressively reviewed my work. I also engaged in peer de-briefing with colleagues in the field of mental health and alcohol and drug service organisations in the local community. Discussions with the collaborator and peers helped uncover taken-for-granted biases, perspectives and assumptions as well as test emerging themes and see if they seem reasonable.

### 2.12.2 Transferability

Lincoln and Guba (1985) suggest that describing a phenomenon in detail enables a reader to evaluate the extent to which the conclusions drawn are transferable to other settings, situations, people and times. I have given a description of the diverse combination of families in different circumstances that capture variation as well as the Australian and West Australian context. Through three-dimensional vignettes from consumers, significant-others and significant-others/consumers and the context in which these are embedded, I have provided a thick description of ambiguous loss associated with MIH.

However, as the authors suggest, strict ‘transferability’ is impossible in an interpretive paradigm and therefore it is up to other researchers to decide if the sampling, context and level of abstraction described in this study are applicable to other settings and populations.

### 2.12.3 Dependability

Through the use of computer software, I created an ‘audit trail’ which provided transparency and consistency to the process of the investigation and findings. Lincoln and Guba (1985, p. 319)
describe audit trails as key components of a study to demonstrate credibility, dependability and confirmability. Throughout the process of the investigation, I kept a research diary in which I continuously identified and recorded methodological decisions and the reasons for these, reflections upon what was happening in terms of my values and interests, assumptions about emerging data. I discussed these with the collaborator, and the taken-for-granted concepts and language, bearing in mind my particular background of social work training and practice in a mental health setting. For example, the collaborator probed me about the taken-for-granted concepts in the mental health setting of ‘denial’ and ‘lack of insight’ when a consumer declined medication. By going through the data again and discussions with the collaborator, it emerged that consumers resisted medication because of the uncertainty of diagnosis and weight-gain resulting from medication, thus I named this sub-category ‘resisting the surge’.

2.12.4 Confirmability

From my readings of Lincoln and Guba (1985), I understand ‘confirmability’ to mean the extent to which the data and interpretation are grounded in events as opposed to my personal construction. To give explanatory power to the study, I followed the strict principle of line-by-line open coding of all interviews followed by formulation of categories and concepts that fit the data. My supervisor’s continued reminder that ‘it is time to let go of Boss and see what the data is telling you’, kept me firmly grounded in the data.

2.13 Bracketing

Fischer (2009, p. 583) describes bracketing as two forms of researcher engagement: firstly, the setting aside of a researcher’s values and assumptions, and secondly, constant revisiting of data and questioning oneself how each new insight may change earlier understanding. The author uses the term engagement to emphasise that the goal of bracketing is not only for the purpose of objectivity but also to emphasise that engaged, dynamic development of understanding (often referred to as hermeneutic) differs from the distanced, deductive means of reaching conclusions through quantitative research. In order to view the emerging data freshly, the assumptions and interests I brought to the study were continuously placed in ‘brackets’ and ‘shelved’ through discussions with the collaborator, peers and supervisors. In the first chapter, I have shared my own background and how my perspectives are informed by my work as a social in mental health services and also as a first generation migrant to Australia. I have explained my perspective throughout this thesis but readers may choose to take a different perspective and develop
alternative readings of the data or perhaps find that it opens them to new knowledge. As Lincoln and Guba (1985) write, the important perspective of a naturalistic inquiry is that the researcher as a human instrument brings tacit as well as propositional knowledge to the study.

2.14. Summary

An aim of this study is to generate substantive theory on how people with mental ill health manage the ambiguities associated. To do so, I undertook a collective case study to investigate perceptions of loss associated with MIH within a family context and also investigate how people experience the additional stressor of ambiguity associated with such losses. Chapter 2 presents the methodology and methods adopted to answer two research questions and one sub-question: 1) How is loss perceived by those affected by MIH?, 1a) How do people experience the additional stressor of ambiguity associated with MIH? and 2) How do people manage the ambiguity associated with MIH? I begin with a description of the Australian and West Australian mental health sectors so that readers understand the context of the study. I then explain the location of the study within the interpretative paradigm of symbolic interactionism, followed by a description of the procedures and techniques of data collection and data analysis using combinations of grounded theory methods of Strauss and Corbin (1990); Miles and Huberman (1994); Charmaz (1988, 1995, 2000) in the qualitative collective case studies of seven families. This is then followed by a discussion of middle-range theory as an approach to theory construction. The chapter then describes participant recruitment, participant characteristics, field procedures, data analysis, the use of diagrams and matrices followed by a brief description of data management through Atalst.ti computer software, and the trustworthiness of the study. In the following chapter, I discuss assertions of the research question 1: How is loss perceived by those affected by MIH?, and 1a) How do people experience the additional stressor of ambiguity associated with MIH?
Chapter 3: Findings of the Study — Perceptions of Loss Associated with Mental Ill Health (MIH) and Experiences of Ambiguity Associated with MIH

3.1 Introduction

In Chapter 3 I will present the findings of my primary research question: How is loss perceived by those affected by MIH? and the findings of the sub-question: How do people experience the additional stressor of ambiguity associated with MIH?

For multiple case analysis, I used a mixed approach of variable and case-oriented strategy with themes of loss that cut across cases and cases that fall into three groups — consumers, significant-others and significant-others who had developed symptoms of MIH and consider themselves as consumers now. I will refer to the latter group as “sig. other/con”, but when they have specifically given their perspective of having experienced mental ill health in themselves, I have included that perception in the consumer group. This means that a sig. other/con may have knowledge of three different experiences, that of a consumer, significant-other and also sig. other/con. Through vignettes, I will present perceptions and experiences as reported by the three groups thus allowing them to speak for themselves.

Each theme of loss and the additional stressor of ambiguity will be defined and their properties listed. Using the data display methods of Miles and Huberman (1994), I have represented the findings of the analysis of the first research question and the sub-question in Figures X and Y respectively.

Firstly I will present perceptions of loss associated with MIH. I call this overall theme, reverberating losses. There are four sub-themes that come under the rubric of reverberating losses: 1) losing “self”, 2) losing family ties 3) losing connectedness, 4) losing functionality. Figure X displays the analysis of the first research question: How is loss perceived by those affected by MIH?

Secondly I will present two themes of ambiguity as an additional stressor associated with MIH experienced by participants. These two themes are: 1) spinning in a whirlpool and 2) being adrift at sea. Figure Y displays the analysis of the sub-question and two themes of ambiguity and three groups of participants.
3.2 Reverberating Losses

“Reverberating losses” emerged as the “rubric” or the major theme of losses. This major theme will be fully explicated through the description of the sub-themes which it subsumes. The four sub-themes are: losing “self”, losing family ties, losing connectedness and losing functionality. The stories from participants illustrating the sub-themes are heard repeatedly and have a cyclical nature where each loss flows on to the other, thus reverberating throughout their lives.

3.2.1 Losing “Self”

For the purpose of this study, I consider losing self to be an internal loss. The properties of this sub-theme include loss of confidence, control, credibility, self-esteem, faith, freedom, will to live, dreams of the future, time, identity, physical health and social status. The internal dialogue impacts on the individual as well as their interactions with each other.

Consumers exemplify loss of self this way:

A2 sig. other/con. speaks about her will to live from her perception as a consumer:

I wanted to end my life basically, just wanted to go to sleep and never wake up. I just felt shockingly depressed.

Consumer F1 speaks about her loss of dreams:
All my brothers ... they’ve all got partners ... families and good jobs and buying their own house. I feel like I should be doing things like that. I’m still ... like a teenager, I’ve just moved out of home, never really set myself up, I still get quite a bit of help from mum and dad with caring for my daughter.

B1 sig. other/con. speaks from her perception as a consumer:

The greatest loss I think is the self-image, self-belief, self esteem

Consumer C1 speaks about his loss of time:

The biggest loss I’ve had associated with mental illness would be the loss of time. In terms of being diagnosed with schizophrenia and for many years, three to four years, under medications and things ... I’ve lost a lot of time.

Consumer G1 describes about her loss of identity, time and dreams:

I lost my identity. I had to kind of go back to the drawing board of who I was. I feel like I lost time, as well ... someone my age would have maybe had children, had a degree, some kind of career and things like that. I have some education but ... because I spent so much time, particularly with being unwell, and with drug and alcohol use [...] and losing things like travelling, and not doing things like my brother and sister had done.

E1 sig.other/con refers to her loss of status from a consumer’s perspective:

Before I had mental illness problems, I enjoyed a good social standing in the family and in the community.

This is how significant-others report their loss of personal dreams for the consumer:

Significant-other C2 said:

I grieve for him not for my loss ... I’m saddened that the potential that a child has may not ever come to fruition ... but I grieve for his loss, when he had the insight to understand that he did have a mental illness and his life will not be normal again.

Significant-other G2 refers to loss of time for the consumer and their own confidence in parenting:

I felt there were so many lost years with her when she was unwell — it’s really like a loss in time.

There were lots of what-ifs, and if I’d done this or if I’d done that, or questioning myself about her upbringing.

A1, a sig.other/con refers to loss of faith and trust due to parental mental illness:

My father’s paranoid delusional disorder was very severe and he was violent. I witnessed him bash my mother several times and put her into hospital so I think that was one of the things that caused the disassociation and that may be the start
of my depression as well, lack of trust because I didn’t have any faith or trust in either of my parents to protect me.

The above quotes from the three groups of participants exemplify perceptions of losing self. Whilst they had similarities, they also had differences. The differences in turn lead to different meanings and experiences attached to these losses; for example, making meaning of the context of MIH in parents influences the sig. other/con’s perceptions of their own situation. A key feature of the theory of symbolic interaction is that the human being has a self. They can act towards themselves as they might act towards others. The meanings the three groups give to their lived experience of loss in this study are formed, sustained, weakened, strengthened or transformed through their interaction with each other. Therefore losing self has a reverberating effect and flow on to other losses, as will be discussed in the following sections.

### 3.2.2 Losing Family Ties

Losing family ties relates to disruption of family life. The properties of losing family ties include losing family harmony from arguments and violence, losing family life through separation and divorce, losing innocence and childhood or taking on incongruent roles in the family due to parental MIH and losing confidence through conflict and negativity. Some of these outcomes are exemplified through quotes of lived experience.

Consumers illustrate losing relationships and losing family harmony:

**Consumer D1** says:

> Because my illness was not properly diagnosed or dealt with, I don’t have good relationships with my mother or my sister ... and the same applies to my sons. Because I fall into a sort of a less serious spectrum of mental illness, it didn’t matter how I tried to communicate that I had problems, nobody saw a need to do anything about it.

**Sig. other/cons E1** says from her perception as a consumer:

> I think I was struggling to cope with the negativity from the family, because they knew I couldn’t function like before.

> I think deep down my children know that I have a deep love for them and I think it is reciprocated but not demonstrated. And that is something which I think is a loss. If they come here, if we see them out in public or a function they won’t come up to me and give me a kiss and a hug or put arms around my shoulders. I would like that but that is something that I do not have. The perceptions of some of their cousins about my mental health might not be sort of the same what they think about me, so they don’t want to openly show affection. There is aloofness.

**Consumer F 1** says:
My daughter spends like a bit of time with my mum and with my sister, so even my relationship with my daughter suffers quite a bit. It’s not that I’m nasty to her or anything, but when I’m down it’s not good for her. She just doesn’t want to be around me.

Significant-others exemplify fear of losing relationships:

Significant-other B2 says:

It was scary, it was unnerving, and we thought we were going to break-up, the marriage was going to go.

Significant-other C2 says:

My husband and I had dreadful arguments about [John]. And of course it was always at the tea table. And [John] would walk away and my husband and I would end up arguing at the tea table. [John] could hear all this; my husband talks as if he wasn’t even there. And once again, you can’t do that. [John] can hear — he listens. We had a huge argument and I said to him something very hurtful — “you are supposed to be a Dad, will you just be one, act like one, and do something rather than sit here and talk at him. Talk with him”. It hurt my husband very much, because he is a family man, he loves his children very much, and it hurt him but after about two days he actually never said anything, but there was a turnaround at the table. And for the first time in many years, he made an effort. And it wasn’t the best effort, but he made the effort. And I think perhaps that’s the saving grace of our marriage. That he tried. And he still tries to this day.

Sig.others/cons explained losing relationships and childhood:

A1 says:

I think the childhood that I experienced or the trauma that I experienced and lack of a real father role model probably didn’t equip me to be as good a father for him as what he needed at times, so that probably under prepared him for relationships and emotional growth that he didn’t achieve because of what happened to me, I think it was passed on to a degree, not consciously but unconsciously.

A2 says:

I suppose the loss of long periods of normal family life because of the tension in the home that was associated with my father’s mental illness and perhaps in my case and probably in [my sibling] as well, we had to grow up very quickly. ... My father became violent and I had to help my mother have him involuntarily admitted to hospital which involved going to lawyers and all that, getting him committed.

The above quotes from participants exemplify differing perceptions of losing family ties. Consumers’ perceptions attribute loss of family ties to failure of diagnosis, negativity from family and attitudes of extended family. Significant-others attribute loss of family ties to family conflict which leads to fear whilst sig. others/cons attribute losing family ties to parental mental illness and the subsequent intergenerational effect. Although participants attribute differing intervening conditions and meanings, they have all experienced losing family ties. Through their social
interaction with each other and the meanings attributed to loss of family ties, they also experience loss of self with a reverberating effect.

Through triangulation, multiple versions of the same phenomenon were examined and were useful in bringing hidden and submerged conflict to the surface such as the tensions in family relationships exemplified in the quotes above. Triangulation also assisted in identifying overlapping identities where a consumer identified herself/himself as both a consumer and a significant-other.

### 3.2.3 Losing Connectedness

Losing connectedness relates to consumers and sig. other/cons feeling disconnected from people around them. Losing connectedness is observed by significant-others. Properties of losing connectedness include losing ability to feel emotions, feeling alienated, and inability to be intimate. In this group of participants the properties are seen as changes in personality after onset of ill health. Particular to this sub-theme was the fact that participants were unsure if “losing connectedness” was due to the effects of MIH or if it was a side effect of medication.

This is how consumers explain inability to relate and feelings of alienation:

**Consumer C1 says:**

In a group or crowd of people I felt kind of separate, isolated, and very sad.

**Sig. other/con B1 from a consumer’s perception says:**

I’ve lost my ability to cry. Whether it’s to do with the whole thing or not, I don’t know, but I consider that it is, whether it’s … the medication I’m on, it’s just two and a half Lithium a day plus one Prozac, I don’t know.

I’m reluctant at making new friends, I have this thing that I’m not like — there is part of me that has disappeared. I always was one for loads of friends, and go places and do things. Now I’ve turned into a much quieter person.

**Sig. other/con D2 from a consumer’s perception says:**

I don’t do intimacy very well. And I don’t see enough of my son and his family. And that’s up to me to make contact. Now they don’t make contact — very rarely. But I could make contact and be welcome or not welcome, depending upon the circumstances, but I don’t … and I’m not sure what that’s about.

**Consumer G1 says:**

It’s like being frozen. It’s the only way that I can describe it and that’s where I think I’ve lost friendships, for a period of time after school, you know, they would ring me, do you want to come along, then at some point they just stopped inviting me, and then - stupid Facebook — now you can tell if they’ve caught up. And their bloody pictures of them, and “Oh, thanks for inviting me”, but why would you? because I
never go. I think that that’s probably the best example of that, that group of friends, where I just couldn’t maintain the friendships, not because I didn’t want to but because I was so stuck in my own head, and my own stuff that was going on, that I just couldn’t.

This is how significant-others report on how consumers lose connectedness:

Sig. other/con A2 says from a significant-other’s perception:

The drugs seemed to nullify their emotions. Particularly my father became quite ‘zombified’ for a better word because of medication, it seemed to numb all emotions, good and bad.

Significant-other B2 says:

It has dampened her a bit. The enthusiasm that was there I suppose, which attracted us in the first place, has been dampened.

Sig. other/cons C2 says:

He was no longer with me. I had someone else sitting next to me, I said to him, I don’t know where I’m going, and there would be no response. It was catatonic, almost, and then he believed that the Mafia were there and he was being shot at and we’d visit friends, or relatives, and where is my son - he was underneath the car outside.

This is how sig. other/con A1 explains losing connectedness:

I think there is no doubt that it stopped me from getting closer to her, from sharing my life with her more, because I had learned to be unemotional as a way of coping the same as what my father and mother were and because I was unemotional you can’t build that life with each other, you can’t know each other because you are not sharing that emotion with each other.

Losing connectedness is experienced by consumers and sig. other/cons. In contrast, losing connectedness is observed by their significant-others. Participants are confused as to whether loss of connectedness is a result of the effects of MIH or of side effects of medication. Such confusion is a barrier to assigning meaning to an event, and blocks action. Consumers and sig. other/cons describe their inability to make meaning by saying “I’m not sure what that’s about”, “It’s like being frozen”. C2 a significant-other describes the physical presence and psychological absence of a son as “he was no longer with me”. Such confusion results in inability to form shared meanings within families leading to conflict and misunderstandings. Thus losing connectedness also reverberates with former categories of losing self and losing family ties.

3.2.4 Losing Functionality

Losing functionality relates to skills that all three groups report as being lost because of MIH and experienced by consumers and sig. other/cons but observed by significant-others. Properties of losing functionality include consumers’ loss of previously held skills achieved through education,
social skills, memory and concentration. These losses inevitably lead to loss of employment and income.

Consumers explain loss of previously held skills:

Consumer D1 says:

Prior to this breakdown or whatever you’d like to call it, I was working, and one of my duties was to balance the monthly payments and I think there was something like five, fifty thousand dollars or something to balance and, obviously if I was making mistakes someone would have noticed, so obviously I wasn’t. And now when I add up, like for example I know one and one is two, but I’ll write down three. I make those types of mistakes. And apart from making mistakes, I assume I’m also much slower.

That’s the brain fog. If a support worker comes, or a friend comes, and something needs to be done, I can sort of throw on some clothes on top of my pyjamas, because the whole concept of getting, dressed and changed, is too difficult for me, and I can dart off with those people, get done what needs to be done, and then sort of come home and collapse again. If I needed to do that by myself, I wouldn’t be able to do it, because you’ve got to get dressed and changed and catch public transport and be alert and aware for a longer length of time.

Consumer F1 says:

... it’s the inconsistency of things — I tend to have a good couple of months and then, a bad couple of months, be really good for a couple of months of say, even getting to a job and ... or even like courses and stuff like that but then, I just sort of end up finding it really hard to even, go out of the house and don’t even like even going down to the shops and even seeing family.

This is how significant-others report on how consumers lose functionality:

C2 says:

I find with his essays, the content, he knows. He has read everything, he knows it, but putting it down in essay form, he has difficulties with the fluidity, the continuity — it doesn’t flow. So, helping [Eric], I’m not such a great help, because the content is there, his essay structure — I believe, because of his mental illness, it doesn’t flow, the logic is not — it doesn’t flow from one to another.

E2 says:

She just struggles from day to day. She can’t clean her house. She cooks a meal, she’s become quite weak, mentally, as far as her children that are left at home rule the roost, you know, they just run the household. Yes, she’s walked over a little bit because they can! She dresses herself in the morning and she can cook a meal or something, but simple chores of the day are all too much for her.
For sig. other/cons there was a reminder of their relative’s loss of functionality. The meaning and interpretation of their own loss of functionality now takes place within a social context of previous interaction with a family member with MIH. B1 exemplifies this as:

It's like, how do you put it, first of all I looked at my sisters and my brother and thought, oh my God I don’t want to be like them. My twin sister her loss was, she wasn’t able to work.

Consumers and sig. other/cons experience loss of functionality whilst significant-others observe loss of functionality of the consumer. It has a reverberating effect as it has an effect on consumers' loss of self, exemplified by being aware that they were “making mistakes and were slower”, loss of family ties exemplified by “children rule the roost” and “walked over a little bit”. Although it affected each in different ways, all three groups were able to identify with the loss of functionality. Although there was no shared meaning between family members, it affected them with equal power. Loss of functionality of consumers therefore becomes a family affair.

3.2.5 Exploring Perceptions of Losses Within its Context

The importance of exploring losses within a family’s internal context is highlighted in this study by a family who experienced the death of a child before onset of mental illness in another. C2, a significant-other, referring to the losses associated with MIH says:

What is my loss? I haven't lost him. Loss to me is when there is no more. Gone. Complete. I still have him, so, whilst I have him there is always hope of recovery, no matter how bad the situation. We have him, and regardless of whether he wasn’t doing too well, at least we have him, and will he be a burden? It would certainly test the patience when he’s not well, and the other medications certainly didn’t help that much but at least we have him. And I’ve spoken to other people who say, we prefer not to have our child, because this is not the child that we had. But I fail to see, if they had experienced true loss, it’s not the same. You may have lost parts within that person, but you physically still have them, and when they smile, or look at you, when those moments of absolute clarity — you’ve got them, still.

The internal context is composed of the structural, psychological and philosophical contexts of a family whereas the external context is composed of the historical, economic, developmental, hereditary and cultural contexts (Boss 2002). Viewed from a psychological context, whilst the significant-other identified with the four categories of losses associated with MIH she perceived them within the context of losing a child to death and was able to foster hope for the child affected by MIH. She spoke at length about the illness of her child that died and also illustrated how family members had a shared meaning of the diagnosis, effects of the illness and prognosis. Parents and siblings shared in the care of their ill relative. She did not speak of conflict within the family. However as a family, they struggled to come to a shared meaning about MIH. The
consumer and significant-other participating in the study identified with the four sub-themes of, losing “self”, losing family ties, losing connectedness and losing functionality associated with MIH, the themes are heard repeatedly and have a cyclical nature with each loss flowing on to the other. The perceptions of the consumer and significant-other fit within the model of reverberating losses associated with MIH. However, the significant-other in this situation did not perceive it as “true loss”. Although her perception, appraisal and definition of the stressful event of MIH have uncertainties and she acknowledges the psychological inaccessibility and physical presence of her child, she also had an element of hope. This, then, is an opportune time to discuss ambiguities associated with MIH that may lead to difficulties of arriving at shared meanings, appraisals and definitions within families.

3.3 How do People Experience the Additional Stressor of Ambiguity Associated with Such Losses?

3.3.1 Introduction

Participants in this study express confusion about diagnoses saying that information about the illness is unclear and that they were not able to form an opinion. They also say that health professionals or other people around them did not acknowledge their experiences. Further there is uncertainty about when a relapse may occur, resulting from a poorly understood illness with changes in diagnosis. By analysing the narratives of participants, I arrived at two themes of ambiguity 1) Spinning in a whirlpool and 2) Being adrift at sea. I will now explain each and exemplify through vignettes.

FIGURE Y

<table>
<thead>
<tr>
<th>Experiences of ambiguity</th>
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<tbody>
<tr>
<td>Spinning in a whirlpool (internal process)</td>
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<tr>
<td>consumer</td>
</tr>
<tr>
<td>Being adrift at sea (external process)</td>
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<tr>
<td>consumer</td>
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3.3.2 Ambiguity of “Spinning in a Whirlpool”

The ambiguity of spinning in a whirlpool is experienced by all three groups. Consumers say they felt something was not right and their mind played nasty little tricks on them but they could not make sense of their experience. Similarly significant-others observe that something was not right for their loved one but did not know what it was. Significant-others perceive behaviour related to MIH as incongruent with the personality of the person as they knew before. The incongruence leads to high tension in relationships as exemplified by B2 above: “she was becoming more difficult to live with”. In contrast the sig. other/cons group was attempting to make sense of their symptoms in the context of the trauma of witnessing the symptoms of MIH in a relative. Through previous interaction in similar situations, this group was attempting to make sense and define how to act in their current situation. I identify spinning in a whirlpool as an internal process. The properties of spinning in a whirlpool include participants being unable to make sense of symptoms, in themselves or for significant-others confused about symptoms or behaviour in their loved one through observation. Sig. other/cons recognised the symptoms in themselves and referred to past experiences of MIH in a family member.

The following vignettes illustrate the confusion about MIH and not being able to make sense of symptoms.

Three consumers explain their confusion:

Sig. other/con D2 as a consumer, reports as:

I had actually been quite unwell, and that had shown up at work. I didn’t know anything about bipolar disorder at that point. I didn’t know what was wrong. No-one knew what was wrong and no-one knew how to handle it. So it was absolutely awful.

Consumer F1 says:

I didn’t know exactly what the problem was to even go and talk to someone it was very hard to explain to them how I was feeling. When I went to psychiatrists, I found it very hard to explain the way I felt.

Consumer G1 says:

Clearly, I had quite chaotic thinking. I possibly was in the prodromal phase, leading up to the psychosis and so I was thinking about everything all at once. But I wasn’t officially diagnosed with anything at that point in time.

Because the nature of being unwell is that you kind of isolate yourself, because your mind plays nasty little tricks on you, you isolate yourself more, which makes you more depressed, because you’re by yourself all the time and only have your brain, with this very unreliable information telling you that you’re worthless and all the stuff that it does. There’s a ... general sense of grief with all of those things. There’s a kind of all-encompassing kind of loss of time.
Significant-others referred to being unable to make sense of the symptoms of a consumer.

Sig. other/con A2 as a significant-other says:

He started having delusions that my mother was having an affair with my brother, which was so utterly bizarre and it culminated in my father pushing my mother out of bed at night and things like that, so strange because he was such a passive person.

Significant-other B2 says:

I knew she was becoming more difficult to live with. I did say it to some of my friends that her behaviour was a bit off the wall, and they would tell me, nah … I mean I recognised there was something wrong but I couldn’t put my finger on it.

Significant-other G2 says:

And I certainly knew that something was wrong, because she kept ringing me on her phone. She didn’t come home for a couple of days, but she’d ring me and tell me where she was, and she was just rambling on, right off her face. So I’d say to her, are you coming home? And she just was talking nonsense. You know, she was psychotic by that stage. I had no idea about anything like that. I didn’t have anybody I’d known — lots of people have depression, but … I’d never heard of anyone being psychotic before.

Sig. other/con A1 described uncertainty about symptoms as a consumer by saying:

I guess looking back I probably had some depression may be back into my childhood, I am not that actually sure whether it was depression itself, I do believe now after investigating that it’s probably also as much dissociative behaviour that I developed to protect myself from things that were happening around me and that was not sort of a voluntary type decision, it was more of an involuntary thing because I think it was my brain protecting me from the situations that were occurring around me.

Sig. other/con A2 as a consumer says:

Sometimes I wonder if the fact that my father had been so ill earlier that culminated in me and in between we lost a business, we had to sell and it was a major move to move in here. I just wonder if all those things just caught up with me and then sometimes I think it was purely hormonal because it’s funny it happened when I had a child, and again at that stage of my life where I was probably going into menopause and I often wonder if it was more that than anything else, because I coped with everything all along the way. So I often wonder if being a female had anything to do with it.

In summary, all three groups in this study were unable to gain a sense of coherence. Their internal world was unpredictable and they lost confidence in themselves. As a consequence, they struggled to make meaning and to judge reality. The responses of participants indicate that they are not able to make sense of their experience because of the ambiguities of MIH and the experience was similar to **spinning in a whirlpool**.
3.3.3 Being Adrift at Sea

The ambiguity of being adrift at sea is experienced by all three groups. Participants are unable to gain a sense of coherence with their external world being unpredictable. Diagnoses are unclear and lack information and there is no probability that things will work out for them. At the time of the study, 2011-2012, MIH is still poorly understood. Diagnosis and treatment are usually based on description given by consumers and behaviour observed by others. This observation is subjective. Sometimes collateral information is gathered from family members or significant-others which again is subjective. Coming to a diagnosis is always through interpretation by the clinician, usually a clinician with medical education and training. The perceptions of clinicians are often different adding another layer of ambiguity to all three groups. This also results in differing and constant change of diagnoses. I identify being adrift at sea as an external process. The properties of being adrift at sea includes diagnoses being unclear or constantly being changed by health professionals; sometimes different diagnoses being given by different medical professionals with no explanation; patients not being given sufficient information about the illness when concerns about symptoms were not validated by health professionals or other family members; and experiencing stigma of MIH.

Consumer D1 experienced not being validated:

I was seeing psychiatrists and I would repeatedly say that I'm depressed and suicidal, and I'd just go back and say that again, and nobody did anything or gave me any strategies or anything of that nature.

Sig. other/con D2 exemplifies confusion in diagnoses:

My son was diagnosed with bipolar disorder. At which time I thought to myself, my god! I have given him this. I rang the person who was my psychologist at the time — and she said, very strongly, very clearly, very slowly, you do not have bipolar disorder. ... So that was very interesting, because some years beforehand that psychologist had recommended a book to read. I read the foreword, and it talked about borderline personality disorder so I didn’t read any more. So that must have been what was in her mind, perhaps, who knows.

Consumer F1 exemplifies confusion of changes in diagnosis:

I’ve just started at a psychiatrist, and he’s just put me on dexamphetamine. He said consider it like ADHD, it sounds like, not necessarily bipolar, but maybe just like a slight sort of mood disorder, or personality disorder.

Consumer B1 experienced stigma:

I discussed it with the psychiatrist that I was seeing at the hospital at the time and he just said, unless you know that you’re going to get positive reception ... not to make
an issue of it, because out there, for the people that have the illness, the stigma’s still there. I mean, like one of my friends said to me, no you couldn’t have, did you go for a second opinion? Then the other side, there’s the fear that they’re going to kill you, that they’re going to be violent, and they’re going to be terrible people … it’s like there’s so many bad vibes, negative vibes …

Significant-others also experienced not being validated and confusion in diagnosis.

C2 says:

And did we seek help? Yes, we did send him to a counsellor, he did go to a couple of doctors, but it was, no there’s nothing wrong with you, get a life, from two doctors. And the counsellor, I believe saw us as an income. He needed to see him three times a week.

F2 says:

I think it was about 14, she just got really bad in the way that she just always dressed in black, she wouldn’t shower, she just was not a happy person, she was always moody, fly off the handle, she’s been to emergency wards for overdose, she’s been to various hospitals, we paid $180 an hour for family counselling, she’s been public, she’s been private, but nobody’s ever, I don’t think fully, that I know of, fully diagnosed her.

A1, a sig. other/cons, experienced stigma:

Because mental illness was such a stigmatised condition back in those times we couldn’t tell anyone even family or relations because it wasn’t talked about and my mother also made me promise not to tell anyone for fear of retribution from my father. So I couldn’t tell my friends at school, friends that I did have so it was very much an isolating experience for me.

Sig. other/con E1 experienced not being validated as a consumer, confusion of diagnosis and stigma:

A psychiatrist wrote a very damning report about my mental health but the reports by treating psychiatrist, after 18 months, say that I no longer fit the criteria for major depression, and I was okay. It was the PTSD, I think that is a form of major depression or something like that, but he said, oh, you know I still probably have got a little bit of depression, anxiety, which he encouraged me to continue treatment for.

I think the belief was that their mother was sick so they’re all sick. Like, it’s in the blood. Yes, it’s a stigma they’re all crazy, some more crazy than others. And I was considered in the “more crazy” category.

There was confusion among all three groups whether negative symptoms were exacerbated by some psychotropic medication or were a symptom of the ill health, e.g. "I lost my ability to cry" and "it nullified his emotions". This confusion was akin to being adrift at sea. The stigma of MIH also results in not being validated by people around them. All of the above adds layers of complexity and confusion to all three groups of participants.
3.3.4 Differing Meanings and Interpretation of Situations

Evidence of situational features that made it impossible for people to obtain factual information was provided by two families. In Family C there were two siblings, one with cancer and the other with MIH. The family were given clear information about cancer and thus had a shared meaning of the diagnosis, the effects of the illness and the prognosis. Parents and siblings shared in the care of their ill relative but as a family they struggled to come to a shared meaning about MIH. In Family F the significant-other compared MIH to diabetes where information about effects of diabetes was given and an extended family member with diabetes cared for her grandchildren when the illness was stabilised and family members agreed that she would not be able to care for the children at a time of relapse. This did not happen with her daughter with MIH who cared for nieces and nephews when she was well but at times of relapse was prevented from undertaking this care with no explanation. These situations were considered losses and ambiguous because of the objective feature of the situation.

The ambiguity of “spinning in a whirlpool” and “being adrift at sea” was experienced because of a lack of clarity due to either lack of information or lack of coherence in the available information. This came from stimuli that were vague, incomplete or fragmented. The ambiguity also came from stimuli that were contradictory, inconsistent and incongruent and could not be clearly defined or understood. These interpretations suggest that the situation of MIH was not only unpredictable, but also ambiguous as family members lacked definitive information even about the present. The study produced parallel stories about grief without closure, and thus complicated and chronic grief. If not recognised, complicated grief has the potential for relational conflict as well as threats to health and resilience.

3.4 Summary

In summary, in this chapter I illustrate how people with MIH and their significant-others perceive the losses associated with MIH. Reverbearing losses emerged as a major category subsumed by the four sub-themes of losing self, losing family ties, losing connectedness and losing functionality. Through use of genograms and eco-maps, perceptions of participants were explored within their internal and external contexts to examine other factors that may influence family vulnerability in addition to the stressful event of MIH.
I also illustrate how they experience the additional stressor of ambiguity associated with MIH. The responses relating to the lived experience of participants show that losses reverberate through many aspects of participants' lives. The additional stressor of the ambiguity of the illness results in different meanings and interpretations of the situation. Not only is the situation of MIH unpredictable, but it is also ambiguous – lacking definitive information even about the present. The culture around patients offers no accepted pattern for response. This results in grief complicated by ambiguity. The two sub-themes of *spinning in a whirlpool* and *being adrift at sea* emerged as additional stressors of ambiguity.

The situational demands of loss coupled with ambiguity tax the capacity of participants to adapt to crises of MIH. Using grounded theory methods for analysis of data, ambiguity of mental ill health emerges as the problem faced by participants in the substantive area of research of my study. In Chapter 4, I will discuss the basic social process of navigating through the additional stressors of ambiguity.
CHAPTER 4: NAVIGATING THE WINDS AND TIDES OF AMBIGUITY TO STAY AFLOAT

4.1 Introduction

In Chapter 4 I will discuss the findings of research question 2: How do people manage the ambiguities associated with MIH? Throughout the chapter, I italicise the key processes, concepts, courses and categories and sub-categories for ease of reading.

Managing the ambiguities associated with MIH occurs within the context of overpowering emotions which are open-ended and ongoing or oscillating. The seafaring metaphor that I have chosen can be compared validly to the findings of other researchers. For example, Omori (2008), retrieving a number of citations of conventional metaphors from the British National Corpus, found that metaphors derived from natural phenomena were outstanding in number and that a huge mass of moving water in the natural domain has been used as a conventional metaphor for emotion; she asserts that it is a cognitive device of crucial importance for the comprehension of emotion. The author also suggests that this concept is significant cross-culturally.

“Sailing to uncharted waters” is a metaphor often used to denote being faced with a situation not previously encountered because the sea is often construed as the unknown and the unpredictable. Thus “being adrift at sea” and “spinning in a whirlpool” encapsulate many of the personal responses to ambiguity. Seafaring metaphors have also been used in biographical literature and first person accounts of people with mental ill health (Jamison 1997; Stakes 1985; Ruocchio 1991; Molta 1997), and more widely for dealing with the ‘journey of hope’ (Advanced Life Skills 2010). The impact of mental ill health is so confusing and disorienting that the authors of biographical literature and first person accounts had difficulty describing it in words and frequently used seafaring metaphors to describe the experiences. Out of all forms of water, the sea is the largest in the natural world. The winds and tides associated with the sea helped me capture the oscillating activities of managing ambiguities in this study. The sailing metaphor also helped me use the conditional matrix to track the intervening conditions to capture the activities of resisting and controlling as well as activities that required flexibility and dialectical approaches. The rubric captured in the metaphor described in navigating the winds and tides of ambiguities to stay afloat captured all of these activities. Theorising through the use of metaphorical language permitted me to encapsulate complex connotations as well.
Analyses of the data gathered indicate that those affected move through the tension of MIH over time by conducting the core social process of *navigating the winds and tides of ambiguity to stay afloat*. In doing so, participants oscillate between course 1, *steering through choppy waters* and course 2, *negotiating to smooth the voyage*, depending on the context and the intervening conditions. The term *staying afloat* is an accurate metaphor for what people do in a cyclical condition such as MIH and the findings indicate that courses 1 and 2 are also oscillating processes. *Staying afloat* is a constant non-linear journey. The core social process of *navigating the winds and tides of ambiguity to stay afloat* is also a three-dimensional view of a complex phenomenon where three groups, i.e. consumers, significant-others and sig. other/cons at times take different courses but share some courses as well. When first faced with signs of MIH all three groups face the course of *steering through choppy waters* which entails both costs and benefits and therefore requires a “balancing act”. As time went by, all three groups were *negotiating to smooth the voyage* which required dialectical approaches of integrating “this and this” rather than “either this or that”, where they took one or more courses of action concurrently but also at times oscillated with actions of other courses.

The basic social process of *navigating the winds and tides of ambiguity to stay afloat* and its oscillation is dynamic and takes place in the context of complex conditions: funding of consumer and carer organisations (national level — Australia), establishment of the Mental Health Commission of WA and the rise of consumer and carer organisations that value the lived experience of mental ill health (state level – West Australia). Even though this study is located at the action and interaction level of the individual and family, conditions at all levels have relevance to the basic social processes discussed in the findings.

At the action and interaction level, the following contexts influence participants’ movement between courses: (a) degree of support from family, (b) side effects of medication, (c) degree of loss of functionality, (d) degree of perceptual differences among family members as well as among health professionals, (e) clarity of information about MIH, (f) duration of symptoms and (g) frequency of episodes of MIH. The following intervening conditions also influence participants’ movement between courses: (a) cumulative stress, (b) age of onset, (c) biology and genetics, (d) timing and type of rapport with health professionals, and (e) availability of information and support.

The following diagram depicts a full representation of the process represented in the metaphor of *navigating the winds and tides of ambiguity to stay afloat*. The conditional matrix has been incorporated into the diagram through boxes at various levels. The inner level denotes the action
taken to deal with ambiguities associated with MIH. It includes courses of action, categories and sub-categories. The second level denotes the individual and context of the family and friends and interactions which included activities such as negotiating, learning, discussing and self-reflection. The third level denotes the West Australian context with the State Government, organisations and sub-organisations with their own politics, regulations, values, economics, structures, rules and histories. The outermost level denotes the Australian context which includes national politics, regulations, values, economics, structures, rules and histories. Conditions at all these levels had relevance to my study.
Figure Z - Navigating the Winds and Tides of Ambiguity to Stay Afloat

Australian Context

West Australian Context

Individual/Family Context (consumer, sig-other, sig-other/con)

Navigating the winds and tides of ambiguity to stay afloat

Steering through choppy waters

Consulting maps/charts

Resisting the surge

Dulling pain/feeling excluded

Seeking a safe harbour

Finding solace/feeling excluded

Avoiding crosswinds

Minimising conflict/feeling excluded

Going with the flow

Finding some improvement/weight change, physical health concerns

Negotiating to smooth the voyage

Determining which way the winds are blowing and state of tides

Facing the storm and adjusting your sails

Sailing to parts unknown and knowing current location

Developing the spirit of an adventurer

Taking the helm and trying a different tack

Building rapport

Individual/Family context

West Australian context

Australian context
4.2 Steering Through Choppy Waters: An Overview

The two groups, consumers and significant-others/consumers, experience considerable distress with onset of signs and symptoms of MIH. Those who are significant-others only, observe the signs and symptoms and they experience confusion. The lives of all three groups may be considerably disrupted before they seek assistance from health professionals. An early motive for seeking help is an awareness of the inability of consumers and significant-others/consumers to function in their previous social roles. Participants in this study indicate that having good rapport with a general practitioner is a critical factor in seeking assistance and gaining help in supportive and sensitive ways. *Steering through choppy waters* in relation to managing ambiguity associated with MIH consists of five possible sub-categories. The first, *consulting maps and charts*, is shared by all three groups. The second sub-category, *resisting the surge*, is specific to consumers. The third, *seeking a safe harbour*, is shared by consumers as well as significant-others/consumers. The fourth, *avoiding crosswinds*, is shared by significant-others and significant-others/consumers. The fifth, *going with the flow*, is shared by consumers and significant-others/consumers.

I will now present an exposition of each of the five sub-categories of *steering through choppy waters* and exemplify with vignettes.

4.2.1 Consulting Maps and Charts

*Consulting maps and charts* is an attempt to make sense and it also involves seeking help. It is a journey shared by all three groups and occurs in diverse ways. Psychosocial explanations such as MIH being triggered by a stressful event in the past is the most common factor that participants identify. Particular to significant-others/consumers is that they attribute their own MIH to the stressor event of parental MIH. Participants exemplify triggering stresses this way:

Consumer C1:

I moved out from the city, and then went out to a far place away, where there’s no public transport, getting to places, if you want to have a few beers, it’s hard, so I guess the boredom and isolation kicks in, the pressure etc., and it goes on and on. So it was the demographics of where I was living at the time. If I lived in [the city], I would have been alright, because I would have had friends just around the corner.

Significant-other B2:

I thought I will retire, and I think the fact of me saying that —I think that triggered something in her ... I don’t know the actual trigger. I think it was a gradual build up. When we [migrated to Australia] initially, she was suffering from depression ... it’s as if she had come down and she sort of stayed down, ever since. And then [I got sick]
... the kids were down, and she was down, and I seemed to be the only one who tried to get up and go. And bang ... so probably at the back of it all was just pure stress.

Significant-other/consumer E1 says:

[My mother] was the only one of her family here in Australia and consequently, after about four or five years here, she became very depressed, she suffered from melancholy, homesickness, and she became mentally ill. And she was hospitalised several times, ... and I found myself in the role of being mother to my younger sisters so I had an adult role at a very early age. And that role was sort of imposed on me.

Consulting maps and charts or attempting to make sense when faced with loss is a universal experience and the first step towards making-meaning. In this study, this takes place mostly at an individual level and sometimes at a family level. However, when information is unavailable or ambiguous there is incongruence in perceptions. Making-meaning becomes difficult at a family level and collective action is blocked.

The sub-category of consulting maps and charts includes the property of seeking help. In the early stage, those who sought help were significant-other/consumers predominantly in the age groups of 50 to 70 years. This is how participants exemplify this sub-category:

Participant B1, a sig. other/con, says:

I feel so blessed that I had a GP that really respected you, she was really so helpful. And I was able to confide in her beforehand of my family [background] so she had an idea of where I was coming from.

Sig. other/cons seek help early, recognising symptoms from a relative with MIH. Of particular note is that consumer participants in the age group of 20 to 40 years do not discuss seeking help at the early stage.

4.2.2 Resisting the Surge

Resisting the surge describes metaphorically self-medicating to “dull the pain” or resisting seeking help. Consumers and one significant-other/consumer experienced this sub-category. It is observed and vicariously experienced by significant-others in a different way.

Consumers say that self-medicating brings them temporary benefit. The significant-other/consumer resists the urge to seek help for fear of diagnosis of MIH. Significant-others observe resistance in consumers and say it has an alienating effect on them.
Participant C1, consumer, says:

I used alcohol I guess to kill the pain ... not only to keep me occupied, but to kind of just numb the feeling of loneliness and sadness ... definitely alcohol was a contributor to kind of cope with emotional sadness.

Participant G1, consumer, says:

I started to smoke cigarettes and then I started to smoke marijuana when I was about 20 or 21, it gave the illusion that it was making me feel better but it wasn’t.

Participant A3, sig. other/con, exemplifies resisting seeking help this way:

I spoke to the doctor about this, probably about 9 months ago now, and he wanted me to go and see a psychiatrist. I said no, it’s too hard getting time off work — that, and probably the fact that I’m a coward.

Consumers say they are confused, preoccupied and overwhelmed by their “inner world”. They try to relieve the pain by self-medicating. The coexistence of MIH and alcohol or substance misuse adds another layer of challenge to families, leading to blame by significant-others and feelings of being excluded by consumers. Fear of diagnosis is a factor in resisting seeking help for one sig. other/con. To him, this is a reminder of his genetic vulnerability.

4.2.3 Seeking a Safe Harbour

*Seeking a safe harbour* is a metaphor for isolating themselves from others. It is a course consumers and significant-other/consumers take to manage exposure to stimuli and has the benefit of providing solace. Significant-other/consumers experience it as a balancing act of costs and benefits with the benefit of solace and cost of alienation and feeling excluded. Significant-others experience sadness and feeling excluded when consumers take the course of *seeking a safe harbour*.

This is how participant F1, a consumer, exemplifies *seeking a safe harbour*:

When I’m not in the best mood, I just know not to come. I’d never sort of say I will or I won’t go. Basically get to that day and just see how I feel. If I’m in a good space then I will go.

Participant A1, a significant-other/consumer, exemplifies *seeking a safe harbour* and the costs and benefits of such an action as:

It stops me from getting close to people because it's something that I am aware of in myself but I have to have a barrier of sorts to protect myself.

Significant-other F2 experienced feeling excluded as:

She'll go home and isolate herself and say, oh well, you can have my child, and she’ll just stay at home and do nothing. So that’s often been very painful.
Health professionals often promote seeking a safe harbour or taking time-out as a coping strategy to help manage the overwhelming feelings experienced by consumers from exposure to stimuli. However, findings of this study indicate that this strategy has the potential to isolate consumers from other family members.

### 4.2.4 Avoiding Crosswinds

**Avoiding crosswinds** is an action taken by significant-others and one sig. other/con. In the context of this study, it is a metaphor that connotes that one could easily offend a person with MIH and is often referred to as “walking on egg-shells” or “skating on thin ice”. This strategy has both costs and benefits. The benefit of avoiding crosswinds is to minimise conflict but the cost is feeling excluded through implicit rules of ‘no talk’. This is how significant-others exemplify avoiding crosswinds.

Significant-other/consumer A2’s perception as a significant-other is:

> From the time of the major incident you always had to tread a little bit carefully about what you said because ... could take offence very easily. We all learnt how to cope with him.

Significant-other E2 says:

> Sometimes I’ve felt a little bit like I’m treading on ice, I’ve got to be very careful. I probably alienated myself away from ... a bit, because I didn’t know how to deal with it.

In this situation, sharing perceptions between family members is prevented by implicit “no talk” rules of a poorly understood illness. If left unchecked, it has the potential to be a lifelong family coping strategy alienating members of the family from each other.

### 4.2.5 Going with the Flow

**Going with the flow** suggests taking prescribed medication and is an action taken by consumers. It has the benefit of bringing some improvement in symptoms of MIH but has the costs of side effects and unintended medical outcomes such as gaining weight, metabolic syndromes and sleep disorder. This is how participants from each of the groups exemplify the costs and benefits of going with the flow.

Consumer C1 who is not able to pursue a career due to gaining weight says:
I actually wanted to be a ..., I did a ... course at TAFE ... but due to the medications, or some of the anti-psychotics, I put on weight. And I go, oh man, this sucks, this really sucks.

Consumer D1 who sees the benefits says:

Because just recently I’ve been put on this new medication, it seems to have improved a lot of things. I’ve become a lot more functional.

Significant-other E2 says:

A lot of her mental illness had a lot to do with medication. She actually died of diabetes but because she was misdiagnosed and put on all sorts of different medication, it didn’t help her.

Significant-other/consumer D2’s perception as a consumer is:

Because the schizophrenia with all the years of medication, [results in] diabetes, heart bypass, and a vulnerable liver. So I need to check what this one that I’ve now got onto in the long term makes me vulnerable to.

Participants speak of giving up their future dreams due to gaining weight caused by medication. One participant finds medication useful and that it helps functionality. Participant D2 oscillates between going with the flow and developing necessary sailing skills, a sub-category of negotiating to smooth the voyage, a course taken by consumers with time and experience of navigating the health system.

4.3 Negotiating to Smooth the Voyage: An Overview

Negotiating to smooth the voyage in relation to managing ambiguity associated with MIH consists of six sub-categories. Each sub-category adds to the skills gained from a preceding sub-category and vice versa. For example, participants gained skills in facing the storm and adjusting your sails which involved gaining knowledge of the situation and changing their attitude from sailing to parts unknown and knowing current location which involved joining self-help groups or a new community and also maintaining relationships with family and friends. Similarly, participants gained skills in taking the helm and trying a different tack, developing the spirit of an adventurer from building rapport and sailing to parts unknown and knowing current location. Despite the ambiguities of MIH, participants achieve ‘staying afloat’ in this study by taking a non-linear journey. All three groups take one or more courses of action concurrently and at times oscillate with actions of steering through choppy waters. The sub-categories of negotiating to smooth the voyage are: 1) building rapport, 2) taking the helm and trying a different tack, 3) developing the spirit of an adventurer, 4) sailing to parts
unknown and knowing current location, 5) facing the storm and adjusting your sails, and 6) determining which way the winds are blowing and the state of tides.

4.3.1 Building Rapport

In this sub-category, consumers and sig. other/cons and significant-others valued building rapport with health professionals from public, private and the non-government sector as well as family and friends. This is how the two groups exemplify this subcategory.

Consumer C1 says:

Finding the right doctor or the person you can relate to the most in terms of [health professionals], I found that if you find one you like, you’re more likely to open up and relate to them.

Consumer D1 says:

[Name] is just absolutely brilliant. Anything I need help with, she says yes to it, and no sooner said than done and there are some things she says no to, but she explains to me why she says no.

Significant-other/consumer E1 says:

I have a great deal of faith and trust in my treating physicians. All my [health professionals] were very good and from the same culture.

Participants value the capacity of health professionals to respond in a sensitive and culturally appropriate manner, despite the ambiguity of MIH.

Participants value support from family, friends and religious personnel.

Consumer G1 says:

The people who were my friends, you know, my real friends, I guess, anyway, they’ve stood the test of time.

Consumer C1 says:

So with the help of Father J, a very good priest and a very nice person to me, he ... really did help out a lot and he was very good.

Significant-other C2 says:

He needs a lot of support. And I don’t work. I am there for him because I do believe that you need to be there to support them, because if they have no support they lose hope, and when they lose hope they accept the abnormality of a mental illness as normality.

Significant-other/consumer D2 says:
I was actually feeling distressed, unhappy, and I was talking to D1 about it, who was being a good listener. But she said when I get into a space where I don’t know what to do, where I’m confused, where I don’t seem to be able to know what to do, she said, I think what would D2 do? And then it all comes clear. And we talked about it, and called it her inner “D2”. And it just felt great. I just felt really, really valued.

D1 and D2 were an example where they were marginalised from their family of origin and had formed a bond of connection as an “intentional family”.

However, when analysing the different perceptions of stakeholders symbolised by the metaphor of building rapport, it became obvious that it fitted awkwardly with the perceptions gathered and described in the metaphor being adrift at sea discussed in Chapter 3 under 3.3.3, where participants perceived that they had no rapport with each other or health professionals when concerns about symptoms were not validated. Grounded theory method minimises this problem of awkwardly fitting material but does not eliminate it.

Building rapport also minimalises the power differential between consumers, significant-others and health professionals. White and Epston (1989) as well as Freedman and Combs (1996) argue that there is an inseparable link between knowledge and power. As an example they say that people whose voices dominated the discussion about what constituted madness occupied powerful positions and had the potential to separate the people they saw as “mad”. This point will be discussed more fully in Chapter 7, under 7.8 Implications of the study for clinical practice.

### 4.3.2 Taking the Helm and Trying a Different Tack

All three groups in this study attempt to seek information from various sources. In the initial stage, information about MIH is not given to them by health professionals and they have to search for it themselves. Some find it through studying formal educational courses. Significant-others find it helpful to have an official diagnosis from health professionals. They can then search for information themselves. All valued the opportunity to follow their own judgement. The three groups give examples of taking the helm and trying a different tack.

Consumer D1 says:

> When you sort of went there, on a table there was another pamphlet telling you about what other things they have. So I made a connection with that other person
that was on the pamphlet. And that was very rewarding. I am now doing things at the level that I feel I’m at, and not at the level that other people think I should be at.

Significant-other/consumers A1 and B1 say respectively:

I went back to [college] and studied Community Services and then Mental Health Certificate 4, and then got a job in Crisis Care of People with Mental Illness at [...] and was there for 5 years, helping look after people with acute psychiatric problems.

I appreciate the backup, the help I got when I was sick, and a lot of life is – you have to reach out, it won’t come to you.

Significant-other C2 says:

We were officially diagnosed. And then we were no longer in the dark ourselves as to what was going on. I think we were all just so grateful that we knew what was wrong, that we could actually do something about it.

I guess my reaction at first was just sort of so shocked. But then my reaction was really to find out all I could about it.

While I was conducting this study, the Mental Health Commission of WA sponsored a number of community information sessions to increase the public’s awareness of MIH. I attended one session (field notes 10th May 2011). During this session I observed that there were sig.other/cons and significant-others in the audience.

4.3.3 Developing the Spirit of an Adventurer

All three groups speak positively of their experiences when they developed shared interests where problems of MIH have no influence. They also speak positively when they are able maintain their own interests.

Consumer C1 says:

I get on well with my brother — we both have similar interests, have a big skateboarding half pipe in the shed there. We like surfing, skating, swimming at the beach. ... This is his house, but he does not live here, he only comes over at weekends.

Significant-other B2 says:

Family life is good [too] and we go over to our [child] who has kids. We both love our grandkids. That’s a common interest. We also have the common interest of travel but I am going travelling on my own soon as [B1] has trouble with her knees so she’s quite happy letting me off, doing that.

Significant-other/consumer D2 says:
Our togetherness has been about going to the movies. We go to the movies once or twice a week, usually on the weekend and sometimes one or other of us is not in a space to go but mainly we get there twice a week.

The same participant maintaining her own interest says:

There was a group of women [from my professional group] who met on a regular basis. And out of that group of three, one of them I see every Friday night now.

These relationships are fresh in the narratives of participants and their interests are relevant to day-to-day experiences of life.

**4.3.4 Sailing to Parts Unknown and Knowing Current Location**

Except for two consumers, participants in all three groups discuss joining consumer and carer organisations, self-help groups, religious organisations or an interest group. This involved interacting with people not known previously. These are positive experiences when the relationships are reciprocal. One consumer, two significant-others and two significant-other/consumers discuss maintaining old ties (metaphorically described as knowing current location) as well. These participants are of an older age group. Onset of MIH has been later in their developmental trajectory. Participants discuss *sailing to parts unknown and knowing current location* this way:

Significant-other/consumers A2 and D2 say:

I think by getting myself involved in the community again, a gradual re-entering the community that has been what has helped me with a stable family life. I had to do a lot with this centre to get it off and running and I was able to use the skills that I have had from my [younger] days and I've had lots of lovely feedback about it.

I do some voluntary work so I was their [worker] so that took me straight into activism, as a consumer [and] I am putting things into this society. ... I have a very good friend where I was working before [whom] I see every Friday night. She and I are very close.

Significant-other C2, a member of a health service management committee, says:

I really enjoy that. I feel as if I have an input. They listen. And they try and do something with the input.

The same participant says of staying in touch with home:

It's probably only the last six months I've actually had more time to catch up with my friends at ..., still we're very close, but actually making the effort to go out.
All three groups sail to parts unknown in joining new communities to make a difference in the lives of other people and contribute to society. Those who join consumer and carer mental health organisations believe they have a valued contribution to make from their lived experience. With time, some participants knew their current location.

4.3.5 Facing the Storm and Adjusting your Sails

Facing the storm and adjusting your sails is a metaphor suggesting that participants change their attitudes in diverse ways. Some drew strength from their spirituality and religion, and others by fostering hope and humour and living mindfully in the present.

Consumer D1 says:

Perhaps against all odds, I managed to pull through this stuff and create some sort of semblance of a happy life.

Significant-other/consumer B1 says:

The loss, I’ve accepted it with the knowledge, other families have other illnesses, other things; this is my family, I call it heirloom! And I say to my children, look, you have this awareness, that it comes from my family, that there are a few people who are mentally unwell, and it’s like [if] your parents, grandparents, had bowel cancer, you need to go to your doctor and have a colonoscopy or whatever. To me this is the same as that. It’s not different. It’s like this happened, and nobody’s to blame.

Significant-other C2 says:

The one with mental illness, there is always hope that maybe they will come back, and maybe, maybe, they might even have children. Maybe they might be able to even work, or ... it doesn’t matter, work. But there may be a sense of normality. There is that hope factor.

In this study, participants change their perceptions in time, knowing they cannot change the situation. A sign on a wall of one family home I visited reads: “It is not the load that breaks you down, it’s the way you carry it” (field notes 22nd March 2012), capturing the essence of this sub-category.

4.3.6 Determining Which Way the Winds are Blowing and the State of the Tides

Determining which way the winds are blowing and the state of the tides is an ongoing action and interaction that oscillates as new information becomes available as well as when there is a recurrence of ill health. They take the action of taking the helm and trying a different tack to
advance their understanding of MIH, whilst at the same time building positive contributions to others in similar situations by taking the course of *sailing to parts unknown and knowing current location*. This is how the three groups exemplify the ongoing course of *determining which way the winds are blowing and the state of the tides*.

Consumer D1 says:

I believe you can't move from where you're at unless you actually experience the other, and one of the sort of talks I went to recently, my personality, the response of my personality to what's happened to me would have been one of the attitude, the grass is always dead on both sides of the fence.

Consumer G1 says:

I was quite passionate about sharing my story and making sense of the experiences and that's evolved over time. But I always had hope; that kind of got me through, that hope that it would improve and get better.

Significant-other/consumer E1 says:

But I know that there are genetic factors, and there are environmental factors, and in the case of our mother ... her illness was situational. If she had been in her country of origin, surrounded by her social network, I doubt whether it would have happened. But she was so isolated here, and unsupported.

It was a very hostile environment because of the assimilation policy. The men who went out to work, they were okay, they were able to learn English, but the women who were at home looking after children, and the home, they did not have the opportunity to learn English, and of course they wanted to associate with people from their own culture, to speak the language, and so there was quite a bit of discrimination if you didn't assimilate, or if you didn't mix with Anglo-Australians you weren't considered to be part of the Australian society. So that's what I mean by the hostile social environment.

Significant-other/consumer D2 says:

A whole lot of stuff has been happening in Perth around schizophrenia not being genetically determined, but being trauma determined.

Significant-other/consumer A2 says:

It is possible that my father's breakdown resulted from many years of insults and abuse as a child being [from an ethnic background] in an Australian school who couldn't speak English for a while when he first went to school and he actually had his arm broken when he was only 6 or 7 at school because he was a new Australian. They say it's possible in later life that's how that manifested itself, years of him feeling out of things because he was [ethnic], I guess we would never know that either.
4.3.7 Particularisation/Unique Experiences

Stake (2010) defines particularisation as attending to what is important about the cases at hand. To understand the phenomenon of ambiguous loss associated with MIH requires an understanding of the historical, political, economic, cultural, social and personal contexts as well. Recognising the consistencies, as well as the uniqueness of the cases, activities and events is important to qualitative case studies. Stake (2010, p. 31) writes that by providing experiential accounts, readers can be drawn easily to this sense of uniqueness.

4.3.7.1 Migration

The uniqueness of the experiences of migration has been critical to the understanding of ambiguous loss associated with MIH and how some participants attempt to make sense of their experience and put it in the context of migration. Three families, Families A, B and E, referred to the experience of migration and the possible contribution of this effect to MIH.

Significant-other A3 speaking about his father’s MIH says:

Racism was … I mean people talk about racism now, trust me, it ain’t anywhere near like it used to be. I mean, I can remember what I got at school. Anyway, I got told that my grandmother’s answer to the racism that the kids were getting at school was that she wouldn’t let the kids speak [language of heritage]. They had to all speak English, because she figured that if they spoke English they’d lose the accent, they wouldn’t get picked on as much. So that is the only thing I can think of, is that because every time, as long as I can remember, I wanted to go to [country of origin of father], and I wanted to know all I could about my heritage.

A3 attempted to make sense of the experience of his father’s MIH and the effects of migration by revisiting his heritage. He has been visiting the country of origin of his father and meeting with extended family. There were many photos of him with his extended family on the walls of the house (Filed notes 1st June 2012). He was also attending evening classes to learn the language of his ancestry.

Significant-other B2 said:

I don’t know the actual trigger. I think it was a gradual build up. When we came out to Australia initially, she was suffering from depression. And she never really — it’s as if she had come down and she sort of stayed down, ever since we arrived in Australia. ... I didn’t have a big support network here, because most of that would have been in [country of origin].

Significant-other/consumer E1 distinguishes the genetic factors from the environmental factors that contributed to the MIH of her mother by saying:
I know there are genetic factors and environmental factors. In the case of my mother, her illness was situational. If she had been in her country of origin, surrounded by her social network, I doubt whether it would have happened. But she was isolated here, and unsupported.

She also considered Australia to have been a very hostile environment at the time of her parents' migration because of the assimilation policy and that there was discrimination if migrants did not assimilate.

She further perceived that treatment regimes differed for people of non-English speaking background:

And I see that there’s disparity in services between what is provided for the Anglo-Australian community or shall we say mainstream community and the culturally diverse .... with my mother, she was categorised according to her status as a migrant, non-English speaking person and there was a set treatment regime for such a category, and she was given that treatment regime, and I mean, treatment was not denied, but that was the treatment regime: medication, shock therapy, but of course her improvement couldn’t be sustained and so that’s why she was constantly breaking down.

By sailing to parts unknown and knowing current location E1 was helping migrant women with MIH and was making a positive contribution to others in similar situations.

The overall level of migration to Australia has grown since World War II, war in Vietnam and more recently war in the Middle East. Forced uprooting of refugees and the numbers seeking asylum continue to grow. The country now has a diverse migrant community. Culturally and linguistically diverse (CALD) policies continue to be implemented at all levels of government and public service. However, migration adds another level of ambiguity to losses when people leave behind their support networks or they are stigmatised and discriminated against because of race and/or colour. This is also akin to being adrift at sea.

4.3.7.2 Intentional Families

The uniqueness of the experience of forming a bond of connection by virtue of being marginalised through MIH is exemplified through the experience of D1 and D2 who participated in this study by taking family in its broadest sense. Although the bond of connection was made through the experience of MIH, they shared a common interest in going to the movies two or three times a week. Referring to this shared interest D2 says:

We first met at a Consumer Advisory Group. We were both members. And that’s about ten years ago. And since then, our togetherness has been about going to the movies together. She and I go to the movies once or twice a week, usually on the
weekend and sometimes one or other of us is not in a space to go but mainly we get there twice a week.

This unique interest stood outside the dominant story of their MIH. This brought forth a different narrative about their lives and relationships and was categorised in the metaphor of developing the spirit of an adventurer.

This also demonstrated the importance of psychological kinship which lies at the very roots of social behaviour. Psychological kinships, which I have named intentional family, are a powerful force and can be extended to networks beyond the biological family.

Examples of the effects of migration and psychological kinship that emerged from the data of my study demonstrate the importance of taking into account internal and external contexts when considering the impact of stress on a family.

4.4 Summary

In summary, this chapter illustrates a circular model of managing the ambiguity of MIH where those affected move through the tension of a complex phenomenon of ambiguity over time, conducting the core social process of navigating the winds and tides of ambiguity to stay afloat. This is a constant non-linear journey with oscillating actions and interactions. It is also a three-dimensional view of a complex phenomenon involving three groups: consumers, significant-others and significant-other/consumers. Participants experienced MIH as a cyclical condition that requires moving between steering through choppy waters and negotiating to smooth the voyage depending on the context and intervening conditions. The course of steering through choppy waters included consulting maps and charts, resisting the surge, seeking a safe harbour, avoiding crosswinds and going with the flow. The three groups sometimes take different courses but share some courses as well. The course of negotiating to smooth the voyage included building rapport, taking the helm and trying a different tack, sailing to parts unknown and knowing current location, facing the storm and adjusting your sails and determining which way the winds are blowing and the state of the tides. The three groups took one or more courses of action concurrently but also at times oscillated with actions of other courses. There were consistencies as well as uniqueness of cases, activities and events. Both the internal and external contexts of families under stress have implications for the management of stress.

It appears that there is incongruity in perceptions not only with individuals and family members but with health professionals as well. With each new item of information, those affected by MIH attempt to make sense of their experience of loss through the actions of consulting maps and
charts and determining which way the winds are blowing and the state of the tides. This sense-making is at times hampered by the seemingly lack of reliability in the charts and shifting winds and tides.

In the following chapter, I will compare the findings of my study with results recorded in relevant scholarly sources.
Chapter 5: Comparison with the Literature

This study set out to explore three research questions. The first question involved ascertaining how loss is perceived by those affected by mental ill health (MIH). The findings were that losses are perceived as losing 'self', losing family ties, losing connectedness and losing functionality. These losses reverberate through many aspects of participants' lives. The second question involved ascertaining the uncertainties associated with MIH. Findings suggest that the experience of MIH is similar to spinning in a whirlpool and being adrift at sea in that it is unpredictable, uncertain and often not validated by people around those involved. This results in grief complicated by ambiguity. The third question of the study was to ascertain how people manage this associated ambiguity of MIH. Substantive theory generated from the analyses of the data gathered is that families manage the ambiguity by conducting the core social process of navigating the winds and tides of ambiguity to stay afloat.

The purpose of this chapter is to compare the findings of the present study with results recorded in relevant scholarly sources. Exploring the extent of the literature and conducting a comparative analysis presented a number of difficulties. The first difficulty was that a search of published literature indicated that ambiguous loss theory had been applied to diverse situations and samples but only in one instance was the theory applied to MIH and, even in that case, only to siblings. It is possible that its limited application to MIH is a result of the theory's multidisciplinary roots and linkages (Boss 2006). Another difficulty of conducting a comparative analysis was that the majority of publications alluding to the ambiguity of MIH are based on testimonials from consumers, significant-others and health care professionals and are therefore not theorised in a scholarly way.

Classic grounded theorists (Glaser & Strauss 1967) suggest that researchers delay their review of the literature until the data analysis is completed. They argue that by so doing, a researcher is not unduly influenced by earlier understanding of the area of research and could therefore import preconceived ideas into their work. However, Strauss and Corbin (1990) argue that we bring considerable background in professional and disciplinary literature and that it is important to acknowledge and use that as well as open these up and to find new meaning in them. I acknowledge the professional and disciplinary background that I have brought to the study by discussing key points from clinical experience, existing literature and earlier theories in Chapter 1, in Rationale for the research (1.2), Contextual Background (1.3) and A Historical Development (1.4).
For selection of literature for comparison with my study, I searched the databases of Medline, CINHAL, Psychinfo and OVID using key words selected from data that emerged from interviews with participants. Charmaz (2006) argues that for grounded theorists, writing a thorough but focussed literature review often means going across fields and disciplines. For this study, in order to address the complex dynamics of managing ambiguity associated with MIH and make intriguing comparison, I have taken a critical stance towards a range of earlier studies spanning just over five decades and juxtaposed it against the findings of my study.

This chapter is organised into two parts. Part one will give a brief summary of the current knowledge about loss and grief associated with MIH. Part two compares the findings of my research with ten other empirical studies that used some form of qualitative method to study the perspectives of consumers or significant-others about MIH. In Chapter 6, I will draw upon family stress theories focusing on meanings and perceptions, theories surrounding the stress vulnerability model of Mental Ill Health and theories of loss and grief.

5.1 Current Knowledge About Loss and Grief Associated with MIH

Current understanding of loss and grief associated with MIH derives from three domains: (1) testimonials from family members, consumers and health care professionals, (2) clinical contributions from observations by clinicians in varying disciplines, (3) systematic studies of the presence of loss and grief which are mostly quantitative.

While the above are useful, when studying human beings starting with the lived experience will give researchers the most valuable information and is the basis of the phenomenological tradition. Although objective approaches can produce valuable findings, it is the first person accounts that will enable researchers to learn the multiple perspectives that could be brought to bear on a phenomenon even within one family. These multiple perspectives help a researcher understand the distinct as well as the common ways people manage an ambiguous situation. By exploring and understanding these multiple views, researchers and clinicians may be able to develop the most useful theory to help those whom we serve. In this chapter I will only compare my findings with empirical studies that used some form of qualitative methods to study the perspectives of consumers or significant-others.
## 5.2 Comparative Literature Analysis

### Table 5 - Comparison between ten empirical studies

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<td>1. Clausen &amp; Yarrow (eds) (1955) USA</td>
<td>Qualitative, longitudinal study of perceptions and reactions of thirty-three wives of patients aged 20-60 years during or post the first admission to a mental hospital.</td>
</tr>
<tr>
<td>2. Creer (1975) UK</td>
<td>Qualitative study of eighty relatives to ascertain how the patient functioned at home and service availability.</td>
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<tr>
<td>3. Hatfield (1978) USA</td>
<td>Survey of eighty-nine relatives to determine how care-givers and families were affected by the illness of their relative.</td>
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<tr>
<td>5. Baxter &amp; Diehl (1998) USA</td>
<td>Comparison of companion family education programs on loss and the process of recovery for consumers (BRIDGES) and relatives (Journey of Hope) of people with severe mental illness.</td>
</tr>
<tr>
<td>7. Wasow (2000) USA</td>
<td>Findings from a cross-sectional study of 120 in-depth interviews with relatives to ascertain their experiences of having a relative with severe mental illness.</td>
</tr>
<tr>
<td>8. Stein &amp; Wemmerus (2001) USA</td>
<td>Qualitative study using a life course perspective to ascertain how consumers and their relatives understand and accommodate life changes that result from schizophrenia.</td>
</tr>
<tr>
<td>9. Mauritz &amp; Meijel (2009) The Netherlands</td>
<td>Qualitative study of ten patients using the grounded theory method to understand the lived experience of grief in schizophrenia.</td>
</tr>
<tr>
<td>10. Henderson (2011) Australia</td>
<td>Qualitative study of fifteen consumers using the grounded theory method to ascertain their perspectives of recovery from the effects of a severe mental illness.</td>
</tr>
</tbody>
</table>

The focus of the studies above and the demographics of participants differed between studies. They also differed from my study. The majority of publications are from the USA. There is one each from the UK, Norway, The Netherlands and Australia.

It is noteworthy that in the ten publications listed in Table 5, spanning just over five decades from 1955 to 2011, the phrase ‘ambiguous loss’ is only used once. Kristoffersen et al. (2000) reported on their findings of the presence of mixed feelings of grief, hope, anger, guilt and shame and say that these feelings are interrupted by four interrelated factors: ambiguous loss, the fluctuating nature of the illness, an inner prohibition of feelings and the tendency of others to invalidate the feelings. Only three studies contained parallel perspectives involving both the consumer and family member (Davidson & Stayner 1997; Baxter & Diehl 1998; Stein & Wemmerus 2001).
Davidson and Stayner (1997) alluded to the perspectives of health professionals but this has not been included in the comparison with my study but will be discussed in the section on implications for practice in Chapter 7.

I will now go through each of the publications in chronological order, summarising them and their relationships to the findings of my study.

5.2.1 Comparison of findings of my study with Impact of mental illness on the family (Clausen & Yarrow (eds) 1955)

The study of the impact of mental illness on the family when one of its members becomes mentally ill and is hospitalised in a mental hospital was one part of a project by the Laboratory of Socio-environmental Studies within the Research Branch of the National Institute of Mental Health. The purpose of the major part of the project was to develop a research program bearing upon significant sociological and social-psychological issues relating to the cause, treatment and consequences of mental illness in order to increase the understanding of the cultural and social systems through which mental illness is defined and dealt with (J.A. Clausen & M.R. Yarrow 1955b). The researchers obtained systematic data on: the process whereby the illness is defined and dealt with inside the family; the course of the family’s functioning during the illness, in terms of its members’ attempts to cope with the situation, both psychologically and materially; and the ways in which family members relate to each other, the consumer, the hospital, and the society. The findings, observations and implications are presented in six papers (Clausen et al. 1955; Yarrow et al. 1955; J.A. Clausen & M.R. Yarrow 1955c; Yarrow, Clausen & Robbins 1955; Deasy & Quinn 1955; J.A. Clausen & M.R. Yarrow 1955a) in the *Journal of Social Issues*.

Thirty-three wives of consumers between 20 to 60 years of age participated following the first admission to a hospital. Data was collected by a series of interviews starting at the time of the admission to hospital and ending six months after the husband’s discharge or at the end of his first year of hospitalisation. Interviews were held in their home, weekly for the first month and monthly thereafter until discharge. In their findings of the psychological meaning of mental illness in the family, (Yarrow et al. 1955) report that:

many recall their early reactions to their husbands' behaviour as full of puzzling confusion and uncertainty. Something is wrong, they know, but, in general, they stop short of a firm explanation. (p.19)

The fog and uneasiness in the wife's early attempts to understand and cope with the husband's difficulties are followed, typically, by painful psychological struggles to resolve the uncertainties and to change the current situation. (p.19)
These correspond with the findings of my research that the experience seems like *spinning in a whirlpool* (full of puzzling confusion and uncertainty) and *being adrift at sea* (something is wrong they know, but, in general, they stop short of a firm explanation), followed by feelings of *loss and grief* (painful psychological struggles). Although the authors found painful psychological struggles, there were no references to loss and grief. The researchers also found that the wives had difficulty defining the husbands’ problems and that several conclusions or interpretations of the problem are “suspended in balance”. These interpretations shift back and forth in emphasis and relief (p.22). The strategy of moving back and forth to make meaning and manage the situation bears similarity to *steering choppy waters* and *negotiating to smooth the voyage* where participants in my study also moved backwards and forwards in an attempt to manage the uncertainties and the costs and benefits of the five courses of action - *consulting maps/charts, resisting the surge, seeking a safe harbour, avoiding crosswinds* and *going with the flow*. As described in Chapter 4, the first two courses were shared by all while the rest were specific to certain groups.

In the article on the findings of the social meaning of mental illness (Yarrow, Clausen & Robbins 1955)

The authors conclude that:

> Unlike other situations which may befall the family, such as death or physical illness, in which expectations regarding behaviour are relatively clear, and in which forms of help and sympathy from others are socially prescribed and formalized, no similarly clear guides or patterns for response are apparent in the case of mental illness. (p.33)

This statement concurs with the theme of *being adrift at sea* and also the core finding of the first research question of my study, that losses associated with MIH are ambiguous, unpredictable and lack definitive information even in the present.

According to the authors, the findings of studies of public attitudes towards MIH in the 1950s suggest confusion as to what mental illness is (p. 33). Findings of my study six decades later reveal that confusion still exists for consumers and their significant-others.

In addition to the ambiguity of MIH, the authors also infer the lack of rituals and validation from the community when they say that MIH has no forms of help and sympathy from others that are socially prescribed and formalised. This is synonymous with *being adrift at sea*. Through analysis of interviews, the authors of these six studies come to several conclusions. The following relate to my findings:
• The consequences of mental illness in the family manifest in changes in the structure and functioning of the whole family, both during the illness and afterwards (J.A. Clausen & M.R. Yarrow 1955b, p. 3).

• Perceptions of mental illness were in line with general findings in studies of perceptions. i.e. “Behaviour which is unfamiliar and incongruent and unlikely in terms of current expectations and needs will not be readily recognized, and stressful or threatening stimuli will tend to be misperceived or perceived with difficulty or delay” (Yarrow et al. 1955, p. 23).

• Unlike physical illness where there are relatively clear-cut patterns for getting diagnosis and treatment, with MIH the lack of clarity as to what is happening, the family’s inability to decide which way to turn and in some instances consumers’ lack of cooperation are all important reasons for the difficulty in dealing with mental illness (J.A. Clausen & M.R. Yarrow 1955c, p. 31).

These concepts were encapsulated respectively in the categories of **reverberating losses**, **spinning in a whirlpool** and **being adrift at sea**.

A surprising finding for the researchers was that all of the consumers returned home to live in contrast to reports by hospital social workers of the frequency with which families reject consumers. Although consumers returned home, the researchers also found that wives had feelings of anger, frustration and of being badly used by consumers (J.A. Clausen & M.R. Yarrow 1955a, p. 62) and the consumers’ difficulties were often explained in ways that exacerbated stresses that the family was undergoing and led to bitter hostilities (J.A. Clausen & M.R. Yarrow 1955b, p. 3). The feelings and actions expressed inferred **losing family ties**.

Following this study done in the 1950s, the researchers imply that the requirements of public education about MIH differ from those of other chronic illnesses, because the manifestations of mental illness are varied; the interpretation therefore requires knowledge of its context (J.A. Clausen & M.R. Yarrow 1955a, p. 63). The implication about public education is perhaps due to the fact that the authors’ study was conducted nearly six decades ago, before the emergence of theories of the bio-psychosocial and stress vulnerability of MIH. The researchers’ implication is in contrast to the findings in my research where participants taking the course of **taking the helm and trying a different tack** found public education to be helpful. However, the philosophical underpinning of my study concurs with the authors that manifestations of MIH are varied and that
knowledge of the context is important for the process of naming the disorder and formulating treatment.

In summary, similarities exist between the findings of these six studies and my study into the ambiguous nature of MIH. Findings of my study differed from conclusion about the requirements of public education about MIH not being suitable. My study found that public education enabled participants in *taking the helm and trying a different tack* to manage the ambiguities of MIH.

### 5.2.2 Comparison of Findings of My Study with ‘Living with schizophrenia’ (Creer 1975)

The purpose of Creer’s study was to report on findings about how relatives manage the disability of MIH within a family situation. Data were derived from a larger research project carried out in 1973 while she was the research social worker at the Institute of Psychiatry in the United Kingdom (UK). The aim of the larger research project was to find out more about how the consumers functioned at home and mostly to find out what kinds of services relatives felt would be useful and whether they had any criticism of services they had accessed. The author says that the National Mental Health Plan of the UK at that time envisaged that the traditional protective functions for patients once discharged from hospital would be taken over by a variety of social agencies set up by local authorities and voluntary bodies whilst the short-term medical treatment would be met by small local psychiatric units in general hospitals.

The sample included fifty relatives belonging to the National Schizophrenia Fellowship and residing in the geographical areas of London, the Midlands and the north of England. By way of comparison, a parallel survey included thirty relatives living in south-east London, making a total of eighty participants. Relatives reported that consumers had lost the complex skills required for social interaction and avoided company, which is comparable to *losing functionality* in my study. Although consumers avoided company, relatives also found that they craved companionship and felt deeply lonely. This observation of relatives is similar to reports by consumers in my study of *seeking a safe harbour* to manage exposure to stimuli and *finding solace* from this strategy but on the other hand, *feeling excluded*. Creer found that relatives were often puzzled and distressed by this behaviour of consumers and were uncertain whether interaction with others should be encouraged or if the withdrawal was considered to be more protective. This is akin to *being adrift at sea*. Significant-others in my study experienced sadness and *feeling excluded* by consumers *seeking a safe harbour*. In both studies significant others were distressed and sad about the behaviour.
Relatives in Creer’s study described the consumer spending long hours in total inactivity, not being able to concentrate, lacking leisure interests, hardly speaking to others, not seeming to hear what others said to them or conversing only in monosyllables. All of these descriptions are properties of loss of connectedness in my study.

The author writes that depression was common among relatives and that “many felt a sense of grief and loss because the patient was now so unlike his former self” (page 4) and that this depression was also associated with a sense of failure. The sense of failure described by relatives in Creer’s study is included in properties of losing ‘self’ in my study not only for significant-others but also consumers. All of the emotional reactions described by relatives resulted in ‘considerable friction between members of a family’ (page 4) which is similar to losing family ties in my study, again not only for significant-others but also for consumers. In describing all of the effects of MIH on families, the author suggested that the effects seemed likely not only to affect the marital relationship but also to rebound on the children, suggesting reverberating losses. The author concluded that the emotional reactions of family members can often be seen simply as reactions to a confusing, incomprehensible situation that cannot be modified. This is similar to findings of my study that, because they do not have sufficient information to form an opinion about the most appropriate strategies to use, people react in ‘normal’ ways to an abnormal situation.

In summary, although the purpose of Creer’s original research was different to my study, the relatives’ experiences of loss and grief and the confusion surrounding MIH are similar to many of the findings in my study. The situational demands of managing the disability reverberated throughout all members of the family and placed enormous stress on the family unit.

5.2.3 Comparison of Findings of My Study with ‘Psychological costs of schizophrenia to the family’ (Hatfield 1978)

Hatfield (1978) studied the responses of eighty-nine relatives to determine the behaviours of their ill relative that they found disturbing and the severity of stress provoked by such behaviour. In an open-ended question, participants were also asked to describe the effects of their relative’s MIH on themselves and their families. Eighty-five percent of the participants were parents and the remaining 15% were siblings, spouses or other close relatives. All participants were members of the Schizophrenic Association of Greater Washington (SAGW).

Behaviours that respondents found most disturbing were categorised as bizarre and abnormal behaviour, intrusive and disturbing behaviour and poor task functioning. Phenomena
encapsulated in bizarre and abnormal behaviour were: ‘thinks people talk about him or her; ‘hears voices’, ‘tries to commit suicide’ and ‘talks without making sense’ (Hatfield 1978, p. 357). All of these phenomena are comparable to properties of losing ‘self’ for the consumer in my study and were observed by significant-others. Of the phenomena encapsulated in ‘intrusive and disturbing behaviour’ only two corresponded with the findings in my study: ‘drinking too much’ and ‘using harmful drugs’. These two behaviours were incorporated in the sub-category of resisting the surge in the course of steering through choppy waters to manage ill health. This behaviour was reported by three consumers in my study and observed by their significant-others. The other manifestations of ‘intrusive and disturbing behaviour’ in Hatfield’s study — argues too much, has unusual eating and sleeping patterns, breaks and damages things, tries to hit or hurt others, upsets the neighbours, steals from the family and “mooches” from others (Hatfield 1978, p. 357) — were not found in my study. This is perhaps because participation in my study called for consumers who had recovered and their significant-others.

The behaviours encapsulated in ‘poor task functioning’ were synonymous with the properties of losing functionality except for ‘refuses medication’ which I included in the sub-category of resisting the surge in the course of steering through choppy waters. By way of explanation, I believe including consumers’ perceptions in my study highlighted the side effects of medication which was considered a cost as well as a benefit by them. However, ‘poor grooming and personal care’, ‘handles money poorly’, and ‘fails to consider future’ that Hatfield included in ‘poor task functioning’ were not reported in my study, although three significant-others spoke of having to support the consumer in financial matters.

The open-ended question in Hatfield’s study requesting relatives to describe effects on family life revealed findings most similar to the sub-theme of losing family ties in my study, i.e. causes hardship for siblings, poses a threat to parents’ marriage, disrupts the family’s social life, disrupts personal life of family members and places a burden on one member of the family. In my study, except for one spouse, significant-others who participated were mostly mothers and sisters, which implies that the stress was mostly experienced by female members of families. This is supported by Hatfield who says that participants of her study were generally suburban women. All of the phenomena in Hatfield’s category of ‘effects on family’ suggest reverberating losses.

In the category of ‘emotional burden’ Hatfield includes stress, anxiety, resentment, grief and depression. Surprisingly only 22% reported grief and depression but 65% reported stress. However, Hatfield says that the grief was mostly related to the loss of their once-promising child who now seems to be a different person and all but a stranger in the family. Hatfield (1978, p.
also states that working through grief and disappointment is made more difficult by the cyclical nature of MIH, with hopes raised and dashed, exacerbated by the covert resentment felt by care-givers towards their fate in life, the lack of understanding and resources. These findings are comparable to being adrift at sea.

In summary, unremittingly disturbed family life marked by stress emerged as the primary theme of Hatfield’s findings, and on this basis she asserts that intervention and support should include family members, not only the consumer. Her conclusion supports my assertion that sharing perceptions with all family members will decrease the stress on families. Hatfield made a major contribution to mental health services by highlighting the stress of MIH, as this places emphasis on stress and ‘dis-ease’ rather than dysfunction. The findings of my research extend the findings of this author that it is important to explore the stress posed by ambiguity that leads to complicated grief.

5.2.4 Comparison of Findings of My Study with Davidson and Stayner (1997), ‘Loss, loneliness, and the desire for love: Perspectives on the social lives of people with schizophrenia’

In their study of the subjective factors that internally shape how individuals view the nature and consequences of schizophrenia, Davidson and Stayner (1997) drew data from a larger study on the phenomenology of social functioning in schizophrenia to compare three core images that best capture the essence of MIH. These images were from the perspectives of clinicians (image of an ‘empty shell’), of family members (image of a poker player hiding his or her emotions) and of individuals with MIH (image of a caged panther). Their aim was to bring these images together to provide a three-dimensional view of a complex phenomenon. Although my study also offered a three-dimensional view, it did not include the perspective of clinicians. In contrast, it brought the perspective of significant-others who had developed symptoms of MIH and viewed the effects of MIH from both these perspectives. In comparing the researchers’ findings to my study, I will only focus on the perspectives and images of family members and the individuals with MIH. The perspectives of clinicians will be discussed in Chapter 7 in relation to implications for practice.

Family members’ image of their ill relative was compared to a ‘poker player’ who experiences emotions he/she cannot or will not reveal. The authors suggest the ‘caged panther’ as an image consumers had of themselves which they derive from a poem by Rilke (1907-1981) and explain that:

... the panther has become so accustomed to encountering only the bars of the cage in which it lives, rather than the world that lies beyond the cage, that it has since
ceased even to attempt to muster a response to the impressions that continue to slip into its awareness through the bars. (Davidson & Stayner 1997, p. 10)

The latter image, they say, captures the sense of immobility and stifled desire (Davidson & Stayner 1997, p. 3) of consumers. The authors write that despite the social disability, withdrawal and isolation, and apparent emotional disconnectedness, family members held on to the belief that their ill relative somehow remained “hidden” somewhere but appeared disconnected because of overwhelmed feelings and the depletion of internal resources to manage these feelings. The authors report that the consumers continue to describe a fervent wish for love and relationships.

Described in images to capture the essence of an illness which is ambiguous in its manifestation, the study by these authors supports the assertion reached from the data of my study of the important strategy of sharing perceptions of consumers and family members. Ambiguous situations tend to be misperceived, result in differences in perceptions, and have the potential to create barriers between groups.

Although the aims of the two studies differed, important findings from these researchers’ study were that they identified experiences of loss and grief from the perspectives of both family members and consumers. Family members expressed a profound sense of loss of their relative with MIH, and a growing chasm between who this person was before getting unwell, and who he or she had since become, comparable to a loss with the additional stressor of ambiguity. At the same time, they recognised that their relative with MIH also experienced their own sense of profound loss of the lives and dreams they had prior to becoming unwell. The relatives’ sense of loss has similarities with losing connectedness which they observe in consumers, but when they recognise that their relatives experienced loss of dreams for the future this had similarities with losing ‘self’, not only for themselves but also observed in the consumer.

Significant-others also describe the cyclical nature of MIH and the dynamic tension inherent in managing such a situation. At times of improvement, they saw glimpses of the consumer’s former self and their hopes were raised only to be dashed when symptoms reappeared. The authors describe the ensuing tension created by the cyclical nature of the illness and observed a back and forth movement between significant-others’ need to accept the reality of the illness, their need to protect themselves from its effects and also their hunger for the return of the former self of the consumer (Davidson & Stayner 1997, p. 6). This is similar to the courses of steering through choppy waters and negotiating to smooth the voyage. This ‘approach/avoid’ strategy is similar to oscillating and dialectical approaches taken by participants in my study to manage the ambiguity inherent in MIH.
The authors write that unlike grief over a loss which can eventually lead to acceptance, the experience of a partial loss and partial hope, suspends significant-others in a no-man’s land (Davidson & Stayner 1997, p. 6). This statement encapsulates the theme of being adrift at sea.

The authors also write that themes of loss of interpersonal relationships, loneliness and social isolation pervade the narratives of consumers where they described MIH as robbing them of access to themselves as well as to others, which corresponds with losing ‘self’ and losing connectedness respectively. At the same time, there were also themes of the desire for, and attempts to establish, social connections. This is similar to the properties of the sub-category sailing to parts unknown and knowing current location.

In the study of these authors, consumers attributed their experience of loss, isolation and loneliness to certain obstacles and barriers that prevented them from connecting with others. These were stigma, poverty and unemployment. The authors suggest that alienating behaviours of MIH such as consumers responding to perceptual disturbances, demonstrating poor social judgement and not attending to personal hygiene may also alienate them from others. Participants in my study only identified stigma as a barrier to connecting with others. This was encapsulated in the category of being adrift at sea. The authors also identified consumers ‘becoming numb or shut down altogether’ (Davidson & Stayner 1997, p. 7) as a response to hypersensitivity to stimulation. This is similar to the sub-course of resisting the surge in managing ambiguity of the illness taken by consumers. Whilst it helped them in dulling pain it led to feeling excluded.

In relation to consumers’ struggles to connect with others, the authors suggest that:

... one way for them to cope with this state of affairs would be to share their internal struggle with others by articulating their experiences of the difficulties and obstacles they encounter. (Davidson & Stayner 1997, p. 9)

However, they also suggest that the impact of the disorder may be so confusing and disorienting that they may have difficulty describing it in words. This statement supports the findings of my study when F1 said “I did not know exactly what the problem was ... and found it very hard to explain the way I felt’. This confusion was included in properties of the theme of being adrift at sea to describe the confusing and disorienting nature of MIH.

The authors assert that only by continuing to develop empathic bridges to the experience of consumers will clinicians be able to avoid ‘treating the shell as empty’. This implies that participants in my study, both consumers and significant-others, who had developed building rapport are experiencing empathic relationships.
In summary, to gain a comprehensive understanding of this complex phenomenon of ambiguity associated with MIH, the authors opine that researchers need to explore the perspectives of all three groups: consumers, significant-others and service providers. This supports my assertion that differences in perceptions of MIH lead to difficulties in collaborating to provide the best possible service to those experiencing MIH.

5.2.5 Comparison of Findings of My Study with Baxter and Diehl (1998), ‘Emotional stages: Consumers and family members recovering from the trauma of mental illness’

In this article, Baxter and Diehl (1998) describe several conceptual models of loss and introduce two additional models specific to the experience of people with mental illness and their family members. The consumer program named BRIDGES is an acronym for Building Recovery of Individual Dreams and Goals through Education and Support (Baxter & Diehl 1998, p. 351) and is a 14-week peer-taught program. The companion family education program is named Journey of Hope and is a 12-week course for family members, also taught by peers. Within these companion programs, the models function to validate participants’ experience of loss as normal and to provide a structure for a new sense of self.

The researchers write that consumers have used the “emotional stages of recovery” in their course to make sense of their suffering and losses, and to progress to an integrated sense of self. However, they do not identify particular losses experienced by consumers.

The goal of the Journey of Hope family education program is for significant-others to achieve empathy for loved ones and to help them resolve the emotional trauma of having persons with MIH in the family (Baxter & Diehl 1998, p. 351). Although grief is identified as an emotional response and the authors write that the grief process may deepen as the seriousness of the illness becomes clearer to significant-others (Baxter & Diehl 1998, p. 353), they do not identify particular losses that lead to the grief. The researchers do not indicate how the course was developed but they quote an article by Hatfield (1987) which suggests that family members go through the phases of stress, coping and adaptation. By developing companion models, their aim was to offer information and supportive environments that answer the distinct needs of consumers and family members, and establish a common knowledge base and set of skills to ease interactions between consumers and their loved ones. Their study does not reveal if the consumers and significant-others come together to share perceptions.

In developing the courses they acknowledge that ‘mental illness is a more nebulous and stigmatized form of loss and is thus harder for many to conceptualize’ (Baxter & Diehl 1998, p.
This statement is synonymous with the ambiguity of MIH and lack of validation and corresponds with being adrift at sea. The authors acknowledge that in the course of recovery from a loss, a person searches for ways to conceptualise it. This corresponds with the theme in my study of consulting maps and charts as well as determining which way the winds are blowing and the state of the tides and the difficulties of conceptualising losses associated with a nebulous illness. However, they do not identify how consumers or significant-others manage the nebulous nature of MIH.

Although the authors describe ‘stages’ in the process, they acknowledge that neither of the processes in BRIDGES or Journey of Hope is linear and that participants are often working back and forth across the model and that there may be numerous opportunities for lack of synchronicity (Baxter & Diehl 1998, p. 353). This supports the findings of my study of steering through choppy waters and negotiating to smooth the voyage in that both consumers and significant-others go back and forth across the process of managing ambiguity and this process does not indicate synchronicity.

In summary, whilst there were some commonalities between the authors’ description of the nebulous nature of MIH and the emotional phases of recovery and the core process symbolised by the metaphor of navigating the winds and tides of ambiguity to stay afloat, my study defines the losses and the ambiguity of MIH and how this ambiguity and the nebulous nature of MIH are managed.

5.2.6 Comparison of Findings of My Study with Kristoffersen, Polit, Mustard and Min (2000), ‘Towards a theory of interrupted feelings’

Kristoffersen et al. (2000) used hermeneutical methods for the collection, systemising and interpreting of data to identify the central aspects of feelings in relation to the experience of being a sibling of a person with schizophrenia and to develop the theory of interrupted feelings. Hermeneutic methods use the ‘text’ of stories, also called narratives, of participants as data sets to analyse and interpret data (Merriam 2009). Sixteen siblings participated in their study. Four central aspects of the feelings were identified: ambiguous loss, fluctuation, prohibition and invalidation. The theme of ambiguous loss formed the background for understanding the other themes. They described a lonely and painful experience expressed by participants deriving from the paradoxical nature of their loss, i.e. grieving over a loved one who is living, but in many ways unavailable for contact (Kristoffersen et al. 2000, pp. 24-25). The authors opine that this paradox interrupts the feelings in a decisive way and is reflected in the other themes: (a) the fluctuating
nature of the illness, (b) an inner prohibition from grieving over someone who is physically still present because hope is destroyed by grieving, and (c) invalidation in that the environment does not recognise and respect their emotions.

The study by of these authors focused on feelings, while my study focused on perceptions of loss. Although the focus of the two studies differed, the main theme of ambiguous loss in their study corresponds with the central finding of *loss complicated by ambiguity* in my study. Whilst my study identified the particular losses, theirs does not. The fluctuating nature of MIH that complicated the feelings of participants in their study was demonstrated in the process described by the metaphor *of navigating the winds and tides of ambiguity* with participants in my study going back and forth in their journey of managing. The fluctuation between hope and hopelessness, between happiness when there is improvement and grief when illness returns, interrupted the emotions for their participants. This is similar to the theme *spinning in a whirlpool* in my study. However in my study, the property of being unable to make sense of symptoms was also included in this theme.

The theme of ‘invalidation’ in the study of Kristoffersen et al. (2000) is synonymous with the theme of *being adrift at sea*. Participants in their study said that society did not validate their feelings because it was difficult for them to understand and share grief in relation to a person who is physically present as well as because of the stigma associated with MIH. However, in my study the theme also included the properties of diagnoses being unclear, being constantly changed by health professionals, different diagnoses being given by different health professionals, not being given sufficient information about the illness as well as symptoms not being validated by health professionals.

Whilst the theme of ‘ambiguous loss’ formed the background for the understanding of other themes of loss for siblings in the study of these authors, my study goes beyond the study of these researchers by analysing perceptions of loss and ambiguity associated with MIH from three perspectives: that of consumers, that of significant-others and that of significant-others who had developed symptoms of MIH. These significant-others included mothers, a spouse and a close friend as well as siblings.

In summary, the ambiguities associated with MIH in the study of Kristoffersen et al. (2000) are similar to my study, i.e. *spinning in a whirlpool* and *being adrift at sea*. However participants in their study were siblings whilst mine included consumers, significant-others and significant-other/consumers, thus taking a three-dimensional view.
5.2.7 Comparison of Findings of My Study with Wasow (2000), The skipping stone: Ripple effects of mental illness on the family

In the book The skipping stone: Ripple effects of mental illness on the family (Wasow 2000) the author presents findings from a study of in-depth interviews with one hundred and twenty relatives of people with serious mental illness to better understand the experiences of family members. In conducting her research, she acknowledges that she ‘wears three hats’: first and foremost the hat of an endlessly grieving mother; second, that of a social work educator; and third, that of a clinician. In comparing her findings, I will only focus on Chapter VII entitled ‘Grief without end’, as this directly relates to my study.

In presenting the findings of her research, Wasow (2000, p. 132) writes that grieving about a relative with mental illness is a special sub-category for three main reasons: it involves a family member, chronic loss and the brain. Grief within the family is unique and powerful she writes, because when family members are grieving at the same time they are often absorbed in their own sorrow and often have no strength left for each other. Furthermore, grief changes people, necessitating adjusting to being with changed family members and generating emotional ripples throughout the family (Wasow 2000, p. 133) as well as reorganising life-styles, perceptions of themselves and belief systems, all of which have an enormous effect on the entire family. All of these aspects involve losses and thus support the theme of reverberating losses.

She writes that chronic conditions such as MIH involve chronic grief so that family members may not find any closure. Additional factors that add to the complexity are society’s and mental health professionals’ lack of acknowledgement of this grief. This statement bears similarities to the theme of being adrift at sea.

She writes that family members lose their original relationships with ill relatives, as well as their dreams and beliefs about their futures. This bears a similarity to losing family ties and losing ‘self’. She goes on to write ‘much confusion ensues when we interact with someone who looks the same but in many ways is not. This complicates our mourning’ (Wasow 2000, p. 135).

This statement poignantly describes the confusion that arises for significant-others from the ambiguity of being with a person who is physically present but psychologically inaccessible, a confusion akin to spinning in a whirlpool.

In making sense of the data collected in her study, she suggests that many health professionals do not recognise symptoms of MIH in its earliest stages and, since no one else does either, it is a confusing time for all concerned (Wasow 2000, p. 139). This
highlights the ambiguity of MIH and the confusion that it entails, and is comparable to ***spinning in a whirlpool***.

From the findings of her research, she says that two different things tend to happen in the initial reactions when family members attempt to cope with their grief; at one extreme they cope by avoiding the facts and at the other, they preoccupy themselves with them (Wasow 2000, p. 139). This is comparable to the ‘avoid/approach’ strategy taken by all three groups in my study and ***steering through choppy waters and negotiating to smooth the voyage***.

Participants in her research found self-help groups such as the Alliance for the Mentally Ill gave them validation and social support. Similarly, participants in my research, both consumers and significant-others, found ***sailing to parts unknown*** gave them validation and much needed social support.

She says that the early years are fraught with desperate searching for answers (Wasow 2000, p. 139). My study differed from this in that participants’ search for answers, which I categorised as ***consulting maps and charts*** and ***determining which way the winds are blowing and the state of the tides***, occurs not only in the early years but is an ongoing process.

The author concludes that the grief process for significant-others varies enormously because of the many factors affecting the outcome; some of these are the personality and degree of illness of the relative, ages of other family members, economic situation, religious beliefs, availability of community resources and support networks. Therefore, when supporting people affected by the grief of MIH, it is important to take into consideration the context. This supports the case study approach of my study.

To summarise, the research findings of the study by Wasow (2000) on the grief of family members support the findings of my study of the additional stressors of ambiguity associated with MIH – ***spinning in a whirlpool*** and ***being in adrift at sea***. Her findings also support my findings of ***losing ‘self’, losing family ties*** and the ***reverberating losses*** that ensue. However, while she identified ***consulting maps and charts*** as a strategy in the early years after diagnosis, my findings indicate that it is an ongoing process which I categorise as ***determining which way the winds are blowing and the state of the tides*** as time went by.
5.2.8 Comparison of Findings of My Study with Stein and Wemmerus (2001), ‘Searching for a normal life: Personal accounts of adults with schizophrenia, their parents and well-siblings’

The authors used a life course perspective to describe the reciprocal impact of MIH on families (Stein & Wemmerus 2001, p. 726) and, from the accounts of participants, they describe how families understood and accommodated life changes that resulted from MIH (p.725). Similar to one of the procedures I used to guide analysis of data in my study, the authors used the procedure of Transcendental Realism, outlined by Miles and Huberman (1994), as one method to guide analysis of their data. By including the consumer in their study, their research took a two-dimensional view. They interviewed twenty-two individuals from six families. There were six adults with schizophrenia, twelve parents and four siblings. By taking a life course perspective, these authors investigated whether major social role transitions were on course with ‘social time-tables’, i.e. living independently, achieving education and gaining skills for employment, developing intimate relationships, having children and retiring from work. They described both the strengths and challenges faced by participants as well as the way participants interpreted and responded to challenges of MIH.

The theme of ‘loss of normal life’ in the researchers’ study includes properties of loss of control over thoughts and feelings, being ‘off-track’ in life tasks compared to others of their age (p.733) (loss of dreams), and concerns about the way they interacted with the world (p.734), and is similar to the theme of losing “self”. Losing functionality is reflected in their statements of losing cognitive skills and abilities, and losing family ties is reflected in a vignette from a consumer saying that her children moved away from her to live with her brother (p.734). However, unlike in my study, the properties of loss of normal life did not include losing connectedness.

Losing ‘self’ for significant-others is reflected in their findings that parents lament the loss of their child’s abilities and potential (loss of dreams), and when parents question their actions or effectiveness as a parent and wonder if they have in some way contributed to their child’s illness (p.735).

In ‘the search for a valued social role’, the researchers indicated that their study revealed that for the participants the search was cyclical, with continued hope and active searching. What participants hoped for also changed as time went by, requiring the development of different strategies. This is synonymous with the process summarised in the metaphor of navigating the winds and tides of ambiguity to stay afloat where consumers as well as significant-others go
back and forth between actions taken. The authors also found that family history and context shape how families define their losses and identify ways of managing the complexities of MIH. This statement reflects the importance of taking into account the context, as I have done in my research by adopting a case study approach.

Importantly, their study reflects perceptual differences between family members. Consumers generally had a more optimistic view of their recovery than family members. The authors conclude that given the level of cohesiveness of families in their study, it was surprising that the consumer was excluded from discussion of transfer of care from parents to other family members or the public mental health system.

To summarise, similarities exist between the losses identified by the authors of this study and the losses reported in my study. The authors’ work supports the view that managing MIH is a cyclical process. The purpose of of the study by Stein and Wemmerus (2001) was to describe the reciprocal impact of schizophrenia on family life whilst the purpose of my study is to develop a critical understanding of ambiguous loss associated with MIH and identify how families manage the associated ambiguities.

5.2.9 Comparison of Findings of My Study with Mauritz and van Meijel (2009), ‘Loss and grief in patients with schizophrenia: On living in another world’

The aim of the study of Mauritz and van Meijel (2009) was to address the lived experience of grief in schizophrenia. Using a qualitative grounded theory approach within the context of symbolic interactionism, they analysed data from semi-structured interviews of ten consumers. The purpose of their research was to gain a better insight into the losses experienced by consumers and the reactions of grief that may follow, in order to contribute to interventions helping consumers to cope more effectively with these losses. Participants included nine men and one woman with a mean age of 26.6 years. So that the experience of losses of participants was relatively new, the period since the onset of their first episode of psychosis ranged from six months to seven years.

These authors used ‘sensitizing concepts’ of ‘internal loss’, ‘external loss’ and ‘grief’ to categorise data from the initial interviews. In subsequent interviews, they used grief and coping as central concepts and concentrated more on the concept of coming to terms with these losses.

In summarising the data of internal loss, the authors say it is like living in another world:
In terms of consequences, a psychosis first of all causes respondents uncertainty and self-doubt regarding the workings of their brain and sense. They can no longer rely on their own observations and thought processes. (p.254)

They also say that, as symptoms of MIH subsided, respondents realised that:

There is incongruence between the picture formed of themselves and the surrounding world. This demands a reorientation as a new reality has to be accepted. Subsequently respondents fear a new psychotic relapse and the resulting loss of control. (p.254)

These statements are comparable to *spinning in a whirlpool* in terms of the uncertainty and self-doubt experienced by consumers regarding their own brain and senses as well as fear of loss of control for the future. *Spinning in a whirlpool* was considered an internal process in my study and also in the study by Mauritz and van Meijel (2009).

The authors state that commonly reported perceptions of loss include faulty memories, garbled thinking and loss of energy, which participants referred to as impaired functioning compared to their functioning before onset of MIH. These concepts were included in the theme of *losing functionality* in my study.

In summarising the data of ‘external loss’, the authors use the theme of ‘Not Belonging’ where participants’ social networks decreased and they found it difficult, if not impossible, to enter into or maintain intimate relationships (Mauritz & van Meijel 2009, p. 254). This was due to the loss of cognitive skills and the presence of positive and negative symptoms. These concepts bear similarity to the theme of *losing connectedness*. Findings of my study differed where participants were confused as to whether *losing connectedness* was a result of symptoms of MIH or due to a side effect of medication.

In coping with the MIH, participants in Mauritz and van Meijel’s study deliberately avoided social situations to escape stress, and they said that ‘their friends and acquaintances simply did not understand’ (Mauritz & van Meijel 2009, p. 254). This statement is akin to how consumers in my study managed the ambiguity by *finding a safe harbour* and *finding solace* but *feeling excluded* by doing so. The researchers opine that participants in their study are thrown back upon the most basic relationships of all, family ties (Mauritz & van Meijel 2009, p. 254), but write that these relationships change because consumers grow increasingly dependent, but they do not associate this dependency with *losing family ties*.

In summarising the data of ‘expressions of grief’, the authors found a twofold denial in the beginning where participants denied the diagnosis and the need for treatment as well as the limitations and adjustments needed to manage the illness, despite being given information. The
authors also say that not accepting medication and rules of life caused the symptoms of MIH to increase. They do not indicate what they mean by ‘rules of life’. Three consumers of my study questioned their diagnosis and declined medication because of lack of clarity of diagnosis as well as side effects of medication. In contrast to Mauritz and van Meijel (2009), I termed these strategies **resisting the surge**, as consumers in my study considered medication to have costs and benefits and they weighed these two factors before taking action.

The authors used ‘in vivo’ codes such as “coming to terms with ‘it’” and “coping with ‘it’” as part of the mourning process and described the strategies used by their participants. They described cognitive strategies used by participants to come to terms and cope with MIH as:

nourishing hope, living from day to day, seeking an explanation, and giving meaning to life with schizophrenia. (p.256)

Seeking an explanation, giving meaning to life is an ongoing process for all participants in my study. I termed this process **consulting maps and charts** as well as **determining which way the winds are blowing and the state of the tides** in managing ambiguity and it is akin to seeking an explanation and giving meaning to life in the study of the researchers. As part of this process, participants in my study engaged in **sailing to parts unknown and knowing current location** and **taking the helm and trying a different tack**, strategies also used by participants in the study of Mauritz and van Meijel (2009).

In summary, the study of the above researchers and my study both identify **losing functionality** and **losing connectedness** as major losses, although the terms are used differently. Similar to the theme of **spinning in a whirlpool**, participants in the study of the researchers were confused and had feelings of incongruence in their experience of themselves which the authors describe as ‘living in another world’. Whilst my study found **resisting the surge** as a strategy of managing ambiguity, the researchers found ‘denial’ of the diagnosis and need for treatment as the beginning of the mourning process. The authors identify ‘coming to terms’ as a part of the mourning process of finding new equilibrium. Participants in my study used six different strategies in each of the courses of **steering through choppy waters** and **negotiating to smooth the voyage** to find new equilibrium to manage the associated ambiguities of MIH. **Consulting maps and charts** is akin to searching for meaning; **sailing to parts unknown and knowing current location** and **taking the helm and trying a different tack** were strategies used by participants in both studies.
5.2.10 Comparison of Findings of My Study with the Study of Henderson (2011), ‘A substantive theory of recovery from the effects of severe persistent mental illness’

The aim of the study of Henderson (2011) was to investigate the process of recovery from the effects of a severe persistent mental illness and to explain the mechanisms by which this occurred. The study was underpinned by a form of symbolic interactionism and grounded theory methods were used to collect and analyse data. Fifteen consumers participated.

The author investigated a one-dimensional view of recovery from MIH by consumers whereas my study takes a three-dimensional view of consumers, sig. other/consumers, and significant-others perceptions of ambiguous loss associated with MIH and how participants manage the associated ambiguity. Despite these differences, loss emerged as the basic social psychological (BSP) problem faced by consumers in the author’s study. The threefold loss he identified as (1) mental health; (2) cognition and affect; and (3) social functioning including the loss of a sense of inclusion (Henderson 2011, p. 569). His findings are supported in my study in that consumers and sig. other/consumers identified loss of mental health for themselves and it was observed by significant-others in their relatives. My study differed in that loss of cognition is identified as a property of losing functionality, and loss of affect is identified as a property of losing connectedness. The author’s findings of loss of social functioning, including the loss of sense of inclusion, were also supported in the findings of my study. However, I separated these two categories into two themes, where loss of inclusion in family was a property of losing family ties, and loss of inclusion by the wider social network such as feeling alienated and inability to be intimate was a property of losing connectedness.

Henderson labelled ‘overcoming loss’ as the Basic Social Process (BSP) that emerged which resolved the Basic Social Psychological Problem (BSPP) of loss (Henderson 2011, p. 565). ‘Overcoming loss’ in the author’s study involved three phases: recuperation, moving forward and getting back (Henderson 2011, p. 567). However, the core category that emerged through theoretical coding and by which participants managed the ambiguity is labelled in my study navigating the winds and tides of ambiguity to stay afloat. Because I analyse perceptions from three dimensions, the basic social process (BSP) that emerges in my study is a complex process and requires multiple avenues of action rather than a phase process. With situations of ambiguous loss, a single truth is unattainable and thus truth is relative and subjective. Actions and strategies to manage ambiguity are gleaned from a continuous taking the helm and trying a different tack and consulting maps and charts as well as determining which way the winds are blowing and the state of the tides. As such, participants take diverse paths to manage
ambiguity. However, participants in my study perceived that they manage to live well, despite unanswered questions. This is comparable to ‘acknowledgement’, a property of the ‘Recuperation’ phase of Henderson’s study. In contrast, participants in my study did not refer to accepting the loss as found in the findings of the author’s study. Because the ill health was perceived as ambiguous, they continued to search for answers.

Participants in the study by Henderson described how by being ‘other-centred’ they adjusted to their loss. According to the author, being other-centred occurred when consumers took on advocacy roles and contributed in some way to the community. Similarly, participants in my study managed the ambiguity by sailing to parts unknown such as being involved in self-help organisations and a board of management in a local clinic and undertaking advocacy roles. All significant others in my study used a dialectical approach of staying in touch with home exemplified by maintaining ties with family and friends whilst sailing to parts unknown. Staying in touch with home was described as more difficult by six of the seven consumers and three of the five significant-other/consumers.

Henderson categorised ‘reducing social contact’ and adopting an ‘at risk’ role as ‘protective behaviour’ (Henderson 2011, p. 568). However, in my study participants described ‘reducing social contact” as a way of managing overwhelming symptoms and as such I labelled this behaviour as seeking a safe harbour. However, the complexity of the process that requires multiple avenues of action is reflected in the report of participants in my study that seeking a safe harbour involved finding solace as well as feeling excluded.

In Henderson’s study participants described using ‘positive social withdrawal”, which he conceptualises as a ‘protective behaviour’ primarily associated with stigma and which I conceptualised as invalidation by others. Participants in his study managed stigma by reducing or limiting personal contact with others or by concealing their disability. This conceptualisation is akin to being adrift at sea in my study.

Henderson’s study found that:

Positive social support involved interpersonal acceptance and engagement in reciprocal relationships between the participants and those involved in helping them to recover (Henderson 2011, p. 569).

These findings could be compared to participants in my study who describe developing shared interests with those involved in helping them to recover which I termed developing the spirit of an adventurer.
In summary, the philosophical underpinning of the two studies and methods used to collect and analyse data are similar. Both studies were conducted in Western Australia. Similar to my study, loss emerged as the BSP problem faced by consumers in Henderson’s study although the categorising of these losses differed in my study. ‘Overcoming loss’ was identified by the author as the BSP of resolving the BSPP of loss. In contrast, as my study focused on managing ambiguity of MIH by three different groups of people, the BSP is depicted as a more complex process requiring multiple avenues of action. In managing ambiguity, participants in my study used the strategy of sailing to parts unknown and knowing current location as well as developing the spirit of an adventurer. ‘Being other-centred’ described by participants in Henderson’s study is comparable to sailing to parts unknown and knowing current location and ‘positive social support’ is comparable to developing the spirit of an adventurer in my study. The stigma experienced by participants in Henderson’s study is akin to being adrift at sea and a form of ambiguity in my study. Most importantly though, that loss emerged as a basic social and psychological problem identified by consumers lends credibility to the findings of the first research question of my study.

5.3 Summary of Comparison with the Literature

Irrespective of the purpose, time and place of the studies and phrases or conceptualisation used to describe the experiences, all ten studies identified loss and grief associated with MIH and the ambiguity inherent in MIH. This lends trustworthiness and credibility to the findings of my study. Although the study of Kristoffersen et al. (2000) identified ambiguous loss associated with MIH, it was a one-dimensional perspective involving only siblings. My study takes a three-dimensional view taking into account the stress of ambiguity for families, including that of consumers.

Other common characteristics identified in the ten studies above and comparable to my study are: (1) stress (J.A. Clausen & M. Yarrow 1955, p. 3; Creer 1975, pp. 3-4; Hatfield 1978, p. 358; Wasow 2000, p. 3); (2) the complicated process of working back and forth between strategies of managing MIH alluded to by Creer (1975, pp. 2-3), Davidson and Stayner (1997, pp. 6-10), Baxter and Diehl (1998, p. 351) and Wasow (2000, p. 139).

Although the ten studies described some common elements of managing ambiguity, none of the studies completely reflected the findings of navigating the winds and tides of ambiguity to stay afloat. My study have increased the scope and depth of Boss’s theory of ambiguous loss and added to existing research on loss and grief associated with MIH and thus complicated grief.
The findings of my study has also expanded on Boss’s theory of Ambiguous Loss (Boss 1999; 2006) to a population previously not studied and provides a three-dimensional view, that of consumers and significant-other/consumers and significant-others experiencing losses with the additional stressor of ambiguity inherent in MIH.

As demonstrated in the ten studies above, situations of ambiguity created stress and distress. Therefore, in the following chapter I will compare the findings of my study to family stress theories focusing on meanings and perceptions and theories surrounding the stress vulnerability model of Mental Ill Health.
Chapter 6: Comparison with Broader Theoretical Literature

6.1 Comparison with Broader Theoretical Literature

The central proposition of the core process defined metaphorically as *navigating the winds and tides of ambiguity to stay afloat* was that families affected by MIH continuously moved through a process of oscillation. The courses for consumers and their significant-others were indistinct and iterative where they sometimes experienced two courses at the same time as well as revisited a course, depending on the intervening conditions operating in their lives at a particular time. As each of the three groups moved through the courses of managing ambiguity, there were numerous opportunities for lack of synchronicity. The process symbolised in the metaphor of *navigating the winds and tides of ambiguity to stay afloat* was richly descriptive and elucidated personal meanings of loss and ambiguity. At the same time the process allowed for the consideration of a narrative structure that included the larger family and social context.

The use of the metaphor of *navigating the winds and tides of ambiguity to stay afloat* evolved from the study of the phenomenon of ambiguous loss associated with MIH in a small group of participants in Western Australia and is in contrast to formal theory that emerges from a study of a phenomenon examined under many different types of situations (Strauss & Corbin 1990, p. 174). Whilst theorising the findings metaphorically supports the research in the substantive area in which it is based as discussed in Chapter 4, it also supports other bodies of theoretical literature. The concepts, patterns, trends and tendencies uncovered in the metaphor of *navigating the winds and tides of ambiguity to stay afloat* also compare with theoretical perspectives of family stress theory, theoretical constructs of stress and coping and constructs of loss and grief theories. Integration of theoretical perspectives from various disciplines and bodies of research encourages cross-fertilisation that will ultimately benefit families stressed by the ambiguity of MIH and help people bear the impact of the stressors with greater resilience. In addition, the transcendental nature of ambiguous loss associated with MIH, and the complexity uncovered in the analysis of data in my study, suggest that no one theory can explain what is going on.

The substantive theory that emerged in my study can also be compared to the stress-vulnerability model of Mental Ill Health and has the potential to extend the stress-vulnerability model from a person-centred to a family-centred model.
In this chapter, I will first compare the findings of my study with family stress theories relating to meanings, perceptions and sense of coherence about a stressor event. Secondly, I will compare the findings of my study with situational demands of MIH from the perspectives of stress and coping. Thirdly, I will discuss how the lived experience captured by the metaphor of *navigating the winds and tides of ambiguity to stay afloat* compares with the stress-vulnerability model of MIH and how it has the potential to extend the model from a person-centred to that of a family-centred model derived from symbolic interaction and narrative theory. Fourthly, I will discuss how the theory compares with the Dual Process Model (DPM) of coping with bereavement and theories of loss and grief.

### 6.2 Family Stress Theory

Family stress theory provides a framework to generate propositions that increase our understanding of the context surrounding families that will influence their ability to manage stress. Contextual family stress models are rooted in symbolic interactionism and akin to social constructionism. A major tenet of social construction theory is that there is a multiplicity of “truths” resulting from the reciprocal interaction between individuals and the environment rather than a single “truth”. This also suggests intervention processes that involve co-constructing possible meanings that will work better for the family as a whole as well as each member of that family.

The specific metaphors that I have chosen in the analysis of the data of my study can be compared validly to the finding of other researchers and formal theories of family stress.

Boss (2002, pp. 47-48) explains that a stressor event is not synonymous with stress. In contrast, because a stressor event disturbs the status quo of a family it has the potential to lead to change in the family. The degree of stress experienced depends on a family’s perception of the stressor event and the meaning attached to it, and is also highly influenced by the family’s external context such as the time in their lives and the place in which they live.

Boss and Mulligan (2003, p. 1) summarise eight new ideas in family stress theory, three of which are relevant to my study: (1) the postmodern emphasis on meanings and perceptions, individually and collectively, of the family’s stress or crisis situation as well as the perception of the community surrounding the family; (2) expansion from individual to a more systemic perspective of managing stress that includes family, friends and community attachments and interaction; and (3) the emphasis on health rather than dysfunction which she calls the mind-body-family connection for managing stress.
I will now compare some of the concepts, patterns, trends and tendencies of the process summed up by the metaphor of *navigating the winds and tides of ambiguity to stay afloat* with theories that emphasise the importance of perceptions and meanings of a stressor event, expansion from individual to systemic perspectives of managing stress and theories that emphasise health rather than dysfunction. In the first section I will compare my theory with that of Hill (1949, 1958) in the theory of generic features of families under stress; Antonovsky (1979, 1987) in the salutogenic theory; Antonovsky and Sourani (1988) in the theory of family sense of coherence and Fravel and Boss (1992) Boss (1999); (2002, 2006, 2007; 2010, 2012; 2013) in the theory of ambiguous loss.

### 6.2.1 Theories Relating to Meanings, Perceptions and Sense of Coherence about a Stressor Event

#### 6.2.1.1 Reuben Hill

Reuben Hill (1949,1958) called for ongoing research into family life by emphasising the importance of the family to individuals and society. He considered the family as the “bottleneck” through which all problems pass and writes that strains and stresses of life are mostly reflected in the life of a family. He defined family crises as those situations which create a sense of sharpened insecurity for a family or which block their usual patterns of action and call for new ones. In this way, a crisis is defined in terms of the effects it has on a family. Hill (1949, p. 9) lists three variables that determine if a given event becomes a crisis for any given family:

1. the hardships of the situation or event itself,
2. the resources of the family, its role structure, flexibility, and previous history with crisis, and
3. the definition the family makes of the event; that is, whether family members treat the event as if it were or as if it were not a threat to their status, their goals, and objectives.

Hill (1949); (1958) made an important contribution to family stress theory which has remained relevant to date and has been a foundation for future research. Beginning with the researcher’s (1949) study of families under stress and adjustment to the crises of war separation and reunion, and the conceptual framework he offered to practitioners (Hill 1958) for viewing families in crisis, the perception, meaning and appraisal attached to the stressful event has remained relevant. Hill (1958) writes that the stressor event must be seen as a variable rather than as a constant in family crisis research because the power of the event is dependent on the demands that the
event places on the competency of a family and the meaning or the definition of the event to a family.

Both the first point, i.e. the hardship of the situation and event itself, and the third point, i.e. the definition the family makes of the event, are noteworthy in relation to the findings of my study. In relation to the first point, **reverberating losses** emerged as the major theme of losses where losses had a cyclical nature with each loss flowing on to the others thus reverberating throughout their lives. This provides an explanation of the hardship of the situation of MIH and Hill’s (1958) explanation that the impact of a stressor ranges according to the several hardships that may accompany it. In relation to the third point, the findings of my study were that the complexities of the stressor event lay in perceptions of ambiguities associated with MIH. For example, the internal world of participants was unpredictable and they struggled to make meaning and to judge reality, resulting in **spinning in a whirlpool**. Participants were given differing diagnoses and were thus unable to obtain information to begin the cognitive process of making meaning resulting in an additional stressor and thus **being adrift at sea**. As such, perceptions differed between family members, contributing to **losing family ties**. Such differing perceptions of the event could be viewed as a threat to their status, their goals, and objectives. Differing perceptions among family members, conflict, loss of morale through such conflict as well as loss of morale through stigma as identified by Hill (1958), serve well to explain the many difficulties that built up for families in my study and led to **reverberating losses**.

Hill (1958) also writes that the close nature of the family is selectively opened for transacting business with other groups and agencies at different points in the life cycle of a family. The author also asserts that intra-family events such as mental breakdown, which are defined as stressful as well as stigmatising, are more disorganising to the family because they arise from troubles that reflect poorly on the family’s internal adequacy. This suggestion serves to confirm the findings in my study in several ways. Mothers in my study questioned the adequacy of their parenting. Similarly, the cultural definition in the form of stigma, resulted in “dismemberment” of consumers as well as significant-others from the broader society. The sub-category of **feeling excluded** identified in my study is akin to Hill’s “dismemberment” which he defines as loss of a family member. This then added a further layer of stress to the losses experienced by participants. Hill (1958, p. 142) opines that most crises of “dismemberment” that continue over time sooner or later involve demoralisation. Both combinations of “dismemberment” and “demoralisation” that the author described were evident in my study when participants experienced **being adrift at sea, losing ‘self’, losing family ties, losing connectedness**” and **losing functionality** and contributed to reducing participants’ capacity to manage the stressor.
The Australian Concise Oxford Dictionary (Hughes, Michell & Ramson 1992) defines demoralisation as “destroying a person’s morale or to make hopeless”, and dismemberment as “partition or divide up”. Hill (1958, p. 142) suggests that loss of morale and family unity leads to demoralisation. The findings of my study serve well to explain that the combination of feeling excluded and losing family ties contributed to reducing the participant’s capacity to manage stressors.

Hills’ (1958) theory supports my assertion that sharing of perceptions in such crises through a consultative process between family members is important and that professional services will make their greatest contribution to preventative health if made with the total family context in mind, especially in case of crises of dismemberment and demoralisation.

6.2.1.2 Aaron Antonovsky

Aaron Antonovsky made a major contribution to the sociology of health by making a distinction between the study of disease and of dis-ease and the physiological response to stress (Antonovsky 1979, 1987). He coined the term “salutogenesis” (Antonovsky 1987, pp. 12-13), a word originating from the word salutary or health-giving. The author explains salutogenesis as having a complementary relationship to pathogenesis where certain factors push a person towards "ease" and "dis-ease" in a continuum of health and wellbeing. Therefore salutogenesis can be viewed as multidimensional and not seen as absolute health or absolute illness. With stressors being ever-present in people’s lives, he writes that the consequences need to be viewed as salutary, contingent on the characteristics of the stressor and the successful resolution of tension. He suggests that thinking salutogenically compels us to invest our efforts in formulating and advancing theories of coping. This conceptualisation compares with the process described metaphorically as navigating the winds and tides of ambiguity to stay afloat in how participants in my study who had recovered from MIH continued to manage the stressors of ambiguities associated, by utilising different courses captured connotatively by the metaphor steering through choppy waters when factors pushed them towards “dis-ease” and other courses in the metaphor of negotiating to smooth the voyage when factors pushed them towards “ease”.

The concept of salutogenic thinking led the author to formulate the idea of a sense of coherence (SOC), a theoretical model that explains the relationship between life stresses and health. The three components of the SOC are: comprehensibility, manageability and meaningfulness (Antonovsky 1979, p. 123). A sense of coherence goes beyond personal agency to include the worldview that indicates that a person can eventually find some understanding in a distressing
Antonovsky and Sourani (1988, p. 80) opine that the three components of comprehensibility, manageability and meaningfulness are inextricably intertwined. Comprehensibility is the cognitive component (making sense) and also implies that the stressor event is predictable and explicable. The authors’ theoretical model of SOC provides an explanation of the findings of my study in several ways. Because of the ambiguities and cyclical nature of the illness, MIH is not predictable or explicable – participants were unable to make sense. The study demonstrated that uncertainty obstructs comprehensibility. Manageability can be defined as the behavioural component. Participants of my study managed the ambiguity of MIH by using various strategies as well as moving back and forth between strategies. Factors that obstructed manageability were lack of information, side effects of medication, isolation and family conflict. Participants drew upon internal as well as external resources to manage ambiguity. The course of *facing the storm and adjusting your sails* was considered an internal resource and the course of *sailing to parts unknown and knowing current location* was considered an external resource. Meaningfulness can be defined as the motivational component. Participants in my study viewed themselves as having recovered and were motivated. Eleven out of the fifteen participants were involved in advocacy roles in mental health organisations. They also drew upon spiritual experiences to create meaning and hoped for better services and medication in the future.

The authors further argues that the SOC is perceptual and includes both cognitive and affective components and, that a strong SOC is synonymous with a solid capacity to judge reality but does not at all imply that one is in control. Instead, it views one as a participant in the processes of shaping one's destiny as well as one's daily experience in a given time, given category and given social space, with the location of power being where it is legitimately supposed to be. The emphasis on perceptions is reflected in my study where I sought to understand how participants perceived the losses associated with MIH, as well as conceptualising participants shaping their destiny by actively taking the courses of *taking the helm and trying a different tack, sailing to parts unknown and knowing current location, developing the spirit of an adventurer*. All of these courses contributed to *negotiating to smooth the voyage* and to *stay afloat* which I have summarised in the process described metaphorically as *navigating the winds and tides of ambiguity to stay afloat*. In doing so, I have chosen gerunds – nouns made from a verb by adding “-ing” to emphasise movement, steering and volition.

Antonovsky (1979) suggests that a strong sense of coherence (SOC) moves people to the salutogenic end of the continuum rather than the pathogenesis end. He links the SOC to
Generalized Resistance Resources (GRR). The author (Antonovsky 1979, p. 99) defines GRR as any characteristics of the person, the group, or the environment that can facilitate effective tension management, and points to three major variables that enter into every coping strategy: rationality, flexibility and farsightedness (Antonovsky 1979, pp. 112-119). He defines rationality as the accurate, objective assessment of the extent to which a stressor is indeed a threat to one, given who one is, in the broadest sense. This conceptualisation is reflected in my study when participants were unable to come to an accurate assessment of the stressors of MIH because of paucity of information, or when the information kept changing and the symptoms were confusing. I termed this as being adrift at sea because this metaphor captures a sense of “being lost”.

The author views flexibility as the availability of contingency plans and tactics and of a willingness to consider them. Participants in my study found it difficult to develop contingency plans when symptoms were confusing, information was lacking or changing constantly. He also suggests that farsightedness goes beyond rationality and flexibility to anticipate the response of the environment, inner and outer, to the actions envisaged by the strategy. In choosing the metaphorical rubric of navigating the winds and tides of ambiguity to stay afloat, I considered the strategies that participants said were helpful in their environment in consulting maps and charts and determining which way the winds are blowing and the state of the tides for effective tension management. In particular, the four courses of building rapport, taking the helm and trying a different tack, developing the spirit of an adventurer and sailing to parts unknown and knowing current location all contained positive components of the environment that facilitated tension management.

Antonovsky (1979) writes that the most substantial and promising field of relevant research into a strong SOC is the GRR of social supports. He writes, “The extent to which one is embedded in social networks to which one is committed, I suggest is a crucial GRR” (Antonovsky 1979, p. 116). Although he acknowledges that social network is a complex, multidimensional concept which is not easily made operational, he writes that reciprocity in these social networks is crucial. This conceptualisation is reflected in the courses of sailing to parts unknown and knowing current location and developing the spirit of an adventurer. Both these courses involved social networks with reciprocal relationships.

The SOC construct was originally formulated to assess an individual’s perception of a stressor event, however in 1988 Antonovsky and Sourani (1988) designed a study of a sample of married Israeli men with a disability through injury or illness, to consider the possibility of translating the
SOC from the individual to the level of the family and to test the hypothesis that the family sense
of coherence (FSOC) is related to family adaptation. The FSOC, as did the SOC, specified health
as only one type of wellbeing – essentially physical health — and avoided “the slippery concept of
mental health” (Antonovsky & Sourani 1988, p. 81). The “slippery concept of mental health” that
they refer to suggests ambiguities associated with MIH. The sample only included persons
disabled in civilian life such as in traffic, at work or other accidents, or a result of physical illness.
Data was collected by an experienced rehabilitation social worker who visited each family at
home where each spouse completed the two questionnaires, Family Sense of Coherence
(FSOC) and the Family Adaptation Scale (FAS), separately and simultaneously. The two
essentially sought to find out how well the respondents thought his or her family fitted together
and fitted into the community. The authors first analysed data on the individual scores and, to
examine the relationship between the FSOC and FAS, they set cutting points to divide both
husbands and wives into three groups as equal as possible on each scale and found that, in each
case, the two variables were strongly related. The authors write that the data provided strong
support for the hypothesis that whether one looks at the perceptions of husband and wife, or joint
perception, the relationship is extremely strong.

Despite avoiding MIH in their study, it is worth considering their conclusions that levels of family
sense of coherence, taken singly and jointly of husband and wife, were very closely associated
with the extent to which the spouses were satisfied with different aspects of family life. As such
they argue that a strong SOC shared by the couple provided:

the motivational, perceptual and behavioral basis for successful resolution of both
the instrumental and emotional problems posed by stressors. (Antonovsky &
Sourani 1988, p. 89)

Antonovsky and Sourani (1988, p. 80) write that the SOC is flexible in that one selects
coping behaviours that are judged to be appropriate to oneself, depending on the situation
and the surrounding culture. This was reflected in my study, with strategies selected by
participants varying radically depending on their situation and the environment surrounding
them. Despite the ambiguities inherent in MIH, participants moved towards the continuum
of negotiating to smooth the voyage and seeing life as meaningful which provided them
with motivational drive to engage in confronting the problem by taking five courses of
action: facing the storm and adjusting your sails, sailing to parts unknown and
knowing current location, developing the spirit of an adventurer, taking the helm and
trying a different tack and building rapport. However, at times when symptoms of MIH fluctuated they moved towards the continuum of steering through choppy waters, the strategies of which involved costs as well as benefits.

The three components of comprehensibility, manageability and meaningfulness in the theory of the sense of coherence, and the characteristic of social support in the generalised resistance resources identified by Antonovsky (1979, 1987) are captured by the metaphor of “navigating the winds and tides of ambiguity to stay afloat”.

6.2.1.3 Pauline Boss

Pauline Boss made a vital contribution to family stress theory by the introduction of the construct of ambiguous loss and boundary ambiguity (Boss 2004, 1992, 2010; Boss 1999; Boss 2006; Boss 2012; Boss 1977a, 2013, 2002, 2007, 1980, 1977b). Boss also extended the model that Professor Reuben Hill (Hill 1958) began by introducing the variable of ‘context’. She did so by studying the experience of loss in the context of an additional stressor, ambiguity, to describe a loss where there is no validation or clarification of the loss which thus complicates grief, confuses relationships and prevents closure. Thus, she coined the term “ambiguous loss”. Boss (2010) writes that it is a newly identified type of loss occurring when a loved one is physically absent but psychologically present, or physically present but psychologically absent or inaccessible. Mental ill health is just one example of physical presence with psychological absence or inaccessibility and is the focus of my study.

The author writes that ambiguity coupled with loss creates a powerful barrier to coping, grieving and managing stressful events because confusion freezes the grieving process. Those experiencing ambiguous loss find themselves in painful limbo, struggling to make sense of the ambiguity. Such rupture in meaning has the potential to lead to characteristics such as depression, anxiety, sleep disorders, withdrawal, guilt, hopelessness, irritability and somatic symptoms (Boss 2012) as well as personal and family problems. When viewed from a contextual perspective, such characteristics, personal and family problems cannot be attributed to flaws in the psyches of those experiencing the loss because the situation is beyond their control and/or an objective feature blocks cognition and the grieving process. Boss (2002) advanced Hill’s conceptual framework of family crisis by suggesting moving from a linear use of the framework to a circular contextual framework and also advanced Hill’s roller-coaster model of family crises by suggesting that a family may go into a crisis following onset of a stressor situation, be in a state of disorganisation and, depending on the family’s ability to change, may go into a period of recovery.
(Boss 2002, pp. 64-65). She writes that finally the family reaches a new level of reorganisation that is higher, lower or equal to that experienced before onset of the stressor situation. However, when information is ambiguous or unavailable such as in MIH, and the condition fluctuates, family members’ cognition as well as structural reorganisation was also blocked. The process of navigating the winds and tides of ambiguity metaphorically depicts these processes and suggests that participants managed the situation by moving back and forth between avoiding and approaching the stressor event. With each episode of relapse, the level of reorganisation is also threatened.

Boss (2002, p. 59) defines the meaning of a stressful event to a family as the family’s perception. She chooses the word ‘perception’ as it embodies both cognitive and affective processes. She goes on to write that the family’s perception of an event or situation is critical in determining the degree of stress experienced as well as the way they manage the stressor. When there is ambiguity involved in a stressor event, as in the findings of my study of stressors associated with MIH, family members’ perceptions of the event and ways of managing differed. Although one can argue that there is no such thing as ‘family perception’ as each member of the family may have different perceptions which are not always congruent, Boss (2002, p. 61) argues that ‘the family’s definition of reality is powerful and may even supersede the meaning that individual family members give to the same event’. By bringing members of a family together for dialogue about MIH, a family has the potential through language, rituals, rules and roles to co-construct a symbolic reality, on the basis of their shared meanings or lack thereof. How families perceive a stressful event, and the meaning they attribute to it, determines how they manage the stressor. This supports the assertion from the findings of my study that when a stressor will not change and remains ambiguous such as in MIH, its fluctuating nature and associated stigma, the only windows of opportunity for change lie in perceptions and meanings.

Whilst the situation of a loss with an additional stressor of ambiguity is called ambiguous loss, an individual’s or family’s interpretation or perception of this situation of ambiguous loss can lead to boundary ambiguity. Boss (2002, p. 95) defines boundary ambiguity as not knowing who is in and who is out of one’s family, and an outcome of a situation of incongruence between physical and psychological presence. Boundary ambiguity, Boss writes, is not defined by biological membership nor is it defined by the composition of a household. In contrast, it involves relationships and processes based on one’s perception of who is there for them, within a family or outside a family or even partly in and partly out. People experiencing MIH are often marginalised from others by virtue of their illness. In my study, the sub-category of ‘feeling excluded’ is similar to Boss’s definition of boundary ambiguity. By including those considered family in the
broadest possible sense, one participant, D1, invited a friend whom she considered to be her “significant-other” to participate in my study. I called this family an *intentional family*. This is akin to Boss’s definition of psychological family (Boss 2006, pp. 25-34). She writes that to assist people manage ambiguous loss, it is important to know about their psychological family because those members provide motivation and resilience for managing what may seem an untenable loss and trauma.

Boss also identifies “visibility” and “non-visibility” as another variable of chronic stressor situations (Boss 2002, p. 55). This applies to MIH in that the ill health is not physically noticeable and as a consequence, lacks community validation. Findings of my study reflected such a variable with participants perceiving that they were judged rather than sympathised with. Such a situation added a further degree of stress to consumers as well as their significant-others.

In 2007, the journal of The National Council on Family Relations, *Family Relations*, published a series of papers illustrating how a new generation of scientists and practitioners applied ambiguous loss theory to understand previously unstudied situations and populations. From this collection of papers, Boss (2007, pp. 105-107) identified seven core assumptions underlying the theory of ambiguous loss which are noteworthy in relation to my study. I will now go through each of these and compare them to the findings of my study.

1. Ambiguous loss theory assumes that a psychological family exists and that this perceived construction of one’s family may differ from the physical or legal family structure. The *intentional family* identified in my study is akin to Boss’s psychological family where Family D perceived each other to be their intentional family providing comfort and resilience.

2. Although ambiguous loss as an external situation is assumed to be neutral, how it is perceived has valence. Boss says the higher the degree of boundary ambiguity the more negative the outcome. In my study, *losing family ties* was a negative outcome. Each of the three groups had differing perceptions attributing to *losing family ties*. Consumers perceived factors such as failure of diagnosis, negativity from family and attitudes of extended family. Significant-others attribute family conflict to fear whilst significant-other/consumers attribute this theme to parental mental ill health and the subsequent intergenerational effect. Through *losing family ties* they also experienced loss of self with a reverberating effect.

3. Cultural beliefs and values influence a family’s tolerance for ambiguity and how it is perceived. All three groups experienced the *stigma* of mental ill health, a property of the
theme being adrift at sea. As E1 said, the belief in her community was that because her mother was sick they were all sick, as if it is in the blood, and that some were more crazy than others and she was considered in the ‘more crazy’ category.

4. With situations of ambiguous loss, truth is unattainable and thus relative. Information for my study was gleaned from analysing conversations and narratives using the interpretive approach. Participants attempted to find meaning in the situation through *consulting maps and charts* as well as *determining which way the winds are blowing and the state of the tides* in a constant oscillating manner despite the absence of information and persisting ambiguity.

5. Ambiguous loss is inherently a relational phenomenon. The findings of my study helped me understand the process where building family relationships is obstructed by ambiguity. Although participants described characteristics of complicated grief such as depression and anxiety, the culprit was in the context outside the individual and their family relationships.

6. Boss assumes that there is a natural resiliency in families. Participants who requested to be included in my study considered themselves to have recovered from their mental ill health and had varying approaches to maintain resilience despite the ambiguity. Through the process of *navigating the winds and tides of ambiguity to stay afloat* participants illustrated their natural resiliency.

7. Boss assumes that a perceptual phenomenon such as ambiguous loss that is expected to change over time lends itself to qualitative study rather than quantitative study. By using qualitative methodology, my study identified two sub-categories of ambiguity associated with mental ill health: 1) *spinning in a whirlpool* and 2) *being adrift at sea*.

Some of the effects of ambiguous loss that Boss (2012) identified in care-givers of people with dementia were evident in the findings of my study, not only in care-givers or significant-others of those with the MIH but also in consumers. What the two have in common are:

- Ambiguity surrounding the ill health kept people confused thus preventing them from making decisions – Boss writes that family members of people with dementia sometimes chose an irrational response such as ‘closing-out’ the person affected. A similar process was identified in my study with consumers *feeling excluded* when seeking a safe harbour as well as in the process of significant-others *avoiding crosswinds* to minimise conflict.
- Participants in my study did not perceive that they were offered official validation of a loss and the customary markers that follow such official validation. There were no “get-well”
wishes offered for people with MIH, unlike physical illnesses, and as such no social support. The stigma as well as confusion about diagnosis leads to perceptions of being adrift at sea. This is akin to Boss’s findings that care-givers of people with dementia are not offered the usual rituals and supports of bereavement and as such have little social support or “solid land”.

- Boss writes that the occasional lucidity seen in people with dementia gave false hope to care-givers. Similarly, C2, a significant-other in my study, also witnessed moments of absolute clarity in her young son with MIH. Whilst this significant-other experienced being adrift at sea, these moments of clarity also gave her hope of recovery for her son. Boss writes that a cycle of hope and hopelessness that lasts for decades becomes a roller-coaster experience for care-givers of dementia. A similar process was identified in my study of spinning in a whirlpool, not only by significant-others and care-givers but also by consumers.

- Boss writes that for care-givers of people with dementia, there was often no sense of coherence because of the ambiguity surrounding the illness until people found meaning through discussion with peers experiencing similar ambiguous losses. This process is similar to both consumers and significant-others in my study of sailing to parts unknown. These communities were self-help groups and carer organisations.

Whilst the onset of dementia is typically seen in people of older age, the onset of other mental ill health as seen in participants of my study is typically in adolescence and young adulthood. When the ill health lasts for decades, such as in psychotic illnesses, the effects described above leading to the frozen grief of ambiguous loss which causes complicated grief have far-reaching effects for all members of a family. As seen in the findings of my study, the complicated grief associated with MIH results from a relational disorder that is frozen in ambiguity.

Following her research with caregivers of people with dementia, Boss (2010) found that people managed ambiguity through a more chaotic and dialectical pattern and a pattern of up-and-down, back-and-forth, rather than a linear process. Her findings are similar to the findings in my study that participants managed the ambiguity of MIH by oscillating between courses depending on the context and the intervening conditions in steering through choppy waters and negotiating to smooth the voyage, and that staying afloat was a non-linear journey that required multiple avenues of action.

Dialectical patterns of managing ambiguity found by Boss in her research are akin to the sub-categories of sailing to parts unknown and knowing current location and developing the
**spirit of an adventurer.** In the former, participants joined new communities such as carer organisations or self-help groups but at the same time maintained old ties, metaphorically described as **knowing current location.** In the latter, participants spoke positively of experiences when they developed shared interests where problems of MIH have no influence but also when they were able to maintain their own interests. Boss suggests that in the absence of clear information the dialectical approach of both/and thinking and tolerance for paradox is important for finding meaning as there may not be any other way of gaining the resilience needed for dealing with ambiguous loss (Boss 2006).

By including consumers in my study, I have advanced Boss’s theory that this process is experienced not only by significant-others but also by consumers. The findings of my study imply that the journey for these different groups is not necessarily synchronised and as such the nuances of a complex dynamic process of complicated grief have been exacerbated.

The perspectives, patterns, trends and tendencies discussed by Boss following her research into ambiguous loss have strong resemblances to the findings of my study. The demands posed by the ambiguities of MIH taxed the capacity of participants in my study to adapt. However, as illustrated in the process described metaphorically as **navigating the winds and tides of ambiguity to stay afloat,** managing is a better term than coping or adapting to describe what persons do with a stress that is ambiguous and a situation that fluctuates such as MIH, as it captures the sense of an ongoing complex effort. Boss (2002, p. 72) supports my assertion that managing is more a reflection of what families ideally do when highly stressed.

All of the theories discussed above support the findings and assertion of my study that, for the purpose of family stress management, the need for information enabling the co-construction of perceptions and meanings is profound. Even if a family is unable to get a unified view of the stressor of MIH, in order to strive to get a collective view a family needs information and also to come together to share their perceptions. The symbolic interaction perspective focuses on interaction within a family and symbols of interaction such as language and rituals. For a stressed family to co-construct a symbolic reality, they need information and need to come together to share meanings.

### 6.3 Comparison of Situational Demands of MIH from the Perspectives of Stress and Coping

Drs Judith Wrubel, Patricia Benner and Professor Richard Lazarus conducted research on social competence from the perspective of stress and coping. The joint research project
they conducted in the 1970s was on the daily life stresses, coping efforts, and outcomes of adaptation of middle-aged, community-dwelling men and women. Following completion of their project they published a paper on social competence from the perspective of stress and coping (Wrubel, Benner & Lazarus 1981) which yielded a number of theoretical constructs which they emphasised were highly appropriate for an understanding of social competence. They define social competence as effective participation of a person in the activities of his or her society and view that social competence as having a clear emphasis on the full range of human functioning rather than merely the avoidance of pathology (Wrubel, Benner & Lazarus 1981, p. 62). Of importance to my study are their findings of the characteristics of situational forces that operate in any given coping process. They opine that the meaning attached to the situation as well the situational features have an effect on the competence to cope. All four situational demands that the researchers (Wrubel, Benner & Lazarus 1981, pp. 79-84) identify as taxing the capacity of people in adapting to a crisis are noteworthy in relation to my study: (1) uniqueness, (2) duration and frequency, (3) pervasiveness and (4) ambiguity. I will now go through each of these and give examples of how they were reflected in the findings of my study.

1. Uniqueness. The researchers gave two examples of unique situations that put stress on people: (a) when a person has no previous experiences or cultural practices to provide the knowledge and skills with which to respond, and (b) when a person exhibits subtle non-verbal communication and deeply held implicit views and beliefs about the world. The latter is suggestive of stigma associated with MIH and was reflected in being adrift at sea experienced by participants in my study. In comparing the former, participants in my study perceived their experiences as unpredictable, uncertain and unique and one consumer (F1) said that she had no words to explain her experience when she went to see her psychiatrist.

2. Duration and frequency. The researchers define duration as the length of time the demand is present whereas frequency is related to the repetition of the discrete demand. Both these factors influence the degree of stress. The long duration and frequency of fluctuations of MIH was identified by participants in my study. Consumers and significant-other/consumers aged between 50-60 years of age had been diagnosed in their teens or young adulthood. This persistent nature of the stressor situation disturbed the equilibrium of a family leading to losing family ties. Because of the fluctuating nature of MIH, these situations were repeated adding another layer of stress to participants.
3. Pervasiveness. The researchers write that when situational demands permeate every aspect of a person’s experience, or when one demand leads to series of additional demands, they become pervasive. This is akin to **reverberating losses** identified by participants in my study.

4. Ambiguity. The researchers write that situations that are highly explicit, structured or institutionalised give clarity to people whilst situations of stress that are ambiguous where people are unable to apply their usual coping strategies present a major demand in an already-threatening situation. The findings of my study reflect that situations of MIH were ambiguous and lacked clarity. Participants were unable to make sense of symptoms in themselves and significant-others perceived the behaviour related to MIH as incongruent with the personality of the person as they knew before. The incongruence led to high tension in relationships and the experiences were like **spinning in a whirlpool**. Not only were their internal-worlds unpredictable, but also their external-worlds when receiving differing diagnoses, constant change of diagnoses, or unclear and inadequate information. This again was an ambiguous situation where participants experienced **being adrift at sea**.

### 6.3.1 Professor Emeritus Agnes Hatfield

Professor Emeritus Agnes Hatfield together with Professor Harriet Lefley, edited two books on stress and the coping and adaptation processes of families of people with MIH (Hatfield 1978; Hatfield & Lefley 1987). By synthesising the work of theorists who had researched adaptation, Hatfield (1987) offers a conceptual framework for understanding the coping and adaptation processes, taking into account the perspectives of families of those with MIH. She writes that when a person’s resources for coping are inadequate to meet the environmental demands of MIH, a state of crises occurs. In particular, she identifies the four situational demands of (1) uniqueness, (2) duration and frequency, (3) pervasiveness and (4) ambiguity identified in the research of Wrubel, Benner and Lazarus (1981) as a useful perspective from which to view families coping with MIH. The conceptual framework she offers adds to the trustworthiness and credibility of my study in two ways. Firstly, the four situational demands of uniqueness, duration and frequency, pervasiveness and ambiguity were all identified in my study. Uniqueness was identified in my study where MIH was unpredictable and the society around offered no patterns of response. Duration was identified by the length of time that the older group of participants experienced the demands of MIH in their lives and frequency was identified by the cyclical nature of MIH. Pervasiveness was identified as **reverberating losses** where the demands of MIH permeated other experiences of participants. Ambiguity of MIH was identified as **spinning in a whirlpool** and **being adrift at sea**. Secondly, Hatfield writes that families of those with MIH go
through a highly traumatic sense of loss that is unrecognised by those around them because there has not been actual bodily death. This is akin to the sense of being adrift at sea found in my study.

She compares the grief of MIH to chronic sorrow identified in family reaction to mental retardation in a child (Olshansky 1962) and writes that this chronic sorrow is a normal reaction to an abnormal situation. The chronic sorrow that she identified is similar to complicated grief identified in my study. (Hatfield 1987) concludes that the literature was devoid of any significant discussions of loss and mourning associated with MIH. She writes that mutual support groups were the only support offered for easing the pain for those who experience loss as a consequence of MIH. This is akin to sailing to parts unknown identified as a strategy of managing in my study.


I will now discuss tenets of the stress-vulnerability model of mental health that bear resemblance to findings of my study and also how the model could be advanced from a person-centred model to a family-centred model using the central proposition that the metaphor of navigating the winds and tides of ambiguity to stay afloat captures the specificity of systemic perspectives.

6.4 Stress-Vulnerability Model of Mental Ill Health

The Stress-Vulnerability Model of MIH was first proposed in 1977 by Dr Joseph Zubin and Professor Bonnie Spring. In formulating the model, they were attempting to reconcile descriptive and causal models and knowledge about schizophrenia from different theoretical perspectives (Zubin & Spring 1977). Whilst many researchers have raised conceptual problems in relation to the model proposed by Zubin and Spring (Ingram & Luxton 2005; Rudnick & Lundberg 2012), it has evolved into several versions since the model was originally proposed to understand the onset and course of schizophrenia and it continues to be used as a dominant conceptual framework for understanding the relationship between stressful life events as perceived by a person and the onset of MIH (Perera & Baily 1998).

Zubin and Spring (1977) suggested that both exogenous and endogenous challenges have the potential to evoke a crisis in all humans. In proposing the model, they limited discussion to the exogenous or the external stressors which are usually referred to as life events and suggested
that life stresses befall people regardless of their temperament or behaviour. The authors wrote that containment of homeostasis and prevention of an episode of MIH is dependent on the intensity of the stress evoked and the threshold a person has for tolerating the crisis. The threshold for tolerating a crisis is termed as one’s vulnerability (Zubin & Spring 1977, p. 103). Ingram and Luxton (2005) conceptualise vulnerability as a pre-dispositional factor, or a set of factors, that makes possible a disordered state and they use the terms vulnerability and diathesis interchangeably. They argue that, although vulnerability may in many cases be permanent and enduring at a genetic level of analysis, when the level of vulnerability is analysed through a psychological rather than genetic level change may be possible (Ingram & Luxton 2005, pp. 34-35). The authors suggest that the notion of therapy is based on just this premise. However, they also distinguish vulnerability from “external” stress or life events but the findings of my study on being adrift at sea where participants experienced stigma suggest that the perception of the general community that they lived in was an external stressor and also had the potential to make them more vulnerable to stress than others.

The process represented by the metaphor of navigating the winds and tides of ambiguity to stay afloat extends the stress-vulnerability model of Zubin and Spring (1977) to a systemic perspective that includes attachments with family, friends and the community, and the interactions and reciprocal relationships with these groups that has a major influence on how people perceive and manage stress, crises or traumatic events. By taking a systemic perspective, the findings of my study suggests that sailing to parts unknown and knowing current location, developing the spirit of an adventurer, building rapport were all positive strategies and influenced how participants perceived and managed the ambiguities of MIH.

The process described by the metaphor of navigating the winds and tides of ambiguity to stay afloat thus could be utilised as a preventative model for the complicated grief of MIH as well as a family-centred model for managing the ambiguities of MIH.

Zubin and Spring (1977, p. 111) suggested five variables that need to be taken into account when considering a person’s response to a stressor event:

a) the normatively perceived severity of the life event stressor,
b) the individual’s perception of the stressfulness of the load,
c) the capacities or general competence level of the individual,
d) the coping efforts exerted in dealing with the stressful situation, and

e) the vulnerability of the individual.
In taking account of the above factors and comparing them to the findings in my study, the number of risk factors elicited by the ambiguity of MIH provides a rich source of examples which play a substantial role in challenging a family's threshold for tolerating a crisis and making members of the family vulnerable to complicated grief. It also gives mental health practitioners a conceptual framework to understand how they may be able to eliminate some of the stressors for families and formulate ways to help increase their vulnerability threshold. I will now compare the findings of my study to some of the sources of stress suggested by Zubin and Spring (1977).

6.4.1

Participants in my study found that MIH did not offer them any forms of coping that were culturally sanctioned for the stress-producing event of ambiguity. The authors acknowledge that the subtle nature and complexities of behaviour that have been proposed as signposts of the beginning of an episode of schizophrenia magnify the difficulty of determining the onset. This is true for most MIH. These two factors of lack of cultural sanction and complexities of recognising the onset are both identified in my study. I have chosen metaphors of being adrift at sea to explain lack of cultural sanction and spinning in a whirlpool to explain complexities of recognising onset.

6.4.2

The authors suggest that failure in the process of adaptation may take longer, be complicated or even be prevented in episodes of psychiatric disorder by the adverse effects of institutionalisation and stigmatisation. The findings of my study support the authors' identification that stigma or being adrift at sea complicated the process of managing for participants.

6.4.3

The authors acknowledge that an individual's perception of the stressfulness of the load is a determinant of the vulnerability posed. Participants in my study were unable to make sense of the symptoms. Significant-others observing their loved ones were confused about symptoms as well as behaviour and found the behaviour incongruent with the personality of the person as they knew them before. Participants who had previously observed symptoms in a relative with MIH were attempting to make sense of their own symptoms in the context of the trauma of witnessing the symptoms and behaviour in their relative. The perceptions of all three groups were that it was the ambiguity that caused enormous stress individually as well as collectively. Health professionals, by not acknowledging the ambiguities of MIH as an objective feature of the ill health, increase individuals' as well as families' perception of the stressfulness of the load. The
misperceptions that arise in families as a result of such lack of acknowledgement, increase families’ vulnerability to losing self and losing family ties.

6.4.4

The authors acknowledge that failure in adaptation to stressful events will be observed in those categorised as good at coping as well as those less adept. They say that difficulty in coping is marked as subjective discomfort or distress, feelings of helplessness or tension, withdrawal, inappropriate or ineffectual behaviour, and physiological disequilibrium or vegetative disturbances (Zubin & Spring 1977, p. 117) and these characteristics are not necessarily episodes of mental disorder. All of these characteristics were identified by participants in their stress of managing the ambiguities of MIH. The findings of my study suggest that the culprit producing the characteristics suggested by the authors was the objective feature of ambiguities of MIH rather than a disorder of the individual or the families.

The tenets of the stress-vulnerability model of schizophrenia that is now a dominant conceptual framework for understanding the relationship between stressful life events that make people more vulnerable to MIH, bear strong similarities to the findings of my study. While the tenets are typically applied to individuals, they are just as relevant to families, groups and communities (Bland, Renouf & Tullgren 2009). This significant process characterised in the study by the metaphor of navigating the winds and tides of ambiguity to stay afloat viewed through the lens of ambiguous loss theory has the potential to be a preventative model in that if shared with those affected could assist in an understanding of the complexities and thus enhance family understanding and managing ambiguities. Such an understanding will help identify stressors as well as protective factors that contribute to wellbeing.

Findings of my study demonstrate that grief associated with MIH is complex and multi-faceted. It also shares some commonalities with grief seen with losses through death.

6.5 Theories Relating to Loss and Grief

In the last century scientists from various schools of thought have attempted to explain the universal phenomenon of grief. The phases/stages and tasks of grief have been described by Freud (1917); Bowlby (1960); Kubler-Ross (1970); Kübler-Ross, Wessler and Avioli (1972); Murray Parkes (1971); Worden (2009). These descriptions of phase/stage and task models of grief have been useful and have helped generate a great deal of research, advanced our understanding of grief and improved practice. Despite the useful guidelines of these schools of thought, scholars continued to have concerns about the adequacy of the constructs in these
models and the assumption of universality of these constructs (Stroebe & Schut 1999; Rosenblatt 2013).

Margaret Stroebe and Henk Schut in an attempt to better understand individual differences in the way people come to terms with bereavement, developed the Dual Process Model (DPM) of Coping with Bereavement (Stroebe & Schut 1999). They then put the model out to other researchers for empirical testing for different types of investigations (Stroebe & Schut 2006). The DPM model has parallels with the findings of my study in two aspects, 1) reverberating losses and 2) process of oscillation in managing the stress of ambiguity, and thus provides indirect support for the findings of my study. In support of the findings of reverberating losses in my study, the authors emphasise that earlier phase and task-centred models of studies neglected the possibility of other sources of stress that arise indirectly following a bereavement, such as concerns with finances, legal matters or upbringing of children. As identified by Stroebe and Schut (1999) in their DPM model, my study also identified other sources of stress that arise indirectly following the onset of MIH which I have termed reverberating losses. The four sub-themes that come under the rubric of reverberating losses are losing self, losing family ties, losing connectedness and losing functionality. Reverberating losses have also been identified by other scholars of grief theories (Walsh & McGoldrick 2004; Gilbert 1996). Walsh and McGoldrick (2004) write about the legacies of loss and the multigenerational ripple effects. Gilbert (1996) opines that relationships between bereaved family members and the legacies of their past contribute to a phenomenon which she identifies as “differential grief”, in which family members may grieve in unique ways, at a unique pace, dealing with ideographic issues. She suggests that the interaction of these differences and related conflict may come together to place tremendous strain on a family. The legacies of loss were identified in families in my study where there were participants who were significant-other/consumers. These families had experienced mental ill health in a parent or sibling and spoke of the trauma they experienced and the loss of long periods of normal family life. These legacies of loss were captured in the properties of losing “self” and losing family ties.

In support of the process of oscillation, the findings of my study demonstrated that participants affected by MIH continuously moved through a process of oscillation in navigating the winds and tides of ambiguity to stay afloat. Stroebe and Schut (1999) introduced the constructs of loss-oriented coping, restoration-oriented coping and oscillation to grief literature. According to these authors, loss-orientated coping focuses directly on the stress of the loss itself, including symptoms of grief, loss and sadness, whereas the restoration-oriented coping focuses on secondary stressors that accompany a bereaved person’s new status. Loss-oriented
experiences included grief work, intrusion of grief, letting go-continuing-relocating bonds/ties, denial/avoidance of restoration changes. Restoration-oriented experiences included attending to life changes, doing new things, distraction from grief, denial/avoidance of grief, new roles/identities/relationships (Stroebe & Schut 2010, p. 276). Through a regulatory process of oscillation, bereaved people at times confronted aspects of loss and at other times avoided them. An important postulation of the DPM model is that oscillation between the two types of stressors is necessary for adaptive coping (Stroebe and Schut, 2010).

Participants in my study oscillated between the courses of steering through choppy waters which bears similarities with loss-oriented coping described by Stroebe and Schut in the DPM model, in that participants experienced considerable distress with onset of signs and symptoms of MIH or following a relapse where the five possible sub-categories of consulting maps and charts, resisting the surge, seeking a safe harbour, avoiding crosswinds and going with the flow all included strategies to manage the loss. The courses in negotiating to smooth the voyage are similar to restoration-oriented coping where the focus was on stressors oriented with secondary losses and restoration of loss. The six possible sub-categories of building rapport, taking the helm and trying a different tack, developing the spirit of an adventurer, sailing to parts unknown and knowing current location, facing the storm and adjusting your sails and determining which way the winds are blowing and the state of the tides all included strategies to restore or manage secondary losses associated with MIH. Participants in my study attempted to restore losses associated with MIH in negotiating to smooth the voyage. I have used the term manage in contrast to the term coping used by Stroebe and Schut as the term coping has nuances of putting up with whereas the term manage better demonstrates what participants did to deal with a condition that is ambiguous and was cyclical.

The concepts of oscillation and other sources of stress were crystallised and symbolised in the process described metaphorically as navigating the winds and tides of ambiguity to stay afloat.

6.5.1 Making Meaning of Loss

Making meaning of loss or attempting to make sense plays a central role in many theories of grief and loss (Frankl 1984; Boss 1999; Boss 2006; Neimeyer 2000a; Neimeyer 2000b; Nadeau 2001; Bonanno & Kaltman 2001; Davis & Nolen-Hoeksema 2001). Viktor E. Frankl, a psychiatrist, developed logotherapy from the lessons he drew from his experiences as a prisoner in a concentration camp during World War II and writes that the ability to find meaning was essential to survival. He says that his autobiographical account was written in 1945 simply to convey to the
reader by way of a concrete example that life holds a potential meaning even in the most miserable condition (Frankl 1984, p. 12). He employed the term “logotherapy” as a name for his theory because logos is a Greek word which denotes “meaning”. He writes that according to logotherapy, there are three main avenues by which one arrives at meaning in life (p.146): 1) by creating a work or by doing a deed, 2) by experiencing something or encountering someone, 3) by turning a personal tragedy into a triumph or human achievement. All three avenues have similarities to the findings of my study. Avenues one and three have similarities where significant-other/consumer A2 got involved in a project in her community and said “I had to do a lot with this centre to get it off and running”; C2 was a member of the local mental health clinic’s management committee and said “I feel as if I have an input”. E1 was making a positive contribution to others in similar situations by helping migrant women with MIH and D2 said she did voluntary work that took her into activism and as a consumer “she was putting things into this society”. Frankl writes that when people are faced with a situation that cannot be changed, such as ill health that has no cure, they are then challenged to change themselves by transforming a personal tragedy into a triumph and a human achievement. This process was captured in the metaphor *sailing to parts unknown and knowing current location*. Avenue two has similarities with my study where consumers D1 and D2, encounter through a consumer group led them to consider each other as their “intentional family” and to discovering a shared interest where problems of MIH have no influence. They met once or twice a week to go to the movies and D2 says that “our togetherness has been about going to the movies”. The metaphor of *developing the spirit of an adventurer* captures this process.

6.5.2 Meaning-Reconstruction Models of Grieving.

Robert A. Neimeyer writes from a constructivist perspective and views grieving as a meaning-making process and argues that traditional theories of grief are too superficial and simplistic (Neimeyer 2000a). Both from his research and clinical experience, he advocates for families coming together to share their perceptions. This he writes is important because manners of experiencing and expressing grief may differ among family members. It is only through sharing that each may appreciate the multiple meanings of loss, find ways to “join” and create an atmosphere of understanding. By joining together, each person can tell their own story and the unique struggle in their own words (Neimeyer 2000a, pp. 55-56). Although his theories mainly focus on grief related to death, from a constructivist perspective Robert Neimeyer identifies six fundamental criteria for a useful theory of grief or loss (Neimeyer 2000a, pp. 85-86). All six of these criteria can be identified in the findings of my study. I will now list each of the criteria that he describe and compare them with the findings of my study.
1. “Death as an event can validate or invalidate the constructions on the basis of which we live, or it may stand as a novel experience for which we have no construction” (p.87). In the findings of my study, the ambiguous loss associated with MIH was a novel experience which participants could not make sense of, and at odds with their pre-existing constructions. Thus, the findings of ambiguities of MIH metaphorically described as *spinning in a whirlpool* and *being adrift at sea* can be validly compared to criterion one.

2. “Grief is a personal process, one that is idiosyncratic, intimate and inextricable from our sense of who we are” (p.89-90). The author suggests that this unique significance can be conveyed more adequately in metaphors and imagery than in the lexicon of public speech. Using a case study approach that focuses on the particularity of loss and the unique significance of that loss to each participant and the complexity that ensues, required that I use metaphors and imagery to capture experiences that denotative language could not adequately capture. This can be compared validly to criterion two.

3. “Grieving is something we do, not something that is done to us” (pp. 91-92). This criterion suggests that grieving is an active process of accommodating to a loss. He describes this criterion as vacillation between feeling and exploring the grief versus avoiding intensive “grief work” and instead attempting to adapt to a changed external reality. The author compares this criterion to the dual process model described by Stroebe and Schut. This description of the third criterion can be compared validly to the process of oscillation between *steering through choppy waters* and *negotiating to smooth the voyage* subsumed by the core process encapsulated by the metaphor of *navigating the winds and tides of ambiguity to stay afloat*.

4. “Grieving is the act of affirming or reconstructing a personal world of meaning that has been challenged by loss” (pp. 92-94). In criterion four, the author suggests that loss challenges people to manage the tumult of subjective experiences and objective demands and in this process reconstruct a life which restores a semblance of meaning, direction and interpretability. He writes that meaning reconstruction is central to dynamic grieving and that a narrative model is helpful in understanding this process. Through the approach of qualitative case study and the narratives of in-depth interviews I was able to capture some of the ways that participants attempt to make sense, and the process of meaning reconstruction of ambiguity associated with MIH which I have captured in the metaphors of *consulting maps and charts* and *determining which way the winds are blowing and the state of the tides*. He writes that chronic and protracted losses require continual revisions in the direction of one’s life. This suggestion
is comparable to the process represented in the metaphor of *navigating the winds and tides of ambiguity to stay afloat* in that it was a constant non-linear journey of managing the ambiguity of MIH, and with each new item of information those affected attempt to make sense of their experiences of loss through a dialectical pattern as well up-and-down, back-and-forth patterns. This demonstrates that the findings of my study compare validly to criterion 4.

5. “Feelings have functions, and should be understood as signals of the state of our meaning-making efforts in the wake of challenges to the adequacy of our constructions” (pp. 94-96). From this perspective, the author writes that affective responses such as denial and depression need to be viewed as attempts to grasp meaning and linked to the confusion or restoration of the efforts to make meaning. This conceptualisation of emotions in meaning-making can be compared with the processes of *resisting the surge* and *avoiding crosswinds*, both processes that participants moved through at times of *steering through choppy waters*. They were also both sub-categories of the course of *consulting maps and charts* and involved emotions and actions in participants’ attempts to make sense of the ambiguities of MIH.

6. “We construct and reconstruct our identities as survivors of loss in negotiation with others” (pp. 96-98). From this perspective, the author writes that working through grief is done in three interdependent and nested systems corresponding to the self, family and broader society, respectively. Although my study was at the collective, group and individual level of families, it stands in conditional relationship to the broader society of Australian Federal and West Australian State Government policies and the mental health sectors within them. At the individual and family level, analysis took into account the family structures and processes such as interactions and support. As such, from the findings of my study, the stigma of MIH and concerns about symptoms not being validated by health professionals were both properties of the theme of *being adrift at sea* and can be compared validly to the societal construction of the losses associated with MIH.

### 6.6 Summary of Comparison with Broader Theoretical Literature

In this chapter I have compared the findings of my study with the broader theoretical literature of family stress theories relating to meanings, perceptions and sense of coherence about a stressor event. I have also compared the findings of my study with the situational demands of MIH from
the perspective of stress and coping, the stress-vulnerability model of MIH as well as theories related to loss and grief. The integration of theoretical perspectives from a variety of disciplines and bodies of research lends further support to the findings of my study.

I list below the major findings of my study that are supported by the broader theoretical literature:

1. The perceptions of all three groups, i.e. consumers, significant-others and significant-other/consumers are that it was the ambiguity that caused enormous stress individually as well as collectively. My study demonstrates that health professionals, by not acknowledging the ambiguities of MIH as an objective feature of the ill health, increase individuals’ as well as families’ perception of the stressfulness of the load.

2. The journey for these different groups is not necessarily synchronised and as such the nuances of a complex dynamic process of complicated grief have been exacerbated.

3. Meaning reconstruction is central in the dynamics of grieving for which a narrative model is useful. The need for information enabling the co-construction of perceptions and meanings is also profound. Even if a family is unable to get a unified view of the stressor of mental ill health, in order to strive to get a collective view a family needs information and also to come together to share their perceptions.

4. Misperceptions that arise in families as a consequence of lack of acknowledgement, increase families’ vulnerability to losing ‘self’ and losing family ties.

5. The concept of reverberating losses is important to consider because it is the accumulation of stresses that arise indirectly from the onset of MIH that may determine a family’s level of stress and its subsequent vulnerability to crises.

6. The combination of feeling excluded and losing family ties contributed to reducing participants’ capacity to manage stressors.

7. When participants’ sense of self/coherence were challenged, dialectical thinking helped manage ambiguities and make meaning.

8. Managing ambiguity required participants to oscillate between loss-oriented strategies and restoration-oriented strategies.

9. The process symbolized by the metaphor of navigating the winds and tides of ambiguity to stay afloat, viewed through the lens of ambiguous loss theory, have the potential to be a preventative model for identifying stressors that contribute to mental ill health as well as for identifying protective factors that contribute to wellbeing.
My aim in undertaking this study was to gain a critical understanding of the perceptions of losses associated with mental ill health and how people manage the ambiguities associated. My intention then was to use the empirical data from my study to advance Boss’s theory of Ambiguous Loss to a new and unstudied population. Although Hatfield in 1987 identified that ambiguity of MIH is a situational demand that taxed the capacity to adapt (p.66), my study is the first to analyse MIH through the lens of Ambiguous Loss Theory and extend Boss’s theory to a new population. The findings of my study support the major theoretical premise of Ambiguous Loss Theory that families are most highly stressed by losses that are ambiguous. As such, the theory generated from data of families navigating the winds and tides of ambiguity to stay afloat has not only advanced Boss’s theory of Ambiguous Loss, depicting how families manage the ambiguity of mental ill health, but it has also contributed to the literature of complicated grief and some of the ways of managing losses that arise from it. The findings offer valuable information to mental health services.
Chapter 7: Summary of Findings, Discussion, Suggestions and Conclusion

7.1 Introduction

This thesis is a study about ambiguous loss associated with mental ill health (MIH). Using a qualitative case study approach, guided by ambiguous loss theory (Boss 1999; 2006) underpinned within the interpretative paradigm of symbolic interactionism, I explored the experiences of a sample of people who have been affected by MIH as well as their significant-others to study their perceptions of loss, how they experienced the additional stressor of ambiguity associated with such losses and how they managed the ambiguity. The study was to answer two research questions and one sub-question: 1) How is loss perceived by those affected by MIH? 1a) How do they experience the additional stressor of ambiguity associated with MIH? and 2) How do they manage the ambiguity associated with MIH?

These questions were answered within the framework of symbolic interaction to understand how participants create an understanding, or reality shaped by shared meaning within the family, the larger context outside the family and the interactions that occur between these internal and external contexts. Symbolic interaction theory’s emphasis on the relation between mental and social processes was useful in understanding how participants made meaning. I used a combination of Grounded Theory methods and methods from the framework of Transcendental Realism to analyse data. The transcendental nature of ambiguous loss, together with the complexity of researching a three-dimensional view involving three groups, consumers, significant-others and significant-other/consumers, as well as taking into consideration the context, required me to craft a study using combinations of theories and methods.

7.2 Findings of the Study

In the findings of the first research question, How is loss perceived by those affected by MIH?, reverberating losses emerged as a major theme comprising four sub-themes of losing ‘self’, losing family ties, losing connectedness and losing functionality.

Findings of my study also suggest that the complexities of the stressors of loss lay in perceptions of ambiguities associated with MIH. Family members had differing meanings and interpretations of the situation as a result of the ambiguities. These differences in perceptions between family
members contribute to losing family ties. The culture around them offered no pattern for response. Ambiguities and the cyclical nature of ill health made MIH unpredictable and inexplicable and thus those affected had difficulty making sense of their experience. Not only was the situation of MIH unpredictable, but it was also ambiguous – lacking definitive information even about the present. Uncertainty obstructed comprehensibility. The situational demands of loss, the accumulation of the stresses of MIH coupled with ambiguity, taxed the capacity of participants to manage the crises of MIH. This resulted in grief complicated by ambiguity. This means that ambiguities of MIH emerged as the problem faced by participants in the substantive area of research of my study.

In the findings of the sub-question, How do participants experience the additional stressor of ambiguity associated with such losses? two major themes of experiences of ambiguity could be represented metaphorically as (1) *spinning in a whirlpool* and (2) *being adrift at sea*. 

**Spinning in a whirlpool** is an internal process where consumers are unable to make sense of symptoms in themselves whereas significant-others were confused about symptoms or behaviour observed in their relative as it was incongruent with the personality of the person they knew before. The incongruence leads to high tension in relationships. In contrast, significant-other/consumers attempt to make sense of their own symptoms in the context of the trauma of witnessing the symptoms of MIH in a relative in the past. The metaphor of *being adrift at sea* represented an external process comprising four properties: (1) where diagnoses were unclear or constantly changed by health care professionals with no explanation, (2) where insufficient information was given about the ill health, (3) where concerns about symptoms were not validated by health professionals or other family members, and (4) when the stigma of MIH was experienced. All three groups experienced this theme.

In relation to the second research question, How do people manage the ambiguity associated with MIH? the answer was the core social process of *navigating the winds and tides of ambiguity to stay afloat*. It was a circular model of managing rather than a linear process where those affected moved through the tension of a complex phenomenon over time. This was a constant non-linear journey of up-and-down and back and forth movements with oscillating actions and interactions. An exploration of strategies for managing ambiguity revealed that participants strove to bring coherence to their lives through negotiating back and forth between individual resources and the resources of the environment around them that impact one on the other in endless and unpredictable combinations. This complex phenomenon was also a three dimensional view involving three groups: consumers, significant-others and significant-other/consumers. Participants experienced MIH as a cyclical condition that required moving
between *steering choppy waters* and *negotiating to smooth the voyage*, depending on the context and intervening conditions. The course of *steering choppy waters* included *consulting maps and charts, resisting the surge, seeking a safe harbour, avoiding crosswinds* and *going with the flow*. The three groups sometimes took different courses but shared some courses as well. The course of *negotiating to smooth the voyage* included *building rapport, taking the helm and trying a different tack, sailing to parts unknown and knowing current location, facing the storm and adjusting your sails* and *determining which way the winds are blowing and the state of the tides*. The three groups took one or more courses of action concurrently but also at times oscillated with actions of other courses. There were consistencies as well as uniqueness of cases, activities and events. The findings of my study imply that the journey for these different groups is not necessarily synchronised and as such the nuances of a complex dynamic process of complicated grief have been further exacerbated. The metaphor *navigating the winds and tides of ambiguity to stay afloat* helped me capture the connotations of this complex basic social process in a way that denotative language could not.

The strategy of *seeking a safe harbour* taken to mean managing symptoms or overwhelming stimuli of MIH is supported by health care professionals and is commonly referred to as “taking time-out”. However, this course observed and interpreted through ambiguous loss theory suggests that the very action of *seeking a safe harbour* results in the person feeling excluded from relationships and reverberating to further losses. Feeling excluded corresponds to Boss’s concept of boundary ambiguity and is a perceptual response and a stressor situation.

Through comparative analysis of the literature I found that, similar to most studies of loss and grief, the processes I represent as *consulting maps and charts* or *determining which way the winds are blowing and the state of the tides* and which are referred to as meaning reconstruction in literature on loss and grief are central to the process of grieving. The processes of *consulting maps and charts* and *determining which way the winds are blowing and the state of the tides* were ongoing. My study demonstrated that misconception takes place when meanings are not shared between family members and has the potential to lead to *losing family ties*.

The function of managing was also ongoing and changed in quality and intensity as new information became available. To adapt to the demands of the ill health and the environment that it was embedded in, participants required information, adequate internal and external resources as well as freedom of action.
The study reinforced for me the importance of the relationship between health care professionals and those they work towards helping. Relationships that promoted respectful collaboration taking into account the preferences, knowledge and skills of those who consult health professionals were greatly valued, especially when these relationships included both tangible and emotional support. This process was captured metaphorically in the course of building rapport.

7.3 Comparison of the Findings with Ten Empirical Studies

I compared findings of my study with ten empirical studies which used some form of qualitative methods to study the perspectives of consumers or significant-others. The findings demonstrate that, irrespective of purpose, time and place of the studies and phrases or conceptualisation used to describe the experience of MIH, the ten studies identified loss and grief associated as well as ambiguity inherent. These findings lend trustworthiness and credibility to the findings of my study. Six of the ten studies also alluded to the complicated process of working back and forth between strategies of managing the effects of MIH. This process is comparable to the constant non-linear journey with oscillating actions and interactions identified in the process represented in the metaphor of navigating the winds and tides of ambiguity to stay afloat.

7.4 Comparison of the Findings with Broader Theoretical Literature

The process symbolised by the metaphor of navigating the winds and tides of ambiguity to stay afloat is also supported by other findings of broader theoretical literature, namely theories relating to meanings, perceptions and sense of coherence about a stressor event, situational demands from the perspective of stress and coping, a stress-vulnerability model of mental ill health and theories of coping with grief and loss.

In summary, the study has answered the broad question: How do people perceive the losses associated with mental ill health? It has answered the sub-question: How do people experience the additional stressor of ambiguity associated with such losses? It has also answered the question: How do people manage the ambiguities associated with mental ill health? The findings of the study give insight into the complex phenomenon of grief complicated by the additional stressor of ambiguity.

7.5 Discussion

Whilst the field of research in mental health has grown exponentially over the past two decades with the advent of the second generation of psychotropic medication, the search for biomarkers of mental ill health (MIH), models of care for people with early symptoms of psychosis and models
of recovery, little research has been done on the emotional consequences of loss and grief for consumers, their significant-others and wider families. Most therapeutic models of loss and grief acknowledge that the ability to share one’s feelings and stories of loss with others is healing. My study demonstrates that mental health services, the health speciality dealing with emotions, need to recognise the effects of ambiguous loss on overall mental wellbeing of both consumers and their significant-others.

As this thesis positions itself within the postmodern paradigm and given the broad range of trajectories that emotional consequences of loss and grief can take, it would seem especially important to discuss contributions of consumers and significant-others who discuss the sheer experience of dealing with an unpredictable condition. Such testimonials allude to the ambiguity of MIH and is also indicative of the importance of the subjective, emotional, symbolic and spiritual aspects of losses associated with MIH. Authors of these testimonials name the grief of MIH as “ultimate sorrow”, “grief without end” (Wasow 2000) and “mourning without end” (Willick 1994). Combining objective science together with an understanding of the personal experience, service providers have the opportunity to develop new ways of understanding problems associated with MIH and their effect of people’s lives. Testimonials also demonstrate how our lives and realities are constituted by stories and language. People make sense of their lives through stories. Such testimonials are valuable not only in combating stigma and discrimination but also in critically examining our practice.

In Romulus my father (Gaita 1999), Raymond Gaita an Australian professor of philosophy, observes in retrospect that his mother likely had a mental illness and also describes his father’s descent into psychosis following the suicide of his mother. In After Romulus (Gaita 2011), reflects on writing of the book and the making of a movie in 2007 based on his book of 1999 and says that the most harrowing incidents of his childhood was his mother’s suicide and its aftermath, and his father’s descent into insanity. The author (p.71) describes the presence and absence of his father this way:

The terror I often saw in my father’s eyes expressed his faltering realization that a mind that has been partially lost to madness cannot assure itself that it is sane. He knew he could not trust the efforts he made to face his afflictions as he would have if he had been told that he had a fatal illness.

To battle against the stigma of mental ill health, Stephen P. Hinshaw, Professor and Chair of the Department of Psychology at the University of California, Berkley invited mental health professionals to write about their own personal experience of mental ill health or that of a family
member. In the book *Breaking the Silence* (Hinshaw 2008), he published fourteen narrative journeys contributed by students, clinicians, teachers, and scientists from the mental health profession. The eight core themes that emerged from the fourteen narratives were: (1) confusion, (2) searing pain, (3) aloneness and isolation, (4) vulnerability, (5) everyday lives and experiences, (6) strength and courage, (7) shaping identity and career and, (8) stigma and treatment. In relation to the theme of confusion, the author writes that the symptoms of MIH are confusing to those who suffer and the family members alike. To those who become afflicted, diffusion of identity, exaggerations and distortion of pre-existing characteristics, intense and inappropriate emotional responses and a profound disorganisation of mental life and behaviour are among some of the problems. In contrast, family members experienced a different type of confusion in disintegration of family patterns and roles. He writes that a prevalent theme of the narratives was the difficulties of “getting a handle on the processes related to altered perceptions” (p.14). All fourteen narratives published by the author also expressed the unrelenting and searing pain and grief associated with mental ill health.

To reduce the stigma and discrimination that people with MIH experience, LeCroy and Holschuh (2012) published a series of first person accounts gathered from various sources such as self-published books, historic accounts, internet and blog entries. The core themes that emerged from the accounts in their book were similar to those identified by Hinshaw (2008). Their identification of the themes of confusion and pain are akin to the themes of ambiguities, loss and grief identified in my findings and gives further credibility to my study.

The seafaring metaphor used by Deegan (1988) to describe her experience of MIH as “ships floating on a black sea with no course or bearing” indicates that metaphors are more available emotionally to people when speaking of their experiences.

The *Schizophrenia Bulletin* has attempted to bridge the gap in knowledge between consumers, their significant-others and health professionals by publishing first-person accounts so that mental health professionals learn about the issues and difficulties confronted by consumers and their families and the latter to have a better sense of not being alone. The seafaring metaphor was used by Stakes (1985) in his article entitled “Becoming seaworthy” to describe his experience of surfing before onset of MIH and how he continues to “feel at sea” but with caution, reluctance and fear to enter an activity following onset of MIH. Molta (1997) uses a number of seafaring metaphors to describe her experiences:
I was governed by wild emotions that were mounting, rising waves while I am a dinghy desperately fighting to stay afloat, determined not to get washed away (p.349).

The people we study use metaphors constantly as a way of making sense of their experience. We do the same thing as we examine our data. Miles and Huberman (1994, p. 252) argue that metaphors are pattern-making devices both for ourselves and for the people we study. They are also data-reducing devices taking several particulars and making a single generality of them. Given that my cohort included both consumers, significant-others and an overlap of consumer/significant-others, it seemed to me extremely relevant to use metaphors in analysing narratives attempting to encapsulate experiences of loss and uncertainties associated with MIH. The notion that research should focus only on matter-of-fact, literal and supposedly “actual” description, with cautious, later ventures into interpretation and meaning, is responsible for much intellectual poverty and misery (Miles & Huberman 1994, p. 250)

Since initiation of the policy of moving care of consumers from institutions to the community, families have taken over the majority of the care of consumers, have rallied to support each other and have influenced reform in service delivery. My study demonstrates that grieving is a family affair. A whole of family approach taking into consideration the family in its broadest sense and the shared grief of families therefore needs to be an important aspect of mental health service delivery and policy. In addition to the whole of family approach, this discussion will argue that the model proposed from this study goes beyond a systemic perspective to the postmodern emphasis on meanings and perceptions, how individually and collectively people perceive and manage the trauma of MIH where community perceptions are also included.

The findings of my study of reverberating losses demonstrate that grief associated with MIH is complicated, intense, long-lasting and often takes over the life of the consumer as well as their significant-others. The factors that lead to the complications are the ambiguities of MIH – a situational feature that makes it difficult for participants to obtain factual information surrounding the event of loss and thus taxes people’s capacity to manage the associated stress. The ambiguities freeze the grief process. Closure is not possible. An exploration of strategies of managing ambiguity revealed that participants strove to bring coherence to their lives through negotiating back and forth between individual resources and the resources of the environment around them that impact one on the other in endless and unpredictable combinations.

There have been many contributions to the study of individual grief and loss over the years but most of what we know about grief and loss is what we have learned by studying or observing
people in bereavement through death. Such knowledge has been gained through a modernist approach to life emphasising goal directedness, efficiency and rationality (Stroebe et al. 1996). According to these authors, when a modernist approach is applied to grief interventions therapists work towards assisting people to undertake grief work through tasks that need to be confronted and systematically attended to in order for normality to be reinstated.

Walsh and McGoldrick (2004) were the first to introduce a paradigm shift from individual grief to family grief. They adopted a systemic approach to the impact of the death of a family member on the family as a functional unit, with far-reaching reverberations for every member in the family and their relationships. The authors write that the impact of loss on the family as an interactional system has not been appreciated by the mental health field. In recent times the significance of loss and shared grief in relation to death has been further explored by Kissane (Kissane 1994; Kissane & Bloch 2002; Kissane et al. 2013).

However, families living with a chronic disability such as mental ill health experience loss and grief differently to that of loss through death. In an earlier publication I described family sensitive practice in mental health settings as an overarching framework guided by a set of principles which influence the way mental health practitioners view, relate to and provide services for clients and their families (Perera 2001). Within this framework, clinicians acknowledge that a person experiencing characteristics of mental ill health is learning to adjust to and manage these characteristics and will have difficulties if he or she returns to a family which is unaware of these characteristics and the adjustment that needs to be made. With this approach, the focus was on sharing perceptions as well as uncovering strengths and strategies for managing the ill health, rather than causes and pathology.

By going beyond the systemic perspective to the postmodern emphasis on meanings and perceptions, the study demonstrates that exploring the contexts, both internal and external, is critical to understanding the family stress management process. Hartman (1978) writes that clinicians can get beyond the constraints of linear thought and language by using metaphors and visual models such as genograms and eco-maps. The eco-map, as an ecological metaphor, pictures an individual or family in the life space of the human elements of a complex ecological system. The genogram pictures the relationship system with the history and sociology of a family. Both are effective and practical tools to explore and understand the contexts and can be used to map supportive care networks and other strategic information that may be inadequately portrayed in words. These tools assist in moving from seeing a client isolated with his or her intrapsychic conflicts to seeing them as a family member connected or disconnected with their
extended networks (Stagoll & Lang 1980). In an earlier publication, I recommend using genograms and eco-maps which represent family and other relationships diagrammatically to prompt other service providers to consider family issues when planning intervention (Perera 2001). Through interactive use of genograms and eco-maps with clients, clinicians can enhance their understanding of contextual influences as well as stimulate conversations with them to identify key sources of support, including connections with family members, friends and wider social networks as well as critical events of relational losses or gains in the family through births, deaths, separation, divorce, illness or conflict. However the family’s experience of loss and grief with the additional stressor of ambiguity is yet to be addressed even within this framework.

From their observations of practice settings, two service providers and a care-giver, Young, Bailey and Rycroft (2004) gave several possible reasons for the absence of the subject of grief in the literature and practice of mainstream psychiatry. The authors write that the preoccupation with categorising and diagnosing has led to an emphasis on the tangible and objective as well as overt symptoms of MIH to the exclusion of the more subjective, subtle and disguised forms of grief. They also say that the issue of grief may also be avoided by service providers for fear that such an emotive topic may induce a psychotic episode in consumers and strong emotions from significant-others. A further possible reason they suggest is that discussions of loss may induce hopelessness. Family members and consumers may compare their losses using reference points of before and after onset of ill health, whereas service providers only have periods of relative stability to compare and this can lead to tension between the three groups. Wasow (2000) confirmed this view and found that whilst service providers had genuine concern and care, their hopes for consumers were task-centered and did not focus on the pain of losses of the consumer and family member. Young, Bailey and Rycroft (2004) also raise the possibility of vicarious trauma for service providers. They suggest that organisations that do not recognise or address the impact of grief on all three groups also fail to recognise that service providers too may experience low energy, pervasive hopelessness, fatigue and low morale. This was confirmed in a recent study that investigated the stigma associated with burnout within staff of the mental health sector, where 63% of respondents indicated that their organisation had lacked awareness and understanding of burnout and work stress (Leginhm 2013). Young, Bailey and Rycroft (2004) write that the failure to recognise the impact of grief on service providers of mental health services is in stark contrast to the acknowledgement of loss and grief in oncology units and children’s hospitals where service providers, consumers and significant-others are all expected and encouraged to express their emotions.
A significant finding of this study is participants’ overlapping identities. As discussed in 2.8.4 (Sampling: Bounding the collection of data), as the study commenced, I found that boundaries were not as solid as I had envisaged and that some consumers who volunteered or significant-others who volunteered identified themselves as both a consumer and a significant-other. I named this group significant-other/consumer. Some of the participant who belonged to the stakeholder group of “significant-other/consumer”, attributed the development of mental illness in themselves to the loss, grief and the symptoms associated with stress and reactive distress as a result of having a parent or sibling with a mental illness or migration. The meaning they assigned to their ill health suggests that when stressors persist or increase in severity with major life challenges and family transactional processes, there is the potential for these symptoms to develop into a mental illness. Such families have multigenerational ripple effects of losses. A systemic approach combined with a postmodernist emphasis on perceptions and meanings considers the impact of the loss on the different stakeholders with far-reaching reverberations for other members of a family and all other relationships. The major challenge for this group of stakeholders then involves recognising the losses of each individual, identifying the meaning assigned to the losses and moving forward with life individually as well as together as a family. This was demonstrated in the metaphor “sailing to parts unknown and maintaining current location”, where participants in Family D discussed sustaining bonds by supporting each other through shared interest as well as developing individual interests and relationships outside the family. For participants in Families A and E, the meaning of losses associated with MIH was rooted in multigenerational family legacies of migration and the stressors involved in this process.

Family processes are crucial influences in the factors that facilitate tolerance of ambiguity or complicate the process. These processes are far more challenging for those with overlapping identities. Some of the processes that also need to be considered are intrapsychic processes which may involve some form of denial and/or family members’ inability to communicate their thoughts because of fear of upsetting each other. When symptoms are treated without understanding the meanings assigned and the relevance of the loss, maintaining family relationships and bonds may not be sustainable. By listening to the different perspectives, assisting them to share the differences and clarifying the meaning of losses of each individual, health professionals can assist family members to place hurts and disappointments in the context of life challenges.
7.6 Perspective of my Study

My study moves beyond the systems perspective and provides a postmodernist emphasis on perceptions, individually and collectively as well as community perceptions, and thus provides a new perspective on the family experience of loss and grief with the additional stressor of ambiguity associated with mental ill health. The study recognises the multiplicity of views and takes into account cultural and social variations. The study also demonstrates that patterns of action, including their meanings and significance, are socially constituted and as such are subject to cultural and historical change. The study further demonstrates that privileging of the narrative and social constructionist approach by exploring specific, contextualised details and differences helps identify plural meanings. This means that a useful way of working is for health professionals to engage in conversations to explore patterns of beliefs, understandings and meaning. This perspective centres those consulting health professionals as the experts in their own lives. The confusion for consumers and their significant-others about the differing diagnoses, as found in my study, demonstrates the need to stimulate dialogue about the differing perceptions not only among consumers and their significant-others but also with service providers. By so doing, health professionals help focus on the specific and localised meanings for individuals and the families we work with. Within such a framework, the findings of my study have implications for clinical practice and capacity building in health promotion including advocacy and education of health practitioners. I will now go through each of these areas.

7.7 Significance of the Findings of the Study

Whilst the study supports the major theoretical premise of ambiguous loss theory that families are most highly stressed by losses that are ambiguous, it is the first study to analyse mental ill health through the lens of ambiguous loss theory and as such has applied Boss’s theory of ambiguous loss to a new and unstudied population – those affected by mental ill health. By including consumers, I have further advanced Boss’s theory that this process is experienced not only by significant-others, but also by consumers or those experiencing the symptoms. Thus the study contributes to knowledge of prolonged and complicated grief and how it relates to grief of mental ill health.

7.8 Implication of the Findings of my Study

The findings of my study demonstrate the importance of the postmodern shift to perception. Such perceptions include a family’s appraisal, definition or assessment of a stressful event. Because families do not live in isolation, the contextual maps of the internal context of a family as well as
their external context or the environment a family is embedded in need to be taken into account. These shifts have implications for clinical practice, capacity building in health promotion, prevention of ill health, breakdown of relationships and education of health practitioners. I will now go through each of these areas and discuss my suggestions.

7.8.1 Implications of the Study for Clinical Practice

Reverberating losses associated with mental ill health emerged as a major component of the perceptions of consumers as well as their significant-others and resulted in prolonged grief. The reverberating effect of losses throughout the family indicates that grieving is a family affair. Mental health services have traditionally been very focused on the consumer and the symptoms of the illness. The findings of my study highlight the issues around lived experiences, perceptions, contributions and value of the whole family.

Prolonged grief means grief without closure. Boss (2006, p. 6) writes that ambiguous loss has no possibility of closure. With no possibility of closure coupled with the ambiguity, the overall goal of therapeutic work, she suggests, is to decrease risk factors and strengthen protective factors for individuals as well as the family as a whole (Boss 2006). My study demonstrates that when a stressor remains ambiguous, the ambiguity has the potential to block one’s sense of coherence and manageability. The principles of therapeutic work and preventative intervention suggested in my study are offered to clinicians as a way of helping consumers and their significant-others (1) to articulate and define their losses, (2) to explore the resources they are using at present as well as other resources within the family or community that may be available, and (3) to define and redefine the meaning assigned to losses. However, Betz and Thorngren (2006) write that, because of the inherent nature of ambiguous loss, models of facilitating a family to manage the many stressors may differ from family to family. Therefore, therapeutic work needs to commence by determining the stressors or defining the loss and clarifying what this means to each person in the family. With the central aspects being perceptions, meanings and where people are coming from, therapeutic work in this context might involve elements of narrative therapy originally developed by Michael White and David Epston (White & Epston 1989) and Jill Freedman and Gene Combs (Combs & Freedman 1990; Freedman & Combs 1996) and advanced by others (Morgan 2000; Hamkens 2005; Ungar 2005; Penwarden 2006; Batha 2006) in conjunction with the ABC-X model of family stress formulated by Reuben Hill (Hill 1958) and advanced by Boss (Boss 2002) to a contextual model.

Narrative therapy is a way of working which centres people as the experts in their own lives and seeks to be a respectful, non-blaming approach to counselling and community work (Morgan
Within such practice, meanings and lives are viewed as "storied" and guided by the production of personal and cultural narratives (White & Epston 1989). In narrative therapy questions from health professionals are asked in a way to generate experience rather than just to gather information and a mutual effort is made to identify strengths. From this perspective, health professionals, consumers and their significant-others are not so much preoccupied with what causes a problem but (a) the influence of the problem in their lives and relationships and (b) their influence in the "life" of the problem. We are also interested in the stories that people live out in their personal lives and the stories of the local and wider culture – and how these influence each other.

The ABC-X model of family stress focuses on independent or intervening variables where A is considered the stressor event or situation; B is the resources or strengths that a family has at the time of the event; and C, the meaning that the family, individually and collectively attaches to the event (Hill 1958). By extending it to a contextual model, Boss suggests that what is defined as a stressor event or narratives of meaning is highly influenced by the family's external context which is the time in their lives and the place in which they live (Boss 2002).

Taking into consideration these two theories, the following is suggested as a guide or map to shape interventions rather than a particular set of strategies for practice.

1. My study demonstrates that family needs to be considered in its broadest sense. By doing so, practitioners could help consumers identify their sources of support and nurturance which in this study I name as intentional family and similar to Boss's construct of psychological family. Boss (2006, 2007) writes that ambiguous loss theory assumes that a psychological family exists and that this perceived construction of one's family may differ from the physical or legal family structure and that both are sources of resiliency. Human environments elicited through an eco-map may help families and practitioners focus on the sources of nurturance, stimulation and support that may be available in the intimate and extended environment to help them build resilience to ambiguity. Hartman (1978) identifies some of the most common systems in the lives of most individuals and families as work, extended family, recreation organisations and health care systems. My study found that mutual-help groups, spiritual or religious organisations are also being considered the "intentional" families of participants. The genogram may assist families and practitioners chart intergenerational family history and alliances. The primary value of both these two simulations are their visual impact, especially for those who may have difficulty in verbal expression as found in my study where participants experienced
**losing ‘self’ and losing connectedness.** In Appendix B, I offer a map and questions that may be helpful in raising awareness of their “intentional” family.

2. Being clear of roles and rules increases a family’s resiliency to function despite ambiguity. To explore roles, it is useful to discuss and establish who the family is, who is “in” and who is “out”. When people lose connectedness through lack of roles, practitioners may help families reconstruct roles by discussing options and choices available to them. Bringing in a member from their intentional family may help strengthen the bond while at the same time assisting the member of the intentional family to feel valued.

3. Reverberating losses associated with mental ill health where each loss flowed on to other areas of participants’ lives are referred to by Stroebe and Schut (2010) where the notion of grief work in the phase and task models focuses on the loss of the loved person, neglecting the possibility that there may be other sources of stress that arise indirectly following a bereavement. Through use of genograms, eco-maps and the stress-vulnerability model of mental ill health in Appendix A (Perera & Baily 1998), mental health practitioners could explore cumulative losses experienced in different aspects of people’s lives and factors that may influence a family’s vulnerability in addition to the stressful event of MIH. Therapeutic work might also focus on tangible areas of restoring external resources, e.g. access to income and accommodation as well as internal resources such as individual and family strengths.

4. I have shown that being a collaborator in people’s lives rather than an expert enhances the sense of personal agency. Thus engaging with consumers and their significant-others in collaboration to come to a common understanding of the nature of the loss or problems that constrain them enhances family resilience. Hamkins (2005); (2013) argues for clinical practices that include consideration of biological as well as rhetorical, cultural and interpersonal contributions to a person’s experience of a problem. In addition she argues for practices of meaning-making in the construction of mental health knowledge. Thus narrative conversations with consumers and significant-others can move between the physical effects of a medicine and the meaning the person ascribes to the effects. Lafond (2002) giving a consumer’s retrospective point of view, says, that when she looked back on her journey through illness she realised that while she had at first rejected various significant-others’ points of view, later she had come to use many of
them as points of reference in her management of the ill health, especially when they had been expressed with care and respect.

5. Loss touches us all throughout our life span. However, ambiguous loss and reactions to it need to be clearly differentiated from ordinary loss. With ambiguous loss, the situations are beyond the control of the people experiencing the loss. The grieving process and managing the loss are hampered by outside constraints. As such, when reactions to ambiguous loss are viewed as pathological or as a flaw of the psyche, it will have a profound effect on the lives of people we work with. The findings of my study demonstrate the importance of generating alternative practices. Collaborative work based on the recognition of the ambiguity of the loss and naming it as “ambiguous loss” and beyond their control, frees people to understand and manage it even when ambiguity remains. Families could be introduced to the notion of “ambiguous loss” and also to the notion of normative losses that can also result in temporary feelings of ambiguity caused by developmental transitions such as a young adult leaving home or getting married. Appendix C “Timeline of Losses” may be useful as a visual exercise to assist families to identify losses encountered from birth to the current time where each person is encouraged to mark losses that have been ambiguous or temporarily ambiguous and losses that have been clear-cut. When contextual factors are outside a family’s control, therapeutic tasks that help people differentiate between what can change and what cannot change, may help them live with ambiguity.

6. Decreasing risk factors and strengthening protective factors. Using the stress-vulnerability theory of Zubin and Spring (1977) as a guide, I, together with another clinician developed a visual guide to identify precipitating and perpetuating stresses with families (Perera and Baily 1998). Following the findings of my present study, this has been adapted as in Appendix A (personal communication Dr Steve Baily, 8th August 2014). This guide could be offered to families as a visual guide to stimulate discussion of biological vulnerability, stress and protective factors and the interaction among these three factors. My study demonstrated that participants used internal as well as external resources as their protective factors. By focusing on a strengths and resilience perspective, health practitioners could assist families identify both internal and external strengths and protective factors and stimulate discussion of increasing these.

7. Through ethical curiosity, I suggest that practitioners collaboratively explore the meanings people make of their experiences, intentions and hopes by involving
consumers as well as their significant-others. Practice of ethical curiosity involves both respect and responsibility (Batha 2006). Such practice recognises the diversity of personal experiences as well as the diversity of meaning-making. Gilbert (1996) through her research identified a complicating factor to grief which she names differential grief where family members may grieve in unique ways, at a unique pace, dealing with ideographic issues, and the interaction of these differences and related conflicts may come together to place tremendous strain on a family. She writes that the relationships between those grieving and the legacies of their past may contribute to differential grief. This was demonstrated in my study with some participants losing innocence and childhood or taking on incongruent roles in the family due to parental MIH. One way of mitigating the differences are for meanings to be shared; the stress of ambiguity and uncertainty is also more easily managed when perceptions are shared. My study demonstrated that attempting to make sense and the first step towards making meaning is ongoing. Attempting to make sense takes place mostly at an individual level and sometimes at a family level but when information is unavailable or ambiguous there is incongruence in perceptions. Making meaning becomes difficult at a family level and thus collective action is blocked.

8. Collaboratively exploring the perceptions of those that consult us is vital in practice. For example, consumers in my study seeking a safe harbour to find solace resulted in perceptions of feeling excluded. As discussed before, seeking a safe harbour is similar to “taking time-out” and a strategy promoted by health practitioners. Significant-others and significant-other/consumers avoiding cross winds to minimise conflict also resulted in them feeling excluded. Feeling excluded was a negative outcome. In therapeutic work, assisting people to view “no-talk” rules and “walking on egg-shells” as unhelpful ways of managing ambiguous loss is less blaming and more conducive to revising their attachment.

9. Problems do not define a person’s entire being. The stories that people bring to consultations allow for possibilities and building more detailed descriptions of resilience. In my study all three groups spoke positively of experiences when they shared interests and where problems of MIH had no influence, which I name developing the spirit of an adventurer. When personality characteristics that form one’s identity are lost temporarily or permanently through mental ill health, new identities can be formed through shared interests. In our practice, we recognise that it is important to listen to stories of unique outcomes such as events that stand outside the problem. Deconstructive listening
loosens the grip of restrictive stories (Freedman & Combs 1996). Understanding resilience this way moves practitioners from the belief that the experience of health depends only upon inner capacities to overcome adversity (Ungar 2005) to people linking to their social worlds in building relationships. By viewing resilience this way, we can understand it as the outcome of experiences and identity stories. Through interaction with others, people construct their reality by social confirmation of the reality they are encountering.

10. Externalising problems. Listening to stories of resilience also helps perceive problems as separate from people and start the process of externalising the problems. By naming the problem as ambiguous loss and offering an externalised description of the problem – that is, locating the problems in people’s lives in their broader social context — health professionals could elevate the context of a person’s experience and objectify problems rather than people. White and Epston (1989) introduced the idea of perceiving problems as separate from people. It is more of an attitude than a technique. When MIH is objectified and separated from the person, practitioners can assist family members to separate the person from the problem. By separating the person from the problem, they are able to have a “relationship” with the problem in that they have control over the problem. Morgan (2000, p. 18) writes that “within externalising conversations, problems are often spoken of as separate from people”, and suggests that both health professionals and the people who consult them discuss the problem as being a “thing” sitting somewhere else in the room. In externalising conversations, the language, choice of words and the way one phrases sentences and questions are all crucial in shifting the conversation from an internalised one to an externalised one. For example, in the situation of stigma, the name given to the problem could be “the stigma”. However when engaging in externalised conversations, it is also important to consider the broader context and not reinforce dominant ideas that may be supporting the problem such as issues of power and injustice of stigma.

11. Gather information on families’ skills and knowledge in resisting the ambiguities as well as sources of inspiration, meaning and living as they prefer. The visual guide of the stress-vulnerability model of MIH in Appendix A may be helpful in such work.

12. In the course of negotiating to smooth the voyage, many participants used dialectical approaches to manage the ambiguity and complexity of the situation. They stopped seeking certainty and became strengthened and more resilient through undertaking
processes of this and this, rather than an “either this or that” dichotomy or from a desire for mastery and control. Through communal sharing of narratives and interaction with others, change and movement, participants gained new ideas that helped them make meaning. By providing people with information of external resources of mutual-help groups and consumer organisations, health professionals could assist clients to gain knowledge from others going through similar experiences.

13. Oscillating between approaches to managing ambiguities of MIH is a positive function which prevented participants from becoming overcome by stress. Through strategies of oscillation participants acknowledged the interrelationship between factors and this interrelatedness may be at times harmonious and at other times in tense contradiction. Flexible approaches to clinical practice are fundamental to oscillation as it caters for both individual as well as sub-group differences. When people oscillate between approaches, health professionals need to explore what approaches are perceived as protective factors as well as those that are risk factors. Whilst the emotional aspects of steering through choppy waters to manage ambiguity of MIH may be universalistic, the practical challenges for negotiating to smooth the voyage are much more idiosyncratic and require that practitioners gain an in-depth knowledge of the internal as well as the external contexts of people they work with because the characteristics of the ill health, availability of support, and psychological and social resources all play an important role in the way people manage ambiguity.

14. The findings of this study indicate that participants were aware that some of the strategies that they used to manage ambiguities had both costs and benefits. The diagnosis, effects and sideeffects of medication need to be discussed and written information given to all parties. Consumers chose not to take medication when costs outweighed the benefits or when diagnoses differed, and not necessarily because they lacked insight. By collaboratively exploring how a person is resisting the problem and how that is linked to their personal hopes and values, health professionals will get a better understanding of which resources might best meet their needs (Hamkins 2013). Hamkins (2013, p. 121) writes that a person’s experience of a medicine not only depends on the medicine’s biological effects but also on the meanings the person ascribes to the effects and these meanings are closely linked to their preferences and values. By also embracing concepts such as “dignity of risk” and the “right to failure” practitioners could be providing environments of empowerment for their clients (Deegan 1996). People with lived experience have valuable knowledge, expertise and ideas as a result of their
experience. By recognising that each person’s experience is unique and giving them time and the opportunity to present their knowledge and ideas we are acknowledging that recovery is a process of both *steering through choppy waters* and *negotiating to smooth the voyage*. However, it is important to distinguish between providing an environment for self-determination an environment that puts the person at risk from themselves or others.

15. A problem faced by participants was of receiving differing diagnoses. For them, it was confusing and had the potential to lead to misunderstandings between family members and *losing family ties*. The importance of discussing with consumers and their significant-others when there is no clear diagnosis and working together with them to get a better understanding of their difficulties cannot be overemphasised.

16. Negative characteristics of the illness such as loss of volition, loss of pleasure, loss of motivation have the potential to manifest in characteristics that lead to other losses such as loss of functionality. Participants were confused about negative characteristics of ill health and differentiating them from side effects of medication. It is useful to explore a family’s understanding of MIH. The concept of “episode” may be more congruent with recovery than the term “illness” as MIH is generally episodic in nature. Being sensitive to explanatory models and a family’s previous experience with treatment and their ability to understand complex medical language, especially when working with families from different cultural backgrounds, cannot be overstressed. Information may need to be repeated several times and provided through a variety of communication means, as information given at times of crises is often difficult for people to retain and also because the characteristics of MIH may change over time.

17. When exploring resources available for people, consider both internal and external resources. If families only turn internally for their resources, it can deplete the resources available within that family. Similarly, if people constantly try to use the resources of one friend for managing, the resources can be depleted too. The visual diagram of the stress-vulnerability model of mental ill health (Appendix A) may be a useful document for exploring resources.

7.8.2 Capacity Building in Health Promotion, Prevention of Ill Health and Breakdown of Relationships

Capacity building in health promotion and ill health prevention has been described by many different phrases throughout the years. Phrases that preceded it are community development,
community empowerment and social capital (Labonte & Laverack 2001). In this study, in using the phrase capacity building I refer to the process of facilitating a community’s awareness of the factors and forces that affect its health and quality of life, and of working in collaboration with the community to gain knowledge and skills to take control over and improve mental wellbeing. By community I mean specific groups and networks of groups organised around mental health and wellbeing issues. Health practitioners, by taking on an advocacy role to assist community members to take control of their lives, can bear witness to instances where people transform their predicament into a human achievement. This was demonstrated in my study where many participants joined consumer and carer movements and management committees of health clinics to improve conditions. Group and community work approaches that health practitioners adopt can be developed through an understanding of concepts such as resilience, resources, vulnerability, risks and protective factors (Bland, Renouf & Tullgren 2009). Through the life cycle of individuals, all of these factors operate in some dynamic interaction. By promoting the effective and humane operation of the wider systems and by contributing to the development and improvement of social policy, health practitioners acknowledge the impact of mental ill health on the social context of a person and their family, such as access to affordable housing, work, income security and public transport.

Findings of my study suggest that mutual-help groups assisted in mitigating ambiguity and increasing resilience. This involved interacting with people not known previously. These were positive experiences when the relationships were reciprocal. The metaphor sailing to parts unknown captured this process. This parallels the argument of Boss (2006) that in times of relational loss humans require more support and that individual therapy may inadvertently increase trauma by isolating those struggling to grieve.

Findings of my study demonstrate that being involved in building consumer and carer organisations that can influence mental health reform helps people move from despair to protest. The carer organisation of the State of Victoria in Australia protested the discrimination against carers of people with mental ill health by Human Services in determining their eligibility for a carers’ allowance (Ilsley August 2013). For example, negative characteristics of mental ill health are not specified in questionnaires and tools that assess individuals for social security/income and neither are they specified in assessing family members or significant-others for carers’ allowances. This leads to loss of validation by the community and government organisations and demonstrates that people affected by mental ill health are not only grieving the loss of health but they are also grieving lack of support. In collaboration with these specific communities health
professionals could be involved in the social context and social consequences of MIH by taking on advocacy roles to establish social action projects to bring about social change.

7.8.3 Ambiguous Loss Theory and Practice Education

Education about grief and loss is not specifically included in education programs of mental health professionals. Although ambiguous loss as a broad concept encompasses many facets of human experience such as the sadness over a child leaving home, the trauma of divorce and migration, people usually manage to tolerate the ambiguity of these facets of ambiguous loss by rearranging their roles and identity to cope. However, understanding the unique ways in which people experience grief and the complexities when the loss is inherently uncertain is lacking in mental health education and thus people managing mental ill health are often left struggling to stay afloat in a tide of loss and uncertainty.

My research will be reflected in my own practice and in the way I train others. It is offered in the hope that it will influence the attitudes and perception of colleagues.

7.9 Implications of the Study for Future Research

A key implication of this study is the need for dialogue between consumers, significant-others and clinicians. This is important because the three groups arguably have rather different perspectives on the same phenomenon. For future scholars, it provides some new propositions of what questions are yet to be answered.

In the study of Davidson and Stayner (1997), clinicians’ image of consumers was that of an ‘empty shell’ of who she or he was prior to the onset of MIH (Chapter 5, Comparison with the Literature). In this way, the authors say clinicians implied that the person as a feeling, thinking and intending subject was no longer available. The clinicians' perspective differed markedly from those of family members and consumers. The clinician viewed the ‘empty shell’ as inaccessible, whilst family members appeared to confirm the empty shell image on the surface but differed in one important aspect and this contrasts starkly with the empty shell image described by clinicians. The authors’ study implies that service providers are included but they did not identify loss and grief as observations of professionals’ work with consumers or family members. Family members also suggested that service providers focused exclusively on treatment of the illness, failing to recognise the losses and basic human need of wanting to relate to others despite or because of their disorder and the losses that ensue. Ambiguous situations tend to be misperceived. Differences in perceptions have the potential to create barriers and conflict.
between groups. Conflict takes people away from providing the best service possible to manage ambiguity.

The research of Wasow (2000) focuses on the reduction of such conflict. In presenting findings of her research in the book *The skipping stone: Ripple effects of mental illness on the family*, she wears “three hats”, that of a parent with a child with MIH, an educator and a clinician. She acknowledges that there may be a conflict of interests by wearing three hats however her intention was to bridge a gap in knowledge by finding one voice for all in order to reduce conflict. She names MIH as a “common enemy” (Wasow 2000, p. 2) of all three groups. This again supports my assertion of the need to share perceptions, in this case the shared perception of mental ill health as a common enemy.

A challenge for future researchers would be to craft a study that includes the perceptions of clinicians. A study that includes the perceptions of the larger cultural context would also be valuable. There are many possibilities in the way any given experience may be interpreted. The same stories can be told from different points of view and may have very different meanings. An understanding of how community values and connections affect people’s capacity to manage effects of mental ill health has the potential to contribute greatly to practice as well as formulation of policy.

### 7.10 The Purpose of the Study

The purpose of this study was to gather research-based evidence to develop a critical understanding of ambiguous loss associated with MIH and capture the complicated social process undertaken by families to manage the associated ambiguities. I began with a conceptual framework that I developed from my clinical practice, studies and investigation through the 2005 international study tour sponsored by the Winston Churchill Memorial Trust. Through the process of conducting this study, I was able to refine and transform my understanding of the social processes of managing ambiguous loss associated with mental ill health and attribute new meaning to the issue.

In Chapter 1, I outlined a rationale for the study, a contextual background, a historical overview, the need, purpose and significance of the study, statement of the problem, aims and a brief description of methodology. I also addressed ethical considerations, data storage, access and disposal, participant consent and research questions. In Chapter 2, I discussed the methodology and method I used to investigate the research questions, the Australian and West Australian
context, participant recruitment and selection, participant characteristics, field procedures, diagrams, matrices and theoretical memos, data management through computer software and the trustworthiness of findings. In Chapter 3, I presented the findings of the first research questions: How is loss perceived by those affected by mental ill health? and the sub-question, How do they experience ambiguity? In Chapter 4, I discussed the findings of the second research question: How do people manage the ambiguity associated with mental ill health? In Chapter 5, I compared the findings of the two research questions of my study with findings recorded in relevant scholarly sources. In Chapter 6, I compared the findings of the two research questions with bodies of theoretical literature. Chapter 7 gives a summary of findings, discussion, suggestions and conclusion.

7.11 Particularisation and Transferability of the Theory Generated

According to Stake (1995, p. 8), the real business of case study is particularisation, not generalisation. In my study, I investigated the issue of ambiguous loss associated with MIH in depth in order to get to know it well and gain an understanding of how it manifests in participants’ capacity to manage. The qualitative case study strategy I used gave me the opportunity to explore particular or idiosyncratic findings to achieve a higher level of understanding. There was emphasis on uniqueness but to understand the uniqueness also required knowledge of other different cases. This knowledge was gained by consulting the literature of ambiguous loss theory as well as studies by other researchers using the lens of that theory. However, human activity is not context-free and therefore cannot be generalised. By describing the context of the phenomenon from three dimensions using vignettes, as well as the internal and external contexts, my study attempted to achieve naturalistic generalisation. Stake (1995, pp. 85-90) describes *naturalistic generalisation* as conclusions arrived at through personal engagement in life’s affairs or by vicarious experience so well constructed that the person feels as if it happened to them. This naturalistic generalisation will help readers to take my narrative description and the vignettes to form vicarious experience and my findings to work with the reader’s existing propositional knowledge to consider their own alternative interpretation and thus build on tacit knowledge. As Lincoln and Guba (1985, p. 195) write:

It is not possible to describe or explain everything that one “knows” in language form; some things must be experienced to be understood.

The degree of transferability of qualitative studies depends on the similarity of the two contexts of Australia and West Australia studied. Lincoln and Guba (1985, p. 124) call this “fittingness”. It is
up to future researchers to make the judgement if the information about the context provided in this study gives them sufficient information to replicate the study.

### 7.12 Limitations of the Study

There are many aspects of the study that has placed limits on the conclusions that I have been able to draw and may have also shaped the type of responses obtained. These aspects are: the sample size of fifteen and the fact that they were all drawn from consumer organisations and community mental health services. For another, although two brothers, a son and spouse participated in the study no fathers volunteered.

This study is cross-sectional in that it examines people’s perceptions and experience at only one point in time. Perceptions and experiences do change over time. The perception of participants are retrospective with all the limitations of recall bias, imperfect memory and the absence of the larger contexts that entails. Furthermore, people at different phases of illness are likely to be variably proficient at means of dealing with its repercussions. The findings of this study may be different at a different time or differ from studies done elsewhere as the external context, gender, age, ethnicity, and belief systems all play a part in perceptions and experiences. Participants in this study volunteered, so I do not know the perceptions and experiences of those who did not wish to participate.

Whilst triangulation was adopted to gain an in-depth understanding of the phenomenon of study from different vantage points and helped me understand the complexity of losses associated with MIH by bringing hidden or submerged conflict to the surface, triangulation is not without its tensions. Using grounded theory method minimises this problem but does not eliminate it. For example, when exploring perceptions of losses within its context, C2 a mother who experienced the death of a child before onset of MIH in another, did not consider the losses associated with MIH as “true loss”. She spoke of her perception and experience from different vantage points, that of a mother who lost a child to death and compared it to losing “parts within that person” but physically still having them.

As is the limitation of most case study research the phenomenon of interest, ambiguity associated with MIH, was the focus of attention and there was no way to develop the issue well without temporarily ignoring most other aspects of the case. This resulted in abiding tension between the case and the issue (Stake 2005).
7.13 Summary

Ambiguous loss associated with mental ill health has gone unrecognised by health practitioners. Instead, the grief that accompanies ambiguous loss has often been seen as pathological resulting in healthy expression of grief being seriously inhibited. With ambiguous loss there is no absolute certainty. Our longing for certainty is most poignant in our human relationships and as such coping with ambiguous loss can be debilitating. Managing the ambiguities of mental ill health often leaves both the person affected and their families struggling to stay afloat in a tide of loss and uncertainty.

Family perceptions and individual perceptions frequently vary. However for the purpose of family stress management, collaborative discussion with the consumers and their significant-others is needed to obtain family-level perception of the situation. By so doing, families could reach as much unification as possible to manage an ambiguous situation.

My study provides a new perspective on the family experience of loss and grief with the additional stressor of ambiguities associated with mental ill health. By raising awareness of ambiguous loss we can increase individual resiliency to tolerate ambiguity as well as to live well despite it. By changing our practice to recognise ambiguous loss, health professionals can work towards relieving distress and prevention of relational conflict and isolation for consumers and their significant-others.

In this study, I was primarily interested in deriving meanings of loss and ambiguity, and how people make sense of their lives, experiences and the structures of the world around them. Process rather than outcomes concerned me. To obtain the data to answer the research questions, understand the meaning and process, I went out to participants to observe and gather information in their natural setting because I believe that human behaviour is significantly influenced by the setting in which it occurs and that the social context impacts the lives of the problems. The case study approach created less of a division between my dual identity as a practitioner and a researcher. I considered it important to keep in touch at the grass root level of clinical practice, to keep myself grounded and not forget the reason why I am doing this research.

Although Hatfield (1987, p. 66) identified that ambiguity of MIH is a situational demand that taxed the capacity to adapt, my study is the first to analyse it through the lens of Ambiguous Loss Theory. By so doing, not only have I supported the theory but I have also advanced the theory of Ambiguous Loss to a new population which offers valuable information to mental health services.
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Appendix 1: Advertisement

THE UNIVERSITY OF WESTERN AUSTRALIA

ADVERTISEMENT

LOSS ASSOCIATED WITH MENTAL ILL HEALTH

Volunteers diagnosed with mental ill health are required by the School of Psychiatry and Clinical Neurosciences of the University of WA for a PhD student's study investigating the losses associated with mental ill health. We are seeking:

- men and women diagnosed with mental ill health by a Consultant Psychiatrist,
- who are in recovery,
- aged 18 to 60 years,
- are able to communicate in English,
- are prepared to invite members of their family/significant others (who are also able to communicate in English) to participate with them in the research,
- are prepared to meet with the researcher for a couple of interviews

This study has been approved by the Human Research Ethics Committees of the University of Western Australia, North Metropolitan Area Mental health Service and the South Metropolitan Area Health Service.

If you are interested in participating in this research, please contact:

Kanthi Perera on mobile 0431312263 or

Email 20557609@student.uwa.edu.au

Mohan Isaac
Professor of Psychiatry (Population Mental Health)
School of Psychiatry and Clinical Neurosciences
University of Western Australia
Appendix 2: Participant Information Sheet

The University of Western Australia

Professor Mohan Isaac
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PARTICIPANT INFORMATION SHEET
Research project investigating loss associated with mental illness: How is it perceived and managed by those affected?

I am the Chief Investigator and supervisor of the above project undertaken by Kanthi Perera, a PhD student in the School of Psychiatry and Clinical Neurosciences of the University of Western Australia. Kanthi is also a senior social worker working for North Metro Mental Health Service. We invite you to participate in this research. The Human Research Ethics Committees of the University of Western Australia and North Metropolitan Area Mental Health Service has approved this study.

Nature and purpose of the project
This study aims to investigate how people diagnosed with mental ill health by a Consultant Psychiatrist, and members of their family, perceive and manage the grief and losses caused by the effects of mental illness.

What your participation will involve
Your participation will require that you also invite members of your family to participate with you.

If you agree to participate, Kanthi will meet with you and members of your family to explain the project and answer any questions you may have. If you agree to go ahead, Kanthi will visit each of you separately for one or more face-to-face interviews where she will ask you some questions about your experiences and thoughts about losses associated with your illness. The interviews will be recorded.

Addressing concerns that you may have as a consequence of your participation
As a consequence of the questions asked at interviews, you may experience a range of emotions including sadness or discomfort. If they do trigger emotional responses that you are unable to deal with, it is important that you seek support. Access to family counselors from ARA PMI Mental Health Carers & Friends Association and your key worker has been negotiated, if any of the participants wish to have help to deal with this sadness.
Potential benefits to you and society

The potential benefit of your participation is that those working in health services will have a better understanding of the losses that lead to the complicated grief of mental illness and an understanding of ways to lower the impact of this grief and breakdown of relationships. It will also give us a better understanding of the commonalities and differences in managing losses that are complicated.

Your rights as a participant

This study calls for voluntary participation. If you agree to participate and you or any of your family members become uncomfortable with the process, you have the right to end the interview and withdraw from the research at any time, without any reason or prejudice in any way. Any records of your participation will be destroyed unless otherwise agreed.

I guarantee that confidentiality will be maintained during this study. The records of the interview will be kept in a locked cupboard and only the researcher will have access to the key. Personal details will not be reported in any manner. All information gathered will be destroyed within 5 years of completing the project and writing the thesis. Your participation in this study does not prejudice any right to compensation which you may have under statute or common law.

If you agree to participate, the Consent Form should be signed, dated and returned to Kanthi in the attached stamped envelope.

Yours faithfully,

[Name]

[Title: Professor of Psychiatry (Population Mental Health)]
[Institution: School of Psychiatry and Clinical Neurosciences]
[Additional Information: Consultant Psychiatrist, Fremantle Hospital and Health Services]

The Secretary,
North Metropolitan Area Mental Health Service Human Research Ethics Committee
Private Mail Bag No. 1
Claremont WA 6910

ARAFMI Mental Health Carers' & Friends' Association

Perth
Tel 9427 7100

Midland
Tel 9347 5741
Appendix 3: Matrix of Theme-oriented & Cases-oriented Analysis of “Navigating”
Appendix A: A Stress-Vulnerability Model of MIH

STRESS VULNERABILITY MODEL OF MENTAL ILL HEALTH

Adapted from Stress vulnerability model of mental illness
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Appendix B: Tool for Assessing Your Intentional Family

Tool for Assessing Your Intentional Family
The "family" in this context is considered in the broadest possible sense as that group of people with whom you share a bond of connection. They could belong to your biological (legal) family or they could belong to a 'family' you have chosen because you feel comfortable with them and they support you or you have shared interests with them. In assessing your family of choice some helpful questions to consider are:

- Who is your family? (1) Biological? (2) In your "heart and mind"?
- Who belongs to both?
- With whom do you feel safe and comfortable?
- Whom would you invite to an important celebration in your life?
- Whom would you ask out of duty?
- With whom do you share your interests?
- Whom would you like to share a meal with or a cup of coffee?
- With whom do you feel most whole, least fragmented, most yourself?
- Where are you accepted, just as you are?
- When have you felt loved, guided and supported in a most wholesome way? Who was around you at that time?
- Who are the people in your life that have helped you to feel hopeful or who held hope for you, even when you were feeling hopeless?
- Who provides a nurturing presence in your life?

While you consider the questions above, write the names of those who belong to these two groups below in mind that some could belong to both groups.

Your Biological Family
(legally recognized family)

Your Intentional Family
(The family in your heart and mind)

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References
Time Line of Losses in your Life

1. What clear-cut losses have you experienced?
2. What ambiguous losses have you experienced [if any]? (e.g. divorce, adoption, a breakup of a relationship, a baby given for adoption, a child who ran away from home, a missing parent, a person you care about who is no longer as he or she used to be)?
3. How traumatic was this loss for you?
4. How did you move forward despite the ambiguity?
5. What cultural or religious values/beliefs (if any) helped your resilience?
6. What cultural or religious values/beliefs (if any) hindered your resilience?
7. Have you changed your views about any of your losses?
8. What reconstructions of meaning helped you (or would help you) to move on with your life despite your ambiguous loss?
9. What rituals helped you (or would help you) move on despite your ambiguous loss?
10. Have you ever been in a relationship where the other person seems to be missing emotionally or physically?
11. What mixed emotions or feelings do you have (or did you have) about this [if any]?
12. Do you feel torn about what you should do?