Thai family care givers’ lived experience in a crisis during their care for relatives with a mental illness

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This thesis is submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in Nursing

The University of Newcastle
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Statement of Originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University’s Digital Repository, subject to the provisions of the Copyright Act 1968.

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Statement of Authorship

I hereby certify that the work embodied in this thesis contains published papers of which I am a joint author. I have included as part of the thesis a written statement, endorsed by my supervisor, attesting to my contribution to the joint publications.
Dedication

This thesis is dedicated to my parents, husband, and sons, who have been a source of support and inspiration.
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Without your stories, this thesis would never been written.
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Abstract

The aim of the study was to explore family care givers’ lived experience of the crises that periodically occur in the course of providing care and support for mentally ill relatives. It was undertaken in a rural-urban community in Thailand and many of the participants were involved in subsistence farming while also providing high levels of care and support for relatives with mental illness.

The study was undertaken using a hermeneutic phenomenological approach. In-depth audio-taped interviews, using semi-structured open-ended questions, were conducted with 12 consenting participants. Follow-up interviews were undertaken with 10 of the participants originally recruited to the study. Other data collection techniques included the use of note-taking during the interview and maintaining a reflective field journal. Data were subjected to thematic analysis.

The results suggested that family care givers in rural-urban Thailand face a number of difficulties and challenges in providing care for their loved ones with mental illness; these include: practical daily struggles, confronting relatives’ worrying and disruptive behaviours, personal social and financial difficulties, and their own troublesome personal lives. The lived experience of care giving for the participants was largely one of ongoing predicament, or crisis, which involved four main themes: ‘Out of control’, ‘So alone’, ‘Confusion and chaos’, and ‘No way out’.

Consideration of the lived experience of the participants has highlighted the need for ongoing help and support for family care givers in rural-urban Thailand. It is important that health care providers can recognise and assess the significant burdens associated with family care giving for a relative with mental illness. When care givers face crisis situations it is important that practical help is provided in a timely fashion. Greater emphasis should be placed on improving the mental health literacy of village health care workers in Thailand, through training in basic mental knowledge and skills.
Glossary of terms

**Crisis** Hoff (2009, p. 495) defines crisis as “a state of acute emotional upset in which one’s usual problem-solving ability fails; occurs in response to an identifiable traumatic event, e.g., accident, victimisation, death of a loved one, divorce”. It is similar to a seminal definition of crisis by Caplan which is an upset of the equilibrium of an individual or system by a situation or problem (Caplan, 1964).

**Crisis intervention** “is a short-term helping process. It focuses on resolution of the immediate problem through the use of personal, social, and environmental resources” (Hoff, 2009, p. 4).

**Crisis management** “refers to the entire process of working through a crisis to its resolution and usually includes activities not only of the individual in crisis but also of various members of the person’s natural and/or institutional social network” (Hoff, 2009, p. 4).

**Family care giver** is a person such as a parent, spouse, sibling, and friend who lives with and provides care for relatives with mental illness.

**Mental illness** as defined by Lipsky and Leikin (2003, p. 841) “is any of a number of disorders that disturb a person’s thoughts, emotions, and behaviour. Some mental illnesses cause relatively mild distress, while others result in severe impairment and may require hospitalisation. Mental illness is also referred to as a psychiatric disorder, emotional disorder, or psychopathology. Common mental illnesses include depression, anxiety disorders, eating disorders (anorexia nervosa and bulimia) and psychosexual disorders (For example arousal or orgasmic difficulties and exhibitionism). Treatment depends on the nature of the illness and the severity of the symptoms”.

**Merit making** Burnard, Naiyapatana, and Lloyd (2006, p. 747) drawing upon Miles (1990) define merit making thus: “Merit making consists largely of doing good and is often expressed by a person visiting the temple, offering alms to monks or the poor and, generally, helping other people. Merit making has at least two functions. First, it is
a demonstration of a person’s commitment to the Buddhist principles of living a ‘good’ life: it is a good thing to ‘do good’ for its own sake. Second, it is sometimes felt to be a method of leavening the effects of bad Karma (accrued from this or a previous life). The degree to which it can have this effect is the matter of some debate.”

Psycho* psychiatric nurse is the term used by the Department of Mental Health, Thailand which refers to a professional nurse who has been either trained in a training programme in psychiatric nursing (16 weeks) or has a Master’s degree in Mental Health and Psychiatric Nursing (Division of Planning, 2012). [This definition is interchangeable. In Australia, and the UK, the term used is ‘mental health nurse’ (The Australian College of Mental Health Nurses, 2012; Unite the union, 2012) whilst the term ‘psychiatric-mental health nurse’ is used in the USA (American Psychiatric Nurses Association, 2012).]

Severe mental illness includes “a wide range of psychiatric diagnoses, but they have in common psychological symptoms that persist over time and are functionally disabling in daily living skills and in abilities involving social interactions, family relations, and jobs or education. People with schizophrenia, bipolar disorder, and major depression frequently meet these criteria. People with other disorders, such as anxiety disorders, are less often so disabled and the disorders may be more transitory” (Johnson, 1997, p. 247).
Glossary of Thai terms

Gag  A noise or similar sound made by a corrugated iron door or gate cracking and clanging as it opens and closes.

Baht  The basic monetary unit of Thailand (31.4 THB: USD$1 rate on 16 August, 2012).

Bang Lane  A main street in the area where the study was conducted.

Karma  “Action or doing”

“All kind of intentional action whether mental, verbal, or physical, is regarded as Karma…All good and bad action constitutes Karma” (Sayadaw, 2012).

In this study, most participants believed their situation was the result of sin associated with bad actions of themselves and/or their loved ones with mental illness.

Kratom  It is the common word for Mitragynaspeciosa which is a medicinal leaf harvested from a large tree of the Rubiaceae family native to Southeast Asia. It has also been used as an opium substitute and has a significant effect on mental functions (Kratom Association, 2013; Tanguay, 2011).

Krengchai  “An extreme reluctance to impose on anyone or disturb his personal equilibrium by direct criticism, challenge, or confrontation” (Mahidol University, 2002).

Ku  A derogative form of the first person pronoun ‘I’.

Maw  The word that Thai rural people often use to refer to all health officials.

Pa Nung  A traditional skirt worn by women which is considered too lowly a thing for men to wash.

Powsian  A good luck plant.
Thum-Jai  “A combination of being accepting, patient, understanding, reasonable, and having a sense of obligation” (Rungreangkulkij & Chesla, 2001, p. 123).

Saraburi  One of the central provinces of Thailand. The boundary of the province is located about 50 minutes’ drive from Bangkok.

Vera  Retribution for past sins.

Wai  The way Thais show respect to honourable people.
Conventions used in the thesis

- - -  Pause in speech of approximately 1-3 seconds

...  Previous detail omitted

Coffee  Bold indicates word/phrase spoken loudly

I made it.  Underline indicates crying
Chapter One
INTRODUCTION

INTRODUCTION

The aim of this study was to explore Thai family care givers’ lived experience of the crises that may periodically occur in the course of providing care and support for mentally ill relatives. While working as a nursing lecturer and later as a nurse in the field of mental health in Thailand, the researcher noted that many family members provide care for relatives with a mental illness. Typically, such family care givers are involved in supporting relatives whose mental illnesses are persistent and long term. Therefore, the ongoing involvement of family care givers is an important, if often overlooked, component of the overall care provided for people with severe mental illness.

The problems that often accompany mental illness are well known, and include medication non-compliance (Saunders & Byrne, 2002), the use and abuse of alcohol and illicit drugs, violence and destruction of property (Wellman, 2006), suicidal feelings and behaviours (Hoff, 2009), self-mutilation and running away from home (Finkelman, 1997). While these are often understood and treated as personal troubles, other family members may also be drawn into such problems, and the crises experienced by those suffering from illness can also be recognised as crises faced by family members involved in supporting them (Hoff, 2009).

It has been noted that when such crises occur, for example an episode of mental illness, many family care givers in Thailand do not seek medical or other forms of help early (Dangdomyouth, 2006). This may be because the family care givers involved believe that mental illness is caused by evil spirits. Accordingly, the affected relative may be taken to receive treatment from practitioners of folk medicine. They may also be taken to a temple for spiritual support through the actions associated with merit making and to see a monk who they believe can help release evil spirits out of their body (Burnard
et al., 2006; Dangdomyouth, 2006; Rungreangkulkiij, Chafetz, Chesla, & Gilliss, 2002; Sethabouppha & Kane, 2005). In addition, the poor mental health literacy (Jorm, 2000; Jorm et al., 1997) of care givers may mean that important symptoms are not recognised. In some instances it may be that the remission of symptoms of a previous episode of mental illness are interpreted as the disorder having been cured.

For many family care givers with relatives suffering from mental illness a poor understanding of the nature of psychiatric symptoms and treatments means that when crises such as flashbacks, suicide attempts or aggressive behaviours occur, they are shocked, distressed and find these difficult to manage (Dangdomyouth, Stern, Oumtanee, & Yunibhand, 2008; Gerhart, 1990; Sethabouppha & Kane, 2005). Furthermore, delays in seeking help, for instance, presenting to the hospital, can mean that by the time health professionals become involved psychiatric symptoms have become severe and the costs of hospitalisation, medications and other forms of treatment are much greater, than would have been the case, had help been sought earlier.

A strong case can be made for mental health professionals providing advice and support for Thai family care givers caring for people with mental illness, both in times of crisis and also on a more ongoing basis. However, crisis care should be targeted to specific needs. Exploration of the nature of the crisis is an important aspect of crisis intervention. Thus, any help provided by health professionals to family care givers ought to be based on a sound understanding of specific need.

As the study was conducted in Thailand, it is important that readers understand the socio-cultural and health service context of that country. Accordingly, this introductory chapter commences by providing background information on Thailand and Thai health beliefs. This is followed by an outline of health services in the country. The discussion then turns to consideration of mental health service gaps and the effects of these on family care givers, and precipitating factors of crisis. In the final sections of the chapter the aim and rationale of the study and the research question are set out, and an outline of the thesis is provided.
BACKGROUND

Thailand is located in South-East Asia. Politically the country has been a constitutional democratic monarchy since 1932. The King is the Head of State, the armed forces and the ruling Royal House of Chakri while the Head of Government is the Prime Minister. The official language is Thai.

According to the National Statistical Office of Thailand (2011), the total population is 65.9 million, comprising 32.3 million men, and 33.6 million women. The household size is around three - four persons. Even though married, many couples still live with their parents. In contrast to urbanised areas of the country, in rural areas there are more extended families than nuclear families (The National Statistical Office of Thailand, 2011).

Thai people highly value peace and show great respect and reverence to older people. Seniority is very important in Thai culture. Even in the current period of rapid modernisation, ancestors may exert considerable influence on the lifestyles of younger people (UNESCO Bangkok, 2010).

The main religion in Thailand is Buddhism, with some 93.4 per cent of the population being Buddhists (The National Statistical Office of Thailand, 2011). In addition to the specific spiritual foci of Buddhism, this religious framework also has an important bearing on Thai daily life exerting considerable cultural influence across the life span. A household socio-economic survey conducted in 2007 (The National Statistical Office of Thailand, 2007), showed that Thai people spend around 1.0 per cent of expenditure per household on activities related to religious practice.

Local health knowledge or Thai folk wisdom has been part of the lifestyles of Thai people for centuries and continues to hold considerable sway in relation to current health practices and policies. Evident in many parts of the country is the ongoing influence of traditional folk wisdom, sitting alongside the innovation and technological sophistication of modern medicine (Chakrabhand, 2006).
Thailand’s Ministry of Public Health, which is responsible for promoting, supporting, and coordinating all public health agencies in terms of providing health services, realises the ongoing importance of Thai health beliefs. Thai people have thus been encouraged to view traditional Thai health beliefs and practices as alternative treatment options co-existing with modern medicine. Thus, Thai people may access a variety of therapeutic alternatives, making decisions regarding those which are most likely to fit their community lifestyles, traditions, and cultures (Chakrabhand, 2006).

At the same time, many Thai people believe that mental illness is caused by bad spirits. Given widespread beliefs linking mental illness and evil spirits, many Thai people diagnosed with mental illness choose to use the health practices of folk wisdom rather than modern medicine. Others use both the traditional and modern options; a third group use only modern medicine (Burnard et al., 2006).

In the last decade, the World Health Organisation (WHO) launched an international campaign promoting mental health in public health settings. As a result, health professionals in all health care settings are being alerted to the importance of promoting mental health in the community (WHO, 2005). Despite such developments, large numbers of people continue to suffer from mental illness. The WHO estimates that as many as 450 million people are affected worldwide (WHO, 2010b). It has also suggested that in lower and middle income countries, where the gross national income (GNI) typically ranges between US$1,006 and US$3,975 per capita (World Bank, 2012), people with mental illness often experience barriers in accessing effective treatment and early intervention for mental health problems and disorders. In such countries median mental health expenditures per capita can be as low as US$0.59 and the number of health professionals (i.e. psychiatrists, other medical practitioners, nurses, psychologists, social workers, and occupational therapists) working in the mental health sector is also low at 10.1 per 100,000 population (WHO, 2011).

Thailand is one of the countries described by the WHO as being within the lower and middle income category (WHO, 2011). In 2011, there were more than 1.6 million patients diagnosed with mental illness out of a total population of almost 65.9 million
(Department of Mental Health, 2011). In 2007, Chisholm, Lund, and Saxena (2007) reported that only US$1.20–1.25 per person was expended annually for significant health conditions (schizophrenia, bipolar disorder, depression and hazardous alcohol use) in Thailand. In addition, most mental health professionals work in urban areas and there is a severe shortage of mental health services in rural areas. The general shortage of mental health professionals in Thailand is highlighted in the following statistics for 2008 as set out in Table 1-1 (Sahamethapat, 2011).

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As indicated in Table 1-1, psychiatric nurses are the largest group of mental health professionals in Thailand. Within the limitation of human resources, therefore, Thai psychiatric nurses play an important role in providing health services for mentally ill patients and their care givers. They work collaboratively with other professionals to provide a wide range of mental health services including promotion, prevention, treatment, and rehabilitation for people with mental illness and their families.

While Thailand’s Department of Mental Health, which has been part of the Ministry of Public Health since 1994 (Siriwanarangsan, Liknapichitkul, & Khandelwal, 2004; Wongrajit, 2009), recognises the very limited nature of available services, it also requires that professional services “assist the mentally ill who are unable to take care of themselves so that they stand a chance of returning to society and leading normal, productive lives” (Siriwanarangsan et al., 2004, p. 155). Likewise, Gerhart (1990) and Shore (2006) indicate that families of relatives with a long-term mental illness need professionals to provide assistance across a range of areas of need. For instance, care givers need help to develop knowledge about mental illness and its treatment, especially the signs of mental deterioration in their relatives; to provide coping strategies; to assist with care planning for the future; to facilitate opportunities to meet
with others encountering similar problems; and also to assist in accessing material help such as financial support and respite services.

Siriwanarangsan, Liknapichitkul, and Khandelwal (2004) report that the Department of Mental Health bears the overall policy responsibility for improving the quality of mental health services in the country, including initiatives to provide adequate mental health and psychiatric support; to increase people’s autonomy and involvement in self-care; to expand mental health services and facilities; and to improve the mental health literacy of the community in general, and families in particular. Moreover, there is also a focus on lowering the incidence of mental illness and investing in research on mental health promotion, illness prevention, treatment at all levels and rehabilitation.

Despite the efforts of the Department of Mental Health in trying to improve the quality of life of mentally ill people, accessing mental health services remains a barrier for many of them. Thailand has had a co-contribution health insurance program (30 Baht universal health care coverage policy) since 2001. As a result, Thai people are required to obtain a referral letter from their health care providers with whom they have registered for their health insurance, such as health centres or community hospitals, to access other hospitals without having to pay ‘out-of-pocket’ fees. However, a referral letter is not required when seeking emergency services or admission to hospitals. Holders of a disability identification card can access any public health service without the referral letter. Consequently, in most cases treatment is received from the nearest hospital, which is government funded; only people with very complex problems are referred to specialist psychiatric hospitals. However, the cost of treatments not covered by the universal health care policy, such as the use of some new antipsychotic drugs, is prohibitive (Bureau of Policy and Strategy, 2006).

In 2008, only 4 per cent of patients with mental illness could access mental health services. The high cost of care and the difficulties in accessing good quality mental health services are major problems faced by many (perhaps the majority of) people with mental illness in Thailand. Accordingly, people with severe and persistent mental illness struggle to access appropriate services and even when these are available there
is the problem of affordability. Under such circumstances, many such people discontinue treatment and suffer relapses, readmission, and the associated social stigma (Department of Mental Health, 2009).

In an effort to reduce mental health service gaps, the Ministry of Public Health has included two new generations of antipsychotic and antidepressant medicines in the National List of Essential Medications since 2010. This initiative aims to provide mentally ill patients with more choice in the treatment of mental disorder. Doctors in local hospitals have also been encouraged to diagnose and prescribe medication for mentally ill patients so that the cost of transportation to the psychiatric hospital can be reduced. The aim here is to reduce readmission and relapse rates caused by discontinued medication (Department of Mental Health, 2009). In the meantime, the National Health Security Office (NHSO), which is responsible for developing the health service system, has also supported and provided funding for management support and services for psychiatric patients (Bureau of Service Quality Development, 2011).

In addressing the serious service gaps referred to above, the National Department of Mental Health has adopted a policy direction in which mental health services are to be integrated into every area of the health service. Thailand is divided into 76 provinces, with each of these then divided into districts and sub-districts. Integration of mental health services has been implemented across each level of health care delivery as outlined below in Figure 1-1.
Figure 1-1 Mental health services in Thailand

*adapted from Health care levels in Thailand (Chakrabhand, 2006)
It is important to note that although services at the sub-district level are focused predominantly on health promotion and disease prevention, maintenance of prescribed treatments and referral to secondary or tertiary level care is also provided at the primary care level. At a district level, the focus is on secondary care with attention given to specific treatment for diagnosed mental disorders. At a provincial level, psychiatric, university and large provincial hospitals offer tertiary level services concentrating on specialist treatment and rehabilitation delivered by a multidisciplinary mental health team.

Since 1997, the Department of Mental Health has placed great emphasis on providing better mental health services for Thai people. A recently launched series of “Community Service Projects” provide services: (i) to produce mental health care handbooks that focus on home visiting services; (ii) to set up home visit centres and (iii) to operate home visits to patients discharged from hospital (Siriwanarangsan et al., 2004). More recently, the Department of Mental Health has set out a framework focusing on the further development of mental health services. The aims of this framework are to: a) build capacity so Thai people can achieve good mental health, b) promote and strengthen the role of mental health networks, c) to develop the quality of and accessibility to mental health services and education, and d) establish mechanisms to develop mental health services (Sahamethapat, 2011). Even though mental health services have been well established, family care givers and people with mental illness continuously report that problems caused by mental illness have led to crises.

Research conducted in Thailand by Vanaleesin, Chetchaovalit, Aowchareon and Chaimongkol (2003) found that many care givers of relatives with mental illness also suffer from emotional problems. Similarly, Sethabouppha and Kane (2005) have reported that care givers typically experience emotional distress as well as economic and social problems and often have knowledge deficits about the causes and symptoms of mental illness. As a result, many care givers felt that they struggled to effectively manage and cope with the life circumstances of their mentally ill loved
ones, especially when the latter were experiencing a relapse or a serious deterioration in their condition.

In addition, for many, the care giving role can be a long term commitment (Kendrick, Burns, & Freeling, 1995; Levine & Ligenza, 2002) which from time to time requires having to deal with severe degrees of illness (Johnson, 1997). Furthermore, due to the many possible precipitant factors of crisis, including relapses, high cost of treatment, and severity of signs and symptoms, recurrent crises can be faced by family care givers (Finkelman, 1997; Lefley, 1996; Rose, Mallinson, & Gerson, 2006). The experience of crisis of family care givers is acknowledged as a highly stressful life event (Lefley, 1996). The need for professionals and other support systems for family care givers during times of crisis has also been investigated (Gavois, Paulsson, & Fridlund, 2006; Levine & Ligenza, 2002). Such needs must be recognised and appropriate support provided according to individuals’ experience of crisis (Lewis, 2005; Roberts, 2005). To date, however, there has been a gap in research exploring the lived experience of crises from the perspective of care givers who provide support for their mentally ill loved ones at home in Thailand. In order to better understand the support required by these care givers, it is important that this gap be investigated and addressed.

**AIM OF THE STUDY**

The aim of this research project was to explore care givers’ lived experiences of crisis while caring for mentally ill loved ones. This has been done so that the essence of experience of crises from the perspectives of family care givers of mentally ill relatives in the Thai community can be better understood. It is expected that the outcomes of the study will contribute to the development of strategies that can be used by mental health professionals to assist care givers to more effectively deal with and manage crises associated with providing care and support for loved ones with mental illness.
RESEARCH QUESTION

The study sought to answer the following research question: “What is the lived experience of Thai family care givers in a crisis during their care for relatives with a mental illness?”

JUSTIFICATION FOR THE STUDY

Relatives of mentally ill loved ones expect the care giving period to be long (Chisholm et al., 2007; Kendrick et al., 1995). Existing literature indicates that family care givers suffer difficulties especially during the crises that periodically occur. Crises can result from specific behaviours associated with the mental illness such as suicide attempts, and violence (Finkelman, 1997; Hoff, 2009; Lefley, 1996; Saunders & Byrne, 2002; Wellman, 2006). Care givers can also face crises related to deficits in available services, for example difficulties accessing mental health services, or the high cost of treatment. Any of the crises faced by care givers are likely to be compounded by the social stigma related to mental illness and the shame and embarrassment that care givers may also experience by association (Lefley, 1996).

Crises and a need for crisis management related to mental illness have been reported in many countries (Irving, Adams, & Rice, 2006; Winness, Borg, & Kim, 2010). Previous Thai studies (Rungreangkulkij & Chesla, 2001; Sethabouppha & Kane, 2005) as well as studies undertaken in other countries (Chaffey & Fossey, 2004; Champlin, 2009; Chang & Horrocks, 2006; Daly, 2005; Endrawes, O’Brien, & Wilkes, 2007; Howard, 1998; Johansson, Anderzen-Carlsson, Åhlin, & Andershed, 2010; Jung, 2000; Karp & Tanarugsachock, 2000; Nyström & Svensson, 2004) have highlighted the experiences of care givers providing care for relatives with mental illness. In Thailand, there is a lack of research focusing on the lived experience of family care givers in a crisis. A clear understanding of crises from the care givers’ perspectives within their specific context is necessary so that mental health professionals can provide care givers support which suits their needs. It is anticipated that the findings from this study will raise awareness among mental health professionals regarding the needs of family care givers during
crises. A research approach was needed that would allow family care givers to freely express their experiences of crisis. Accordingly, phenomenological research was selected to conduct the study.

**ORGANISATION OF THE STUDY**

The research project reported in this thesis is presented in six chapters. The introduction, literature review, methodology, and research methods are described in Chapters One, Two, Three, and Four respectively. The findings of the study are presented in Chapter Five. The final discussion chapter also includes a section outlining the researcher’s reflections and a conclusion. An outline of the content of each chapter is provided below.

**Chapter One:** The introduction provides the background, aim, research question, and justification of the study. The structure and organisation of the thesis is also summarised in this initial chapter.

**Chapter Two:** The literature review commences with an outline of the search methods that have been used to access relevant professional literature. The issues that impact upon mental illness, family care givers, care giving, and crisis and their relationship are explored. The major issues surrounding the experience of care givers are discussed.

**Chapter Three:** This chapter introduces phenomenology as the research methodology used to conduct the study. Transcendental, existential, and hermeneutic phenomenology are described. This chapter also provides the rationale for choosing a hermeneutic phenomenological approach guided by the work of van Manen (1990) to conduct the study.

**Chapter Four:** This chapter provides a description of the design and research procedures used to conduct the study. The processes used to collect and analyse the data are outlined and the approaches used to ensure the rigor of the study and to protect the confidentiality and privacy of the participants are discussed.
Chapter Five: The findings of the study are presented in this chapter. The aim here is to present and interpret the data so as to maintain the voice of the participants. The essence of the participants’ lived experience is defined. Themes, sub-themes, and significant statements emerging from data are offered.

Chapter Six: This final chapter concludes the thesis. The four main themes that emerged from the study are discussed in relation to other relevant research in the field, in both Thailand and in other countries. The chapter also includes a section in which the research candidate discusses the findings of the study through the lens of van Manen’s four lived worlds (van Manen, 1990). A further section outlines the implications of the study for education, clinical practice, and further research into the needs of care givers of relatives with mental illness. The researcher also reflects on the experience of conducting the project and discusses the limitations of the study. The chapter ends with a brief section concluding the thesis.

References and appendices are provided at the end of the thesis.

CONCLUSION

This chapter has provided an overview of the study. The background of Thai society as well as health and mental health services has been discussed. Thai beliefs of mental illness effecting treatment choices have also been described. Precipitating factors of crises caused by mental illness as well as the care giving process are presented in brief. Consideration of the factors mentioned above has highlighted the need to undertake research to explore the lived experience of Thai family care givers experiencing a crisis. The aim of the study, research question, justification for the study, and organisation of this study are also provided. The next chapter provides an overview of the literature addressing the family care giver role in the mental health field, with particular emphasis on experience of care givers during crises.
Chapter Two
LITERATURE REVIEW

INTRODUCTION

This chapter reviews the research literature relating to the experience of family care
givers of relatives with a mental illness. It has a specific focus on crises that occur when
caring for people with mental illness. The aim of this literature review is to provide an
overview of existing knowledge related to family care givers’ experiences of crises
encountered during the care of their mentally ill loved ones. In this chapter the reader
will be guided through the search strategy used to obtain the relevant research
literature. The definition of crisis used in this study is presented, followed by a critical
review of the major issues surrounding experiences of care givers. Finally, what is not
known about care givers’ experiences of caring for mentally ill relatives is discussed.

SEARCH METHOD

A comprehensive online search was undertaken using nursing and health databases,
including CINAHL, COCHRANE LIBRARY, MEDLINE, EMBASE, Scopus, MOSBY’S
INDEX and the Joanna Briggs Institute. The search was extended to include Thailand’s
Mental Health Department and Thailand university websites, databases of studies in
the Thai language, Google Advanced Scholar search engine, dissertations, theses and
books accessed via the NEWCAT Catalogue. A manual search was also undertaken to
find relevant articles, books, and unpublished papers not available in the nursing and
health databases. Auto-search alert was set in online databases to update the latest
relevant articles. Abstracts of relevant articles and papers were read. Only articles and
papers related to this study were selected. Duplicated articles were checked and
deleted. Search terms and their synonyms include: cris*, difficult*, challenge*,
experience*, lived experience*, meaning, care giver*, caregiver*, carer*, caring,
caregiving, care giving, family, famili*, mental illness, and mental disorder. Exclusion
criteria for this literature search were ‘health care provider*’ and ‘health professional*’
as care givers were the primary focus in this review. There were further exclusion criteria for relevant articles studied on antipsychotic drugs or medications, adolescents as care givers, and caring for people with cognitive impairment or mental retardation. The search was limited to English language articles and primarily publications from 2002 - 2012. A limited number of articles published before 2002 and in the Thai language have been included where appropriate.

RESULTS

Only material relevant to the research question “What is the lived experience of Thai family care givers in a crisis during their care for relatives with a mental illness?” was included in this literature review. Secondary sources such as books, government reports, theses, and dissertations were used to provide the reader with background knowledge regarding care givers’ experiences of crisis and to reveal the extent of the problem in Thailand. Articles were retrieved mainly from CINAHL, MEDLINE, and EMBASE. The literature examined focuses specifically on care givers’ experiences of crises associated with caring for relatives with mental illness. Topics identified as relevant to crisis and caring for a mentally ill relative include the definition of crisis, mental illness and crisis, and support systems. These topics are discussed in the following sections.

DEFINITION OF CRISIS

The early work on crisis was undertaken by two pioneers Gerald Caplan and Erich Lindemann (Rapoport, 1965). In 1964, Caplan (1964) defined crisis as an upset of the equilibrium of an individual or system by a situation or problem. Rapoport states that a crisis occurs because “the habitual problem-solving activities are not adequate and do not lead rapidly to the previously achieved balanced state” (Rapoport, 1965, p. 24). Similarly to Caplan and Rapoport, Hoff (2009, p. 495) defines crisis as “a state of acute emotional upset in which one’s usual problem-solving ability fails; occurs in response to an identifiable traumatic event, e.g., accident, victimisation, death of a loved one, divorce”.

In this study, the focus is on the impact of crisis experienced by family care givers in the course of providing care to a relative with mental illness living at home. Family care givers may find themselves in crisis for at least two reasons. Firstly, as a result of the mental illness of their relatives (Roberts, 2005), such as relapses (suicide attempts and violence). Secondly, as a direct result of the care giving role, for example financial strain, isolation associated with a lack of support, difficulty accessing mental health services, emotional and physical burdens, and stigmatisation related to community ignorance or fear of mental illness (Lefley, 1996; Levine & Ligenza, 2002).

The stages of crisis

During a crisis, the person finds it difficult to achieve a balance between the stressful event and utilising available resources to deal with it. The stages of crisis were first described by Caplan (1964) and later by others (Hoff, 2009; Roberts, 2005; Rosen, 1997) as:

1. The person’s anxiety level and sense of self-risk is increased as a result of a stressful event. This “[calls] forth habitual problem-solving responses” (Caplan, 1964, p. 40) designed to return the person to a state of homeostasis.

2. Failure to solve the continuously stressful stimuli in the time expected further increases tension. This results in the person feeling upset and being ineffectual in their responses.

3. As tension rises, the person tries to maintain their personal sense of equilibrium using reserves of strength and attempts to seek new methods of coping. The person may explore the stressful event in a new way and may utilise coping mechanisms that have been neglected to that point. As a result, the stressful event may be solved, redefined to achieve need-satisfaction, or avoided through need-resignation.

4. Conversely, if the stressful event continues, the tension and anxiety continues to rise. The person will go beyond the threshold and reach breaking point. Major disorganisation and maladaptation will occur, exhibited by some or all of the following: shock, rigidity, compulsion, suspiciousness, depression, disruptive
behaviours, and extreme withdrawal. Hoff (2009, p. 21) states the effects of crises are manifested in four areas of human functioning:

1. Emotional: anxiety, fear, psychic pain, anger, and shame,
2. Biophysical upsets: nausea, diarrhoea, headaches, chest or abdominal pain, rash, and rapid heartbeat,
3. Cognitive: interference in usual problem-solving ability, and
4. Behavioural changes: cannot perform usual work demands, becoming demanding or withdrawn, acting on impulse or atypically.

Generally, a crisis state has a time limitation of one to six weeks (Caplan, 1964), however, for people with a mental illness a crisis may last longer. They may have prolonged crises frequently throughout their lives as well as an ongoing sense of helplessness, loss of control, disruption to work, social interactions and family life. There is also a degree of perceived danger to self and others (Marsh, 1992).

**Precipitating factors of crisis**

Lydia Rapoport has been the most thorough in describing the precipitating factors of crisis (Roberts, 2005). She stated that there are three relevant factors that contribute to a state of crisis. They are as follows (1965, pp. 25-27):

1. a hazardous event which poses some threat,
2. a threat to instinctual need which is symbolically linked to earlier threats that resulted in vulnerability or conflict, and
3. an inability to mobilise effective coping mechanisms.

Care givers caring for relatives with mental illness may face various factors that lead to crisis during their care for loved ones with mental illness. The details of how care givers may face such crises caused by mental illness are described below.

**MENTAL ILLNESS AND CRISIS**

**Definition of mental illness**

There are numerous definitions of mental illness (Healey, 2010; WHO, 2010a). Lipsky and Leikin (2003, p. 841) define mental illness as:

any of a number of disorders that disturb a person’s thoughts, emotions, and behaviour. Some mental illnesses cause relatively mild distress, while others result in severe impairment
and may require hospitalisation. Mental illness is also referred to as a psychiatric disorder, emotional disorder, or psychopathology...Treatment depends on the nature of the illness and the severity of the symptoms.

Common mental illnesses include depression, anxiety disorders and eating disorders. Psychotic disorders, while less common are usually severe and highly disabling; examples include schizophrenia and bipolar disorder. In this study, diagnosis of a potential participant’s relative with mental illness is defined by The International Statistical Classification of Diseases and Related Health Problems ICD-10 within the code Mental and Behavioural Disorders (F00-F99).

**Mental illness cycle**

Illness can be characterised as consisting of an onset (acute and chronic or persistent), a course (progression, constancy, and relapsing or episodic), an outcome (fatal, shortened life span, and non fatal), and a degree of impairment (mild to severe) (Rolland, 1989). These four characteristics can also be used to explain the mental illness cycle (Marsh, 1992). During the acute phase of mental illness, family care givers must adjust their roles and coping mechanisms to solve problems that arise from psychotic symptoms. At the same time, persistent mental illness may allow time for family care givers to adjust to the illness. However, care givers may face severe symptoms, and unpredictable relapses including suicide attempts, self-harm, and violence from their mentally ill loved ones. As a result, caring for someone with a mental illness requires family care givers to maintain a preparedness to respond quickly to relapses.

The prognosis of severe mental illness is variable and unpredictable with a range of possibilities including complete recovery, partial recovery, or no recovery. Some family care givers may not be able to predict the course of their loved one’s illness. They live with uncertain situations and continually adapt themselves to one extreme change after another (Levine & Ligenza, 2002). The person with a mental illness may be severely impaired and both the person with the mental illness and the family care givers may experience social stigma. As one mother of a son with schizophrenia has said “…[he]’s been laughed at and ridiculed…he will never hold a meaningful position or even marry” (Marsh, 1992, p. 74).
Deinstitutionalisation

Since the late 1960s and early 1970s, a policy of deinstitutionalisation has been adopted in many countries including Australia, the USA, the UK and Italy (Burti, 2004; Hazelton & Clinton, 2004). People with mental illness have been moved from hospitals into the community (Ip & Mackenzie, 1998; Marsh, 1992; Stuart, 2005). Many return home and live with their families who become the primary resource providing care for the mentally ill person. Since 2004, as part of the Asia-Pacific Community Mental Health Development Project, the Thai Department of Mental Health has been involved in a planned process of deinstitutionalisation for people with mental illness. The results of this process have not as yet been reported (Asia-Australia Mental Health, 2008).

Family care givers’ capacity to effectively care for the person with a mental illness has been shown to be negatively impacted by limited resources including qualified staff, underfunding from health budgets, and a lack of structured community mental health services (WHO, 2001). Frequently, there is no support and guidance for care givers (Marsh, 1992) or the community (Stuart, 2005). Family care givers lack the required information and frequently lack the skills needed to provide effective care. They face difficulties dealing with the signs and symptoms of illness which occur repeatedly in the mental illness cycle (Marsh, 1992). As a result, caring for a mentally ill family member has often been reported to be a burden (Hazelton, Habibis, Schneider, Davidson, & Bowling, 2004).

Thus far, it has been noted that families are frequently the primary providers of care for relatives with a mental illness, and that despite there being formal public policy in many countries, deinstitutionalisation has been identified as contributing to the stress associated with the care giving role (Saunders, 1999). Although the impact of caring on family care givers can be both positive and negative (Chen & Greenberg, 2004; Rungreangkulki & Gilliss, 2000), this literature review focuses on crises as experienced by family care givers providing care for their mentally ill loved ones at home.
Mental illness: Precipitating factors of crisis and its impacts on family care givers

The person with a mental illness may experience periods of stability interrupted by crisis, precipitated by factors that are sometimes clearly identifiable, and at other times unidentifiable. To this end, existing knowledge suggests the most common precipitating factors for crises associated with mental illness include medication non-compliance, running away from the home, abuse of alcohol and drug use (Finkelman, 1997), suicidal feelings and behaviours (Hoff, 2009; Kavan, Guck, & Barone, 2006), destruction of property, and self-mutilation (Wellman, 2006). Further precipitating factors include positive symptoms (hallucinations, delusions), negative symptoms (social isolation, a lack of motivation) (Friedrich, Lively, & Buckwalter, 1999; Saunders, 1999), unpredictability of emotion and behaviours, or a history of aggression (Ip & Mackenzie, 1998). These factors impact not only on the person who is ill but also on the care givers. Family care givers repeatedly describe these factors as stressful (Rose, Mallinson, & Walton-Moss, 2002).

In a study conducted in Hong Kong primary care givers supporting a relative with serious mental illness had to deal constantly with the psychotic symptoms of their loved ones including unpredictable emotions and aggressive behaviours, and the possibility of harm to the person who was ill, themselves, or others. Consequently, they were afraid, fearful and tended to avoid situations that might have resulted in tension and disagreement between themselves and their mentally ill relatives. This avoidance behaviour, however, failed to prevent harm occurring. When this happened in a public context, care givers tended to feel humiliated. This humiliation resulted in the care givers withdrawing and becoming socially isolated. As a result, they felt distressed by what they saw as ‘unresolvable behavioural problems’ (Ip & Mackenzie, 1998).

Friedrich et al. (1999) have investigated the impact of mental illness on healthy people living with a sibling with schizophrenia. The participants in this study had been coping with hallucinations, delusions, verbal and physical abuse, and the withdrawal of their
mentally ill siblings. As a result, they faced ongoing psychological distress as well as frustration, embarrassment, anxiety, sadness, and anger.

Saunders (1999) conducted a study to explore the influences of family coping behaviours, psychological distress, social support, and patient behavioural problems on family functioning in families providing care for a member with schizophrenia. The findings of this study indicated that families could function well if they had social support, low family psychological distress, and low behavioural problems of ill relatives. Problem behaviours of the ill loved ones included too much idle time, emotional/social withdrawal, too much reliance/dependence upon people in the home, money management problems, sleeping problems, and odd speech/behaviour or having unusual/unreasonable ideas.

Levine and Ligenza (2002) conducted a qualitative study using focus group interviews with 55 family care givers in the USA. The study aimed at understanding the experiences and needs of care givers in a period of crisis. Participants felt that their lives had changed after the illness. They were faced with having to manage their mentally ill loved one’s symptoms, including bizarre behaviours, poor hygiene, self-abuse, violence, co-occurring substance use, loneliness and isolation, lack of insight, and inability to manage independently. They clearly considered that their loved one’s mental illness could put them into a state of crisis.

Ferriter and Huband (2003) conducted a study of parents with a son or daughter suffering from schizophrenia. Participants described the most difficult behaviours of their children with mental illness as including violence, withdrawal, verbal aggression, undue suspiciousness, and poor self-care. Although they claimed that they were used to such difficult behaviours, as reported by the researchers, participants had limited capacity to cope with troublesome behaviours and often became emotionally distressed.

In the Thai context, the very limited available research suggested that the exhaustion experienced by care givers resulted from their efforts to prevent and/or manage
ongoing symptoms. In the study reported by Dangdomyouth, Stern, Oumtanee, and Yunibhand (2008) family care givers had tried to prevent psychotic episodes occurring for their mentally ill relatives. They used ‘tactful monitoring’: unobtrusive observation (For example, keeping an eye on them, watching them at night, checking medications); verbal communication (such as, asking about symptoms, reminding the mentally ill relative to take their medication); and preventing them from over-consumption of stimulants (For example ‘Red Bull’). In addition, family care givers sometimes used calming-down strategies. They gave their mentally ill relatives medicine, took them to hospitals, offered them their favourite objects, used kind words, and ensured adequate personal space. However, even with these preventive measures, psychotic symptoms still occurred. Care givers frequently provided care over long periods of time without social support or home care services. As a result, those providing care at home frequently faced exhaustion. Many appeared tired and sad during the study process.

Another Thai study found that care givers attempted to control recurring psychotic episodes. They followed the hospital instructions for care including staying calm, presenting reality, observing symptomatic behaviours, and monitoring antipsychotic medicines. However, despite following these instructions psychotic symptoms persisted, and resulted in the need for physical restraint (Sethabouppha & Kane, 2005). A further Thai study stated that care givers often managed a threatening situation by themselves because of a lack of support. For example, one mother threatened with a knife by her mentally ill daughter, stayed calm and spoke softly until another family member arrived to help. In contrast, another just walked away from the situation (Rungreangkulkij & Chesla, 2001).

During relapses evidenced by the reappearance of acute psychotic symptoms, Thai family care givers often took their mentally ill relatives to folk healers for the traditional treatments as would be consistent with their belief system (Sethabouppha & Kane, 2005; Vanaleesin et al., 2003). Despite these efforts, psychotic symptoms still worsened with the result that care givers often become overwhelmed with guilt (Vanaleesin et al., 2003).
In summary, the existing knowledge has highlighted the extent to which some family care givers face difficulties and emotional problems in dealing with psychotic symptoms (Dangdomyouth et al., 2008; Ferriter & Huband, 2003; Ip & Mackenzie, 1998; Rose et al., 2002; Rungreangkulkit & Chesla, 2001; Sethabouppha & Kane, 2005). Care givers may be unable to respond to psychotic symptoms in a timely and effective fashion. As a result, opportunities may be missed to intervene early to manage escalating symptoms, where such intervention might have averted a crisis (Hoff, 2009; Lefley, 1996). Importantly, care givers may also encounter a personal crisis precipitated by difficulties arising from their loved one’s mental illness. While some family care givers may obtain positive resolutions and personal growth from their crisis management, others may be drawn into the psychological distress of their mentally ill loved one. Even though care givers may learn over time and may gain both the knowledge and skills required to cope with difficult behaviours, they still suffer significant distress (Dangdomyouth et al., 2008; Ferriter & Huband, 2003; Friedrich et al., 1999; Ip & Mackenzie, 1998). It is apparent from the literature review thus far that not only are care givers attempting to deal with the crises associated with mental illness, they are also personally affected and may face their own crises arising from the stress and distress of caring for a mentally ill relative (Hoff, 2009). The next section examines the literature specific to the care giving process and crisis.

**Care giving: Stress and burden**

To understand how family care givers might experience the impact of the care giving process, a conceptual model of the cumulative sources of stress for family care givers has been chosen to illuminate this issue (Lefley, 1996). The multiple sources of stress faced by family care givers can be approached under three domains: iatrogenic, societal, and situational (Lefley, 1996). The iatrogenic domain includes clinician deficits, such as ineffective communications by professionals, inappropriate therapy, and inadequate training and/or support for providers.

The societal domain incorporates cultural attitudes to families and people with mental illness and service system deficits. Included here are media announcements that
stigmatise mental illness, the mentally ill and professional and lay care givers, including topics such as the role of parents in the causation of mental illness; the lack of acknowledgement of family burden; the extent to which the stigma of mental illness may include family care givers and other relatives; inadequate funding for research and services on mentally ill persons; negative expectations of recovery on the part of the community; societal abandonment of the mentally ill; difficulties in accessing hospital care when required; legal constraints, premature discharge, and inadequate community support systems.

The situational domain addresses family care givers’ experiences of living with mental illness. The impact of this domain combined with that of the other two domains create a considerable burden for care givers. This burden can be either objective or subjective in nature. Objective burden “refers to the number and type of tasks involved in care giving”, while subjective burden is “the perceived difficulty or distress connected with each task” (Lefley, 1996, p. 67). The iatrogenic, societal, and situational domains as expressed through the notion of family burden may constitute sources of considerable stress for family care givers and may also lead to crises. As Lefley (1989) has pointed out, the interaction of families with emergency services and/or police, and difficulties in finding appropriate treatment, especially hospitalisation, for relatives with abusive behaviours, may be experienced as periodic crises by care givers.

Similarly, Parad and Caplan (1965) and Hoff (2009) have suggested that just as individuals have crises, the stresses and strains of care giving can create a crisis for families. In this sense, family care givers, whilst trying to deal with crisis caused by violence or a suicide attempt may also be exposed to iatrogenic, societal and situational pressures. Thus, although an individual crisis may have been dealt with, the family care givers supporting the person with mental illness may remain in crisis. Previous studies described below demonstrate the impacts of stress and strains toward care givers.

Many studies have found that caring for a mentally ill relative is typically accompanied by financial difficulties (Ambikile & Outwater, 2012; Crowley, I’Anson, Sanders,
Elford, & Nankervis, 2005; Huang, Hung, Sun, Lin, & Chen, 2009; Nagaoka, Furegato, & Santos, 2011; Saunders & Byrne, 2002). Social stigma and legal concerns have frequently been reported by care givers (Huang et al., 2009; Saunders & Byrne, 2002; Tryssenaar & Tremblay, 2002). Difficulties have also often been faced in accessing mental health services and supports (Ambikile & Outwater, 2012; Crowley et al., 2005; Gavois et al., 2006; Harden, 2005; Huang et al., 2009; Nagaoka et al., 2011; Tryssenaar & Tremblay, 2002). Care givers have often been reported as experiencing chronic emotional distress (Ambikile & Outwater, 2012; Crowley et al., 2005; Harden, 2005; Tryssenaar & Tremblay, 2002). Other negative impacts associated with providing care for a mentally ill loved one include having to deal with distressing symptoms, for example social withdrawal, violence, and verbal aggression (Huang et al., 2009; Moleft & Swartz, 2011). Studies have clearly linked care giving with suffering and the burdens of caring (Huang et al., 2009; Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004; Seloilwe, 2006; Sethabouppha & Kane, 2005; Tryssenaar & Tremblay, 2002). The difficulties, burden and suffering associated with care giving in this context have long been recognised as highly stressful (Lefley, 1996).

Ip and Mackenzie (1998) reported emotional expression described by seven primary care givers. These care givers included a wife, a mother, a husband, and a sister providing care for relatives with serious mental illness in Hong Kong. The participants in this study had been providing care for a mentally ill loved one from 3 to over 20 years. Despite differences in sex and relationship to the person with mental illness, participants faced similar difficulties associated with their care giving role, such as disruption to social life and family functioning, a lack of support and financial strain. Ineffective or only partially effective coping mechanisms such as avoidance and denial were typically used in response to the difficulties associated with care giving. Participants faced high levels of emotional distress as part of care giving, for instance, anger, disappointment, frustration, fear, fright, sadness, hopelessness and helplessness. As a consequence, many participants had themselves been suffering from mental health problems.
Tryssenaar and Tremblay (2002) reported ageing care givers’ experiences of caring for relatives with serious mental illness in a rural community in Canada. Care givers experienced challenges associated with rural life including a lack of continuity of mental health services and other supports for example counselling, volunteers, community support workers, and stigma. Stress and burden of care giving were reported as a consequence of a lack of support by the police; this left the participants feeling powerless and helpless. As care givers were of an advanced age, they were exhausted and able to provide only basic care. They felt sad realising that their loved ones had lost their future life.

A qualitative study by Saunders and Byrne (2002) has further highlighted the difficulties associated with caring for a relative with schizophrenia. Care givers were confronted with the relatives’ non-compliance with prescribed medication. The refusal of mentally ill loved ones to take medication was experienced by the participants as extremely frustrating and heartbreaking. Care givers also faced difficulties with the impact of mental health legislation, especially that relating to involuntary treatment during the onset of illness. For some parents, mental health professionals were regarded as an important source of support. In contrast, however, others felt hopeless and helpless in their encounters with mental health services and professionals.

Jungbauer, Wittmund, Dietrich, and Angermeyer (2004) studied subjective burden in 52 spouses of people with schizophrenia. The spouses faced multiple burdens associated with the onset of schizophrenia. These included having to take over unfamiliar and gender-specific tasks which were once the responsibility of the partner with schizophrenia, dealing with conflict between the spouses, and facing crisis in their partnership, such as divorce.

A study by Crowley, I’Anson, Sanders, Elford, and Nankervis (2005) investigated experiences of care givers of people with mental illness including anxiety, depression, and eating disorders using focus groups and individual interviews. Care givers experienced economic losses, and limitation of information, treatment and supports provided from health care professionals. They reported that they frequently
experienced physical and emotional exhaustion, chronic stress, depression and grief as a result of care giving.

A study in Scotland by Harden (2005) reported similar experiences of parents of young people with psychiatric conditions. Parents faced difficulties including a lack of mental health services and emotional distress. They reported that health professionals rarely listened to them and provided inadequate information regarding their children’s illness. They felt isolated, distressed, helpless, frustrated, and excluded from care.

Families with loved ones with mental illness in Botswana experienced stress, burden, and suffering (Seloilwe, 2006). Participants felt stressed and suffered from unpredictable behaviours and relapses of their loved ones. They also suffered embarrassment by being abused from relatives with mental illness. The participants in this study felt burdened due to a lack of resources to assist them in dealing with the demands of care giving.

Gavois, Paulsson, and Fridlund’s (2006) study showed that for the family members of a relative with severe mental illness the initial crisis is often the onset of the illness. During this time, other pressures mount including concerns over the disruption to the mentally ill relative’s daily living and difficulties in accessing health services. Family care givers were often angered and disappointed at what was perceived to be a lack of support by mental health professionals. As a result, they felt socially isolated. In many instances care givers remained in crisis for more than a year, especially if they were disconnected from mental health professionals.

A study in Taiwan explored the experiences of care givers living with someone with long-term schizophrenia (Huang et al., 2009). Care givers indicated the difficulties of a lack of professional and financial support, stigma, and emotional burdens including sadness, worry, and shame. They also faced family conflicts as a result of the interactive barrier among family members including couples and siblings.

In Australia, Foster (2011) reported that family care givers experienced many difficulties during their care for relatives with mental illness. Care givers faced long-
term burdens, including work demands and caring tasks for ill relatives and other family members. Other burdens included troubles with neighbours and the police. Caregivers also reported experiencing a lack of support from health professionals. These burdens affected the mental health of the participants, and involved long periods of stress and grief.

A study in South Africa investigating the experiences of families of people with schizophrenia reported similar findings (Moleft & Swartz, 2011). Family caregivers experienced verbal aggression from their relatives with schizophrenia. They also faced stigma towards themselves and their loved ones. They reported having very little knowledge about their relatives’ mental illness since the doctor rarely provided any information.

A study by Nagaoka, Furegato, and Santos in Brazil (2011) reported the burdens experienced by caregivers as a result of relatives with mental illness being unemployed. These burdens included the caring task, and insecurity regarding the future of their relatives. Caregivers also faced insufficient mental health services and lack of information in relation to their relatives’ illnesses.

Ambikile and Outwater (2012) explored the psychosocial and emotional, social, and economic challenges experienced by caregivers of mentally ill children. The study showed that caregivers were exposed to emotional distress including the stress of the caring task, worrying about their children’s future, and sadness and pain due to their children’s disturbing behaviours. In terms of social challenges, caregivers experienced inadequate social services and supports for their children, stigma and problems with social life, and burden of care. They also pointed to economic difficulties including poverty and the extra expenses associated with their children’s illness.

In the Thai cultural context, families are traditionally regarded as the primary resource of care giving for ill and elderly people. However, it has been acknowledged that living at home with a mentally ill relative presents a particular challenge because there are
limited opportunities for respite. Accessing health professionals’ home health care visits is difficult if not impossible (Dangdomyouth, 2006; Sethabouppha & Kane, 2005).

Sethabouppha and Kane (2005) highlighted that family care givers were responsible for all the housework and were earning all the money required to meet household expenses. They described this as their ‘inescapable’ physical burden or objective burden as defined by Schene, Tessler, and Gamache (1996). They experienced negative feelings and difficulties in dealing with the psychotic symptoms of their mentally ill loved ones. Care givers were frightened that the mentally ill family members could harm or kill them at any time. Another source of suffering was the financial strain of the cost of treatment and medications. The family care givers sometimes had no money to buy medications for their mentally ill loved ones, who, as a consequence, relapsed. Moreover, having a family member with mental illness at home was a source of shame and embarrassment. Care givers avoided talking to neighbours about their sick relative, and felt stigmatised and under constant social strain. Another important source of suffering was the lack of knowledge about the nature and causes of mental illness. The participants felt under constant threat of being assaulted by their mentally ill relatives but did not know how to prevent or respond to such situations.

Previous studies have revealed the nature and extent of the burden associated with providing care for a family member with mental illness. The findings of existing studies indicate the multiple sources of stress to which family care givers are exposed. These stressors can be categorised as: iatrogenic, societal, and situational; there is little doubt that such stressors contribute significantly to crises experienced by family care givers. In the next section, the experience of care givers of relatives with mental illness is discussed. The aim is to report on care givers’ perspectives of what it was like to care for a relative with mental illness.
Experience of family care givers providing care for relatives with mental illness

The previous section described the sources of stress of care givers of relatives with mental illness. This section focuses on the experience of care givers in the course of providing care for relatives with mental illness. Two studies have explored the experiences of family care givers caring for mentally ill people; one in Malaysia (Chang & Horrocks, 2006), and the other in America (Karp & Tanarugsachock, 2000). Egyptian family care givers’ experiences have also been explored (Endrawes et al., 2007). Numerous previous studies have explored the care giving experiences of mothers in Korea (Jung, 2000), Sweden (Johansson et al., 2010), and Australia (Chaffey & Fossey, 2004). The experiences of mothers who live with suicidal adolescents have also been explored (Daly, 2005). The experiences of fathers have been investigated in Sweden (Johansson, Anderzen-Carlsson, Åhlin, & Andershed, 2012; Nyström & Svensson, 2004), and in America (Howard, 1998). Champlin (2009) has studied the caretaking relationship of a mentally ill person and their care givers. Additional studies in Thailand have focused on experiences of family care givers related to culturally specific beliefs (Rungreangkulkij & Chesla, 2001) and on Buddhist family care givers (Sethabouppha & Kane, 2005).

A study in the USA by Howard (1998) presented the lived experience of engaging in the care giving process of 12 fathers of adult children with schizophrenia. Five themes emerged from the study including crisis, learning, involvement in care, unresolved issues, and severity of the event. Participants reported that care giving could be rated among one of the worst experiences in life. They recognised their care giving as being even more difficult than other troubling life events such as the death of a loved one, being at war, or being abused. The participants viewed care giving as a severely stressful life event since the role involves ongoing financial burden, requiring that they assist with the monitoring of medication, helping with housework, and assisting with education. In addition, the duration of involvement is often years rather than weeks or months. Over the two years of the interview process the participants consistently reported high levels of unresolved stress, constant feelings of sadness and frequent
tearfulness. Typically, the response of the fathers included shock, helplessness, and disbelief. In particular, they were aware that such crises could occur repeatedly and they felt ‘an awesome feeling of hopelessness’ which was ‘heart wrenching’.

Jung (2000) interviewed two Korean mothers to explore meanings of life in caring for children with schizophrenia. Mothers experienced mental illness as a gradual, scary, and incurable illness. It caused pain to the whole family. Their lives were full of burdens including financial problems, and a lack of support from family members and health professionals. These mothers also felt as if their lives were under pressure and full of destructive thoughts.

Karp and Tanarugsachock (2000) investigated emotional experiences of family care givers caring for relatives with unipolar depression, manic-depression, or schizophrenia. Knowing that their loved ones were diagnosed with a mental illness shocked care givers. For them it was like being hit by ‘a tornado that allows no preparation’. Care givers were continually frustrated since they could not take on their care giving roles to help their loved ones with mental illness. They could not ‘get beyond a family member’s initial episodes of illness’. One care giver said: “I felt that if I worked hard enough and fast enough I could make her [the daughter] better. Anything [the doctors] suggested, I jumped on with great enthusiasm”. Frustration and a sense of profound loss remained throughout the whole process of care giving especially when their loved ones with mental illness were not getting better.

A study of Chaffey and Fossey (2004) found similar experiences as the studies described above. This study aimed to explore experiences of mothers caring for sons with schizophrenia. The development and initial diagnosis of their sons’ mental illness was a whole new thing for them and this caused great confusion. They were frustrated and confused by a lack of mental health services for their loved ones. While providing care for sons with schizophrenia, mothers could ‘learn along the way’. They felt that they discovered various rewards of care giving. However, as long term care was needed, mothers felt as if they had lost their freedom as well as their loved ones to the mental illness. For these mothers it was difficult to see a future for their sons.
In Sweden, Nyström and Svensson (2004) explored experiences of seven fathers caring for an adult child with schizophrenia. In the initial state of illness, the fathers experienced ‘a chaotic situation’. They were ‘putting up with humiliation in order to get help’ from health professionals who ignored their needs. As a result, they felt as if they lost their self-image and self-esteem and remained in distress for many years. These fathers also worried most about their loved ones’ future.

Daly (2005) explored experiences of mothers who cared for a suicidal adolescent. These mothers felt as if they had done something wrong resulting in their loved ones becoming ill. They faced negative emotions including loneliness in care, helplessness and powerlessness in the struggle. As one said, “It’s out of my control”. They were also sad thinking that their loved ones wanted to die rather than live their lives with their mothers. They experienced living with the suicidal children as ‘walking on the eggshells’. They had to be careful of everything which could cause their loved ones’ suicidal thoughts.

The meanings of lived experiences of Chinese family care givers in Malaysia have been explored (Chang & Horrocks, 2006). The study reported that care givers felt lonely in providing care for their loved ones with mental illness without any help from other family members. They endured the burdens of caring including housework, cooking, and monitoring medication and behaviours of ill relatives. They suffered a great deal of embarrassment and shame in their loved ones’ behaviours. Stigma of mental illness on the families and care givers was found in their society. To protect them from ‘losing face’ over having a family member with mental illness, care givers avoided talking with other relatives and neighbours about their loved ones’ illnesses. Even though care givers often had unpleasant experiences of care giving, they were eager to continually provide care for their loved ones.

Endrawes, O’Brien, and Wilkes (2007) explored the experiences of Egyptian family care givers caring for a relative with mental illness in Australia. The experience of these care givers was often one of ‘shock and disbelief’. They provided care for ill relatives out of ‘duty’ and ‘love’ but with little or no information about the illness from the health care
providers. ‘Feelings of being drained’ reflected the experiences of doing physical work; being abused, and suffering grief over the loss of loved ones to mental illness. Care givers and family also isolated themselves from the wider community to avoid stigmatisation. Even though they experienced the hardship of care, they maintained hope and managed to survive the care giving responsibilities by thinking of good things about their loved ones, accepting reality, and seeking professional help.

Another study in the USA explored the meaning of lived experience of being there for a person with serious mental illness (Champlin, 2009). The first meaning of lived experience as being there was ‘accepting the changed other and grieving the loss of who the other once was’. Next, care givers experienced the need for ‘taking action’ to get help from relatives and close friends. As care givers continually provided care for ill relatives, they realised that their care giving was ‘ongoing’, ‘never ending’ as well as ‘unpredictable’. Concerns surrounding stigma caused them to isolate from other family members and friends. Care givers always felt ambiguous in providing care. They were unsure about what was best for their ill relatives. Care givers also experienced ‘the tension of waiting’. They were afraid that ‘something else would most likely happen that would be a setback’. Therefore, they were constantly alert to the possibility that their loved ones’ signs and symptoms of mental illness might return. Care givers also experienced ‘caring for the other’. They feared for their loved ones and others’ safety. Therefore, they had to ‘be there’ [to care for their loved ones] to ensure their and others’ safety.

Johansson, Anderzen-Carlsson, Åhlin, and Andershed’s (2010) study conducted in Sweden aimed at describing the everyday life experience of mothers caring for an adult child with a long-term mental illness. Mothers described how ‘my adult child who is struggling with mental illness is always in my mind’. They reported that they experienced ‘living a life under constant strain’. Experiencing that their children were affected by mental illness shocked the mothers. They lived their lives in periodic chaos and unpredictability of emotional and behavioural crisis. They experienced ‘living
with an emotional burden’ including the constant sorrows and traumatic feelings. However, they also experienced ‘seeing light in the darkness despite difficulties’.

Johansson, Anderzen-Carlsson, Åhlin, and Andershed (2012) conducted another study to explore the everyday experiences of fathers caring for an adult child with a long-term mental illness. Fathers reported two main difficulties ‘an inherent ongoing struggle to ensure the child’s well-being’ and lack of collaboration between families, health care providers and other authorities involved in providing care for their child. These were experienced as a constant struggle and feeling of powerlessness.

In Thailand, a small number of previous studies have explored the experiences of family care givers caring for relatives with mental illness. As mentioned in the preceding section, Rungreangkulkij and Chesla’s (2001) study explored the culturally specific beliefs and patterns of response of mothers of children with schizophrenia. In this section the findings of this study will be considered in greater depth focusing on the experiences of these mothers during their care for loved ones with mental illness. The mothers believed that Karma and other supernatural phenomena caused mental illness. In response, the mothers used Thum-Jai: “a combination of being accepting, patient, understanding, reasonable, and having a sense of obligation” (Rungreangkulkij & Chesla, 2001, p. 4). Even though the mothers did not want to care for their children, they felt obligated to do so. At the same time, they faced having to accept their loved ones’ inappropriate behaviours resulted from escalating symptoms of illness. When children with mental illness were hostile, mothers had to try to be very patient and speak gently to keep themselves and their loved ones with mental illness calm to prevent situations from worsening.

Another Thai study explored the lived experiences of Thai Buddhist family care givers of relatives with schizophrenia (Sethabouppha & Kane, 2005). These care givers experienced that ‘care giving is Buddhist belief’. They felt obliged to care for their loved ones because of their Karma from past life and this life. They also experienced ‘compassion’: attachment, love, and sympathy by receiving support from other family members, the community, and the government. Another common experience of care
givers was having to manage their own stress, the symptoms experienced by their loved ones, and their treatment. They practiced stress management to deal with emotional distress caused by care giving. The symptoms of their loved ones were managed in different ways; however, when management approaches failed physical restraint sometimes had to be used. As a result of beliefs that magic acts or spirits caused mental illness, care givers took relatives with mental illness to receive treatment from both modern and traditional practitioners. Care givers came to accept that mental illness could not be cured, or ‘fixed’. Care givers also explained how care giving was suffering, and that this involved numerous burdens such as physical demands, emotional distress, economic problems, social problems, and knowledge deficits.

In summary, existing studies of the experiences of family care givers of relatives with mental illness have highlighted a range of burdens associated with giving care. However, only a small number of studies have addressed the nature of crises experienced by care givers (Howard, 1998). Importantly, in Thailand, there is a lack of general and specific information regarding Thai care givers’ experience of crises. The findings from empirical studies confirm that family care givers face numerous iatrogenic, societal, and situational stresses and strains as part of the care giving role (Lefley, 1989, 1996). Under such circumstances it is not surprising that for many family care givers the role is accompanied by high levels of psychological distress (Gavois et al., 2006; Howard, 1998; Ip & Mackenzie, 1998; Sethabouppha & Kane, 2005). The crises faced by family care givers may echo those of a mentally ill loved one, such as an episode of violence or a suicide attempt. Alternatively, care givers may acknowledge a different form of crisis, involving severe financial difficulties or problems in seeking help from mental health services (Gavois et al., 2006; Howard, 1998). The literature suggests the important role played by support systems in helping family care givers to deal with crises. The next section examines the literature outlining the support systems involved in crises.
SUPPORT SYSTEMS

Support systems are discussed here to demonstrate the context surrounding family care givers during crises. The importance of support systems and how care givers assist in dealing with crises is also described. Several studies have presented findings indicating that over time family care givers develop skills in dealing with crisis (Ayres, 2000; Chen & Greenberg, 2004; Rose et al., 2002; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000) and that this can have a positive impact on caring (Chen & Greenberg, 2004). However, such studies also indicate the importance of care givers being able to access formal assistance from health care providers and informal help from family members or other sources of support (Chen & Greenberg, 2004), especially during crises (Copeland & Heilemann, 2008; Ferriter & Huband, 2003; Gavois et al., 2006; Ip & Mackenzie, 1998). Throughout the crisis period, care givers may face distressing emotions including stress, anger, anxiety, worry, desperation, grief, and feelings of guilt (Copeland & Heilemann, 2008; Gavois et al., 2006). Many family care givers may resort to the use of maladaptive coping mechanisms, including avoidance and denial. For many family care givers the role brings change, often faced as a severe disruption to social life (Ip & Mackenzie, 1998). Ineffective crisis management may result in a negative resolution, inadvertently setting up the conditions for subsequent crises. However, in situations where the resolution has been positive there may be personal growth and the mobilisation of sufficient support to reduce the likelihood of future crises (Hoff, 2009).

Definition of support systems

For Caplan (1974, p. 7) support system refers to the “continuous ties that play a significant part in maintaining the psychological and physical integrity of the individual over time”. Support systems are categorised as follows (Caplan, 1974; Caplan & Caplan, 2000):

Natural support systems: These support systems include the marital and family group as the kin and kith support that is central to providing guidance, direction, and self-
validation. In some crises, or under circumstances of chronic deprivation, members from these systems are often recognised as the most helpful for sustaining those in crisis.

**Organised support not directed by care giving professionals:** The main types identified are voluntary service groups and mutual self-help groups. These sources of support typically aim to provide training and support to help those in crisis take up a more disciplined style of life.

**Religious denominations as an organised support system:** These support systems are often the most accessible in the community. Therefore, in times of crisis, a person can seek help from a religious organisation, the members of which gather together for services daily or weekly. Such people share common values and traditions and are thus usually happy to help each other in crisis periods, such as birth, death and illness.

**The contributions of community mental health professionals:** This group of people provides support through initiatives such as setting up a new support system both inside and outside the community, and offering consultation and education for individuals and organisations.

**Support systems and crisis**

Several studies have addressed the sources of support for family care givers during crisis (Ferriter & Huband, 2003; Gavois et al., 2006; Saunders & Byrne, 2002). Consistent with the early categorisation developed by Caplan (1974; Caplan & Caplan, 2000) families and friends have generally been shown to be the most helpful during crises (Saunders & Byrne, 2002). Likewise, Ferriter and Huband (2003) found that the most helpful in providing support were families, self-help groups and the police. On the other hand psychologists, social workers and psychiatrists have been identified as being among the least helpful. Family care givers contacted mental health professionals only if they needed information. In contrast, a grounded theory study in Sweden found that families needed mental health professionals to help them during the early stage of crisis. The earlier that help and information was provided by mental
health professionals, the better the crisis was understood and dealt with (Gavois et al., 2006). Conversely, Thai studies have mentioned the need for support for family caregivers during the onset of mental illness, in consultation with other relatives and neighbours. Subsequently, help was sought from a monk or a folk healer regarding their beliefs (Dangdomyouth, 2006; Rungreangkulkij & Gilliss, 2000; Vanaleesin et al., 2003) and later on from professionals at the hospital (Vanaleesin et al., 2003).

In summary, many studies point to the importance of support systems in dealing with crisis situations and mental illness symptoms. Many caregivers realise that the help received from their natural support system is likely to be better than that received from health professionals (Dangdomyouth et al., 2008; Ferriter & Huband, 2003; Rungreangkulkij & Gilliss, 2000; Saunders & Byrne, 2002; Vanaleesin et al., 2003). The support from professionals, however, may be needed, especially in regard to the provision of accurate information about the mental illness and treatment options (Gavois et al., 2006).

Thus, to provide such help for family caregivers in dealing with their crises, it is important for mental health professionals to understand these crises from the family caregivers’ point of view, and to understand the issues surrounding their crises as well as the needs for crisis management (Winness et al., 2010). Such understanding would help professionals to be more sensitive in helping family caregivers dealing with mental illness, assessing negative experiences, and increasing caregivers’ understanding of illness, treatment, symptoms, and relapse (Sethabouppha & Kane, 2005). In particular, it is critical to acknowledge that the support systems needed are different according to each person’s individual resources (Caplan, 1974). Family caregivers are thus likely to benefit from being able to better recognise and mobilise resources to manage crisis effectively.

**CONCLUSION**

This literature review has presented three areas of crisis that periodically occur with family caregivers. The main areas discussed include exposure to the psychotic
symptoms of a mentally ill loved one, the stresses and strains of the care giving process, and a lack of support systems for dealing with crises. The literature review also provided an outline of the broad range of experiences of family care givers providing care for relatives with mental illness.

Family care givers play an important role providing care for their mentally ill loved ones and periodically face crises themselves. The existing literature has indicated the precipitating factors that lead to crises caused by mental illness (Dangdomyouth et al., 2008; Friedrich et al., 1999; Ip & Mackenzie, 1998; Kavan et al., 2006; Levine & Ligenza, 2002; Rose et al., 2002; Rungreangkulkij & Chesla, 2001; Saunders, 1999, 2003; Sethabouppha & Kane, 2005; Vanaleesin et al., 2003) as well as how it is that family care givers can be drawn into crises during their care for their loved ones (Ambikile & Outwater, 2012; Crowley et al., 2005; Dangdomyouth, 2006; Foster, 2011; Gavois et al., 2006; Harden, 2005; Huang et al., 2009; Ip & Mackenzie, 1998; Jungbauer et al., 2004; Moleft & Swartz, 2011; Nagaoka et al., 2011; Saunders & Byrne, 2002; Seloilwe, 2006; Sethabouppha & Kane, 2005; Tryssenaar & Tremblay, 2002). Most studies, however, were conducted in western countries. Even though there are studies focusing on the experience of crisis, the aim here has been to evaluate crisis intervention services which are well established in specific areas (Levine & Ligenza, 2002; Winness et al., 2010).

Other research, including phenomenological studies, have focused broadly on the general experiences of family care givers providing care for a relative with mental illness (Chaffey & Fossey, 2004; Champlin, 2009; Chang & Horrocks, 2006; Daly, 2005; Endrawes et al., 2007; Howard, 1998; Johansson et al., 2010, 2012; Jung, 2000; Karp & Tanarugsachock, 2000; Nyström & Svensson, 2004), particularly schizophrenia. Previous Thai studies have mainly focused on religious and cultural beliefs towards care giving (Rungreangkulkij & Chesla, 2001; Sethabouppha & Kane, 2005). The present study focused specifically on the lived experience of family care givers in a crisis during their care for relatives with mental illness. However, the experience of crisis may go beyond family care givers providing support for loved ones diagnosed with high impact psychotic disorders such as schizophrenia. Indeed, the burdens of
Care giving and associated crises, may be experienced by family members providing care to any form of mental illness.

The literature review has revealed a lack of research addressing the lived experience of crisis from the perspective of family care givers providing support for mentally ill loved ones at home. By better understanding the family care givers’ lived experience of crisis, mental health professionals would be in a better position to provide effective support and advice. It was anticipated that this would likely contribute to improved life circumstances of not only the family care givers, but also the quality of support available to their mentally ill loved ones. The next chapter provides an outline of how the research was conducted to address this gap in the literature.
Chapter Three
METHODOLOGY

INTRODUCTION

This chapter describes the qualitative research perspective and the theoretical frameworks that underpin this research project including the constructivist paradigm, phenomenology, and van Manen’s hermeneutic phenomenological approach. The broad theoretical and methodological tenets of phenomenology are described after which the three main forms of phenomenology are outlined: transcendental, existential and hermeneutic phenomenology. The final section of the chapter provides a more focused discussion of the methodology used to conduct this study, van Manen’s hermeneutic phenomenological approach.

DEVELOPMENT OF THE QUALITATIVE PERSPECTIVE

This section presents three major research traditions: quantitative, qualitative, and mixed methods. It aims to provide a broad overview of each approach. Then, the development of the qualitative approach informing the decision making of the researcher to conduct this study is described in more detail followed by a broad overview of the paradigm. This section concludes with an outline of the constructivist paradigm which was used to frame the research project.

Research is the “careful study of a subject, especially in order to discover new facts or information about it” (Hornby, 2010, p. 1299). O’Leary (2004) suggests the need for research knowledge to understand and solve problems in the world. Moreover, the researcher can carry out research to evaluate the success of problem-solving strategies and the findings of research will add to the body of knowledge. Three broad research approaches which can guide the researcher in conducting research are set out below.

Quantitative research is “often characterised as an objective positivist search for singular truths that relies on hypothesis, variables, and statistics, is generally large
scale, but without much depth” (O’Leary, 2004, p. 105). It aims at testing hypotheses and deductive logic using scientific methods. It is also needed for objectivity and the value of quantification (O’Leary, 2004). The findings, presented as numbered data are analysed using statistical procedures (Creswell, 2009; O’Leary, 2004). In broad terms quantitative research can be separated into experimental and non-experimental designs. Experimental research designs include randomised controlled trials in which subjects are randomly allocated to treatment conditions and quasi experimental research designs which are single-subject designs. The non-experimental designs are, for example surveys including cross-sectional and longitudinal studies (Creswell, 2009).

While quantitative research aims at testing objective theories (Creswell, 2009), the qualitative approach aims to explore and understand the meaning of the experience of people. Qualitative research is “a situated activity that locates the observer in the world...[It] involves an interpretive, naturalistic approach to the world” (Denzin & Lincoln, 2011a, p. 4). Qualitative researchers conduct their studies in natural settings and attempt to make sense of, or interpret phenomena from the meanings given by individuals (Denzin & Lincoln, 2011a). There are a variety of qualitative approaches that the researcher can use to investigate the experience of people including ethnography, grounded theory, case studies, and phenomenological research (Creswell, 2009; O’Leary, 2004).

The third approach, mixed methods research, is the combination of these two approaches (Creswell, 2009). It aims to integrate or connect qualitative and quantitative data to strengthen the research study by adding depth and insight to quantitative data (O’Leary, 2004). The data may be presented either separately in qualitative and quantitative forms or merged into a large data base. In general, there are three research strategies within mixed methods: sequential, concurrent, and transformative. Each of these three procedures has different strategies of inquiry. Sequential mixed methods research seeks elaboration on findings of one method with another. For a concurrent mixed methods study, quantitative and qualitative data were merged to provide a
comprehensive analysis of the research question. Transformative mixed methods procedures require the researcher to use a theoretical lens as an overarching perspective to guide the study (Creswell, 2009).

For this study, the research question is ‘What is the lived experience of Thai family care givers in a crisis during their care for relatives with a mental illness?’ As presented in Chapter Two, the literature indicates that there is little information about the experience of care givers in crisis. Therefore, this phenomenon needs to be explored from the care givers’ perspective. A qualitative research approach which aims at investigating the meaning of lived experience is thus well suited for the study.

The use of qualitative approaches to research can be traced back to at least the 5th century B.C.E. when the Greek scholar, Herodotus, and later in the 2nd century C.E. when Sextus Empiricus, a Greek philosopher conducted cross-cultural investigations. Their work provided the primary foundation for comparative knowledge about human ‘lifeways’ until the late 19th century, which was documented in the descriptive form (Erickson, 2011).

In the mid-19th century a debate developed around the definitional foundations for the systematic conduct of social inquiry. As part of this debate, Auguste Comte (1798/1857) named the study of society ‘sociology’, establishing this as a science in its own right (Vidich & Lyman, 1998). Adolphe Quetelet (1796/1874) used statistics to validate what he termed ‘social physics’. Like Comte, others, for example Morgan (1877) and Tylor (1871), conducted social inquiry with a view to generalising findings to other settings. In contrast, Wilhelm Dilthey (1833/1911) suggested that social inquiry was ‘human studies’ and should be called ‘social science’ as it focused on day to day actions and their meaning. He also argued that the aim of ‘social inquiry’ ought to be to understand rather than examine facts or to make predictions. Dilthey’s ideas influenced many late 19th - early 20th century scholars including Max Weber, Georg Simmel, Edmund Husserl, and Martin Heidegger. Mid-20th century scholars such as Hans-Georg Gadamer, Jurgen Habermas, Ernest Gellner, and Clifford Geertz were also influenced by Dilthey’s ideas (Erickson, 2011).
In the last quarter of the 19th century the term ‘ethnography’ began to be used by anthropologists to describe the ‘lifeways’ of a particular group of people in colonial communities around the world (Vidich & Lyman, 1998). In 1874, the British Society for the Advancement of Science launched a manual to guide data collection using observation and interviewing techniques. The manual influenced qualitative inquiry until the late 19th century. However, everyday life was described from the outsiders’ observations (the researcher) rather than from the point of view of the person being studied (Erickson, 2011).

Malinowski (cited in Erickson, 2011) pointed out that ethnographic description should aim to understand the point of view of people, their relationship to life, and their world vision. During World War I, he spent considerable time in the field using the local language to conduct ethnographic research. He described everyday life focusing on individual orientations and meaning perspectives. His data set presented the entire system of everyday life, and accurate nuances of local meaning. This was a shift in the interpretive (hermeneutic) stance within ethnography, which then became known as realist ethnography (Erickson, 2011; Vidich & Lyman, 1998).

Even though realist ethnography was (and continues to be) used as a basic approach in qualitative inquiry worldwide, there were conflicts and serious concerns regarding its use. Firstly, different researchers conducting qualitative research in the same place, presented their findings differently. Secondly, findings were presented as representative of a whole community rather than a particular setting within a large community or institution. Lastly, after World War II, people being studied began to react adversely to researchers’ findings as they felt that the report did not accurately present their point of view. The researcher, as an outsider, could not accurately observe and interpret the meaning of the insider’s everyday life especially when unequal power relations between the researcher and the informant existed, which occurred frequently.

In response to these concerns other approaches to qualitative inquiry emerged. Action research came into existence in the 1930s. It required people to work together to
address key problems in their community. This approach aimed to make changes which would be beneficial for themselves (Whitehead & McNiff, 2006). Kurt Lewin (1946) and Whyte (1989) were two famous pioneers of this type of research. As this approach gained influence it came to be used in combination with other qualitative approaches.

After 20 years of action research, there was an emerging of participatory action research. The aim here was to reconstruct the actual lives of ordinary people (Swantz, 2008). Orlando Fals Borda (Borda, 2006), the pioneer of participatory action research, has suggested the use of participatory action research in research fieldwork with ordinary people. In terms of conducting this kind of research, the researchers need to (i) work collaboratively in every step with people rather than one step ahead, (ii) pay attention to those people’s knowledge, (iii) discard jargon and communicate with everyday language, and (iv) work with collectives and local groups to empower them for social change.

From the late 1940s, there was the development of applied anthropology. It aimed to study the differences of humans. Following this, critical ethnography emerged with the concern of the researchers focusing on social injustice. They used the approach to bring about positive social change (Carspecken, 1996). The emphasis on bringing about change was very much directed to rectifying what were seen as injustices and/or imbalances of power.

Although qualitative research is used across different disciplines and fields, it is widely considered to have five broad foundations (Erickson, 2011). The first is that each qualitative research study orientates on social science theory. Next, the role of the researcher can be as collaborator, joint author, or editor working with the people being studied. Therefore, the roles of these people and the researcher are blended during the qualitative research project. A subsequent foundation is that the report of the study is partially interpreted from the standpoint of the life experience of the researchers. They may report it in a form of novel, poetry, or fiction. Finally, the findings of the research project are reported to the audiences who are the people being studied and who may
also be participating in the writing process. In addition, action research is more likely to be presented to popular audiences.

The qualitative approach is comprised of five basic foundations as described above and needs to clearly identify the tradition or paradigm within which the research is framed. “Paradigm is a set of beliefs that guide action” (Guba, 1990, p. 70). Each paradigm holds a different set of beliefs or worldviews (Creswell, 2007). Moreover, paradigms can shift from the current to a new paradigm. This occurs when an existing paradigm is inadequate to inform the conduct of the qualitative research project (Lather, 2006).

As presented above, qualitative approaches have developed over time and have done so alongside paradigm shifts. For example, critical ethnography has much in common with the critical paradigm while early ethnography was informed by the interpretive tradition (Denzin & Lincoln, 2011b). Examples of major qualitative paradigms, presented in order of their appearance in qualitative research practice, include: post-positivist, constructivist-interpretive, critical, and feminist post-structural (Creswell, 2009; Denzin & Lincoln, 2011a). Detailed discussion of all research paradigms is beyond the scope of this chapter.

As the current study sought to understand the phenomenon of the experience of care givers from their own perspective, the methodological basis of the study was with the qualitative approach and was guided by the constructivist or interpretive paradigm (Denzin & Lincoln, 2011a). More detail on this paradigm and its philosophical assumptions underpinning this research project are provided below.

Constructivist paradigm

Constructivism is an alternative to the positivist paradigm and seeks to address a number of considerations that are often said to be overlooked or denied in conventional scientific approaches (Schwandt, 1998). The philosophy underpinning constructivism is idealist. That is, what is considered to be ‘real’ is a construction in the minds of social participants. Constructivism is also pluralist and relativist, since there can be multiple and conflicting constructions (Schwandt, 1998). To construct is to
create realities which exist together with the persons who create and hold them (Guba & Lincoln, 1989). Therefore, constructivism has the goal to understand the complex world of lived experience from people’s points of view (Schwandt, 1998).

Denzin and Lincoln (2011a) discuss two philosophical branches underpinning the constructivist paradigm: ontology and epistemology. They define ontology as a construction of knowledge through the lived experiences and the interactions with other members of society. This means that the researchers participate in the research process with the participants to ensure the knowledge constructed by them reflects the experiences of the participants.

For epistemology, Denzin and Lincoln (2011a) note that humans are shaped by their lived experiences which are always reflected in the knowledge generated by researchers and in the data generated by subjects. To put it more simply, lived experience and its meaning are constructed by people who live in a particular social situation, place, and time. Constructivism implies that to interpret is to understand the world of meaning.

In summary, as described above, constructivism aims to understand and interpret meanings of phenomena. The meanings then become the foundation of knowledge which is constructed from the experience of individuals interacting with others and the environment (Denzin & Lincoln, 2011a). Phenomenology, which aims to describe lived experience and to develop a deeper understanding of how meanings are constructed, was chosen to conduct the study. The next section provides a more detailed discussion of phenomenology.

**PHENOMENOLOGY**

Phenomenology is both a philosophical approach and a research method which studies the lived experiences of humans or descriptions of phenomena (Hammond, Howarth, & Keat, 1991; Lopez & Willis, 2004; Munhall, 1994). A phenomenon is anything which presents itself to someone or as one experiences it (Hammond et al., 1991). Swanson-Kauffman and Schonwald (1988) have stated that phenomenology is a philosophy
because it deals in the realm of the ideal, pure, and perfect. It is also a methodology dealing with the practical world of concession, compromise, and approximation.

Edmund Husserl (1859/1938), a significant figure in the development of phenomenology defined the term as follows:

a method by which I want to establish, against mysticism and irrationalism, a kind of super-rationalism which transcends the old rationalism as inadequate and yet vindicates its inmost objectives (cited in Spiegelberg, 1960, p. 84).

There are four basic foundations of phenomenological philosophy: a return to the traditional tasks of philosophy, the search for a philosophy without presuppositions, the intentionality of consciousness, and the refusal of the subject-object dichotomy (Stewart & Mickunas, 1990). These foundations will now be discussed in more detail.

Phenomenological researchers believe that to do research is to seek knowledge of what it means to be human in the world. Husserl introduced the concept of phenomenology as an attempt to bring back the reality of individuals’ life-world, to capture its meaning, and to revive philosophy of human science (McIntosh, 1997; Munhall, 2007). People desire knowledge of themselves and their world, and philosophy helps them understand it (Stewart & Mickunas, 1990).

Phenomenology attempts to describe the essence of phenomena without presuppositions or judgements. To do this, phenomenological researchers need to situate themselves at a distance from all theoretical presuppositions and interpretations (1990). This calls for ‘natural attitude’ or epoche’. As Husserl (1980, pp. 54-55) stated:

the natural world, however, the world in the usual sense of the world is, and has been, there for me continuously as long as I go on living naturally. As long as this is the case, I am “in the natural attitude”...undisturbed in it by the new attitudes.

Thus, researchers attempt to suspend all questions while turning to the phenomenon under study and focus on describing it as it is.
Another tenet of phenomenological philosophy is the intentionality of consciousness. The word ‘intentionality’ comes from the Latin word ‘tendere’ which means referentiality, relatedness, directedness, and ‘aboutness’ (Crotty, 1998). Intentionality means that when the mind is conscious of something, it reaches out to and into the object (Stewart & Mickunas, 1990). Husserl (1960, p. 33) stated:

Conscious processes are also called intentional; but then the word intentionality signifies nothing else than this universal fundamental property of consciousness of something…

Following this idea, phenomenological researchers seek to ask how people experience the world as it is lived. The inseparable connection to the world is the principle of intentionality (van Manen, 1990). What is postulated here is that there is an intimate connection and an active involvement between the conscious subject and the object of the subject’s consciousness (Crotty, 1998). The subject’s consciousness is directed towards the object and the object is shaped by that consciousness (Crotty, 1998). Therefore, human beings are intentionally related to their world (Crotty, 1998). Crotty (1998, p. 45) concludes that:

…no object can be adequately described in isolation from the conscious being experiencing it, nor can any experience be adequately described in isolation from its object...Subject and object, distinguishable as they are, are always united.

Phenomenology seeks the meaning of phenomena. Humans are seen as ‘being-in-the-world’ through their consciousness. They describe the world by giving meaning to it. The meaning they make of the world appears to their consciousness. Interpretation of this consciousness of an object is created by experiencing it; for example through hearing, seeing, or smelling it. Consciousness cannot therefore be separated into subject and object. This challenges the perspective of the subject-object dichotomy often attributed to Descartes (Stewart & Mickunas, 1990).

The application of phenomenology to research is also seen as a methodological approach to investigate the phenomena. Phenomenology is described as a rigorous, critical, and systematic approach (Carpenter, 2007), which aims to:
explicate the structure or essence of the lived experience of a phenomenon in the search for the unity of meaning which is the identification of the essence of a phenomenon, and its accurate description through the everyday lived experience (Rose, Beeby, & Parker, 1995, p. 1124).

There are several methodological interpretations of the philosophy of phenomenology (Carpenter, 2007). For effectiveness, the selected method must fit with the research question of the proposed study. It also has to relate to the theory underpinning and guiding the study.

In the section that follows three main phenomenological methodologies will be discussed - transcendental phenomenology, existential phenomenology and hermeneutic phenomenology. The intention here is to outline the fundamental points of each method, before going on to a more detailed outline of the approach which has been chosen for this study - hermeneutic phenomenology.

Transcendental phenomenology

Husserl is widely recognised as the father of pure or transcendental phenomenology (Laverty, 2003; Polkinghorne, 1983; Stewart & Mickunas, 1990). Transcendental phenomenology looks at the lived experience from outside, from the viewpoint of a detached observer. Husserl’s work concentrates on experience and focuses on epistemological questions of knowing (Koch, 1995).

Husserl’s transcendental phenomenology comprises three main themes: intentionality, essences or constitution of meaning, and phenomenological reduction or bracketing (Koch, 1995). Intentionality means that the mind is directed toward objects of which it is conscious (Husserl, 1960; Koch, 1995; Laverty, 2003), as has already been mentioned above. Spiegelberg (1960, p. 110) described Husserl’s interpretation of intention thus:

...[Intention] as that component of any act which is responsible not only for its pointing at an object but also for (a) interpreting pre-given materials in such a way that a full object is presented to our consciousness, (b) establishing the identity between the referents of several
intentional acts, (c) connecting the various stages of intuitive fulfilment, and (d) “constituting” the object meant.

Humans’ thoughts, feelings, and actions are always about things in the world. This results in the development of a description of reality (Laverty, 2003). This includes producing the meanings and describing the humans’ life world in terms of essence (Koch, 1999).

Essence is the next theme to be discussed. For Husserl, essence is a particular type of object or experience which is unique from others (Laverty, 2003):

The “unity of an imagination” is manifestly nothing other than the unity of a possible experience or the modification of neutrality of a unity of experience. But this unity affords precisely the ground for the essence: unity of experience (Husserl, 1973, p. 171).

Husserl suggested that in order to study lived experience it is necessary to share the essence of humans’ conscious mind. It is also required to return things to themselves and to the essence which constitutes the consciousness and perception of their world (Koch, 1995). Thus, Husserl’s phenomenology becomes a descriptive phenomenology.

Central to Husserl’s approach is bracketing or epoche’: the procedure of phenomenological reduction. This is a starting point for researchers employing descriptive phenomenology (Hammond et al., 1991). Researchers working with this approach seek to ignore their previous prejudices and experiences of the outer world and individual biases (Stewart & Mickunas, 1990). They attempt to disconnect from the past to reframe their judgement of the present in order to successfully achieve contact with essences (Laverty, 2003). The researchers defend the objectivity of interpretation against their self-interest (Koch, 1995). For Husserl this enabled the researcher to see the phenomenon as it really is.

Existential phenomenology

While existential phenomenologists were influenced by the later work of Husserl which focused on the lived-world from the detached observers’ perspective, existential philosophy understands that observers cannot separate themselves from the world
Existential phenomenology shifts from the reduction of transcendental phenomenology to concerns of being and ontology. Ontology examines questions of relatedness to being and existence (Ricœur, 1967). Heidegger’s work ‘Being and time’, argues that the world and consciousness are not separate (Polkinghorne, 1983). Existence or being is always ‘being-in-the-world’ (Heidegger, 1962). He stated that “… we must keep in mind that the expression ‘phenomenon’ signifies that which shows itself in itself, the manifest” (Heidegger, 1962, p. 51).

‘Being-in-the-world’ means that human reality is situated in a context of the concrete world. The actions of each person define the context in which they situate themselves. The world-context defines and sets limit to their action (Stewart & Mickunas, 1990). Valle, King, and Halling (1989) agree that people and their world are an indissoluble unity and co-constituted. They cannot be apart from each other. Therefore, humans experience the world as they live it. (More details of Heidegger’s ‘being-in-the-world’ are discussed in the following section - hermeneutic phenomenology.)

Existential phenomenology emphasises the concepts of: owned body, freedom and choice, and inter-subjectivity (Ricœur, 1967; Stewart & Mickunas, 1990). Merleau-Ponty extended Heidegger’s existentialism, and emphasised the relationship between the structures of experience and the embodied condition of human existence (Polkinghorne, 1983). Merleau-Ponty termed the word ‘owned-body’ or the individual’s body as it is lived in and experienced. He concentrated on an embodied ‘being-in-the-world’ (Merleau-Ponty, 1962; Moss, 1989).

The body is the vehicle of being in the world, and having a body is, for a living creature, to be interwoven in a definite environment, to identify oneself with certain projects and be continually committed to them (Merleau-Ponty, 1962, p. 82).

The human perspective of the world comes from the body which provides the situational context for conscious experience. Merleau-Ponty’s existential phenomenology thus describes consciousness as it exists in and toward the world experienced through the body. Therefore, human realities can be understood through
the body which is always conscious of something (Ricœur, 1967; Stewart & Mickunas, 1990).

The advocates of existential phenomenology believe that humans have a choice to freely exist and open themselves up to possibilities. Jean-Paul Sartre’s work Being and Nothingness, focuses on freedom (Ricœur, 1967). Freedom is a situated freedom of past, present, and future. The present context influences action and may affect future possibilities. It also determines what the past may possibly mean (Stewart & Mickunas, 1990). Humans realise their freedom when they make choices and perform actions. Even though people do not choose to be free, they are free. Therefore, they have to make choices even if they do not want to choose (Stewart & Mickunas, 1990). Merleau-Ponty’s concept of ‘owned body’ incorporates this theme of freedom. Owned body means that the human ego and the world join together. If the body is the origin of expressive movement of being in the world, the experience of freedom is always in the situations in which people choose to act or behave (Ricœur, 1967). Hence, people are seen as choosing to exist, themselves rather than other possibilities of existence.

While people are seen as having freedom and choice, the concept of inter-subjectivity is vital in understanding existential phenomenology. Embodied humans exist in a world that is occupied by others. They thus have to be aware of the freedom of others and the limitations it places on the individual. Human actors thus recognise their own humanity so that they can recognise the humanity of others. People find themselves in a social world as a part of their being-in-the-world (Ricœur, 1967; Stewart & Mickunas, 1990). As Sartre put it:

the existence of the Other with the experience of being seen, of being caught by a gaze which freezes me in my tracks, reduces me to the condition of an object, steals my world from me, and takes away my freedom along with my subject position (cited in Ricœur, 1967, p. 212).

The (descriptive) system of inquiry based on existential phenomenology makes up and presents human experience by investigating the various structures of orientation toward their world (Polkinghorne, 1983).
**Hermeneutic phenomenology**

Hermeneutic phenomenology is a philosophy of the individual (van Manen, 1990). It focuses on a human experience as it is lived and aims to create meaning and gain a deeper understanding of lived experience (Laverty, 2003). van Manen (1990, p. 18) asserts:

> To do hermeneutic phenomenology is to attempt to accomplish the impossible: to construct a full interpretive description of some aspect of the lifeworld, and yet to remain aware that lived life is always more complex than any explication of meaning can reveal.

Various commentators have attempted to outline the basic tenets of hermeneutic phenomenology (Allen, 1995; Koch, 1995; Plager, 1994; Stewart & Mickunas, 1990). However, there is no consensus on the principles that might guide methodology, since different schools have contributed to the development of what is now thought of as hermeneutic phenomenology (Dowling, 2004). The work of Heidegger and Gadamer is recognised as pioneering in the field of hermeneutic phenomenology. Several important principles derived from their work will be addressed in the discussion that follows: pre-understanding, co-constitution, interpretation, and the hermeneutic circle.

Heidegger was Husserl’s student and assistant; who later deviated from Husserl’s transcendental phenomenology. In his major work ‘Being and time’ Heidegger argued that hermeneutics is one among a variety of methods of investigating phenomena. While in his philosophy Husserl primarily focused on epistemology, Heidegger focused instead on ontology (Stewart & Mickunas, 1990). Heidegger was concerned with the nature and relations of being. His phenomenological ontology is based on the hermeneutic of human beings as ‘being-in-the-world’ (Cohen & Omery, 1994; van Manen, 1990).

Heidegger’s term ‘pre-understanding’ is used to describe the meaning and culture which exist in the world before people understand them. When persons position themselves in a situation, they bring their stories or pre-understandings with them.
Such stories come from their background and it is thus impossible to bracket human’s pre-understanding as it is the structure of their ‘being-in-the-world’ (Koch, 1995).

Humans and the world are co-constructed; that is the world constructs people and people construct the world in which they live from their experience and background. Thus, the world and persons cannot be understood as separate (Koch, 1995). Heidegger used the words ‘Dasein’ (being-there) to stress that individual existence is always existence in the world and ‘Sein’ to refer to Being or presence (Cohen & Omery, 1994; Ricoeur, 1967). The formal meaning of Dasein’s existential constitution is:

In determining itself as an entity, Dasein always does so in the light of a possibility which it is itself and which, in its very Being, it somehow understands (Heidegger, 1962, p. 69).

Heidegger (1962) stated that even though a state of mind is suppressed, it always has its understanding. Therefore, Being is understanding. It is a fundamental characteristic of a mode of human ‘being’ in the world (Koch, 1995). It has its own possibilities to develop itself because it is a potentiality for Being. The development of understanding is called ‘interpretation’ (Heidegger, 1962). Individuals’ interpretation is based on their background and culture. They have the world and life at a cultural level through acts of interpretation (Koch, 1995). Heidegger contended that “to be human is to be interpretive, for the very nature of human realm is interpretive” (Polkinghorne, 1983, p. 224).

Gadamer was one of Heidegger’s students. Building on Heidegger’s hermeneutic phenomenology he produced his major work ‘Truth and Method’ (Dowling, 2007). Gadamer agreed with Heidegger that understanding is the foundation of people existing in the world (Ray, 1994). He made two important propositions regarding the historical and interactive conditions of human understanding (Polkinghorne, 1983). First, individuals’ perceptions, prejudices or their ‘horizon of meaning’ are part of their linguistic experience. Second, people interpret their understanding through their language (Dowling, 2007). They are involved in a process of interpretation which is related to ‘being-in-the-world’; the result is ‘understanding’ (Spence, 2001).
Gadamer continually claimed that the interpreter gains understanding by grasping the meaning of text through the lens of their prejudgements including their personal beliefs, practices, concepts, and values. Thus, interpretation is constructed between the interpreters'/researchers' own language and the language of the text. As the text is approached by various interpreters, it continues to speak in various ways. Thus, there can be no ‘correct’ interpretation. The interpretive process is conceptualised as a spiral moving back and forth from the part of the text to the whole to increase the depth of understanding (Koch, 1996). This process has been called ‘the hermeneutic circle’ (Polkinghorne, 1983).

So far in this chapter, the major concepts of the constructivist paradigm and of different phenomenological methodologies have been briefly discussed. Each school of thought shares similar foundations, however each has developed its own perspective for the application of these foundations in practice. Koch (1999) has asserted that to understand clients or a community, or to improve nursing care, nursing research questions are best answered interpretively. Hermeneutic phenomenology is well placed as a methodology to address the research question that drives this research project since it aims to understand the significance of practical activities in our everyday experience (Plager, 1994). In reviewing the importance of hermeneutic inquiry for understanding nursing practice, Allen (1995, pp. 180-181) concluded that:

1. Nursing practice must be interpreted within its social-political locations;
2. Nursing researchers need to take more seriously the fact that all forms and criteria for rationality, including health care decision making, involve social processes;
3. Hermeneutics is essential to both describing and explaining nursing practice in two senses: first all scientific activity is hermeneutic in that it is a socially structured, meaning-generating and perspective-dependent human pursuit; and second, the understanding that nurses, patients and other actors in the health care arena assign to their own and each other's activities are important to describing and explaining clinical practice.

Hermeneutic phenomenology is especially relevant to the research of nursing researchers as it provides a way in which they can be involved in the study/experience
of the world (Boyd, 2001; Munhall, 2007; van der Zalm & Bergum, 2000). The researchers engage with people under study to explore their lived experience. Therefore, they mutually unfold in the experience investigated (Munhall, 2007). The hermeneutic approach to research assists nursing researchers to better understand themselves in relation to the research participants and the research process, as the way of being in the world. Research undertaken using hermeneutic phenomenology as the philosophical and methodological underpinnings is likely to provide opportunities for insightfulness, reflectiveness, and emancipation (Thompson, 1990).

In the past few decades, hermeneutics has been used extensively in nursing research, nursing care, and nursing education (Annells, 1996; Thompson, 1990). For example, Patricia Benner and Judith Wrubel (1989) have used it to study nursing practice. Nancy Diekelmann adopted this philosophy to improve the nursing curriculum (cited in Thompson, 1990). Wilson and Hutchinson (1991) have suggested that nursing researchers use a hermeneutic method to investigate ‘human responses’ in health and illness which are recognised as complex phenomena of people (i.e. personal problems and concerns; interpersonal interactions; relationship to cultural, political, social, economic; and environmental context). In his article, Peter Draper (1991) has recommended to British nurses that they use the hermeneutic approach to conduct what he refers to as human science research. In 1994, Beverley Taylor (1994) published a book which offered examples of uncovering and interpreting the phenomenon of ordinariness in nursing.

In recent decades, Max van Manen’s hermeneutic (interpretive) phenomenological approach has been highly influential in nursing research (Dowling, 2007). One of the strengths of van Manen’s approach is that it articulates phenomenological concerns and perspectives in each of the process steps outlined (Boyd, 2001; Cohen & Omery, 1994; Plager, 1994). For commentators such as Dowling (2007, p. 138), van Manen’s approach provides a means of dealing with the difficulties of phenomenological reduction, and “reflects the ongoing transformation of phenomenology as a methodological approach”.

van Manen’s hermeneutic phenomenological approach

For van Manen, being grounded in both German and Dutch philosophy, “phenomenology is a philosophy of the unique; it is interested in what is essentially not replaceable” (van Manen, 1990, p. 7). The hermeneutic phenomenological approach is described by van Manen as follows:

Phenomenology describes how one orients to lived experiences, hermeneutics describes how one interprets the “texts” of life, and semiotics is used here to develop a practical writing or linguistic approach to the method of phenomenology and hermeneutics (van Manen, 1990, p. 4).

For van Manen (1990) the study of humans who have consciousness and act purposefully in the world by creating the meanings that express such existence is human science research. The broad aim of such research is to interpret the meaning of phenomena and to understand the lived structures of meanings.

Human science researchers interpret and explore descriptions which are sufficiently detailed to understand and explain how we know what we know (van Manen, 1990). They focus on the object of study which presents in front of them in a unique and personal way (van Manen, 1990). This is an epistemology of human science related to the belief that meaning comes from the interpretation of people as they engage in the world and it emerges when consciousness engages with them. Meaning cannot be described as objective or subjective (Crotty, 1998). Objectivity and subjectivity need to be carried and held together permanently to construct the meaning (Crotty, 1998). To gain any deeper understanding of lived experience, the researcher needs to focus on subjectivist points of view toward the object using methods such as description, interpretation, and self-reflection or critical analysis (van Manen, 1990).

In particular, phenomenology studies day-to-day lived experiences of people which present themselves to consciousness (van Manen, 1990). van Manen’s approach is an attempt to explore experience without bracketing the researcher’s understandings about that experience. It is only through consciousness that people are able to interpret
their experiences and the effect of the world on their physical embodiment. van Manen (1990) offers a conceptual framework of phenomenology, as set out below.

*Phenomenological research is the study of lived experience.*

For van Manen, phenomenology is the study of the lifeworld of humans. It aims to gain a deeper understanding of the meaning of everyday experiences and insightful descriptions of the way people experience the world. For van Manen, lived experience is an immediate and pre-reflective experience; as such lived experience does not involve conceptualisation, categorisation or reflecting. Individuals cannot control the world but with plausible insights, they can have contact with the world directly.

*Phenomenological research is the explication of phenomena as they present themselves to consciousness.*

Human beings present themselves to consciousness. Thus, people access or relate to the world through their consciousness. “Consciousness is always transitive…and cannot be described directly” (van Manen, 1990, p. 9). This means that individuals cannot describe the experience while they are living in it. They reflect retrospectively on experience which is already passed or lived through.

*Phenomenological research is the study of essences.*

Phenomenology attempts to find and describe the internal meaning structure of lived experience or essence. The essence of a phenomenon is universal. It may be grasped through the study of instances as they are encountered in lived experience. For example: “What is the nature or essence of the experience of learning?” (van Manen, 1990, p. 10). The essence of lived experiences is described and supported by the descriptions which fully present the significance of the experiences (van Manen, 1990).

*Phenomenological research is the description of experiential meanings as we live them.*

Phenomenology focuses on lived or existential meanings. The meanings are described and interpreted until they reach the depth and richness of understanding. The meanings are also explicated as they are lived through.
Phenomenological research is the human scientific study of phenomena.

Phenomenology is human science research. It is comprised of five characteristics of scientific ways of knowing. First, it studies the subject matter, the structures of meaning of the lived human world. Second, it is systematic. It employs specific practices of questioning, reflecting, focusing, and intuiting to conduct the study. Third, it is explicit. It attempts to articulate the essence, the structures of meaning of lived experience as we live through the form of text. Fourth, it is self-critical. Phenomenological study continually checks its goals and methods in trying to deal with the faults of its approach. The last characteristic is inter-subjective. Phenomenology is inter-subjective because it allows the researchers to develop a dialogue with others to validate the phenomenon under study.

Phenomenological research is the attentive practice of thoughtfulness.

Phenomenological researchers are interested in studying everyday practices that concern them. They know how “to act tactfully in [their] situations on the basis of a carefully edified thoughtfulness” (van Manen, 1990, p. 8). The researchers may be teachers, nurses, or parents who are responsible for people with whom they are involved. For example, nurses may be interested in studying their everyday practices associated with being with patients or clients. Thus, the use of phenomenological study related to the researchers’ role is a ministering of thoughtfulness.

Phenomenological research is a search for what it means to be human.

Phenomenology searches for the meaning of lived experience. Importantly, individuals’ background, the socio-cultural and the historical traditions from which they come, gives meaning to their ‘being-in-the-world’. Thus, the meaning of being as a human in the world is fully revealed. This serves the ultimate goal of hermeneutic research which is to fulfil human nature, “to become more fully who we are” (van Manen, 1990, p. 12).
Phenomenological research is a poetising activity.

The result of phenomenological study is characterised and presented by the passion and aim of the research process (Boyd, 2001). Phenomenology is a poetising project in which the original experience is presented as ‘a primal telling’; it aims to include the voice of the participants to the world (van Manen, 1990). Language does not speak of itself but it echoes the world (Boyd, 2001). Therefore, the findings of the approach are full of all reality from the participants’ voice (1990).

The purpose of the study reported in this thesis was to develop an in-depth understanding of the phenomenon of interest: the lived experience of care givers caring for relatives with mental illness during crises. A hermeneutic phenomenological approach guided by the work of van Manen (1990) was selected as a research methodology for several reasons. First, this approach provided the researcher with an opportunity to explore and gain a deeper and richer understanding of the meaning of the lived experience of the family care givers. Second, the approach allowed the researcher to acknowledge her background and previous knowledge regarding the experience of care givers in crises but that this prior knowledge was less important and separate from these care givers’ experience. Third, van Manen’s hermeneutic approach offered clear procedural steps for the researcher to follow. Finally, using this approach the participants had an opportunity to not only share their experience but also to reflect on it; what it meant to them to care for their ill loved ones in crises.

CONCLUSION

In this chapter, the development of qualitative research and philosophy underpinning this study were discussed. Three different phenomenological forms were presented - transcendental phenomenology, existential phenomenology and hermeneutic phenomenology. van Manen’s hermeneutic phenomenological approach was clarified and selected to guide the study. Phenomenology provided the philosophical framework to gain deeper understanding of the lived experience of care giver caring
for their loved one with mental illness during crises. The next chapter will present methods used to conduct this study.
Chapter Four
RESEARCH METHODS

INTRODUCTION

The aim of this chapter is to explain the methods that were used to answer the research question ‘What is the lived experience of Thai family care givers in a crisis during their care for relatives with a mental illness?’ The most appropriate means to address this question involves applying qualitative methods and taking a hermeneutic phenomenological approach guided by the work of van Manen (1990).

This chapter commences with an overview of the research methods used and a discussion of associated principles and considerations. The methods used in this study to inquire into the lived experience of care givers of relatives with a mental illness are then presented. Subsequent sections include a description of the collection process and analysis of the data for the study. The chapter concludes with a discussion of the requirements concerning research rigor, privacy and confidentiality of the participants and an outline of ethical considerations.

METHOD

Creswell (2009) describes research methods as the steps in the research process which involve data collection, analysis, and interpretation. This process undertaken in association with the hermeneutic phenomenological approach was used to conduct this study. In broad terms, the phenomenological method is the process of going back and forth searching for the meaning of being human in the particular person (Munhall, 2012). For the purpose of this research, an interpretive approach was required. Therefore, van Manen’s hermeneutic (interpretive) phenomenological approach was used as it is well suited to the research question that was addressed in the study, as outlined in Chapter Three.
The next section describes how van Manen’s method of inquiry was employed in the conduct of the study.

**METHOD OF INQUIRY**

As outlined in Chapter Three, hermeneutic phenomenology was used to assist the researcher to gain a deeper understanding of the experiences of the participants. van Manen describes the methodological themes of the hermeneutic phenomenological approach (1990, pp. 30-31) as follows:

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigating experience as we live it rather than as we conceptualise it;
3. reflecting on the essential themes which characterise the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. maintaining a strong and oriented pedagogical relation to the phenomenon;
6. balancing the research context by considering the parts and whole.

Each of these considerations will now be elaborated in more detail.

**Turning to a phenomenon of concern and interest to the researcher**

In this study, the phenomenon of interest was the lived experience of family care givers in crisis during their care for relatives with mental illness. The researcher is a psychiatric nurse, and a nursing lecturer in the mental health field, and in a number of cases the care givers are her friends and colleagues. Family care givers and their mentally ill loved ones have therefore been central to her teaching, practice and personal life. In various conversations surrounding the processes involved in care giving, the major issues have often been difficulties in sustaining the role over time, and especially how to deal effectively with the problem behaviours of mentally ill relatives as they occur. However, before strategies can be developed to help care givers deal more effectively with such difficulties, it is necessary to gain a better understanding of what it is like to provide care to a relative with a mental illness, and
especially the circumstances under which the stresses and strains of care giving may precipitate a crisis. Accordingly, this study was designed to focus on the experience of providing care for family members with a mental illness, with particular emphasis on the experience of crisis as part of that care giving role.

In discussing this initial step, van Manen identifies the problem of pre-understanding the phenomenological inquiry, that is, researchers ‘know too much’ (1990, p. 46) about the phenomenon being investigated. This may cause the researchers to interpret the phenomenon too early with the risk that the significance of the phenomenon will not be fully discovered. Therefore, phenomenologists suggest the use of bracketing to make more explicit the researchers’ pre-understanding of the phenomenon of interest (Dowling, 2007). However, in practical terms it is impossible to “try to forget or ignore what we already know” (van Manen, 1990, p. 47).

In this study, the researcher sought to make clear her assumptions about the phenomenon during the research process rather than bracketing them. The researcher’s pre-understanding of care givers’ experiences in providing care for a loved one with mental illness was derived from her professional and personal life as already indicated in Chapter One. The researcher’s Thai cultural background as well as the literature review undertaken for the study also formed such pre-understanding. Being aware of this prior knowledge, it was impossible for the researcher to ignore it. Rather the researcher, when faced with the data, asked the question ‘Is this result interpreted by prior knowledge or by the voice of the participants?’

Phenomenology is a study of “the nature of the phenomenon as meaningfully experienced” (van Manen, 1990, p. 40). The participants in the study were asked to reflect on their lived experiences in crises during their care for loved ones with a mental illness. During the interviews, the researcher tried to focus on the research question emphasising this lived experience. To avoid bias, the terms ‘difficulty and challenge’ were used instead of the term ‘crisis’. The researcher also asked what it was like to care for a mentally ill relative to orientate them to the lived experience. These
strategies were designed to assist the researcher to gain a deeper understanding of the participants’ lived experience.

**Investigating the lived experience**

For van Manen, the purpose of phenomenological study is to “gather other people’s experiences because they allow us to become more experienced ourselves” (van Manen, 1990, p. 62). In this study the phenomenon of interest, the lived experience of care givers during crisis, was studied as it was lived out by the participants. Accordingly, the study design concentrated on capturing the participating family care givers’ experiences of the phenomenon of interest, with the research questions being framed for this purpose. Care givers were encouraged to use their own voices to talk about lived experience in crises. van Manen also suggests that the process of gathering and analysing the experiential materials “should be seen as part of the same process” (van Manen, 1990, p. 63). Hence, the researcher interviewed the care givers and conducted preliminary analysis of the interview transcriptions. Then, the researcher attended follow-up interviews with participants in order to validate the preliminary themes that had emerged from the initial interviews; and to gain a deeper understanding of that lived experience.

As indicated in the preceding chapters, the researcher undertaking this study has had some preliminary exposure to care givers, discussing aspects and difficulties associated with the role. To this end, steps were taken to limit the impact of any prior experience the researcher had that would potentially influence the findings of this study. One aspect of this approach was to maintain a reflective journal for the purpose of exploring the researcher’s previous interpretations, as these relate to the unfolding of the current study. More details of the reflective journal are described in a later section.

**Reflecting on the essential themes**

The broad aim of phenomenological reflection is to understand the essential meaning of something (van Manen, 1990). The process of reflection must be appropriate and clarified to make explicit the structure of the meaning of that lived experience. van
Manen (1990, p. 78) says, “meaning is multi-dimensional and multi-layered”. To understand the meaning of the text, the phenomenon described in the text is analysed as themes.

An important component of the phenomenological approach used to conduct this study was reflection on the descriptions arising from the research interviews. Three levels of thematic analysis were involved and these are set out in some detail in the section entitled data analysis (See page 96). The broad purpose of the reflective activities referred to above was to gain insight into and describe the essential meaning of the experience that was the focus of the study.

**Hermeneutic phenomenological writing and rewriting**

The aim of hermeneutic phenomenological writing and rewriting is to present a phenomenological text and to illustrate the lived experience for the people involved; to see its meaning. For van Manen (1990, p. 7) hermeneutic phenomenological research fundamentally involves a writing process. To this end, he (1990, pp. 125-127) has suggested:

> Yet for the human sciences, and specifically for hermeneutic phenomenological work, writing is closely fused into the research activity and reflection itself…Writing fixes thought on paper. It externalises what in some sense is internal; it distances us from our immediate lived involvements with the things of our world…writing creates the reflective cognitive stance that generally characterises the theoretical attitude in the social sciences…To write is to measure the depth of things, as well to come to a sense of one’s own depth.

Thus, the researcher is expected to write and rewrite; moving back and forth until the phenomenon emerges from the writing (Munhall, 1994).

In this study, the researcher came close to the lived experience of care givers through the writing process. The researcher asked questions (For example, is this what the experience is really like?) to reflect on the texts and to create a deeper understanding of
the lived experiences during crises of the participants involved. The theme was rewritten until it ‘spoke’ the lived experience of participants from their point of view.

**Maintaining a strong and oriented relation**

van Manen states that the hermeneutic phenomenological researcher needs to reflect, speak, and write in a manner that is both ‘oriented and strong’ in a pedagogic sense (1990). “Pedagogy is an embodied practice and that pedagogical research and theorising, too, are pedagogic forms of life” (van Manen, 1990, p. 139). To apply this concept in practice, the researcher constantly focused on the research question and the phenomenon being studied. If the participants went off track, the researcher brought them back to the phenomenon of interest. During the interview, the researcher did not bring prior stories from previous interviews into the current one. She treated each interview as if it were ‘fresh’ to her. Meanings from participants’ lived experience were centrally oriented.

**Balancing the research context**

It is important that the researcher carefully forms the overall design of the text in relation to its parts. Each part must also be significant to the total documented structure of the phenomenon of interest. This entails the researcher checking and rechecking the content given for the whole text and its parts to confirm the connection between them. van Manen (1990, p. 161) suggests:

…the researcher needs to be creative in finding approaches and procedures uniquely suited to this particular project and this individual research…we need to approach method always contextually, while keeping in view the fundamental research question.

In this study, in-depth interviewing was used to gain access to the lived experience of family care givers of relatives with mental illness. Then, the interview transcripts were analysed and utilised carefully to produce themes to present the phenomenon of the study. The analysing and interpreting process was designed to focus on the research
question described above. These processes were reviewed continuously to set the essential themes for the whole group in respect to the text of individual participants.

DATA COLLECTION

In-depth interviewing

An in-depth interview is a conversation which aims to achieve a specific purpose (Minichiello, Aroni, Timewell, & Alexander, 1995). To the extent to which this kind of interview “seeks to obtain descriptions of the interviewees’ lived world with respect to interpretation of the meaning of the described phenomena” (Kvale & Brinkmann, 2009, p. 27), it was an appropriate method for this study. The central idea of the study was to gain access to participants’ perspectives of crisis; their interpretations and meanings associated with such experience. These can be gained by accessing participants’ words using in-depth interviews (Minichiello et al., 1995). The interview attempted to understand the lived experience of crises encountered in the course of providing ongoing support for a mentally ill family member, from the perspective of the family care givers involved.

Twelve initial interviews and 10 follow-up interviews were conducted with 12 consenting individual family care givers. The interviews were guided by semi-structured open-ended questions focusing on care giving and associated crises as detailed in an interview schedule (Appendix One - Interview schedule). Those questions were reviewed after each interview to improve the flow of conversation during subsequent interviews. The initial interview began by asking participants a number of demographic questions, before moving on to address their involvement in care giving broadly, and their experience of crises more specifically. Follow-up questions were asked depending on the nature of participants’ responses to the initial questions. All interviews were recorded using digital recording equipment. The recorded data were then transcribed verbatim and analysed. The follow-up interviews were held approximately one month after the initial interview. The purpose here was for the researcher to have an opportunity to assess the accuracy of data and produce a
preliminary identification of phenomenological themes. The follow-up interview which was designed to allow participants to clarify their lived experiences of crises, was sought with all twelve participants. However, only 10 out of the 12 original participants agreed to be interviewed again. In the follow-up interview, participants were asked to comment on and validate key points arising from the earlier interview. All 10 follow-up interview participants agreed with the summary of the preliminary identification of phenomenological themes and that the summary captured their main concerns. Further clarification and exploration of key experiences were sought and the interviews continued until the participants had nothing more to say. The data generated from the first and second interviews was sufficiently rich, that it was considered that further follow-up interviews were not necessary. The researcher terminated the interview with each participant and left the study site. A thank you letter was sent expressing an appreciation for participating in the study; this letter also included the research candidate’s contact details. Participants were also advised that should they wish to obtain a summary of the research they would be able to do so once the examination process had been completed (Appendix Two - Thank you letter).

The approximate length of time for each interview was planned to be around 45-60 minutes. However, this varied from one participant to the next. In practice the length of the interview varied from 30 minutes to 1.27 hours. From the 22 interviews undertaken, five initial interviews and one follow-up interview took more than 60 minutes whereas one initial interview and seven follow-up interviews took less than 45 minutes. During the interviews, some participants became distressed in recalling what for them had been very difficult circumstances. In such circumstances, the researcher asked participants if they would like to stop the interview until they felt able to continue, or whether they would like to recommence the interview on another day or as soon as the participant was ready (Holloway & Wheeler, 2010). They declined to stop the interview and continued until it was finished.

Other data collection techniques used in the study included the use of note-taking during the interview and maintaining a researcher reflective journal. The researcher
was aware that the taking of notes may disturb participants (Holloway & Wheeler, 2010). Therefore, notes were only taken regarding important information in a short form for the purpose of prompting the researcher to ask further questions related to the lived experience of crisis associated with care giving. Consequently, family care givers were encouraged to tell of their experiences freely without interruption, and the essence of their experience of crises was not lost.

As indicated above, the researcher also kept a reflective journal. Reflections were written immediately after each interview and included thoughts, interpretations, impressions, and questions related to the interview (Roulston, deMarrais, & Lewis, 2003) (Appendix Three - Reflective journal). This helped the researcher record her immediate impressions and also formed part of the data record which was used to enhance the understanding of the participants’ experiences. The researcher also reflected on every day encounters and experiences of the study process (Kahn, 2000a, 2000b; van Manen, 1990). The recording of the reflective journal increased the confirmability of the study as it provided an additional contemporaneous source of data upon which to reflect when undertaking the data analysis (Holloway & Wheeler, 2010) (See Chapter Six - Limitations of the study).

Guided questions such as those following, were used to structure entries into the reflective journal (Roulston et al., 2003, p. 665):

1. How do I think I did with the explanation of the research purpose?
2. How do I think I did with the explanation of the consent process and form?
3. How did the interview context enable or constrain the interview process?
4. How did I do in building rapport with the participant?
5. What kind of questions did I ask in the interview?
6. What kind of responses did I get?
7. How did my questions influence the participants’ responses?
8. Did I put possible responses into the questions?
9. Did I ask closed-ended questions or open-ended questions?
10. Did I use more than one question at a time?
11. How did I handle silence within the interview?
12. Was there overlapping talk or interruptions in the interview?
13. Did I use continuers such as um, okay, mm-hmm?
14. Do I treat interviews as conversation? If so, what was my input into the conversation?
15. Did I evaluate the participants’ responses to my questions within the interview? If so, how did the participant respond to this evaluation?
16. Were my interview questions focused on the purpose of the research and my research questions?
17. What would I do differently if I were able to do the same interview again?
18. What suggestions for improvement do I have for my own interview techniques?

The study site

During visits to Thailand in July and December 2009 the researcher was able to informally observe mental health services in the hospital and health centres in which it was proposed the study would be undertaken. The community hospital in this region provides diverse mental health services, such as treatment, counselling, home visiting and teaching resources for family care givers. Informal discussions with a psychiatric nurse working in the area indicated that despite the availability of such services, crises related to mental illness (often precipitated by the behaviours of mentally ill relatives such as violence, suicides, and property destruction) occurred regularly in this community.

On these same visits to Thailand the researcher also had the opportunity to visit the house of a family providing care for a mentally ill loved one. Family care givers who accessed such services raised issues regarding their experience and what they considered to be precipitating factors of crisis. The difficulties they experienced in caring for relatives with mental illness included accessing health services, a lack of knowledge about mental illness, a lack of money earned in households and to spend on treatments, and experience of abuse by both mentally ill loved ones and care givers.
These issues were similar to those noted in the literature review that precedes this chapter.

The researcher had also informally discussed difficulties experienced by family care givers in dealing with the local mental health services. There was general agreement that there was a pressing need to develop programs to provide help for family care givers. However, it was also felt that predisposing and precipitating factors for crises associated with the care giving role were as yet poorly understood, and that it was thus difficult to develop well targeted intervention programs. Similarly, it was felt that there was insufficient understanding of the ways in which family care givers experience such crises, or their views on the kind of assistance that would likely be of benefit. Given the potential for the project to generate information which could be used to help family care givers experiencing such crises, mental health care providers in the area expressed considerable interest in the study; indicated ‘in principle’ willingness to collaborate; and expressed the hope that successful completion of the study would contribute to the development of services to better help and support the family care givers.

Data for the study was collected between October 2010 and March 2011 in the community located in the central region of Thailand on the outskirts of Bangkok, around 40 minutes drive from the centre of the city. It comprised of one district, seven sub-districts and 68 villages and had a population of around 85,000. The main occupations of people living in the target community were farmers and wage earners with low incomes of approximately 2,500-5,000 baht/month/family (AUD$80-180) (Sainoi Hospital, 2009). The majority of these people are Buddhist (80.61 per cent). In terms of age structure 56.02 per cent are under 40 years of age and those aged 40 and above comprise 43.98 per cent of the population (Information and Communication Technology Center, 2011).

Regarding the educational level of people in the target community, it was not possible to obtain information on education and literacy within the district in which the research conducted. However, historically access to schooling has been limited in
Thailand. It was thus common for people aged 40 and over to have very little schooling. According to The National Statistical Office (2005), 11 per cent of the population 40 years of age and over was illiterate. Subsequently, the national literacy level has gradually increased. The National Statistical Office of Thailand (Statistical Forecasting Bureau, 2011) reports that the population aged 15 and over (53.1 million people out of 65.9) had an average of about eight years of schooling. For about half this population (26.6 million people) the level of education was elementary or less. Approximately 24 million of this population had no education. Based on these figures and given the kind of work conducted by most people living on a low income, it would seem reasonable to assume that the literacy and education level of people in this district are not up to the national level. The majority of participants were illiterate.

Data collection was conducted in a community hospital and three (out of 14) health centres in the district in which the study was undertaken. The community hospital has 60 inpatient beds and also provides outpatient services. The health centres within the region offered only out-patients services. Two of the three participating health centres were located towards the centre area of the target district, while the third was located more distantly on the outskirts; approximately 30 minutes drive from the more centrally located health centres. These three health centres were selected for data collection because they provided similar mental health services to those of the community hospital. The most commonly occurring mental disorders in this district were schizophrenia, epilepsy, anxiety, and depression.

Participants and sampling

A purposive sampling technique was used in the study to ensure a focus on the phenomenon of interest (Creswell, 2007; Morse, 1991): the lived experience of family care givers in crises associated with their care giving role. Participants in the study were consenting family care givers of relatives with mental illness who met inclusion criteria and were willing to talk about their challenging or difficult experiences of care giving, especially where these contribute to the development of crises. The specific inclusion criteria were set as follows:
- Providing care for relatives diagnosed with mental illness (as defined by The International Statistical Classification of Diseases and Related Health Problems ICD-10) for at least six months during the last year;

- Ability to speak Thai;

- Aged 18 and over;

- Prepared to provide written consent to participate in the study.

The intention was to recruit family care givers who had provided care for a relative with mental illness for six months or more to ensure they had had sufficient involvement in care giving to be able to speak in depth about their experience.

All participants needed to be able to speak Thai so they could express their experiences, engage in a conversation, and respond to the questions in their mother tongue. This also ensured that the researcher who is Thai was able to understand their experiences.

The research design and data collection techniques for the study required that participants would be able to converse in the Thai language and have sufficient understanding to be able to talk meaningfully about their experience of providing care for a family member with mental illness. It was also necessary that they be able to understand what it was that they were agreeing to when providing written consent to participate in the study. The study was conducted in a rural-urban community, with family care givers aged 18 and over; given the limitations of Thai education system in the past, it was possible that some prospective participants would not be literate. At the same time it seemed important that their experiences of crisis be heard. To take account of such circumstances, the study protocol made provision for family care givers who were illiterate to have the study documents read to them by a nominee. Such participants indicated their willingness to be involved in the study by writing their signature on the consent form (rather than providing a finger print as had
originally been planned) (See Appendix Four - Information statement and Appendix Five - Consent form).

**Exclusion criteria**

Family caregivers of people with cognitive impairment, including dementia, delirium and mental retardation were excluded. The basis of this exclusion was that the needs of such groups have been explored in some detail in the literature, both internationally and in Thailand. In addition, these disability groups require special mental health services. In Thailand, there are specialised institutions providing specific services for people with mental retardation. Potential participants with a physical disability that would impede their ability to freely and easily communicate in the planned in-depth interviews were also excluded.

**Study sample**

Phenomenological studies using interview techniques for collecting data on individual experiences have usually recruited between 3 and 10 participants (Daly, 2005; Endrawes et al., 2007; Jung, 2000). The use of modest sample sizes in this type of research is considered adequate, or even desirable, because the main purpose is to investigate the meanings that people give to their lived experience (Dukes, 1984). Small sample sizes allow participants to tell of their experiences and to reveal these as they are lived out. This typically involves in-depth interviewing and detailed data analysis, and is thus often labour intensive. However, Morse, Barrett, Mayan, Olson, and Spiers (2002) state that to increase the scope, appropriateness, and adequacy of the data, the researcher needs to interview new participants rather than repeatedly interview the same participants. Each participant should be interviewed two or three times to gain a depth of understanding of the phenomenon under consideration and/or to address a gap in the data. In this study it was anticipated that initially between 5 and 15 participants would need to be recruited for the aims of the study to be realised.
Recruitment

Permission was granted to conduct the research from the Human Research Ethics Committee (HREC) of the University of Newcastle (Appendix Six - Ethics approval) as well as from authorised persons in the area in which the study was conducted (Appendix Seven - Permission to collect data). Consenting participants were recruited from the mental health and psychiatric unit in the community hospital and from the mental health and psychiatric clinic in the three health centres described in the preceding section. The psychiatric nurse in the community hospital agreed to be an initial contact person in the recruitment process. Her role consisted of advertising the project, following the ethics approved protocol and having initial contact with potential participants.

The psychiatric nurse and professional staff providing mental health services in these facilities were oriented to the process of the study by the researcher before commencement of the project. Following this orientation, the psychiatric nurse distributed the advertising flyers in the community hospital, health centres and community centres. This flyer included the possible precipitating factors of crises and examples of crises to assist family caregivers to decide whether they would like to be involved in the study (Appendix Eight - Advertisement flyer). There were a number of reasons for adopting this approach. First, there was a lack of crisis intervention and/or outreach services throughout Thailand and thus the nature and impact of crises were not well understood and managed in Thailand and thus crisis assessment tools were not readily available. Second, crises are typically internal states (Lewis, 2005) and personal problems (Faul & Hudson, 1997; Hudson, Mathiesen, & Lewis, 2000). Hence, the meaning of crisis can depend on an individuals’ subjective experience (Lewis, 2005).

The psychiatric nurse approached prospective participants who visited the facilities described above with their mentally ill relatives and provided them with copies of the advertisement flyer as well as the information statement. In addition, the psychiatric nurse presented the invitation to take part in the research to prospective participants
during her health care home visits. The psychiatric nurse explained the study to potential participants and advised that the decision to participate or not to participate was completely voluntary and would not entail any benefits or disadvantages. Prospective participants were encouraged to ask the psychiatric nurse any questions regarding the study; they were also encouraged to take the documents (the flyer, the information statement, and the consent form) home for further consideration. Those who decided to participate in the study were able to contact the research candidate directly (via details provided in the information statement). If the person provided with the information was not a primary care giver, encouragement was given to pass the information pack on to those family care givers whose characteristics most closely matched the inclusion criteria for the study. Those who agreed to participate in the study were asked to place the signed consent form in one of four labelled locked boxes located in either the hospital or the health centres for this purpose.

Overall, 19 consent forms were collected from the labelled locked boxes. The researcher contacted prospective participants using the contact details provided in the consent form. Six prospective participants who were willing to give consent did not meet inclusion criteria as they were family care givers of people with cognitive impairment. One consenting participant met the criteria but was not available for interview. These seven prospective participants were ruled out from involvement in the study. Twelve participants who met selection criteria and agreed to share their experiences were accepted into the study. The first interview commenced in November, 2010 and the last interview was conducted in February, 2011. After the two rounds of data collection (12 initial interviews and 10 follow-up interviews), it had become clear that the data being generated was of sufficient depth to do justice to the phenomenon under investigation. Participants’ profiles are presented in Table 4-1 in the order in which the participants were recruited to the study.
**Table 4-1 Participants’ profile**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Marital Status</th>
<th>Occupation</th>
<th>Education Level</th>
<th>Mental Illness</th>
<th>Caregiver Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tong</td>
<td>50-55</td>
<td>Widowed</td>
<td>Food seller</td>
<td>One year</td>
<td>Schizophrenia</td>
<td>16 years</td>
</tr>
<tr>
<td>Mee</td>
<td>67-70</td>
<td>Married</td>
<td>Housewife</td>
<td>Two years</td>
<td>Schizophrenia</td>
<td>3 years</td>
</tr>
<tr>
<td>Kit</td>
<td>50-50</td>
<td>Single</td>
<td>Wage earner</td>
<td>Uneducated</td>
<td>Depression</td>
<td>10 years</td>
</tr>
<tr>
<td>Na</td>
<td>5-60</td>
<td>Married</td>
<td>Wage earner</td>
<td>Two years</td>
<td>Schizophrenia</td>
<td>13 years</td>
</tr>
<tr>
<td>Rung</td>
<td>85-85</td>
<td>Married</td>
<td>Househusband</td>
<td>Two years</td>
<td>Schizophrenia</td>
<td>30 years</td>
</tr>
<tr>
<td>Num</td>
<td>36-36</td>
<td>Single</td>
<td>Grocer</td>
<td>Nine years</td>
<td>Schizophrenia</td>
<td>10 years</td>
</tr>
<tr>
<td>Pat</td>
<td>54-54</td>
<td>Married</td>
<td>Wage earner</td>
<td>Four years</td>
<td>Schizophrenia</td>
<td>13 years</td>
</tr>
<tr>
<td>Den</td>
<td>75-75</td>
<td>Married</td>
<td>Unemployed</td>
<td>Four years</td>
<td>Depression</td>
<td>20 years</td>
</tr>
<tr>
<td>Pond</td>
<td>50-50</td>
<td>Divorced</td>
<td>Employee</td>
<td>Bachelor of Arts</td>
<td>Depression</td>
<td>1 year</td>
</tr>
<tr>
<td>Samorn</td>
<td>64-64</td>
<td>Widowed</td>
<td>Wage earner</td>
<td>Four years</td>
<td>Schizophrenia</td>
<td>30 years</td>
</tr>
<tr>
<td>Pla</td>
<td>75-75</td>
<td>Married</td>
<td>Housewife</td>
<td>Two years</td>
<td>Schizophrenia</td>
<td>12 years</td>
</tr>
<tr>
<td>Taew</td>
<td>75-75</td>
<td>Widowed</td>
<td>Retired</td>
<td>12 years</td>
<td>Schizophrenia</td>
<td>24 years</td>
</tr>
</tbody>
</table>

* From interviews with caregivers, symptoms that appear are likely to be due to Schizophrenia.

** From interviews with caregivers, symptoms that appear are likely to be due to Depression.

**Requirements for participants**

The requirements of participation in the study were outlined in an information statement that also included an invitation to participate in the study. Prospective participants received information regarding the purpose of and procedures involved in conducting the study. Twelve family care givers who consented to participate and were accepted into the study attended the initial interview. Ten of the original twelve
participants attended the follow-up interview one month after their initial interview. The duration of the interviews, which were digitally recorded, was between 30 and 90 minutes. The interviews were conducted at a mutually agreed, safe location such as at the community hospital or the health centres. Following each interview the digital recording was transcribed and any personal identifying information was removed. Pseudonyms were used instead. The interview schedule included a series of questions designed to elicit information regarding participants’ overall experience of care giving associated with their care giving role. During the follow-up interviews, participants were asked for validation of the preliminary identification of phenomenological themes arising from the earlier interview. Further clarification and exploration of key experiences was also sought. None of the participants requested to stop the recording at any point during the interviews.

**Data retention and management**

Maintaining confidentiality and ensuring the security of research data are important considerations in any study. All CDs and interview transcripts were kept in a locked cabinet and stored at the Boromarajonani College of Nursing, Chang Wat Nonthaburi which was the researcher’s work place during the data collection period in Thailand. The researcher returned to Australia in March, 2011 and all of the CDs and documents were transferred into a locked filing cabinet in the School of Nursing and Midwifery on the Callaghan campus of the University of Newcastle, Australia. The only people having access to these research materials were the researcher and the two research supervisors. In addition, the personal contact details of the participants were kept separate from all the other information pertaining to the study. As all data were de-identified it was not possible to identify individuals from transcripts or information published either in the final thesis or subsequent publications reporting the outcomes of the study.
Data management

Data from individual interviews were recorded by the researcher using a digital recording device. Data recorded on the digital recorder were transferred to the researcher’s notebook computer and onto several backup CDs. Both computer and CDs were password protected.

On completion of the study, electronic data were downloaded to an external hard disk and several back up CDs. Data were then deleted from the computer system. All data has been securely stored for a period of five years in a locked room of the School of Nursing and Midwifery, Faculty of Health, Callahan campus, of the University of Newcastle. A data storage list is being maintained. No names or identifying information have been kept. At the end of the required five-year period, all data will be destroyed following University of Newcastle procedures for shredding of sensitive documents and the external hard disk will be cleaned and back up CDs will likewise be destroyed in a way consistent with the current University research data disposal policy.

DATA ANALYSIS

Phenomenological research seeks to uncover the meaning of lived experience. To describe the phenomenon, the human science researcher becomes involved in a process of crafting a text in order to come to grips with the structure of meaning of the text or themes (van Manen, 1990). van Manen (1990) states that phenomenological themes are the structures of experience. Therefore, a theme can be thought of as “the experience of focus, of meaning, of point, and the form of capturing the phenomenon one tries to understand…Theme formulation is at best a simplification” (van Manen, 1990, p. 87). In this study, themes were developed following the approach described by van Manen (1990) as set out below.
Uncovering thematic aspects

The interviews were conducted in Thai language. Within three - five days following each interview the recording was transcribed by a professional transcription typist and translator; the interview transcript was initially prepared in Thai language. This document was then translated from Thai to English. The accuracy of the transcripts, both Thai and English versions, were checked by the researcher by listening to the digital recording while simultaneously reading the transcripts. This process was repeated until an accurate interview transcription was achieved. This process also provided an opportunity for the researcher to engage with and reflect on the text. The researcher also looked for areas for more exploration and further clarification. English transcripts were also submitted to the supervisors for independent review.

Isolating thematic statements

During this stage of the process, the researcher repeatedly listened to the digital recordings, reread transcripts, and reflected on the text. This was maintained throughout and following the period of data collection. Three levels emerged in this thematic analysis:

- A holistic or sententious approach: Initially the whole text was read and described in terms of a phrase. The aim here was to capture the fundamental meaning of the text as a whole.

- A selective or highlighting approach: The recorded data were listened to and read a number of times. The aim here was to identify statement(s) or phrase(s) which seem particularly essential to or revealing about the phenomenon or experience being described and highlighting these.

- The detailed or line by line approach: The text was read line by line to examine the sentence(s) which reveal the phenomenon of interest, in this case the lived experience of family care givers in crises during their care for relatives with mental illness.
From the steps outlined above, thematic statements from care givers’ own words were isolated. Table 4-2 (below) provides an example of an emerging theme from the interviewed data from one participant.

### Table 4-2 Example of conducting thematic analysis of one essential theme in an interview

<table>
<thead>
<tr>
<th>Holistic approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring for a loved one with mental illness means a difficulty in having to live with fear. Fear comes from “don’t know what’s going to happen”. There are a lot of unpredictable situations resulting from the loved ones’ symptoms of mental illness that create the feeling of fear.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with fear</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Selective approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>“If our son dies, we would cry once, right? But then if our son got lost. We never know if he would starve. I would indeed suddenly awake, scared in my sleep.” (Tong, p. 5)</td>
</tr>
<tr>
<td>“It is very difficult to live with people like this. I have to make provision. But he does not hurt anyone. But he once pressed my arm to the floor. Press down. I told him, “Dee, this is Mother.” He regained himself and released me. He told others that he teased me, teased me for fun. We did not know what our son would do.’ (Tong, p. 6)</td>
</tr>
<tr>
<td>“Stunned with fear, of course. My son ran and would the cars hit him dead? Oh, my. Then I hired the car. Take it three hundred, four hundred [Baht]. One time he ran to Bang Lane [A main street in the area where the study was conducted]. One time I was frightened, my heart sank, he stood there stiff and black. I was frightened that I might not find him anymore. If we could not find him, we could not find him, because being mad, he would run on and on, right? He had not taken any medicine at all.” (Tong, p. 13)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Line by line approach</th>
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<tbody>
<tr>
<td>“Stunned with fear...”</td>
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<tr>
<td>“...I was frightened, my heart sank...”</td>
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<tr>
<td>“I was frightened that I might not find him anymore.”</td>
</tr>
<tr>
<td>“We did not know what our son would do...”</td>
</tr>
<tr>
<td>“...We never know if he would starve.”</td>
</tr>
<tr>
<td>“...I would indeed suddenly awake, scared in my sleep.”</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Essential theme</th>
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<tr>
<td>I’m overwhelmed with fear</td>
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</table>

In this study, the participants were provided with an opportunity to consider and comment on the emerging preliminary themes. Following the initial interview, preliminary identification of phenomenological themes of each participant was undertaken using data from the Thai language transcriptions which was then
compared to English transcriptions. The purpose here was to gain an understanding of
the meaning of the lived experience without losing its essence in the process of
transcription and translation. Where participants agreed to undertake a follow-up
interview, they first received a letter describing the researcher’s preliminary
understanding of their lived experiences as captured in the initial interview. The letter
summarising those themes was written in English and sent to the supervisors for
review (Appendix Nine - English letter). Following consideration by the supervisors,
the letter was translated back into Thai by the researcher and sent to the participant
two to three days prior to the follow-up interview (Appendix Ten - Thai letter). This
letter of summary from the first interview was used as a starting point for further
exploration in the subsequent interview and for engaging participants in a process of
interpretation in which the themes emerged through conversation with the researcher.

Participants in the follow-up interviews were asked to confirm the preliminary
identification of phenomenological themes arising from the initial interview as
outlined by the researcher. The follow-up interviews were recorded, transcribed,
translated and analysed using the same process described above. The material from the
first and second interviews was compared for each participant; this contributed to the
development of new themes and the amendment and refinement of those initially
identified. The researcher constructed tables and diagrams to identify the relationship
of the themes between each participant. As themes were built up they were constantly
checked against the interview transcriptions to ensure they reflected the phenomenon
of interest. The thematic descriptions and explanations were carefully chosen to
demonstrate the essence of the phenomenon. Through this process the themes and
thematic phrases alluding to the phenomenon of interest for the whole group were set,
in respect of individual participants. An example of a developing essential theme of the
whole group is presented in Table 4-3.
Table 4-3: Example of conducting thematic analysis for the whole group

<table>
<thead>
<tr>
<th>Descriptions</th>
<th>Thematic analysis</th>
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<tr>
<td>Then one day, I didn't know why she became like a being possessed, convulsing with her eyes rolled back. I was with her when she fell into an irrigation ditch. I had to pull her up and carry her. Since that night, she has never been well again...Since then, there has not been a night that I can sleep. It has not been good. From then on, she became more and more ill...Oh my, these difficulties...how many years and how many lives [Buddhists strongly believe in reincarnation] has it been...more than twenty years, maybe? (Rung, p. 9-10)</td>
<td>The participant experienced caring for a loved one with mental illness as a prolonged burden.</td>
</tr>
<tr>
<td>When he went for treatment in [the provincial] hospital for about two months, it was difficult. And I have looked after him continually ever since he became ill. I must feed him food and water. And if he was not happy about something, he would throw the rice away spilling it all over my face. That was what he did, when he was unsatisfied about something. And when he did a poo, oh my, sometimes he smeared it all over the sleeping place. It has not been easy at all. Oh my, I am tired to death of it. Sometimes I sit and cry alone. Why does Ku have to be in such a hardship as this? Truly, truly, you see. Oh my, I have such great hardship. (Pat, p. 4)</td>
<td>Prolonged burden resulted from having to care for a loved one in every way for a long time.</td>
</tr>
<tr>
<td>Taking care of this kind of person is burdensome to my heart as well as to my body. It is harder on my heart, think, why is my son not like other people? Why does he have to be like this? I keep thinking about this and that, so many things. I watch and I keep my eyes on him. My ears would catch some noise, Gag! And instantly, I thought, &quot;Oh, he must be out again!&quot; This tires my heart. And I never have rest. Scolding him all the time makes my head ache and spin like a top...He kept trying to get out, again and again. So I was stressed. I had to get out too. I need to earn our living. When I let him stay home by himself, he just wanders away. I have to work in the rice field...It is tiring, very, very tiring. It's a great burden to my heart. (Mee, p. 6-7)</td>
<td>This participant also experienced caring as a prolonged burden.</td>
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<tr>
<td>The three descriptions presented in Table 4-3 demonstrate the lived experience of participants having to care for their loved one with mental illness over an extended period of time. In each case the participants expressed great tiredness in their caregiving roles. A thematic statement was set to represent this experience as ‘living with prolonged burdens’.</td>
<td></td>
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</table>
Composing linguistic transformations

Thematic statements were captured in more phenomenologically sensitive paragraphs using methods such as writing and generating illustrative examples pertaining to the phenomenon of interest. Importantly, the building up of these thematic statements involved ongoing dialogue with the project supervisors. For example, the thematic statement set out in Table 4-3 ‘Living with prolonged burdens’ was composed and changed to ‘There is no end in sight’.

Gleaning thematic descriptions

Descriptions explaining themes were developed with close attention being paid to maintaining the essence of the phenomenon of interest - the lived experience of family care givers in a crisis whilst caring for a mentally ill family member. This involved reflection on how to group the identified experiences of care giving, and care giving associated crisis, using a genuine artistic expression. Further to this from Table 4-3, descriptions of the interviewed transcriptions were selected and used to support the theme (See Chapter Five - There is no end in sight).

INTERPRETIVE ACTIVITIES

In the interpretative process, themes were identified from the interview data by the researcher working closely with the project supervisors who independently reviewed and cross-checked the interpretations. In this study, interpretation was undertaken by enabling participants to use their own words to tell their story; to use their experiences as the basis for interpretation. The significance of the themes was interpreted in light of the original phenomenological question. The appropriateness of each theme was weighed by asking: ‘Is this what the experience is really like?’ Findings were validated through repeated readings by the research candidate working closely with the project supervisors.

In the final stages of interpretation, the task was to authenticate the meaning or essence of the lived experience of the participants. All research materials, including
transcriptions, the preliminary thematic analysis documents, letters to the participants, tables of themes and diagrams representing the phenomenon of interest were read again and compared to each other, in order to capture the essential meaning of the phenomenon under investigation. This process of immersion in each interview included relating each of the parts to the whole.

During the interpreting process, the researcher continuously reviewed English language descriptions used in analysis and interpretation of the data in order to improve the quality of results and to make them clear to an English speaking audience. The accuracy of the Thai language and the original English transcriptions were re-checked. The original English transcripts were then retranslated by the researcher in consultation with the English advisor of the Faculty of Health, at the University of Newcastle. The researcher took precautions to maintain the integrity of the original Thai transcriptions. These precautions included the Thai culture and Thai colloquialisms. Therefore, Thai terms were maintained in the thesis and their meaning is provided in the Glossary of Thai terms (See pages 13-14).

PRESENTATION OF FINDINGS

The participants were informed that the research data would be presented in the form of a research higher degree thesis, and also subsequently reported in conference presentations and/or journal publications. Once the thesis examination process is completed, participants will be able to request a copy of a brief summary report on the project. Details of how to obtain a copy of the summary report were provided on the project information statement.

RIGOR

While quantitative research approaches assess for validity and reliability, qualitative research assesses for trustworthiness of how a study has been undertaken and findings have been arrived at (Morse et al., 2002). In practical terms, this entails an evaluation of the responsiveness of the researcher to the data being collected, analysed and
interpreted. This requires the researcher to analyse data continuously and the recruitment of new participants is based on patterns emerging in the analysis and consideration of the inclusion and exclusion criteria for the study. New potential participant recruitment, then, is determined to guarantee replication and confirmation (Morse et al., 2002). To this end Morse et al (2002) have set out criteria for verifying the trustworthiness of the qualitative research, addressing: methodological coherence, theoretical sampling and sampling adequacy, an active analytic stance, and saturation.

Methodological coherence: The research question and the components of the method used must be congruent. The congruence of method, data, and analysis procedures continues throughout the process of the study. To answer the research question addressing the lived experience in crises from family care givers’ perspectives, a phenomenological approach had been chosen to conduct the study. In-depth interviewing was used as the primary mode of data collection to gain information on family care giver’s experience in crises. The data collected was analysed to capture the phenomenon as experienced by the participants. A field visit from one of the supervisors during the early stages of data collection provided the opportunity to review congruence and adherence to the chosen methodology.

Samples must be appropriate: The anticipated number of participants to achieve the aims of the study was 5-15. Twelve family care givers of relatives with mental illness participated in the study. A minimum of one in-depth interview was conducted with each participant to explore their lived experience of crises, seeking to gain as much in-depth information as possible about the phenomenon of interest. A follow-up interview was conducted with ten of the original twelve participants. The aim was to generate sufficient data with which to build up a trustworthy understanding of care giving and the crises that emerge from it.

Collecting and analysing data concurrently: In seeking to attain trustworthiness, information was collected from participants and at the same time analysed through comparison with each individual’s lived experience. As this process was undertaken, the transcripts were read by the supervisors and the analysis was reviewed to check
the researcher’s interpretation. The intention here was to establish an interaction between what was known from the data and what was needed to build up a more sophisticated understanding of the phenomenon of interest.

Thinking theoretically: Many ideas emerged from the data necessitating ongoing identification and verification. Accordingly, data were checked and rechecked, carefully and continuously, in an effort to ensure that all important ideas were included in the data collected. Moreover, ten of the original twelve participants who attended the follow-up interview were asked to verify the preliminary themes that emerged from the initial interview. The ten participants confirmed the main points of the preliminary thematic analysis.

Theory development: The researcher shifted carefully between collected data (micro level) and the theoretical understanding that underpins the study (macro level). The purpose was to produce ‘the theory of the unique’ (van Manen, 1990, p. 156) which was the lived experience of care givers in crisis during their care for ill relatives. Analysis of the raw data resulted in identification of ideas and patterns. The comparison of individual sets of data with each other, resulted in extracted similarities and differences which were used to build the framework of theory of the unique retrospectively (van Manen, 1990).

ETHICAL CONSIDERATIONS

Ethical considerations in this study were addressed following the guidelines of National Statement on Ethical Conduct in Human Research (Australian Government, 2007). Following these guidelines four main issues needed to be addressed: research merit and integrity, justice, beneficence, and respect (Australian Government, 2007). Moreover, these issues needed to focus on the ethical considerations for undertaking qualitative research using interviews: informed consent, confidentiality, risk of involvement, as well as the role of the researcher (Australian Government, 2007; Creswell, 2007) as detailed below.
Informed consent

To ensure that participants were not harmed in this study, a consent form was prepared following the procedure of the Human Research Ethics Committee of the University of Newcastle (2012), including identifying the project, researcher, appropriate general consent statement, the researcher contact details and place for participants to sign. The consent form also included a clear statement of the right to refuse participation or to withdraw at any time, requesting that any data that had been provided be destroyed. After potential participants were explained the details of the study by the psychiatric nurse, only those agreeable to involvement in the study signed a consent form.

Confidentiality

As this research used in-depth interviewing, data were transcribed and translated from Thai to English by a professional transcription typist. A single person was employed as both transcriber and translator. The transcription typist employed for this purpose signed a confidentiality agreement. She was informed that she could not save, retain or disseminate any data from the study. Participants were also informed that all data would be kept in a locked cabinet that could only be accessed by members of the research team, so that their identity was protected at all times.

Risk of involvement

During the process of sharing their experiences of crisis, some of the participants became distressed. The researcher, who is an experienced psychiatric nurse offered immediate support, and suggested that the participant seek help from a trusted person and a health professional of their choice. The researcher offered reasonable assistance to the participant to make the required contact.

The role of the researcher

The researcher as the interviewer used herself as an instrument to obtain knowledge from the interviewees (participants). This required the researcher to maintain integrity
as an interviewer. To preserve integrity, the researcher followed the ethics protocol as approved by the University Human Research Ethics Committee. The data were analysed carefully and family care givers’ experience in crises was interpreted from their perspectives using the data analysis process outlined above (See page 96). Rigor was also considered as an important issue during this study (See page 102). In addition, a reflective journal was maintained in order to increase the confirmability of the study as detailed in Chapter Six.

**CONCLUSION**

This chapter has provided a description of the procedure used to conduct the study. Following a brief consideration of the theoretical basis to research procedures informed by hermeneutic phenomenology, the approach to data collection was set out in some detail. This was followed by a section discussing data collection including the use of in-depth interviewing, the selection of the study site, participants and sampling, and data retention and management. An important consideration in qualitative research is data analysis and this was considered in the next section. The chapter concluded with discussion of ethical considerations associated with the conduct of the study. In the next chapter the findings of the study are presented.
Chapter Five
FINDINGS

INTRODUCTION

The purpose of this phenomenological study was to understand the meaning of the lived experience of crisis among family care givers in the Thai community as this related to their care for relatives with mental illness. Participants in this study comprised 10 females and 2 males. Face to face interviews were conducted with all 12 participants. The recordings of these interviews were transcribed and translated and a reflective journal was kept throughout as described in Chapter Four; this textual material was then subjected to analysis and interpretation. An individualised letter was sent to each participant outlining the key themes (See Appendix Nine). Ten participants were available for a second interview. In this second interview, clarification of participants’ experiences was sought and the participants were asked to verify the initial themes as outlined in the letter and provided with the opportunity to talk more about their experiences. The next section presents the significant themes that emerged from the data.

FAMILY CARE GIVING AS ‘ONGOING CRISIS’

The data analysis was conducted using a two-step procedure; a systematic process of thematic analysis, followed by a detailed interpretation of the phenomenon of interest. The initial data analysis revealed four emerging domains of difficulties and challenges experienced in the process of care giving, as follows:

- Practical daily struggles (working hard for very little money, not enough food to eat, doing household chores);
- Relatives’ confronting behaviours (episodes of mental illness, aggression, being unemployed, inappropriate behaviours, drug abuse including smoking and drinking);
• Social difficulties (social stigma, insufficient mental health services); and

• Troubled personal lives of family caregivers (painful feelings, prolonged burdens, being mentally and physically ill).

These four domains are illustrated in Figure 5-1 using the participants’ own words and phrases. This early analysis revealed challenges specific to each domain, however each of the domains intersected such that a stark and striking overarching theme was apparent as participants describe their lives as being in a state of ‘ongoing crisis’.

This experience of ‘ongoing crisis’ is reflected in the words of one of the participants:

Living with him is very stressful…I am very stressed these days. (Tong, p. 15)

Examples of the unrelenting pressures of care giving were also expressed by another participant:

Figure 5-1 Difficulties and challenges: Factors precipitating a state of ongoing crisis
It is a long term difficulty. It’s like working, making many things so that we cannot stop quickly; we have to keep working until it is finished. And the [work of caring] is never finished. That’s just how it is (Rung, p. 12)...[It is] terrible. It has affected us until now, made it real terrible. (Rung, p. 14)

The ongoing nature of such pressures is confirmed by yet another participant:

For me, it is a continuous difficulty. (Samorn, p. 20)

As the analysis continued constant reference was made back to the recorded interviews, the transcriptions, the reflective journals and the personal letters sent to each participant at the end of the first interview. This was done to ensure that the descriptions being built up were true to the uniqueness of each of the participants involved in the study. This iterative process resulted in the identification of four main themes with constituent sub-themes representing the meaning of the lived experience of family care givers in ongoing crises: ‘Out of control’, ‘So alone’, ‘Confusion and chaos’, and ‘No way out’.

Factors leading to a ‘state of ongoing crisis’

Before proceeding further to describe the findings in detail, it is informative to examine a broad overview of the difficulties and challenges of the care giving role and the factors influencing the participants’ lived experience and the outcome of these challenges. This is depicted in Figure 5-2 below. Data analysis identified four main areas of difficulties and challenges that participants described consistently. Closer examination of these four areas reveals a state of unrelenting crisis experienced by care givers who are ill-equipped to cope effectively with the ongoing chaos that typifies their lives. This state of unrelieved crisis negatively impacts on the care givers as they experience symptoms of mental and physical illness and levels of distress such that they express their wish to die. These situations then further precipitate an increased intensity of crisis as the care givers struggle to cope with an overwhelming burden of care without relief.
Precipitating factors of ongoing crises

1. Practical daily struggles (working hard for very little money, not enough food to eat, doing household chores)

2. Relatives’ confronting behaviours (episodes of mental illness, aggression, being unemployed, inappropriate behaviours, drug abuse including smoking and drinking)

3. Social difficulties (social stigma, insufficient mental health services)

4. Troubled personal lives of family care givers (painful feelings, prolonged burdens, being mentally and physically ill)

Expressions of ongoing crises

“...don't know what’s going to happen.”
“I don’t know which way to turn.”
“I myself don’t have the wisdom to cope.”
“I don’t know what to say.”
“I sit and cry alone.”
“...then things turned upside down”
“It is a long term difficulty.”
“I have been afraid for many years.”
“I have been caring for him all along.”

Negative outcomes

Emotional problems
Mental disorders
Physical problems
Physical disorders
Self-destructive thoughts

State of ongoing crises represented by four themes:

Out of control
So alone
Confusion and chaos
No way out

Figure 5-2 Factors contributing to care givers experience that result in ongoing crises
THE GRINDING AND UNRELENTING NATURE OF CARE GIVING

While in the following sections the themes are presented separately, the reader is reminded that they are each interrelated, calling forth the others as shown in Figure 5-3 demonstrating the grinding and unrelenting nature of the care giving.

Figure 5-3 A pictorial representation of the four main themes
OUT OF CONTROL

While interacting with the participants during the interview process and later with the transcribed interviews and other materials, the researcher identified the most common difficulties and challenges faced by participants as the episodic nature of mental illness, a lack of knowledge of mental illness, treatments, and the management of symptoms; the confronting behaviours of the loved ones with mental illness; and often severe household budget problems. Participants’ explanations of such difficulties and challenges strongly suggested the theme ‘Out of control’. For participants this meant that the decision to take on the care giving role took away other opportunities and personal choices; in essence, their lives had become shaped by the actions of the mentally ill relative. It is thus not surprising that the experience of care giving had largely become that of ‘ongoing crisis’. This is well captured in the sub-themes that constitute this theme entitled ‘Out of control’: ‘My life has fallen apart’, ‘I’m overwhelmed with fear’, ‘So many painful and difficult feelings’, and ‘So much loss’. Each sub-theme evokes the others as shown in Figure 5-4.
My life has fallen apart

The participants described the great shock associated with being faced with a loved one suffering an acute episode of mental illness. The initial impact was often so unsettling that it felt as if their lives were falling apart. The turmoil and distress that ensued was intensified by the emotional trauma of being witness to a loved one’s deterioration from a normally functioning person to someone who is deeply and
constantly distressed and disturbed. As their loved ones became mentally ill, the participants’ lives changed dramatically - these changes were very difficult to accept:

What was it like? What was it like? **It hit me full in the face.** He went from a good son to this. **Oh, I am almost unable to cope.** He had never had any illness, never. But now, I’m scared that he has become mad and lost his mind. **Oh, when he was ill at the beginning I was shocked. I was shocked. It was very terrifying.** (Tong, p.11)

In the following excerpt from an interview transcript the participant describes how her familiar and comfortable family roles were reversed after her mentally ill husband had been hit by a car:

He provided for me all along until he was hit by the car, then things turned upside down. From him providing for me, now I have to provide for him. (Pat, p. 12)

For many participants the mental illness was the most frightening experience of their lives, and hard to comprehend:

And saliva flowed, **Oh, saliva flowed** [i.e. drooling]. It was like his tongue could not fold and keep saliva in. I said, “**Oh my, I am disheartened to see my child like that.**” I was disheartened right away. (Pla, p. 4)

There was often a sense of not knowing what to do; of great uncertainty:

She was frightened by the earthquake and leapt out of the window…She leapt down from the window. I did not know. She told me, “**Oh, oh, I am so afraid. I don’t feel well.**” But I did not know what illness she had. Later on she just lay languishing. “Huh, what’s the matter with her?”…Oh, my, what should I do? (Samorn, p. 4)

Such experiences clearly left most participants feeling shocked and fearful, both for their mentally ill loved ones and themselves. A feeling of being overwhelmed with fear forms the basis of the next sub-theme.

**I’m overwhelmed with fear**

The sub-theme ‘I’m overwhelmed with fear’ was associated with the feeling of being ‘Out of control’ as described above. The basis to this fear most often seemed to be that participants no longer felt they had control over their own lives and that they were
faced with the unpredictable and sometimes aggressive behaviours of their mentally ill relatives. Participants feared both for their own safety and for that of their relatives with mental illness. Family care givers were particularly concerned that they did not know how to manage the symptoms of mental illness. Other fears included the possibility of losing their loved ones; concern as to their ability to afford the costs of treatment; and whether they would be able to manage the stresses and strains of providing care for a person who is mentally ill.

For most participants, the aggressive behaviours associated with mental illness made them fear both for themselves and for other people’s safety. This is clearly expressed in the following comments:

It was difficult. When he became ill it was very difficult. Sometimes I wondered, damn it, would he strangle me? Damn it! Would he strangle his sister or brother? I had to keep watch on him. I scarcely slept. Some nights, just Gag and I looked, Gag and I looked…would I know when he had become ill? (Tong, p. 8)

In another instance:

He would swear about this and that, walking along and rambling on and on. **Walk.** He is terrifying. I am afraid of him. I must speak nicely. I cannot scold him or he will get so angry. Living with people with mental illness is like this. I am afraid…I have always been afraid, all along. I have been afraid for many years. Never dare to say anything against him. I am afraid he will harm me, see. If he wants to do anything, I just let him. (Kit, p. 7)

The concern expressed in the following excerpts is more clearly related to the potential threat posed by the ill relative to the safety of others:

I was afraid that when he was out, someone might say something that was not nice to him and he might hurt them physically. It was just like that. And we live next to a school. If the children taunt him, I was afraid he might do something to them. (Mee, p. 3)

For some participants the fear was more associated with the risk of a mentally ill loved one harming themselves:

I kept following him. He wanted to die. Sometimes he would run out to let a car run over him, oh my, I was so scared. Sometimes a car was driving past and he just **dashed out in front of it** when we went out into the big street called Bang
Lane. I called him to return but he wouldn’t. "Dee, come back, Son, don’t run away." He just dashed off. Oh my, I was scared many times. (Tong, p. 9, l. 2)

This participant also expressed her fear regarding her brother’s aggressive behaviours. She was concerned for both her own and her brother’s safety:

He came late at night and knocked at the door, bang, bang, bang. He knocked at the door until everyone woke up. He knocked bang, bang, bang very loudly, "What? How can you all sleep? Get up!" See, he came. And then he turned on the TV. It was very loud. No one could sleep. We were scared of him. And we had to keep watch on him, listened and listened to see if he went to the next door neighbour’s. We were afraid that during the night he might go to other people’s houses. Other people would not know who he was and might shoot him. (Num, p. 10)

In the case of one participant the fear was more associated with whether a mentally ill relative might be hurt by mental health services staff. Her concern seemed to arise from a lack of understanding of the nature of psychiatric treatments and also from a previous experience in which her relative had been injured during a visit to hospital:

Like electric shocks, see? He would surely get it, right? Even in front of me, they still slapped him [across the face] two times. (Pat, p. 18)

As a result of these fears, she avoided having her husband admitted to the psychiatric hospital.

My son, from my first husband...said, “Mother, how can you stand him. Put him away [in the psychiatric hospital].” But I am afraid he might get kicked and beaten up. I saw it happen before. (Pat, p. 9)

Most participants were extremely fearful and distraught at the thought that they might lose their mentally ill relative. One participant described her feelings about this:

When I knew my son was missing, my heart sank completely. It seemed like everything had gone from me. I collapsed instantly. I often fainted. Although my son recovered and came back home, I now still faint continually. (Tong, p. 19)

The emotional toll of this constant distress and worry is poignantly described by another participant:

Such great, great distress. Even today, my [nervous system] is not good. I feel great stress because of him. He said his ears heard things and his eyes saw things and so he had to go out. (Mee, p. 8)
The difficulties and challenges faced in accessing treatment for their mentally ill loved ones was a significant source of fear for a number of the participants. They worried that they would not have enough money for the treatment and other associated costs such as transport to and from the hospital. Even though they had very little money, the participants found ways of saving to meet such costs. However, this meant at times that they were left with little or nothing to eat. In the struggle to support a loved one with mental illness, starvation was seen as the price that might need to be paid in the hope of recovery from mental illness for their loved one:

Yes, money to buy medication, it is scarce. Sometimes I have to starve, afraid that my son will not have medication to take. I save it up and when it’s time I go to get it. (Na, p. 13)

Another participant, likewise, had to save money for the cost of transportation to and from the hospital instead of using the money to buy food to eat.

This morning I went to work to cut vegetables for a short time. They paid me in advance a hundred baht which I used for the travel expense [to the hospital]. And I have only got a little money left from before, see. Its yesterday’s wage that I gathered and did not use it to buy food because I planned to come here [taking a mentally ill husband to see the psychiatrist at the community hospital] once again today. (Pat, p. 11, I. 2)

The following comments illustrate the impact upon care givers of feeling that they were facing starvation in order to enable their loved one to be treated and to have enough to eat:

I felt tired and despaired when there was nothing to eat. I must find food and everything for him to eat. (Tong, p. 10)

I am stressed. I am worried about how we don’t have enough to eat and how I am very busy with the problems of my son. I can’t get this out of my head and am distressed. (Na, p. 4)

These ongoing feelings of not being in control further fuelled a number of the participants’ concerns for the future. In particular, some participants feared that there would be no one to take care of their loved ones after they had died. One elderly participant described her concerns as follows:
I worry how my son will live when we die. We must die someday because we are advanced in age now. (Pla, p. 14)

One other participant provided a moving example of fearing for his wife who has depression. His feelings of ‘Out of control’ were very complex; in part this was exacerbated by his son who lived in the same house showing him a lack of respect. Even though this participant wanted to move by himself to another province to escape what was a very uncomfortable situation, he was fearful that his wife would die if he left. Although greatly unhappy, he felt that he had no option but to stay and was thus trapped:

I could not make any move. If I was gone, would she die? She would surely die. She would feel sorry about me leaving as well as being sad about our son. So I chose to be the one who is unhappy. I did not go, and tried to make her happy in everything. I don’t want to make her sad. (Den, p. 17)

In similar terms another participant worried constantly about her daughter, who had run away from home:

I feel that I don’t know which way to turn, to the left or the right...I feel worried about her since she has been gone. I worry she will have no money and no one to stay with. (Pond, p. 29)

The strong relationship between these many fears and the sense of being ‘Out of control’ was clearly evident throughout the transcripts. Participants experienced fear associated with needing to provide care without knowledge of mental illness and the necessary resources to help them deal with the illness: such fears related to both their own situation and that of their mentally ill loved ones. Participants lacked the knowledge to effectively manage the symptoms of mental illness; they lacked the money necessary to pay for treatments and to provide for basic needs; however, they were in a situation where they felt that they had no option but to provide care. They also feared for the future, primarily because of the ongoing care needs associated with severe mental illness; the role of care giver seemed endless. They could not reasonably expect anybody else to care for their loved ones. As the research progressed it became clear that the participants were also experiencing distress associated with fear that came from constant exposure to the unpredictable behaviours of their relatives with
mental illness. This will be explored in the next section which examines the sub-theme ‘So many painful and difficult feelings’.

So many painful and difficult feelings

One source of the fear and distress affecting the participants was the sometimes confronting behaviours of their relatives with mental illness. Indeed, these challenging behaviours and concerns over how best to manage them significantly added to participants’ ongoing experience of crisis. Participants were thus regularly exposed to their relatives’ aggressive and embarrassing behaviours. These behaviours included swearing at people; dressing in an inappropriate fashion; acting immaturely; uncooperativeness and stubbornness, and excessive demands. Such behaviours were often compounded by substance abuse and unemployment. Participants typically felt deeply disturbed and ashamed by such conduct, while they, simultaneously, felt they had no choice but to continue caring for their loved ones. The emotional impact of living with constant distress is captured in the sub-theme: ‘So many painful and difficult feelings’, as illustrated below.

For many of the participants the aggressive, contrary and destructive behaviours often displayed by their loved ones with mental illness caused discouragement and frustration. As one participant said:

- He threw things repeatedly, pounded on things repeatedly. I felt disheartened. Damn it! (Mee, p. 3)

While participants did their best to control such violence, they often felt exhausted and unable to prevent the worst situations. They often felt a combination of distress and resignation, in the face of not knowing what to do:

- I felt sad. My son was not like other people. He destroyed things. He was like this. I did not know what I should do. How could I care for him? What if he walked around and struck people? “What should we do, you guys [family members]? I myself don’t have the wisdom to cope. OK, whatever you guys agree to do, let’s do it.”…Talking about him makes me tired in my heart. I think and am tired in my heart. (Mee, p. 9)
Living with the embarrassment of their loved ones’ unacceptable behaviours was especially hard for some participants, and a cause of great distress and shame:

Sometimes I saw news stories that someone stole other people belongings [including money] to pay for a gambling debt. I even thought how could that person spend money on gambling? And when I faced it myself, I wondered how in the world could she take things from other people to give to that man [her mentally ill daughter’s boyfriend]? Taking things from other people makes my face cold and numb with shame. Now knowing that she took things to give him is like—if I meet with her, I won’t know how to respond to her. (Pond, p. 30)

Another participant expressed similar feelings:

Good heavens! I just could not say anything. She’s the most stubborn girl. She wore eight or nine blouses all at once [in hot and humid weather]...I didn’t know what to do...she would carry a handbag and dressed up in skirts and walked [around the village in a daze]. I was so embarrassed. I did not know what to do, so embarrassing. (Samorn, p. 7)

For some participants, feelings of frustration and anger were clearly associated with having to do everything for their loved ones, including managing the loved one’s personal hygiene. For one participant this was akin to a living hell; having to care for an adult ‘baby’:

When I came back [from Australia] I asked [my son] how things were. “Mother, I have never thought that there is really hell. I have never known it before.” “How was it, son? How was it?” He told me, “Mother, Uncle went to the bathroom to wash his face and brush his teeth and did not turn off the tap. He did a poo and left it, he did not flush the toilet. I had to pick everything up after him. I had to follow him and did everything for him. I know now there really is a hell.”...And this was [for 5 months]. (Taew, p. 12)

Other participants reported fatigue arising from their mentally ill relatives’ demands. They had to keep quiet while their loved ones became more and more demanding. They gave them whatever they wanted to prevent awkward and difficult situations:

I sort of---what shall I say---he would like to eat stir fried vegetables [very late at night and I was very tired of work at the farm], ok, I cooked it for him. Okay. I did this to prevent him from becoming loud and going on a rampage so the neighbours could sleep. If he was loud I could not cope. They would call me names, accusing me of not being able to be responsible for him. (Pat, p. 10, l. 2)

This participant was distressed by her mentally ill daughter’s persistent demands:
Before the work was done, she had already eaten on credit and I paid for her later. And they let her do it. So she went on eating while I was in such great difficulty, **oh my, was in such great difficulty**...I was half starved...I did not know what to do. (Samorn, p. 19)

Several participants were at a loss when they attempted to face their loved ones’ abuse of substances such as alcohol, drugs, and cigarettes. They had tried to stop this substance abuse without success. One participant despaired in the face of her son’s heavy smoking habits:

> I don’t know what to say. When I tell him things and he does not listen, he does not obey, I let him be then. “It is your own body. Do you want to live like this or do you want to die? If you want to die then smoke heavily.” He did not respond. He just kept quiet. I don’t know what to say. (Mee, p. 11)

Another participant felt that she had to keep quiet and let her mentally ill son take drugs whenever he wanted. For her, it was demoralising to see this happening:

> Sometimes he eats Kratom leaves, sometimes not. He used to eat them. If there is none at home, he **will go and seek them elsewhere**...When we speak to him a lot, he gets irritated and so on. [Even though I don’t like him taking drugs], I tell his father, “Don’t say anything. Whatever he says just let him do it. Then he will be quiet soon.” (Na, p. 5)

Most participants were frustrated and irritated when they realised that their loved ones could not work anymore. The participants’ circumstances had changed from being the receiver of care to the care giver. They had to care for mentally ill relatives instead of receiving care from them. Even though they were disappointed, they still felt that they had to care for their ill loved ones, as shown in the example below:

> I think to myself [he was] such a good person who used to work for [us]. When one of us [the family including her son with schizophrenia] cannot work, we are in trouble financially. We have to keep watch and care for him, what he eats and how he lives. (Na, p. 9)

There was not only distress and disappointment, but also embarrassment about the relatives’ failure to participate in meaningful employment or even to assist with daily activities. One participant reported:

> How could it not be difficult? When [we] worked [together]...it was extremely difficult. She was not yet better. I gave her medication and asked her to help carry
the rice that had been harvested, but she could not do it...It was indecent for [her] to sit there nodding off to sleep. I did not know what they [the farm owner] might think. (Samorn, p. 9)

The distress of participants associated with their mentally ill loved ones’ insufferable behaviours clearly displays the theme ‘so many painful and difficult feelings’.

Participants were distressed because they felt like they were stuck in the trap of care giving, as if their hands were tied. They could not accept the behaviours of relatives with mental illness but they had neither the voice nor the choice to say ‘no’, they felt they must provide care. As a result, they deeply felt the loss of their own lives. They had lost their freedom and dignity. This reveals a further sub-theme that of ‘So much loss’.

**So much loss**

The focus of this sub-theme is on the experience of being stranded in the ongoing sense of lack of control the participants’ experienced whilst caring for their mentally ill loved ones. The experience of participants in a state of ongoing crisis began with shock, this led the participants to perceive their lives as being ‘Out of control’; they felt that their situation was uncontrollable. They could control neither the mental illness nor the mentally ill relative. They feared that they had lost their relatives to madness. They experienced a loss of personal ‘freedom’ while caring for ill relatives. The participants also felt that they had lost their dignity as they were forced to care without choice or the option to agree or disagree.

The following participant recalled:

> If I [a husband] don’t do it, who will? I must do it, I must do it all. Even her [a wife with schizophrenia] Pa Nung [a traditional skirt worn by women which is considered too lowly a thing for men to wash] I wash. (Rung, p. 9)

Another participant revealed:

> I have no dignity. If I had to Wai [The way Thais show respect to honourable people], I would Wai. When my child slapped her friend’s face, I had to submit to her mother even though she is not a good woman. She spoke sarcastically to me, I
had to let her. Whatever she said,—I accepted, because my child was in the wrong. I had to bear it all. (Pond, p. 20)

This participant continuously reported the impact of her experience as one of a loss of dignity.

She did bad things to me so many times that I think to myself she is not my child, she is not my child. I am her slave. My status is not that of her mother. (Pond, p. 22, I. 2)

Many participants expressed their experience of care giving as a loss of personal ‘freedom’. One stated clearly:

It has been an obstacle; it stopped us when we wanted to do something. (Rung, p. 13)

Another reported:

There was no freedom at all. How could it not be difficult? I had to [keep] watch [on] her twenty four hours a day. I watched [on] her...Twenty four hours. Whenever she went places I kept watch on her. (Samorn, p. 13)

Another participant gave convincing evidence of the loss of ‘freedom’ in her personal life:

I’m tired. Sometimes I am tired at heart. Sometimes I would like to---would like to visit a temple to pray and make offerings. I would like to be in solitude, by myself, or with my friends. But I cannot. There is a bond between us that I cannot leave. I lock him upstairs. (Taew, p. 12, I. 2)

Participants also perceived the experience of being ‘Out of control’ as further compounded by the ‘loss of their loved one’. They felt as if they had lost their relatives to mental illness and that their loved ones would never be cured. They would never be the people that they once were. As one participant explained:

I was happy initially. I had got my son back. I thought his mind would be like before. But now, it is not quite the same old genuine thing. He is still confused and vacant. Sometimes when his siblings ask him to do something, he acts vacant. At times he acts vacant. I rebuke him, “When you eat and live properly, you are not silly at all.” And he said nothing, he acts as if he does not hear or understand. (Mee, p. 8, I. 2)

Another participant recalled:
I did not know how I felt—it could not be explained in words. It was like—I cried until I went numb. I went back and forth like this, wondering why is it like this? When I thought about her childhood and then about the present, I thought this is not my child at all.” (Pond, p. 28)

Being the care givers of relatives with mental illness results in experiencing a range of painful and distressing feelings. The four sub-themes: ‘My life has fallen apart’, ‘I’m overwhelmed with fear’, ‘So many painful and difficult feelings’, and ‘So much loss’ are all expressions of and a consequence of the participants’ experience of ‘Out of control’. As a result of their care giving, participants’ lives had been turned upside down and were no longer experienced as ‘a normal life. This aspect of the participants’ experience is significant, however, as it relates to the other components of care giving as a part of the whole experience.

**SO ALONE**

The previous theme ‘Out of control’ has illustrated the meaning of the experience of participants dealing with the difficulties and challenges that arise while providing care for relatives with mental illness. The participants clearly reported that they have no choice but to provide care. Caring for their mentally ill loved ones is described as being ‘alone’ in dealing with this inescapable and interminable life of care giving. Not only do participants describe an unremitting life of care giving, their experience reflects the harsh reality of being alone. This is epitomised by the next theme, ‘So alone’, the experience of there being no one to stand beside or assist in the care giving. One participant offered this powerful example:

No one does anything. Only I do all the work. My father and two brothers [with mental illness] cannot do anything. I have to provide everything for them and care for them. (Kit, p. 2)

Another participant described the distress associated with being the sole care provider:

If something happens, I must handle it myself all the time. There is no one else. The difficulty is not that I have to do all the physical work. The difficulty is that I must think and do and cope all the time. Very difficult, I think, oh my! I always think alone—always think. (Rung, p. 10)
The theme ‘So alone’ includes three sub-themes: ‘There is no end in sight’, ‘My life is unbearable’ and ‘I’m ignored and invisible’. They are related to each other as shown in Figure 5-5.

Figure 5-5 A closer look at sub-themes within the theme ‘So alone’

**There is no end in sight**

The sub-theme ‘There is no end in sight’ is used to illustrate the loneliness experienced by the participants caring for their ill relatives while being responsible for all aspects of
their lives over a long period of time. They experience profound tiredness associated with this ‘prolonged burden’ as described in the following excerpt:

Then one day, I didn’t know why she became like a being possessed, convulsing with her eyes rolled back. I was with her when she fell into an irrigation ditch. I had to pull her up and carry her. Since that night, she has never been well again...Since then, there has not been a night that I can sleep. It has not been good. From then on, she became more and more ill...Oh my, these difficulties...how many years and how many lives [Buddhists strongly believe in reincarnation] has it been...more than twenty years, maybe? (Rung, pp. 9-10)

As care givers, participants felt tired all the time. One participant caring for her brother with schizophrenia and paralysis gave the following account:

After I get up, I put away the mosquito net and things. I give him a bath. And then cook rice. After feeding him, I go to work. I am quite tired. I am in a rush because I have to get to work in time as I start work at eight o’clock. I have to hurry and do everything for him. There is also housework. Sometimes I do it, sometimes I don’t. I am the only one; I cannot do it all. (Kit, p. 5)

Yet another care giver described her experience of constant tiredness associated with managing her mentally ill husband’s personal business on her own for a long period of time:

When he went for treatment in [the provincial] hospital for about two months, it was difficult. And I have looked after him continually ever since he became ill. I must feed him food and water. And if he was not happy about something, he would throw the rice away spilling it all over my face. That was what he did, when he was unsatisfied about something. And when he did a poo, oh my, sometimes he smeared it all over the sleeping place. It has not been easy at all. Oh my, I am tired to death of it. Sometimes I sit and cry alone. Why does Ku have to be in such a hardship as this? Truly, truly, you see. Oh my, I have such great hardship. (Pat, p. 4)

For others, they not only had to work and do all the housework, they also had to ‘keep an eye on the relative with mental illness’ to prevent them from behaving in undesirable or unacceptable ways. This meant that they had no time to take a rest which further exacerbated the fatigue associated with relentless work. This participant reported:
[I kept watch on her] very closely. And I also had to work. I did my job and also did housework. I did it all. (Samorn, p. 17)

Another explained the tiredness that resulted from keeping an eye on her husband with mental illness during the night:

He walked. So I had to walk too. I followed him all night. **I did not get any sleep at all.** I could not sleep at all. Even when I locked the door, **he could still get out through the dog hole.** Truly, I did not get any sleep each night. (Pat, p. 6)

For several participants, they felt ‘tired in their hearts’ describing the heartache associated with the intensity of the care giving required. Even though this participant would like to go to work she chose to stay at home to keep watch on her son with schizophrenia because she was afraid of losing him.

**Taking care of this kind of person is burdensome to my heart as well as to my body. It is harder on my heart; I think, why is my son not like other people? Why does he have to be like this? I keep thinking about this and that, so many things. I watch and I keep my eyes on him. My ears would catch some noise, Gag! And instantly, I thought, “Oh, he must be out again!” This tires my heart. And I never have rest. Scolding him all the time makes my head ache and spin like a top…He kept trying to get out, again and again. So I was stressed. I had to get out too. I need to earn our living. When I let him stay home by himself, he just wanders away. I have to work in the rice field…**It is tiring, very, very tiring.** It’s a great burden to my heart. (Mee, pp. 6-7)

Some participants were tired of monitoring the medication for their mentally ill relatives every day but they were even more afraid of an exacerbation of the mental illness that might result if their loved ones missed their medication. This participant explained it thus:

I have to ask him every day. Once it is evening, I have to ask, “Hey, Chat, have you taken your medication, the yellow one?” He says, “I have, I have.” And then he brought the medication pack for me to see, I counted to check, oh, he has really taken it. I am afraid he may cheat…I am afraid he will throw it away. Then he may get ill. **He will have to go to the hospital which is far away and make it difficult for me, his Mother.** (Na, pp. 7-8)

The participants experience overwhelming fatigue associated with their care giving role. Not only do they bear this responsibility alone, but they have borne the load for a
very long time. There is no end to this care. The only end imaginable seems to be if either the care giver or their relative with mental illness were to die.

I am now worried. If I don’t work, where would my son get food to eat? I have to bear it until I die or he dies, that’s how it is, Maw. What else can I do? Who can I dump him on? (Na, p. 11)

Inevitably, this led to participants being confronted with another aspect of the care giving experience which made them feel ‘So alone’. This is the focus of the next sub-theme emerging from the participants’ experience.

**My life is unbearable**

The previous sub-theme provided the meaning of the experience of tiredness associated with the unrelenting nature of the ongoing crises arising from caring for relatives with mental illness as ‘There is no end in sight’. This sub-theme relates to the participants’ experience of the care giving role as one that leads to the thought that ‘My life is unbearable’. This was triggered in different ways. For some, it was associated with managing their loved ones’ personal hygiene. For others, it was associated with the ongoing abuse from the mentally ill relatives. The participants felt that they had no voice to ask for help and no choice to leave. They must provide care, and for most participants, they provided care alone.

Some participants were stressed by the need to manage their loved ones’ personal hygiene. As one participant explained the experience of ‘unbearable’ stress related to this issue:

> Stressed, yes, very stressed, I must do it, must bear it all...I was stressed and I could not think...I just went on doing it. If I don’t do it, who will? Stressed, like this. I must bear it until I die---It’s very difficult. I myself am not strong, and not very well. I have asthma, and am allergic to pollens. When he [the brother with mental illness and paralysis] did a poo, I had to clean it up and it made me vomit. I must clean for him. (Kit, p. 4)

For some participants, the experience of an ‘unbearable life’ is associated with being abused by their relative with mental illness. There was no one else to help them deal with the abusive and aggressive behaviours. There was a deep ‘silence in this
unbearable life’ for the participants who were threatened by dangerous situations. The silence occurred because there was no way out and they could neither say nor respond to their loved ones’ violent attacks; they had to just bear it, as this participant explained:

If I die I will not be sorry because there is no hope. People can live if they have hope, right? But here it seems we see no way out at all—we tried everything. [My mother said], “...You [the participant] are her mother. You have to bear it. No one wants her anymore.”...Another relative asked why she [the daughter with mental illness] abused me. The relative said, “**Too bad! If I were you, I would fight back. If I die, I die.**” I told that person, “Auntie, if she dies, Pond [the participant] will be jailed. If Pond dies, she will be jailed. There is no good to come out of it—- To just bear it would be better.” (Pond, p. 36)

Another participant contributed the following example:

**Oh my, it is hard, very hard to care for this person. If those who say it is easy face such a situation as mine, they will be cold to their gut...If they are slapped in the face, they will know it...When he was very ill, he slapped me right in my face. Slapped my face, pulled my hair and my blouse. He pulled and tore many of them. He did not let go of them, but just pulled and pulled until they were torn, Oh my, he is just so extreme, you see...I just care for him, nowadays, I care for him, you know. I have been caring for him all along.** (Pat, p. 21)

Yet another participant spoke of experiencing abuse:

Raising havoc. My father and mother would not be able to sleep at all. My father would be lying with his hand on his forehead [a gesture of distress or worry]. Distressed. My father was distressed...Sometimes he encounters things from outside and comes home stressed. We have to take notice of his countenance to see if he is under stress or not...If his face looked stressed, we said nothing. If he did something, we would just let him get his way. Suppose he turned on a radio loudly, or the TV was very loud in the house so that it drowned out all other noises—we would not make a fuss. We had to keep cool headed even though we were annoyed by the noise of the radio, see. (Num, p. 6)

The experience of participants was such that they recognised that, as a care giver of a person with mental illness, caring was unavoidable and that they had no choice but to do it by themselves. In most cases the participants did not ask for help. This left them with what can be best described as an ‘unbearable life’.
The next sub-theme follows on from the experience of an ‘unbearable life’. The recognition that their needs are not being met and that this is a direct result of a lack of support introduces another component of the experience of being alone.

I’m ignored and invisible

In this study, the participants were very stressed while facing legal issues arising from their loved ones’ behaviours. They felt as if ‘nobody’ understood that their loved ones with mental illness did not mean to cause problems but that it had occurred because of episodes of mental illness that rendered them out of control. This participant explained:

The owner of the Chinese farm household [the father of the woman whom her son with mental illness went to watch every day because he loves her] was confused and tried to put him in jail. He didn’t listen to reason. He wanted the police to put him in jail...Oh, oh! I was very stressed indeed. I cried every day. “Damn it! My son’s mind is not well and he must be jailed? This Chinese man does not know anything.”...I could not sleep at all. Stressed. Stressed about my son; I was afraid they would put him in jail. Afraid Maw would not help. (Na, p. 15)

Some participants vigorously advocated for their mentally ill relatives’ freedom. They felt disappointed and angry towards the authorities when they did not take into consideration the mental illness of their loved ones. This participant tried hard to protect her brother from being arrested:

The police came in saying there was a quarrel at the hospital. There was a quarrel, and [they] asked if I would press charges against him. They were going to arrest him. “No, this is my brother, no, my brother, my brother is not of sound mind, you cannot arrest him.”...apparently they had heard that there had been hitting and kicking. Someone [the staff at the hospital] had reported this to them and asked them to come and arrest him. (Taew, p. 9)

Another participant was extremely sorry that she could not protect her son with mental illness from being arrested. He was mistreated by the authorities who misunderstood him.

But, oh, this is too much. He was so ill. The police did not know he was not in his right mind. They caught him because my nephew accused him of stealing Powsian
[a good luck plant]. They beat him till he was almost dead. I did not have money for transport so I did not get there in time, see. (Tong, p. 11)

Yet another participant felt as if nobody understood the feelings of a care giver who was in the middle of a moral dilemma. Even though this participant had no idea where her mentally ill daughter had gone, she was very glad to know that she was not arrested:

Do you understand that I was torn in two directions?—I was glad not to have to bear seeing my child [her daughter with mental illness] arrested by the police but where she lives now I don’t know... the one [the neighbour] whose money she stole... said, “... if she contacts you, tell her not ever to step in here again. Whenever she does she will get it.”... That is, they will get the police to arrest her. (Pond, p. 24)

The intensity and extreme nature of the events related to the care required by these mentally ill relatives left the participants with a feeling of being ‘So alone’. These experiences left them in a constant state of stress and distress. They needed help and support but it seemed that their needs had never been met. Other family members left them to care for their loved ones alone. In addition, health care providers and the authorities involved totally underestimated even the most basic of the care givers’ needs. This lack of support highlights the need for change in Thai health services and general awareness and recognition in the Thai community of mental illness. The next theme presents the relationship between underestimated needs and the participants’ sense of confusion.

CONFUSION AND CHAOS

The previous theme, ‘So alone’ demonstrates the high level of unmet need and lack of support that resulted in participants’ experiences of being ‘So alone’. As the interviews with the participants proceeded, the third main theme emerged in the form of participants’ experiences of ‘Confusion and chaos’. This theme is associated with a lack of knowledge about the causes and treatment of mental illness and the provision and availability of mental health services. Care givers described feeling as if they were thrown into the care giving role. They did not know what to do to provide care for
their loved ones with mental illness. This confusion began with the first episode of mental illness as this participant related:

It [his mental illness] came from many things all confusing, you see. **He might be addicted to drugs and take too much medication, things were confusing.** (Taew, p. 18)

There are three sub-themes that support this theme: ‘What caused this illness?’, ‘Nobody explains it’, and ‘Still confused’. Each of them interacts with the others, as shown in Figure 5-6.

Figure 5-6 A closer look at the sub-themes comprising ‘Confusion and chaos’
What caused this illness?

Even though the participants have provided care for their mentally ill loved ones for a long time, most lacked knowledge about mental illness and had never been informed of its cause. This participant gave the following example:

I don’t know because the doctor did not tell me [about her diagnosis and illness]. The doctor just said that she [a daughter with mental illness] told him many things. (Pond, p. 2)

The difficulties of caring without knowledge led them to try and identify for themselves possible causes for their loved ones’ mental illness. For most participants, a lack of knowledge as well as the nature of their spiritual beliefs led them to believe that the mental illness was caused by evil as the following excerpts demonstrate:

He was shaking. I thought he was possessed and took him to get cured…He walked home as though in a daze…He just stood still and acted like he was holding the stars. Stood there with mosquitoes covering his legs. His body was stiff and he would not let me slap the mosquitoes away. No slapping them, no brushing them away. Nothing. (Tong, p. 11)

She lay there for months. Oh, my, what could I do? So I was distressed. She lay in bed for months. So, then, I went to the doctor, the ancient doctor, see. He advised me that---it was the ghosts and possession causing her illness. (Samorn, p. 4)

The potential for there to be different causes of mental illness confused some participants. This participant said firstly that the mental illness was caused by evil and then later by heredity.

And now she became mad, she became possessed. Oh, my. It was a terrible waste of money. Oh, my. (Rung, p. 3)

The child…of her elder sibling…also…had this inclination. Inclined that way. Oh, oh, they are not like others who have no heredity, just look and you know. (Rung, p. 10)

As another participant wondered about the cause of the illness she thought perhaps it was because of a family problem:
He was not ill every year, but, he has taken his medication for many years. Yet, he has become ill at intervals. I want to know what causes him to become ill. If people say it is family problems, my family does not have any problems. (Num, p. 4)

Not knowing the cause resulted in some participants feeling guilty. They then blamed themselves. This participant thought that she was the cause of her daughter’s illness:

*It was wrong to raise her this way...where did I go wrong with her? At what point did I make her like she is now? I don’t know at all what I did to cause her to have this complex problem and these outbursts.* (Pond, p. 29)

Another also described confusion and guilt surrounding the cause of mental illness:

*I was puzzled as to whether this kind of illness came from drug addiction. Was it from that drug store [did I buy substances for him to abuse without knowing] or not? The drug store where he got medication [which was actually substance abuse] all that time even after he was transferred [from his previous workplace], you see.* (Taew, p. 14)

As a result of these misunderstandings, some participants spent a lot of money and time seeking traditional treatments and thus delayed accessing modern medication options:

*I tried the ancient way I went. I went to the ancient doctors. Oh, my, I don’t know to how many places I went. But I tried until I was well-versed in them all.* (Samorn, p. 4)

Then, as the symptoms of mental illness worsened the participants became more confused and hopeless, as this participant reported:

*After taking showers with sacred water and finishing doing rituals [as part of traditional treatments], she lay there stiff again. “Now, what shall I do?” She rambled and got crazy about something. I did not know what. I did not know what to do. I choked...choked up about when she would be cured. I had no idea.* (Samorn, p. 5)

This sub-theme illustrates the confusion arising from a lack of information and awareness of the causes of mental illness. The misperceptions related to potential causes of mental illness then resulted in feelings of guilt, hopelessness and not knowing what to do. There came a time for each participant when they sought modern treatments for their relatives. However, this then resulted in further confusion as illustrated by the sub-theme ‘Nobody explains it’.
Nobody explains it

Most participants reported that they were ‘uninformed’ about the treatment provided for their loved ones at the hospital. They had not ‘a clue’ regarding what was provided as treatment. Their confusion is apparent in the comments below:

They [the staff at the psychiatric hospital] did not tell me. They did not tell, never told me anything. Would they use a kind of electricity? I don’t know. I don’t know. (Pat, p. 10)

He told me that Maw [at the psychiatric hospital] shocked him with electricity. If it was true or not I don’t know. But my son said so. I have no say. I am his mother right? It might be that sometimes they could not restrain him, right? So it is possible that they stimulated him, right? Okay, I don’t blame them. (Na, p. 6)

For others, the lack of understanding about treatment procedures remained a source of puzzlement. They were also shocked by the side effects of the treatment. One participant provided the following example:

Then we came to get treatment. We went to [the psychiatric] hospital one time. They asked for permission for him to get that treatment. They sprayed something on him. I did not know what it was. Would it help him recover from the madness? [the participant thought that exposure to smoke was a form of treatment]...I could not go in [the treatment room] at all. When he came out, he was in really bad shape. His eyes, oh my, they were all red. They told the relatives to sit and wait outside. We could not enter. They let him go in [to the treatment room] alone. Later on, damn it, I felt pity for him, “Why is it like this?” (Pat, pp. 7-8)

As the treatment continued, the participant was even more shocked and perplexed as is apparent below:

Oh my, the next time, he fought with Maw and the person who smoked him [the participant thought that exposure to smoke was a form of treatment]. The fight was devastating. He fought because he was afraid, see. Right? He was afraid because he was there for the second time. The first time was alright. Even then though, they had to wrestle quite hard with him. But the second time he went right on fighting with them. Then Maw came out and said, “Never bring this one in [to the hospital] again.” They would not take him anymore. They really meant it. They never take him now, no matter what happens. It was because he fought them, see. He slapped their face, and hit them with his fists. From what I saw of the incident, my husband was also hit. (Pat, p. 8)
As a consequence of this difficult experience, she stopped attempting to access modern treatments and instead sought traditional treatments for her mentally ill husband.

I sort of tried to be sweet when I faced him, I talked nicely to him, “You should get treatment, okay?” He said he would not go there [the psychiatric hospital] again. I asked him, “What shall we do then?” He said, “Get treatment at home, treat me at home.” So we boiled the herbal medicine for him. I bought it at seven hundred baht a pack, and boiled it for him. (Pat, p. 8)

A further participant’s story provides another example of the confusion surrounding a trial of a modern psychotropic medication. As a result of this experience, this participant also sought traditional treatments for her brother with mental illness.

He got his medication and took it but it could not control the symptoms. He could not sleep much. And we went on with this treatment. I called and told my younger sister who was in the Saraburi province. My sister said, “Should we take him to have a monk look at him?” So I lied to him that we would go [Saraburi province] and took the trip. (Taew, p. 8)

The sub-theme, ‘Nobody explains it’, demonstrates how the lack of information about modern treatments and their side effects confused the participants. This confusion resulted in shock and disappointment. As a result, they decided to revert to traditional treatments for their relatives with mental illness. The outcome of this decision was that the mental illness was less likely to be cured and any recovery would be delayed. In ongoing interviews with the participants, they reported that contact with mental health services also confused them.

Still confused

Most participants experienced confusion arising from a paucity of appropriate mental health services. The difficulties experienced included lack of clarity related to service roles and functions, unavailability of medication, undesirable hospital admissions and contact with services, and inappropriate or early discharge. For some participants, the confusion was further compounded by their lack of money and literacy difficulties. This limited the ability to access care for relatives as this participant relates:

I told them, “Maw [the cashier at the psychiatric hospital], I don’t have the money, seven hundred baht is too much. I hired a taxi to come here because I
don’t know the way”. They replied to me, “Okay, then, you can take medication for only one month. You don’t have to pay for medication for one month.”...I even brought the bill for the health center official to see. I asked, “See, Maw, why do I have to pay?” The official was also puzzled as to why I had to pay even though we had the referral document [I thought that I don’t have to pay out of pocket as a rule of the universal health insurance policy]...But Maw there wanted money. (Na, p. 3)

Another participant confirmed that going to the psychiatric hospital to get treatment consumed a lot of money.

Formerly, we did not have money, see, but occasionally I bought half an ounce of gold to save. But each time he became ill, I sold it until it was all gone. When he became ill, I sold the gold to pay for his treatment until it was gone...I paid five hundred for car hire [to get to the hospital]. I asked the police to help. I had to pay them some money for drinks - 500 Baht. And we had to travel back and forth, so it was a total of three or four thousand. In the old days, I did not know the way to [the psychiatric] Hospital. I had to hire a car and tried to remember the way, so I could go. (Tong, p. 12)

Some participants then decided to get medication for mentally ill relatives from other departments in the health services nearer their home. The lack of medication at those places confused them and they felt hopeless:

My son said medication he took...there is one kind missing. What should I do? I went to talk to Maw. Maw said, “You go get them over there, then. Go to [the psychiatric hospital]”, they told me. When there is the time to get medication we get them from here. We don’t have much money, so we just take them as they are. (Na, p. 16)

For other participants, admission processes at the psychiatric hospital were difficult as this participant describes:

Once they [her brother with mental illness and other family members] arrived [at the psychiatric hospital], but the staff could not admit him, they had to wait until morning. But my brother was drowsy all the time. And he had a mouthful of blood. (Taew, p. 9)

Another spoke of how the treatment provided at the psychiatric hospital shocked her.

When she was very ill, they [the staff at the psychiatric hospital] tied her arms with rope until she got a wound. (Gesturing circling the wrist with her other hand’s fingers)...Yes. Here it bit into her arm causing a wound. Poor her. I myself was shocked, oh my, what kind of a thing to do was that? (Samorn, p. 16)
This participant reported her frustration and feelings of anger when her daughter was discharged early as follows:

“Maw, Maw, you gave her to me. I thought she was cured.” Not cured, she was not cured. I must go and ask for medication from them again and tell them again. Oh my, then…Maw said, “Yes, I was afraid you would leave her here, see.” Who would leave her? No…Well, they were afraid I would leave my patient [her daughter with mental illness], see. They were afraid I would not come to get her, afraid I would neglect her…They hurried to tell me to pick her up. They pushed her on to me, even though she was not yet cured. (Samorn, p. 15)

This experience of ‘Confusion and chaos’ arose as the participants’ needs were underestimated by health care providers. They were very confused when they tried to meet some of the obligations such as accessing appropriate care and medication which are central to caring for relatives with mental illness. In most cases the participants were unhappy and disappointed with the mental health service systems. For the most part they viewed this as abandonment by health professionals. Their expectations had been that the service would provide strategies to minimise the challenge of caring for relatives with mental illness. Participants spoke of coming to the point where they experienced care giving for relatives with mental illness as ‘No way out’ - the next theme to be discussed.

NO WAY OUT

The previous theme illustrated the confusion and frustration associated with insufficient services, a lack of education about mental illness and an absence of advocacy for people with mental illness and care givers. A lack of knowledge about mental illness made the participants believe that mental illness was caused by ‘sin’ from either the present or past life of their relatives with mental illness or themselves - a Buddhist belief. [Thai people are most likely to believe that mental illness is caused through genetics, family problems, sin, and evil and that it cannot be cured as presented in Chapters One and Two.] The participants felt that their lives were governed by this belief. This led to thoughts that they had no way to move forward or to improve the care that they gave their relatives with mental illness.
The sense of there being no way out of this situation also arose from the widespread societal stigma associated with mental illness. The participants experienced stigma directed towards themselves and their mentally ill relatives. This led to sadness as they felt that there was ‘no place in this world’ for their ill loved ones. Two sub-themes constitute the theme ‘No way out’: ‘I’m paying for my past actions’ and ‘Stigma rules our lives’ as shown in Figure 5-7.

Figure 5-7 A closer look at the sub-themes that constitute ‘No way out’
I’m paying for my past actions

This sub-theme, ‘I’m paying for my past actions’ represents the experience of participants arising from how they view their current situation through the lens of their spiritual beliefs. Most participants believed that their life depends on Karma. In this context, Karma is the result of sin in either the present or the past life and these sins are seen as continuing to negatively impact upon both the present and the future of the person who has sinned. The participants thought that they or their loved ones had done something wrong so that they now suffered retribution for their past sin (Vera). This meant that participants felt as if they had no capacity to change or improve anything that happened in their lives. Their lives had already been determined by destiny, i.e. the impact of past sins as shown in the following excerpts:

I felt quite sad. But I could not do anything…we cannot do anything…I can only let things drift along according to Vera and Karma. (Kit, p. 6)

“Such great things are Vera and Karma. It’s better to care for a little baby than a person with mental illness.” So I said, Oh my! (Samorn, p. 19)

Participants repeatedly spoke of a belief that ‘I’m paying for my past actions’:

I thought it was my Vera. He is paying for his Vera, but it is my Karma. It is his Vera to become mad and insane. And it is my Karma to be responsible. He is my son. Where can I abandon him to? (Tong, p. 9)

Even if the spiritual framework underpinning the person’s beliefs was different, participants still experienced the sense of an uncontrollable life. One participant who believed in Brahma [the Hindu belief] said:

It is Brahma, you know. Brahma predestined it, he drew the line…Brahma predestined, Brahma predestined it, drawing the line. (Den, p. 14)

For another, caring for a mentally ill relative resulted in distress related to a sense of having done something wrong:

I cannot sleep at all…I am stressed. I cannot sleep, thinking what Vera or Karma of mine this is. Why was I not born happy and wealthy like others? I keep thinking like this. It irritates me. (Na, p. 10)
The enduring nature of the experience, ‘I’m paying for my past actions’ in conjunction with the other difficulties and challenges associated with care giving further contributed to participants’ feelings of distress and hopelessness:

**She liked being repeatedly ill.** I did not know what to say. **Alas,** if I think about it, I am distressed. “How is my Vera and Karma like this?”...It was so difficult, really difficult...She took medication but did not get better. She was ill again and again. She just kept being ill like that repeatedly. The medication she took was not the right one so she was ill repeatedly...I myself was very stressed indeed. I did not know what to do...Now when she got angry, I would scold her once more, “When will you die and I will be rid of you?”...“When will you die? You keep being ill and not well.” I said, “Just keep being ill. I cannot do anything. I have to sit here keeping watch on you.” (Samorn, p. 12)...Sometimes so distressed, I sat and cried alone. Cried, **“Oh my,** why is it like this? She is ill and will not be well.” I sat, see. When it lasted a long time then I wondered what I should do. What Vera and Karma was this? Just sat there and kept on mourning. (Samorn, p. 18)

It was evident that the participants strongly believed that past sins had caused their loved ones’ mental illness. They then felt that they had to provide care as a result of the sin - Karma. Continuing ruminations associated with this belief that they could not do anything to improve the situation led to their feelings of hopelessness about their loved ones’ lives. This links closely to the next sub-theme that illustrates the experience ‘No way out’ arising from the stigma related to mental illness and the belief systems that contribute to the sense of hopelessness experienced.

**Stigma rules our lives**

This sub-theme aims to present the experience related to the widespread stigmatising behaviours which are directed towards people with mental illness and their families. In the Thai context, there is strong evidence of social stigma against mentally ill people and the family as detailed in Chapter Two. In this study, the participants experienced stigma towards themselves and mentally ill loved ones not only from other family members and members of the community but they also directed stigma towards themselves. They felt that their relatives with mental illness did not deserve to live or even to be recognised as worthwhile.
Most participants found it very hard to accept ‘in their heart’ that their loved ones had become ‘mad’:

When he first became ill, I could not accept it, I was scared…I was afraid of him and ashamed of him. I did not want my friends to know. I could not accept it. (Num, p. 4)

Another added:

Well, I told him to get the treatment for himself…I felt pity for him because he became mad. (Crying, taking tissues to wipe tears) I was overwhelmed. (Taew, p. 10)

Resentment towards the impact of mental illness in the home also made participants feel despondent. Participants reported that they were very sad knowing that other family members were hostile towards relatives with mental illness. For them, it was as if there was ‘no place’ for relatives with mental illness to be a part of the home as one said:

When the elder brother [the ill one] drinks water, the other younger ones avoid it; they dare not drink. They do not like to use the same glass as him. And food that the ill brother eats, they will not touch…He does not have any detestable illness…I think that he, an elder brother, has no an illness that has blood or festered wounds. They still avoid him…I feel, oh, why is there such aversion. I think that if I am to die, he will be in a difficult situation. Even when he is okay, there is still this much aversion from everyone. (Tong, p. 17)

In many cases other family members did not want to live with relatives with mental illness. They were ashamed of having someone with mental illness in the house:

All the brothers and sisters said to chase him away. My elder brother said, “Chase him away, you don’t have to pay attention to him.” (Taew, p. 18)

Most participants were dejected and at times distressed realising that society did not accept people with mental illness. They tried hard to prove that their loved ones were normal and could function in society as other people do. One participant explained what he had tried to do to address this issue:

In the country, in her town, her native land, people said my wife was mad, they said my wife was mad but I have given her good treatment and made her happy in every way [to prove that she is not mad]. (Tears in his eyes) (Den, p. 2)
Some participants experienced the impact of social stigma directed against them as Pond explains:

So I repaid it for her, two thousand and three hundred baht, in total. I did not know she had borrowed money [from that person]; she hid it from me. But when it came out, that person told me she also borrowed three hundred from her. Okay, I gave her back two thousand [the stolen money] and three hundred [the borrowed money] and it ended. But that person went around and told her close friends, “Hey, be careful of Sunny.” And I would think, “Hey, what’s next? Who would dare let Sunny into their home? And whose homes would I dare enter, as her mother?” (Pond, p. 17)

Most participants realised that there was ‘no place’ in the community for their mentally ill loved ones. They were dejected and disturbed knowing that no one in their house or the community accepted their ill relatives. Participants spoke of asking for acceptance from other family members and society without success. Of note, is the added challenge that arose for participants as they sought to accept their loved ones and they spoke of it being so hard to find a place in their own hearts for their ill relatives.

The experience of feeling that there is ‘No way out’ is reported by most participants. Although they had provided care for relatives with mental illness for an extended period, they stated that they still found care giving to be an inordinately difficult and traumatic role. They had continued to experience stigma and had tried to move beyond the barriers created by madness to return to normality. They spoke forlornly of their experience of ‘Stigma rules our lives’ with no one else wanting to be involved or prepared to accept their loved ones. The illness separated the participants and their loved ones from others.

These findings clearly demonstrate the difficulties and challenges that the participants faced throughout the prolonged period of caring for a loved one with mental illness. This prolonged care giving resulted in the care giver experiencing physical and emotional illness:

I had a headache because of him, ache and my [nervous system] went numb… I had strain in my [nervous system], see. Stressed, [and got] a headache. Aching in this place. (Tong, p. 12)
Oh, Maw. I was so worried. I thought and thought until I got a headache. I took medication until my stomach ached. And my blood pressure is high now. (Na, p. 15)

Others described having developed symptoms of mental illness themselves. This participant suffered an episode of mental illness associated with providing care for two brothers suffering from schizophrenia.

I am stressed and must do everything on time. I must bear it. I must use anti-anxiety drugs as well. (Kit, p. 4)

Yet others wondered if they too were mentally ill:

Oh, my! It was as if I were ill along with him. (Mee, p. 8)

Actually, I am the one who should be mad, not my wife. (Den, p. 18)

The intensity, pervasiveness and enduring difficulties experienced by these participants is palpable in their descriptions of how very hard it is for them to care for a loved one with mental illness:

Living with him, Maw just think, living with a mad man, then we are of sound mind so that we cannot cope, see. Oh, sometimes when I see other people’s children dress up beautifully, going out for fun, damn it, my son is---deadly vacant. I am despondent and stressed. (Tong, p. 16)

Another added:

Coming back [from the psychiatric hospital] he was extremely mad and violent. Oh my...I was in such great difficulty. I had to get him to do things, to take a shower, for example, and he hit me right in the face. It was not easy at all to care for an insane person. (Pat, p. 7)

The depth of the experience of ‘There is no way out’ and the despair associated with this experience is such that many of the participants expressed a desire to die:

Sometimes, I would like to jump from a bridge to kill myself. I am tired of life. Why do I have to meet such a situation, damn it? (Tong, p. 16)

Another added that:

See, sometimes I don’t want to wake up. I don’t want to breathe any more. But I never think about committing suicide. I feel like if I don’t wake up, don’t breathe
any more, I will not be sorry---Being a Buddhist, suicide is a sin. But I feel as though I don’t want to live anymore---. (Pond, p. 36)

Yet another participant expressed her despair with the words:

I thought to myself, “If it’s easy to die, let me die first.” (Samorn, p. 20)

**Participants confirm these findings**

The lived experience of ‘ongoing crises’ using the participants’ own words have been explored in this chapter. These findings are strengthened by the strong confirmation that 10 out of 12 of the initial participants provided. These participants were available for a second interview four weeks after the initial interview. As described in Chapter four and in the introduction to this chapter, prior to the second interview, each participant was sent an individualised letter. At the second interview, the participants were asked to reflect upon the letter’s contents, with prompting questions including: “After you read the letter, how did you feel?”, and “Does the letter reflect your experience or is there something missed that you want to tell me?” Each of them responded that the letter they had received captured and echoed their experiences. The following quotes provide an overview of the responses to these questions:

I felt, oh my, very overwhelmed. Everything was exactly as you said. It was so moving. My tears flowed. My daughter said, “What’s the matter, Mother, you are crying.” “Oh, listen, all that Maw said was exactly true.” It is utmost difficult. My mother-in-law was blind. My son was mad and my husband was paralysed. Here, I was in such great difficulty. (Tong, p. 1, I. 2)

I feel that everything that I have read really spoke to my heart. It is the same as what I have done. I search for him. I run around. I care for him. It’s everything that I have read…It absolutely reflects my thoughts. It reflects my thoughts indeed. (Mee, p. 1, I. 2)

Well, it is good and correct. Very good indeed…I didn’t speak well. Here you arranged it so well…Um, that is the true story. It’s just like that. And it is a true story for sure. I did not make it up to please you at all. (Rung, pp. 1-3, I. 2)

Well, it reflects my heart much, right? Well, it reflects my heart very, very much…Yes, and it is exactly as I feel. In fact, I say it is true to what I---, my sincere feeling, right? And I spoke truly. I did not hide anything, you see. You can ask my
next door neighbour or ask Maw [---]. I have tried to care for him all along. (Pat, pp. 5-6, I. 2)

Oh, exactly, right on the mark. What I said, talking about it, in my life, in fact, I cannot find happiness. I am seventy and cannot yet find happiness in my life. I will be tired until my death, really, tired until death. If I don’t work I don’t get to eat. My son, here, his mother is distressed, and I am very distressed. (Den, p. 3, I. 2)

Yes, it means that it is exactly like how I feel, really. It is just like every word that I spoke. You wrote it out completely, nothing is missing. (Taew, p. 7, I. 2)

It is noteworthy, that not only did participants confirm the interviewer’s description of their experience during the second interview but they repeated their stories and accounts of the experience of care giving and confirmed again the over-arching theme of living in a state of ongoing crisis.

**CONCLUSION**

This chapter has outlined the findings that describe the meaning participants attributed to the lived experience of caring for relatives with mental illness. Taken as a whole, the data analysis reveals participants’ lives as being distinguished by a ‘state of ongoing crisis’. The four key themes identified give a deeper understanding of this distressing state. Each theme has been further expanded to reveal sub-themes that expose the rawness of the day-to-day experience of care givers. Presenting the findings in this way has provided the means to derive a meaningful interpretation of the essence of caring for relatives with mental illness in the Thai context.

The final chapter will discuss these findings in relation to published research in this field and consider the implications of the findings for health professional education, clinical practice and future research.
Chapter Six
DISCUSSION, REFLECTION, AND CONCLUSION

INTRODUCTION

This study has been guided by a hermeneutic phenomenological approach and has sought a deeper understanding of the research question, ‘What is the lived experience of Thai family care givers in crisis during their care for relatives with a mental illness?’ The aim was to explore that experience by identifying and extending the understanding of the nature of care giving through the stories and experiences elicited from care givers. Participants in a rural-urban community in Thailand were asked by the researcher to describe their experiences during in-depth interviews conducted in their region. The descriptions of their experience have been analysed to elicit the meaning of the lived experience of the participants. Chapter Five has presented these findings demonstrating an over-arching experience of a state of ‘ongoing crises’. The identification of four main themes arising from the thematic analysis enable a deeper understanding of this grinding, exhausting and relentless state of ongoing crisis as experienced by the participants in this study.

![Figure 6-1 Lived experienced in ‘ongoing crises’ of Thai care givers](image-url)

Figure 6-1 Lived experienced in ‘ongoing crises’ of Thai care givers
This final chapter discusses these findings, examining the themes identified in this study compared and contrasted with the findings of other relevant studies published to date. The findings will then be examined through the lens of van Manen’s notion of four lived worlds (van Manen, 1990). The implications for education, clinical practice and further research are highlighted. Given the confronting and challenging process of immersion in this research project interacting with participants experiencing a state of ongoing crisis, the researcher has chosen to include a personal reflection. This reflection draws upon reflective journals written throughout the course of the study. The chapter concludes with an examination and discussion of the limitations of this study followed by a concluding statement.

**DISCUSSION**

The aim of this section is to discuss the findings of the research project. The discussion is presented in two main parts. First, the findings are discussed from the perspective of the four main themes that have been identified through the process of analysing the data. Each theme will be compared and contrasted with research findings that have been published to date. As detailed in Chapter Two, most of the relevant previous studies were conducted in western countries. There are a limited number of available Thai studies regarding the experience of care givers. Second, to gain a greater understanding of the experience in ongoing crises of participants, their experience is discussed using van Manen’s four lived worlds (van Manen, 1990). However, before proceeding further, it is useful to review the definition of crisis used in this thesis.

In Chapter Two, crisis was defined as a state of disequilibrium. When the tension or stressors that have precipitated the crisis diminish or recede, the person returns to their previous ‘steady state’. On the other hand, the tension may fail to settle and in fact may increase and new coping strategies may need to be developed to return to and maintain a state of equilibrium. If the state of disequilibrium recurs repeatedly, the person’s capacity to adapt may be challenged to the point that they experience mental
and/or physical collapse; in colloquial terms, ‘they may have a breakdown’ (Caplan, 1964; Hoff, 2009; Roberts, 2005; Rosen, 1997).

Previous studies have frequently referred to care givers’ experience of crisis while providing care for relatives with mental illness but have not addressed it directly as the main focus of discussion. Two studies reported the experience of care givers during times of crisis, however, these focused on the experience of receiving crisis services, rather than reporting on the continuing experience of care givers (Gavois et al., 2006; Levine & Ligenza, 2002). The current study focuses on the day to day experience of crises as encountered by care givers caring for their relatives with a mental illness.

This study found that participants faced recurring difficulties and challenges as they cared for their loved ones with mental illness. These difficulties included practical issues, struggles with paying for care and feeding the family, the ill person’s threatening behaviours, social stigma, and their own emotional and physical difficulties. Facing these situations, participants spoke of the ways in which their lives were turned upside down and changed dramatically for the worse. Importantly, the findings establish that these participants experience ‘a state of ongoing crises’. Their experience of ongoing crises can be understood through further examination of the four identified themes ‘Out of control’, ‘So alone’, ‘Confusion and chaos’, and ‘No way out’.

‘Out of control’

The theme ‘Out of control’ illustrates graphically the impact of mental illness as it pulled the participants’ lives apart. When the participants realised that their loved ones had been diagnosed with a mental illness, they were in shock and felt as though they could not control their lives any more. The experience of shock that resulted from knowing that their loved ones were suffering from mental illness is similar to that described in the findings of previous Western studies. Previous studies in Australia (Chaffey & Fossey, 2004; Endrawes et al., 2007) and the USA (Howard, 1998; Johansson et al., 2010) found that care givers were shocked after they learnt of the diagnosis of
their ill relatives. An American study reported that care givers experienced an emotional breakdown in response to the diagnosis (Karp & Tanarugsachock, 2000). A study conducted in Sweden indicated that care givers had lost control of their lives (Nyström & Svensson, 2004).

In addition to the initial shock experienced by the participants associated with the diagnosis of mental illness, they then experienced fear for their own safety, for others’ safety, and for their ill relatives. When their loved ones experienced symptoms, the participants did not know what to do. They feared their ill loved ones might harm themselves, others, or be harmed by others. This finding is similar to previous studies in both western and Asian countries including Thailand. Studies in Hong Kong (Ip & Mackenzie, 1998) and the USA (Champlin, 2009) found that care givers feared for their loved ones and others’ safety. Ip and Mackenzie’s (1998) study also reported that care givers feared for their own safety. This is similar to the findings of a study undertaken in Thailand (Sethabouppha & Kane, 2005).

Consistent with previous studies, these participants experienced further fear associated with the unpredictable and aggressive behaviours of their loved ones describing their own apprehension related to their capacity to manage these concerning behaviours. A number of studies published since 2005 have reported care givers as both lacking information regarding mental illness and lacking the knowledge or skills to manage the associated symptoms. Two studies in Australia found that care givers received little information regarding mental illness from professionals (Crowley et al., 2005; Endrawes et al., 2007). This experience is similar to studies in Scotland (Harden, 2005), South Africa (Moleft & Swartz, 2011), Brazil (Nagaoka et al., 2011), and Thailand (Sethabouppha & Kane, 2005).

Along with the rising tension of relentless care giving, participants feared that there would be nobody to care for their loved ones after they died. Care givers in previous studies also experienced worry for their mentally ill loved ones’ future. A study conducted in Tanzania by Ambikile and Outwater (2012) found care givers worried about the future of their ill loved ones. Likewise, mothers of sons with schizophrenia
(Chaffey & Fossey, 2004) and fathers of children with schizophrenia felt as if they could not see a future for their loved ones (Nyström & Svensson, 2004). This experience was strongly reported by older care givers in a study conducted in Canada (Tryssenaar & Tremblay, 2002).

In this study, the participants continued to fear losing their loved ones. When ill relatives had episodes of mental illness and tried to run away from the home, the participants tried very hard to keep them in the house. In some cases, they had to follow and keep an eye constantly on the ill relatives to avoid losing them. This experience of the participants is similar to a previous Thai study in which care givers used tactful monitoring to prevent their loved ones from disappearing (Dangdomyouth et al., 2008).

A further source of fear and anxiety experienced by the participants related to financial strain arising from the high cost of treatments and other associated costs including the cost of transportation and the extra payment to authorities involved in the transfer process of their loved ones to the hospital. As a result of these costs, more than half of the participants experienced starvation directly related to needing to care for their loved ones with mental illness. The participants’ lack of food was a direct outcome of having to save money for their loved ones’ treatment costs. Results of other studies across a number of countries suggested that care givers of people with mental illness experienced financial difficulties associated with care giving. This included studies in the USA (Howard, 1998), Hong Kong (Ip & Mackenzie, 1998), Korea (Jung, 2000), Thailand (Sethabouppha & Kane, 2005), Australia (Crowley et al., 2005), Taiwan (Huang et al., 2009), and Tanzania (Ambikile & Outwater, 2012). However, none of the previous studies identified the impact of financial problems as being severe and leading to the point of starvation for the care givers. This issue will be discussed in more detail later on page 154.

Noteworthy are the findings of this study that highlight the participants’ experience of fear for their ill loved ones’ safety associated with treatment provided in the hospital. When participants took their ill relatives to access treatment at the hospital, they were
not provided with information about the mental illness and its treatment. Upon witnessing their loved ones suffering from side effects related to treatment, they feared that their relatives would die. This experience has not been reported in previous available literature and will be discussed in greater depth on page 153.

In this study, the participants continually faced not only the relatives’ challenging behaviours but also the impact of their loved ones’ unemployment and substance abuse. This resulted in further painful and difficult feelings. Previous studies have indicated that care givers confronted with aggressive and inappropriate behaviours from their mentally ill relatives likewise experience painful feelings. The findings of a study in Hong Kong (Ip & Mackenzie, 1998) found that care givers were distressed as a result of the behavioural problems displayed by their ill loved ones. An American study by Friedrich, Lively, and Buckwalter (1999) reported care givers’ psychological distress associated with facing the aggressive behaviours and symptoms of their ill relatives. Chang and Horrocks (2006) reported that Chinese care givers in Malaysia felt embarrassed and ashamed of their mentally ill loved ones’ behaviours. In Botswana, Seloilwe’s (2006) study found that care givers suffered and felt stress related to the unpredictable symptoms of the ill loved ones’ behaviours. Two available studies in Thailand found that care givers were shocked and distressed when their ill loved ones acted aggressively (Dangdomyouth et al., 2008; Sethabouppha & Kane, 2005). A further study presented the difficulties arising from the substance abuse of relatives with mental illness (Levine & Ligenza, 2002). A study in Brazil reported findings showing that care givers experienced financial and emotional burden as a result of their mentally ill relatives’ unemployment (Nagaoka et al., 2011).

Not only did the participants continually provide care for the ill relatives, they felt mental illness took away both their loved ones’ lives and their own lives. They felt as if they had lost their loved ones to mental illness. They also felt that they lost their own dignity and freedom. Similarly, the findings of other studies reported that care givers experienced the loss of loved ones to mental illness. A study of Karp and Tanarugsachock in America (2000) found that care givers felt hopeless and thought
that they had lost their loved ones to illness as a result of the chronic nature of the 
mental illness experienced. Chaffey and Fossey (2004) conducted a study in Australia 
and reported that care givers felt the loss of their loved ones to the illness as well as the 
loss of their freedom associated with prolonged care giving. Nyström and Svensson 
(2004) found that fathers of children with schizophrenia felt a loss of self-esteem and 
dignity as a result of having to ask for help from professionals.

The theme ‘Out of control’ has demonstrated the feelings of shock and fear of loss of 
dignity and freedom of the participants which remained throughout the entire process 
of care giving. The participants felt as if they could not control their lives and their 
relatives’ lives anymore. This theme was both similar to and different from previous 
studies. The findings of previous studies did not raise the issue of care givers’ 
experience of starvation arising from financial strain and their fear for the ill relatives’ 
safety while receiving treatment in the hospital.

It could be suggested that these previously unreported experiences may result from 
particular attributes of these participants, limitations in mental health services, 
difference in culture, and personal beliefs. As detailed in Chapter Four, most 
participants have limited literacy skills. It may be very difficult for them to access 
information that could enable them to educate themselves regarding mental illness. 
Moreover, in Thailand there is an identified lack of mental health professionals (See 
Introduction). Thus it may be difficult for mental health care providers to provide 
adequate mental health services for both care givers and relatives with mental illness.

Specific cultural factors impact on the participants. They expressed a belief that asking 
professional people for assistance would interrupt their work. They were afraid that if 
they asked questions, it would be annoying or thought to be disrespectful. They spoke 
of deciding to listen quietly but all the while remained frustrated. Even though they 
knew that there was support available, they dared not ask. In many cases, they also did 
not know where to turn for help or support.
Further impacting on the experience of these participants is the discomfort experienced by Thai people asking questions of someone who is in a ‘higher’ position. For instance, Thai people rarely ask health care professionals questions about illness or other related issues. With the added burden of illiteracy, the participants were also afraid that answers from those professionals might be difficult for them to understand. As a result of these factors, the participants experienced ongoing fear for the safety of their loved ones during hospitalisation.

These difficulties are reflected by the words of one participant. The participant, who has low level literacy skills, felt uncomfortable seeking treatment for her son with schizophrenia at the community hospital where she was required to fill in a request form to see the doctor. She was anxious and asked the researcher over and over during the interview how to do it, “I have to fill in the form saying that I come to get the medication, right?...Tell them [the clerks at the registration point] that I come to get the injection for my son, right? He doesn’t get the injection, right?” (Na, pp. 16-17, I. 2).

This study found that some of the participants were left with nothing to eat resulting in starvation due to the high cost of treatment and other relevant costs. It is reasonable to consider that the negative impact of the costs of treatment would be more keenly felt by these participants as they were mostly low-income earners. They fell within an income range that is described as very low with a minimum wage level of 206-215 Baht per day - around US$7 at the time of the data collection period in 2010-2011 (Planning and Information Division, 2011).

To improve the quality of life for all sections of Thai society, Thailand has implemented ‘the Universal Health Care Coverage Policy (UC)’ since 2001 as mentioned in Chapter One. However, limitations of this policy have been identified and reported, and concerns and suggestions from health care policy makers raised with the Thai government (Bureau of Policy and Strategy, 2009). First, there is concern about the sustainability of the programme and the available funds for each health care level to provide services. If there are insufficient funds, hospitals and physicians have little or no assurance that their costs will be covered. Second, medical facilities are
already inadequate in rural areas. The Thai government needs to provide sufficient funds to cover most primary care costs in order for hospitals to have some certainty that they can be reimbursed for the cost of services provided. This would avert the closure of health care services in the rural areas and avoid a negative impact on the health status of people living in these areas. Finally, equity of access to health care for all citizens needs to be seen as a priority for funding. Policy makers need to be alerted to the plight of patients who have no ability to pay for the cost of treatment. Hospitals and physicians cannot deny providing services to people who cannot afford the costs of treatment. In the same vein, the World Health Organisation (2003) suggests that one consideration in providing funding for the effective treatment or prevention of mental illness is to enhance care givers’ benefits so as to produce a lower burden of care (i.e. better quality of life, fewer work days lost, and less loss of income). This issue regarding the cost of treatment still challenges health care providers to provide adequate support for care givers and their relatives with mental illness in Thailand.

In response to these economic issues, the National Economic and Social Development Board established the Social Safety Net in the 10th National Economic and Social Development Plan (2007-2011). It aimed to “build safety nets and risk management systems for the sectors of finance, banking, energy, factor markets, the labour market, and investment” (National Economic and Social Development Board, 2007, p. 10). In addition, the National Health Security Office of Thailand has increased the budget to help people with mental illness to more easily access mental health services and receive ongoing care (Bureau of Service Quality Development, 2012). Despite the efforts of the Thai government to ‘pursue a Green and Happiness Society’, this vulnerable group, the participants caring for ill relatives, stated clearly that they experienced extreme financial hardship and needed financial support to deal effectively with mental illness.

‘So alone’

The theme ‘So alone’ described the experience of the participants as one of providing care for their relatives with mental illness in isolation from any other support. The care
provided included managing legal problems, personal hygiene of the ill relatives and symptom management. Moreover, the participants felt ‘So alone’ when they were being emotionally, physically and verbally abused by their loved ones. The experience of providing care alone has been reported in previous studies. A study in Australia found that care givers typically faced the difficult time of providing care for the ill loved ones on their own (Foster, 2011). Champlin (2009) and Chang and Horrocks (2006) reported that care givers felt isolated during their care for their ill relatives.

In the current study, the participants experienced ‘constant tiredness’ resulting from providing care for their loved ones alone over a long period of time. This included paid work and house chores, keeping an eye on the relatives during the night time to prevent them from wandering away or making trouble with neighbours, and monitoring their medication. Likewise, previous studies in other countries, as already mentioned in the previous theme: ‘Out of control’, also reported the caring task of care givers. Howard (1998) found that care givers faced a burden of care including financial support, management of medication and education for their loved ones. A previous study in America by Saunders and Byrne (2002) identified the burden faced by care givers having to manage their loved ones’ medication. Two previous Thai studies (Dangdomyouth et al., 2008; Sethabouppha & Kane, 2005) found that care givers experienced difficulty monitoring medication, earning money, doing housework, and doing other caring tasks for their ill relatives, especially preventing their loved ones from going out at night (Dangdomyouth et al., 2008). Chang and Horrocks (2006), Endrawes, O’Brien, and Wilkes (2007), Foster (2011), Nagaoka, Paula, Antonio, and Santos (2011), and Ambikile and Outwater (2012) also reported similar issues of increased burden to care givers providing care for mentally ill relatives including doing housework and caring tasks. It was also difficult for them to monitor medication (Chang & Horrocks, 2006; Huang et al., 2009; Johansson et al., 2010). A Korean study (Jung, 2000) reported that care givers frequently had to manage the burden alone without any support from other family members. As a result, they were constantly
stressed and distressed. Likewise, a Thai study reported that care givers were very
tired and exhausted during their care for the ill relatives (Dangdomyouth et al., 2008).

The participants continually experienced loneliness resulting from managing their
loved ones’ personal hygiene and being abused. They described clearly that they were
very distressed but felt that they had no option but to ‘bear’ it. Similarly, previous
studies reported the experience of care givers being abused by mentally ill relatives. A
previous study in the USA found that family members caring for siblings with
schizophrenia experienced verbal and physical abuse by the ill relatives (Friedrich et
al., 1999). A Thai study also reported that mothers were threatened by their children
with schizophrenia (Rungreangkulikij & Chesla, 2001). A similar experience was also
reported in the study of Seloilwe in Botswana (2006). Another study conducted with
Egyptian care givers found that care givers were abused by their ill relatives
(Endrawes et al., 2007). A study in South Africa reported that care givers were verbally
abused by the ill relatives (Moleft & Swartz, 2011). Even though the experience of care
givers being abused by the ill loved ones was well described in previous studies across
various countries, the experience of care givers being obliged to manage the personal
hygiene of the ill relatives with the result that they felt being trapped in an ‘unbearable
life’ has not previously been reported. This experience will be discussed in more detail
later in this section.

The findings of this current study also found that the participants were very stressed
when facing alone the legal issues arising from the symptoms of the mental illness of
their ill relatives. They described authorised persons and health professionals as
frequently mistreating their ill relatives and underestimating their needs. Likewise, a
study of Tryssenaar and Tremblay (2002) found that care givers living in a rural
community in Canada faced difficulty associated with the police treatment of people
with mental illness. This is similar to the experience of care givers described in a recent
study conducted in Australia by Foster (2011).

Even though the experience of providing care alone was found in previous studies as
described above, the participants in the current study appeared more likely to name
the worst aspect of this experience as resulting from ‘loneliness’. This may be associated with long term care giving in ongoing crises, stigma towards the ill loved ones and themselves, and their personal social values. These factors resulting in the experience of loneliness of care givers are discussed below.

In the current study, it was very difficult for the participants to provide long term care alone in the midst of ongoing crises especially having to manage the hygiene of the ill relatives. As presented in Chapter Four, many participants had provided care for their ill loved one for more than 10 years. They were wage earners doing labour work in fields, farms, or factories. Even though they were very tired after their work, they could not find time to take a rest. They had to do housework and to care for their ill loved ones who had become ‘an adult baby’ and needed care.

Moreover, there was strong evidence of prejudiced attitudes towards ill relatives displayed by both family members and community members. Other family members could not accept them and felt ashamed of having a relative with mental illness. As a result, the participants could not ask for help and support with the basic care needs of their loved ones. Stigmatising attitudes in public toward the ill loved ones and the family had also occurred. Thus, the participants avoided talking to neighbours and felt reluctant to ask others in public or authorised persons to help them manage their loved ones’ personal lives.

In the Thai context, it might be the case that the feeling of loneliness is even more likely to occur. Thai people, especially those who are illiterate and have a low social status tend to listen to what they have been told by the professionals and dare not ask if they do not understand nor argue if they disagree. This can be further explained by considering one of the social-cultural practices which Thai people usually adopt, i.e. ‘Krengchai’. This is described as “an extreme reluctance to impose on anyone or disturb his personal equilibrium by direct criticism, challenge, or confrontation” (Mahidol University, 2002).
‘Confusion and chaos’

The previous theme has addressed the participants’ experience of ‘loneliness’ while providing care for relatives with mental illness. This section examines the experience of ‘Confusion and chaos’ resulting from the unmet needs and absence of support from health professionals during their care for loved ones with mental illness.

As presented in the previous section ‘Out of control’, participants in this study were lacking knowledge about mental illness. ‘Not knowing’ continued to affect the participants leading to a persistent sense of confusion. Even though the participants had cared for their loved ones with mental illness for a long period of time, they had not been provided with information about the cause of the mental illness by the professionals caring for their relatives. Likewise, Harden’s (2005) study found that care givers received little knowledge from health professionals regarding their ill loved ones’ mental illness and symptoms. Care givers in another study reported that the information provided by professionals regarding the relatives’ illness was inadequate (Endrawes et al., 2007). Moleft and Swartz’s (2011) study also reported that professionals neglected to provide knowledge to care givers.

As a result of this lack of knowledge about mental illness, the participants’ postulated many possible causes for the illness including evil, genetics, family problems or Karma. This finding is similar to that described in previous Thai studies. Rungreangkulkij and Chesla found relatives identified Karma and spiritual problems as the cause of mental illness (2001). Other studies reported that care givers believed that natural spirits caused mental illness (Sethabouppha & Kane, 2005; Vanaleesin et al., 2003). Dangdomyouth, Stern, Oumtanee, and Yunibhand’s (2008) study also found that care givers believed that mental illness was caused by evil spirits. A belief in Karma also impacted upon the sense of there being ‘No way out’ which will be discussed in the next section.

As a result of this confusion regarding the potential causes of mental illness, the participants delayed seeking modern treatment for their ill loved ones. They sought
traditional treatment and in a number of cases spent a lot of money on this treatment. Similarly, earlier studies in Thailand have repeatedly reported the use of traditional treatments and religious practices by care givers to treat the mental illness of their relatives. These studies also found that care givers sought help from monks to release the evil spirits from the body of their ill relatives (Burnard et al., 2006; Dangdomyouth, 2006; Rungreangkulkij et al., 2002). Other studies reported the use of traditional treatments by folk healers to cure illness (Sethaboupphpha & Kane, 2005; Vanaleesin et al., 2003). Despite these efforts, the illness continued to worsen and the participants felt guilty and hopeless. This has also been described in the findings of a previous Thai study (Vanaleesin et al., 2003). If participants then sought modern treatment they often experienced difficulties arising from a lack of information being provided about the illness from the treating health professionals.

Many participants persisted in their search for help and continued to seek modern treatment for their loved ones despite remaining uninformed regarding the cause of mental illness and its possible treatments. They described ongoing confusion, shock and disappointment with the services provided for their ill relatives. Some participants discontinued attempts to utilise modern treatments. Others maintained their contact with mental health services in their attempts to gain relief for their relatives. They described an enduring sense of confusion and sadness associated with these contacts.

As participants continued in their efforts to utilise modern medicines for their ill loved ones they faced unhelpful mental health services including shortage of necessary medication, difficulty accessing admission and outpatient services in a timely manner, and early discharge before the ill person was well enough to go home. Likewise, previous studies conducted in Thailand stated clearly the difficulties resulting from insufficient mental health services or the inability to access those services if they were available for people with mental illness (Dangdomyouth et al., 2008; Sethaboupphpha & Kane, 2005). This experience of a lack of mental health support and services from the health professionals for care givers has been found in previous studies across a range of different countries including Taiwan (Huang et al., 2009; Jung, 2000), Canada
This experience of ongoing ‘Confusion and chaos’ resulting from a lack of support from professionals was similar to that described by preceding researchers. Confusion associated with difficulties accessing services from health professionals and authorised people involved in provision of care for the ill relatives is widely experienced by caregivers in a diverse range of countries and cultures. For the participants in this study the experience of ‘Confusion and chaos’ was of such intensity and duration that it appears to have fuelled the hopelessness and despair that led participants to speak of having ‘No way out’.

‘No way out’

The final theme ‘No way out’ portrays the experience of the participants as a result of personal spiritual beliefs and social stigma directed towards the mentally ill relatives and the family. As described in the previous theme, participants believed that mental illness was caused mainly by evil and sinfulness in the present or past life. They believe that their lives have been controlled by Karma - the result of sin. Similarly, as mentioned in previous Thai studies, Thai caregivers believed the most common cause of mental illness was Karma and evil or natural spirits (Burnard et al., 2006; Dangdomyouth et al., 2008; Rungreangkulkij & Chesla, 2001; Sethabouppha & Kane, 2005).

Holding these beliefs reinforced the idea that mental illness could not be cured. As a result, the participants had no sense of a hopeful future or of treatments and assistance that would improve health of their loved ones. Their lives drifted along according to Karma and were thus beyond their control. In contrast, the study of Endrawes, O’Brien, and Wilkes in Australia (2007) found that religious beliefs helped Egyptian family caregivers cope well with mental illness. In Taiwan, Huang’s (2009) study also reported caregivers practiced religion to cope with the mental illness of the ill
relatives. This difference between the findings of the current study and previous studies will be discussed on the next page.

This research also clearly demonstrated the experience and impact of stigma directed against the relatives with mental illness by the participants, other family members, and by the public. Likewise, previous studies highlighted the issue of stigma attached to care givers of the mentally ill and their ill loved ones. Chang and Horrocks’ (2006) study reported that care givers in Malaysia felt shame associated with having mentally ill relatives. This study also found social stigma towards care givers and their ill relatives. An Australian study by Endrawes, O’Brien, and Wilkes (2007) reported that care givers experienced stigma directed towards themselves and their ill loved ones. As a result they often withdrew from public. Champlin (2009) also reported the isolation from society of American care givers in order to avoid social stigma. Huang and colleagues in Taiwan (2009) reported stigma towards the ill members in the house from other family members. Moleft and Swartz’s study (2011) found that there was strong evidence of social stigma towards care givers and their ill relatives in the community in South Africa. Ambikile and Outwater in Tanzania (2012) described their findings, demonstrating that care givers experienced a range of social challenges while caring for ill loved ones including social stigma towards themselves and their ill relatives.

In this study, stigma towards the participants and ill relatives further reinforced the participants’ sense that ‘there is no way out’ for themselves and their relatives with mental illness. In contrast, care givers who were described in a previous study as experiencing stigma towards themselves and their ill relatives were willing to continue to provide care for their ill loved ones (Chang & Horrocks, 2006). A further study reported that even though care givers faced social stigma towards themselves and their relatives, they lived with hope that thing would improve (Endrawes et al., 2007). This is similar to what was reported in the study of Johansson, Anderzen-Carlsson, Åhlin, and Andershed (2010) in which care givers in the USA maintained a sense of hope for a positive outcome and could see ‘light in the darkness despite difficulties’.
The plight of these care givers is stark and confronting as the findings of the current study describe participants as having little or no hope for the future and being burdened by the interminable nature of their role as care givers for their ill loved ones. It could be suggested that this sense of hopelessness arises from the burden of the unrelieved long term care needs of their relatives and their own personal beliefs in Karma. In many cases these participants had cared for the ill relatives for a long period of time and had not seen any signs of improvement or indications that would promote a sense of hope for the future. They believed that this situation had arisen because of the Karma which controlled both their lives and those of their loved ones. This belief was underpinned by a surety that they had done something wrong and that they had to ‘pay for it’. The feelings of hopelessness in some instances were exacerbated by the lack of positive coping strategies; instead, unhealthy coping strategies were used in an attempt to cope with crises. Participants were frequently troubled with repetitive self-destructive thoughts (Hoff, 2009). ‘No way out’ bluntly illustrates the experience of living in a state of ongoing crisis for these participants in which they saw death as a desirable alternative to continuing with their current existence. As one participant said, “I would like to jump from a bridge to kill myself. I am tired of life.” (Tong, p. 16)

Participants’ sense of well-being was shaken to the point where they experienced both emotional and physical illness. Earlier studies in other countries and in Thailand also found that care givers experienced mental and physical illness. Ip and Mackenzie (1998) reported that care givers in Hong Kong experienced emotional problems in having to care for their ill loved ones. Jung’s (2000) study found that Korean mothers caring for children with schizophrenia felt under pressure all the time and had self-destructive thoughts. Ferriter and Huband’s (2003) study stated that care givers in the UK could not cope effectively with their ill relatives’ symptoms. As a result, they experienced emotional distress. Taiwanese care givers (2009) also experienced emotional distress resulting from providing care for relatives with schizophrenia. In Thailand, Sethabouppha and Kane (2005) reported that care givers experienced emotional distress. Similarly, another Thai study found that care givers experienced
exhaustion and sadness while providing care for their relatives over a long period of time without any support (Dangdomyouth et al., 2008). Care givers in another study experienced that the care giving for relatives with a mental illness was never ending (Champlin, 2009).

The four themes arising from the data have provided a vehicle to illustrate the lived experience of the participants in this study who care for loved ones with mental illness. The findings were compared and contrasted with the findings of relevant existing literature. In contrast to previous studies, this study provides a clear picture of a group of participants whose experience of care giving can be accurately described as ‘living in a state of ongoing crises’. As a researcher, the approach to the development and undertaking of this research project has been informed by a qualitative phenomenological approach with an emphasis on van Manan’s phenomenological framework. It is thus appropriate at this point to use the lens of van Manen’s four existentials (1990) to enable a deeper understanding of how the participants experienced this state of ongoing crises.

van Manen’s notion of four existential - ‘lived worlds’

Before examining the findings through the lens of van Manen’s four lived worlds (existentials), it is timely to briefly review each of these existentials as a basis for the discussion that follows. The lived worlds are named respectively lived space, lived body, lived time, and lived other (van Manen, 1990). ‘Lived body’ (corporeality) refers to the reality that people exist ‘bodily in the world’. They initially connect with others in the world through their own body (van Manen, 1990). When people present themselves through their body, they both reveal and conceal something at the same time. van Manen (1990) suggests that the human body can grow greater than its mode of being when it is observed by other people. For instance, our body may turn awkward and its motion looks clumsy under critical observation.

‘Lived space’ (spatiality) does not mean the size of the building where people live or the distance between places (van Manen, 1990). Rather, it refers to the way that people
feel about the space which they are in. A big building may make people feel small. On
the other hand, a small one, for example an elevator may make them feel
uncomfortable, enclosed and restricted.

The definition of ‘lived time’ (temporality) as described by van Manen (1990) is
subjective time. It is different from clock time and depends on how people experience
the world as they live in it. ‘Lived time’ is also the temporary being of humans in the
world. The being of humans is different from time to time. For example, when people
are young they talk about the future and when they get older they talk about the past.
The way of being in the world for people, in the past, influences the way they respond
to the world in the present. The past can be changed by the way that they (re)interpret
it. Humans’ perspective on life comes from their hopes and expectations. This
existential suggests that people maintain hope so that they can have perspective on life.
If they feel fear and lack of motivation to live, they may not have perspective (van

The final existential is ‘lived other’ (relationality). This is ‘the lived relation’ between
people in the interpersonal space which they share with others. The ‘special lived
relation to the other’, is for example ; the parent-child, , sister-brother, and husband-
wife relationship (van Manen, 1990). The ‘lived relation’ happens when two persons
meet face to face and have a conversation with each other. Thus, as two people
converse in relationship with each other, they can be said to transcend themselves as
individuals and enter into the ‘lived other’. van Manen clearly reminds his readers,
that even though each existential is presented separately as detailed above, “one
existential always calls forth the other aspects” (van Manen, 1990, p. 105). These brief
explanations of four ‘lived worlds’ of van Manen (1990) provide the basis for the
following discussion of experience of participants living in a state of ‘ongoing crises’.

In this study, the participants had encountered ongoing crises beginning with the first
episode of mental illness experienced by their loved ones. They described their shock
as they witnessed the bodily changes of their relatives as they turned from normal to
awkward and ‘abnormal’ because of the effects of the mental illness and its treatment.
Given that the ill relatives’ condition did not return to the former state of health and even when there was a period of remission, followed by yet another relapse, the participants lived with repeated experiences of shock. One participant said that her heart broke each time she looked at her mentally ill son who had become dull and developed a robot like appearance after he became mentally ill.

Participants also experienced shock and distress associated with the ‘lived body’ of their relative when they took their ill loved ones to receive modern treatment at the hospital. They observed that the ill relatives’ body was dreadfully affected by modern treatments. They were frustrated and confused as they had no framework for understanding what was happening. For example, one participant saw her husband with schizophrenia coming out of the treatment room red eyed and unconscious (It is likely that her husband received electroconvulsive therapy. Nobody explained to her about the treatment or what to expect). She had no idea what had happened to him and described feeling shocked, angry and upset.

The participants’ own body also contributed to the experience of life as being one of ongoing crisis. When care givers were abused by the ill relatives and their bodies were injured, they became angry and no longer wanted to care for their ill relatives. It was often difficult for the participants to find the willingness and empathy to provide care for someone who had hurt them. Moreover, in some cases the participants had to then use ‘their injured body’ to provide for the personal hygiene of the ill loved ones who had become like an ‘adult baby’ (i.e. requiring assistance with showering, feeding, and cleaning their excretions). Care givers felt terrible at being in the position of having to carry out these tasks while at the same time feeling that they had no option but to do what was needed.

While providing care for the ill loved ones, some of the participants felt as if their body was in starvation mode, a direct consequence of the high cost of accessing treatment for mental illness depleting their very limited income. Most participants were the sole wage earner and had a very low income. They feared that they may not have sufficient money to pay for the costs required for treatment and saved the very little money that
they had for those costs instead of buying food to eat. They then left themselves with very little to eat. As a result, they experienced times of starvation.

Concurrently, participants also sensed a state of crises associated with their ‘lived space’. One important aspect of van Manen’s ‘lived space’ is ‘home’. Home normally provides a very special ‘space’ experience connected with a fundamental component of humans’ being and for optimal functioning should be a secure inner sanctum for the person (1990). In the study, participants were afraid either of losing their loved ones or of what they described as a worse situation where their neighbours were disturbed or harassed by the ill relative. During episodes of mental illness, they tried very hard to keep their ill relatives in the house. They kept watch over them and begged them to stay at home. They believed that home should be a safe place for their relatives.

Paradoxically, while endeavouring to provide a safe place for the ill person, home was a dangerous place for the participants, other family members, and their loved ones. The escalating symptoms of mental illness resulted in aggressive and at times dangerous behaviours on the part of the mentally ill relative. In some instances participants, other family members, and neighbours were threatened and abused by the ill relatives. When those people fought back, the situation became chaotic and relatives were sometimes injured. The participants lived at home with uncertainty, discomfort, and fear and thus their ‘lived space’ became an ‘unsafe space’.

Participants also experienced a sense of ‘lived space’ as an ‘insecure space’ when they took their ill loved ones to the hospitals. In some cases, they and their ill relatives experiencing episodes of illness and sustaining injuries had to wait for hours at the emergency department until their relatives could be admitted into the hospital. Under such circumstances participants felt upset and confused in ‘that space’ i.e. hospital. During the hospitalisation of the ill relatives, participants witnessed their relatives at times incurring injuries as a result of physical restraint, receiving modern treatment, and physical fights. They were worried and wondered what was going to happen with their loved ones, and would they be hurt by the staff.
‘Lived time’ likewise became a problematical issue and was experienced as very slow as a consequence of the chronicity of the mental illness and the state of ongoing crisis. Participants felt as if the provision of care for the ill relatives would never end. They had to work, do housework, and monitor both medication and behaviour for the ill loved ones. The stigma evidenced by others in the house towards the ill person resulted in a lack of support from other family members to help the participants care for the relatives. As a result, the participants were the sole providers of care leaving them with no opportunity for respite or time to care for themselves.

Participants experienced ‘frightening times’ when their loved ones went missing or wandering. Even though they had tried very hard to prevent the ill relatives from disappearing as described above, this still occurred at times. The care giver was then back in a place of numbness and shock. They described feeling their heart ‘sink’ and experienced fear at the possibility of losing the ill relatives. After they found their loved ones and took them back home, they monitored them constantly to prevent them from disappearing again. A state of fear was a continuing reality for many participants. To avoid these problems, some decided to stay at home to keep an eye on their ill relatives rather than go to work as usual. They thought it was tiring to stay in ‘the limited space’ but again felt that there was no choice.

While providing care for the ill loved ones, the participants experienced ‘lived time’ as difficult. They were responsible for everything as previously detailed. All the while, their ‘lived time’ was jolted and jarred as their relatives’ mental illness re-occurred and the person relapsed yet again. The ‘never-ending time’ spent providing care for their ill relatives led participants to think that their ill loved ones would never get better. Their relatives could not live their lives like ‘other normal persons’. A sense of perspective, so essential for maintaining hope and the possibility of a future was missing and participants struggled to conceive of any future for their loved ones.

The final existential is that of ‘lived other’ (relationality). In this study, participants believed their relationship with their ill relatives had been affected by the changes brought on by mental illness. When their ill loved ones acted aggressively, or
demanded and used drugs, it was difficult for the participants to ‘connect with’ them. The participants feared the relatives’ aggressive behaviours. They kept quiet and let them do whatever they wanted. They felt that they had lost the ill relatives to mental illness and this created a barrier to conversation between them and their loved ones. ‘Relationships’ between the participants and the loved ones were impossible to sustain or repair. Their relatives did not feel like the same person they had previously known. Participants felt as if they lived with a ‘stranger’.

The nature of the relationship was so markedly disrupted that participants felt that they were now trying to build a very difficult ‘new relationship: the care giver-ill relative relationship’. They many times unwillingly provided care, especially male participants who had to manage personal hygiene and wash Pa Nung for the ill wives (a skirt worn by Thai women and recognised as a low thing for Thai men to wash). Some of them had to meet with people who were abused by their ill relatives to apologise about what their loved ones had done to them. Even though they were humiliated and did not want to care for their ill relatives, they felt compelled to act the way that they believed care givers should act.

It was also difficult for the participants to provide care for their ill relatives if the relationship between them and the other people involved in care including health professionals and other authorities was distant. When they faced inappropriate mental health services, and legal and other social issues, they were very confused and frustrated. They did not know where to turn to get help or if help was available they dared not ask. They felt that they should not disturb the professionals’ work. They could not develop meaningful and helpful conversations. There was no basis for mutual conversation or relationship. The relationship between the participants and the professionals seemed to be far off. As a result, the participants remained in a state of confusion and isolation, alone and without the benefit of nurturing and supportive relationships.

Viewing the experience of living in a state of ongoing crises through the ‘four lived worlds’ of van Manen (1990) provides a deeper understanding of the meaning of these
experiences. Every aspect of the ‘lived worlds’ of the care giver looking after a person with a serious mental illness in a rural-urban Thai context is crowded with pain and suffering, confusion and fear, isolation and sadness. Hopelessness and despair pervade the descriptions that participants give and the loss of a ‘future’ was apparent throughout. The degree of suffering experienced by these participants demands a closer look at the implications of these findings for the future development of health services in Thailand.

**IMPLICATIONS**

The findings of the study presented the lived experience of care givers from their perspective as they related their stories of living in a state of ongoing crises. These unique experiences reflect the needs of care givers caring for ill relatives. The World Health Organisation reports that family care givers are the main carers for their loved ones with mental illness (WHO, 2003). In Thailand, official statistics indicate that there are 1.6 million Thai people who have suffered from mental illness (total population 65.9 million) (Department of Mental Health, 2011). To provide care for ill relatives, care givers need help and support from social structures and professionals. Importantly, the support from health care providers must meet individuals’ needs (Crowley et al., 2005). The results of this study are important to further develop knowledge, promote understanding, and inform the development of mental health service responses to individual care givers and their relatives with mental illness during times of crisis. Moreover, this study provides a foundation for further studies.

**Education**

Janosik (1986) and Kanel (2007), whose work builds on Caplan’s crisis theory (1964), advocate that in order to help people overcome crisis, health professionals need to have a better understanding of the hazardous events which cause people distress, how they experience those events and the overwhelming tendency to resort to customary coping mechanisms. With this understanding, health professionals are better equipped to change the way in which they practice. A number of examples of the initiatives
designed to improve health professional knowledge are reported in the literature, including a focus on the importance of mental health literacy which aims to improve knowledge and beliefs about mental disorders to enhance mental health care provided by professionals (Jorm et al., 1997). The Canadian Alliance on Mental Illness and Mental Health (2008) used key findings from previous research to develop a framework to improve the mental health literacy of health and mental health professionals, researchers, policy planners, consumers and family members. The findings of this current study indicate that important components include the pressures family care givers of mentally ill relatives face day-to-day, the experience in living in a state of ongoing crises and the implications of this for care givers. These findings should serve as a guideline to enhance the understanding of mental health professionals concerning the experience of care givers in ongoing crises during their care for their mentally ill loved ones.

In addition, the results of this study add to knowledge related to current crisis theory. A crisis has previously been described as a situation of both danger and potential opportunity. People experiencing a crisis may return to a level of functioning post crisis that is consistent with their pre-crisis functioning or may indeed function at a lower or higher level after facing a crisis. Current crisis theory describes this as a state that normally resolves within four to six weeks (Caplan, 1964; Hoff, 2009; Kanel, 2007). (More detail of theory of crisis has been described in Chapter Two.) The findings of this study provide a picture of a group of people whose experience is one of being in a state of ongoing crisis. The data suggests a lower level of functioning epitomised by maladaptive responses and mental and physical illness in the participants arising from the unrelenting nature of the care-giving role.

Practice

The findings of the present study reflect the essential difficulties and challenges that care givers of mentally ill relatives face in Thailand. It also shows care givers as struggling to adapt in effective ways and experiencing major disorganisation in the fourth stage of crisis (Caplan, 1964; Hoff, 2009; Rosen, 1997). Kanel (2007) suggests that
health care providers need to provide crisis interventions for people who are in the midst of crisis because they are more receptive to suggestions and support than when they are in the steady state. Likewise, Gavois, Paulsson, and Fridlund (2006) found that care givers needed support from health professionals during crisis. The provision of adequate support increases the person’s capacity to cope effectively with difficulties and challenges and to adapt well to new circumstances. Thus, appropriate support instituted in a timely fashion has the potential to enable care givers to achieve a higher level of functioning.

To implement the findings of this study, the recommendations of the World Health Organisation (2007) on primary health care as an approach to strengthening health systems should be used to guide the crisis intervention provided for the care givers. Mental health systems enhanced by focusing on community-based services should be seen as a priority as these have historically been reported to be less expensive and more effective (WHO, 2007).

In the Thai community, the village health care workers or community health workers serve as frontline persons to provide primary care for the community. They provide basic help and support for people in the community including serving in the role of educators, communicators, problem detectors, problem solvers, community organisers, and leaders of health (Free medical textbook, 2011). Given the limited availability of adequate numbers of mental health professionals in Thailand (See Introduction), village health care workers provided with appropriate training and support could work collaboratively with health professionals to help care givers cope more effectively with crises.

However, infrastructure and funding to support these roles would be required for effectiveness. This would include formal education and training around the basic mental health issues including responses to crisis situations. A potential tool for increasing the competency of village health care workers could be the provision of training using the validated program Mental Health First Aid (2013). This would need to be translated, validated, and modified for the Thai context. As discussed in Chapter
Four, a crisis assessment tool is not currently available in Thailand. An initial crisis assessment tool should be developed to support the village health care workers in their primary health care roles. The tool should be accessible for use in either actual or potential crisis situations (Hoff, 2009). The precipitating factors for the state of ongoing crises which is frequently the experience of care givers (See Findings) can be used as precise information to develop the tool for the village health care workers. During visits to care givers in the community, such a tool could be used to assess factors which may precipitate crises and refer those who are at risk of crises to health professionals for further assessment and support.

The process of developing such a crisis assessment tool for health care workers and health/mental health professionals could commence with consideration of the findings of this study. Lewis (2005) conducted a study to develop a crisis assessment tool and suggested that a measurement tool helped clinicians justify treatment for people in crisis. It was recommended that an effective questionnaire should include questions related to the person’s thoughts, behaviours, feelings and perceptions of the crisis situation. The findings of this study have identified potential precipitating factors for crises occurring; expressions of distress related to living in a state of ongoing crises, the effects of ongoing crisis on care givers, and their lived experience in ongoing crisis. These findings provide information that can form a solid basis for the development of a crisis assessment tool for use by health professionals and village health care workers in Thailand.

The development of a clinical pathway that outlines the appropriate response to assist the person in crisis would assist the implementation of a consistent response to care givers. Once the assessment process has been completed, clinicians would be encouraged to provide support that is tailored to individuals’ needs. Those involved would also be encouraged to refer care givers and relatives with mental illness to receive help and support from other organisations. For example, the police can help the care givers deal with legal issues. Local government officials can assist by providing a budget to serve the basic needs of people with mental illness as well as employment
projects for disadvantaged people. Monks can assist by providing community-based rehabilitation of people with mental illness using a programme already established in the Thai community (WHO, 2007). Finally, consultation and referral to mental health professionals in secondary and tertiary care could be made if needed.

Research

There is a need for follow up research to investigate what kind of support and intervention would be effective and feasible within the Thai context. The resources available in Thailand are very modest for the provision of care for care givers of relatives with mental illness. For instance, a person with mental illness is paid a living cost by the Thai government of 500 Baht per month (around US$16) (Royal Thai Government Gazette, 2007). Research on how this very limited budget might be spent to provide the best possible support for these people needs to be undertaken.

As mentioned previously, mental health professionals are a very scarce resource in Thailand. Further research needs to be carried out to look at how these available human resources can be best utilised in times of crisis to produce the best outcome for family care givers. This research needs to incorporate an examination of what crisis intervention can be delivered by the village health care workers, health/mental health professionals, and local government officials to support these people to successfully survive crises and prepare more effectively for possible crises in the future (Roberts, 2005).

Care givers of relatives with mental illness are a very important group who make a very substantial contribution to the Thai community. The findings of this study have important implications for education, practice, and research that have the potential to assist this neglected group within the community and to assist them to effectively provide care for their ill loved ones whilst maintaining their own well-being.

The next section presents the personal experience of the researcher in carrying out the study. This will enhance understanding of the current study as detailed below.
PERSONAL REFLECTION

The intention of this section is to present a reflection exploring my personal experience of conducting this study. For the purpose of personalising this section, I have made a decision to write this in the first person to indicate the intensely personal nature of this writing. This extends from but is different to the process undertaken in the rest of the thesis which follows more conventional research protocols in the conduct and writing up of research. I now go beyond that and talk about my personal experience of conducting this research and the impact this has had upon me.

When I first started the current study, I was interested in doing a participatory action research study to improve care givers’ capacity to care for relatives with mental illness especially when they face crisis situations. Being a psychiatric nurse and a nursing lecturer in the mental health area for 16 years I felt I knew everything about care givers’ experiences and needs during times of crisis. At that time, I thought that it would be better if care givers could share their experience with others in a group and then they could learn from each other how to deal with crises. I spent a great deal of time during my first year as a doctoral candidate looking at the possibility of doing such a study using a participatory action research approach. I sought informal contact with authorised persons in Thailand to make sure that this kind of research could be done in the Thai community. They confirmed that crisis situations occurred frequently and suggested that research could be done to ascertain what would help those affected to deal with crises more effectively.

A few months before the completion of my first year of studying this PhD, I realised that in fact I knew nothing about what care givers experience while caring for relatives with mental illness in Thailand. Research was needed to identify how to help these care givers but I did not know what specific crises they faced, and what intervention I should develop to best fit their needs. At this point, I realised that I needed to consider conducting a research project that would help me to understand the experience of care giving during a time of crisis before I proceeded to develop an intervention.
After a period of anxiety and discussion, I decided to use a phenomenological approach to explore with caregivers their experience of care giving. Phenomenology has been used to investigate the experience of many different groups of people by different disciplines in many countries. The idea of conducting a phenomenological study in Thailand was challenging for me. I was concerned about how to most effectively investigate the experience of participants. After more discussion, a decision was made to use in-depth interviewing to try to understand the caregivers’ experience. From my previous experience, Thai people are generally likely to answer “I don’t know” to questions and tend to provide short answers only to health care professionals. I wondered whether I would be able to engage caregivers in a frank discussion about their experience. I attempted to develop an interview schedule that would be suited to the rural Thai people I hoped to interview.

At the commencement of data collection, I went to the study site every day to be ready to provide eligible participants with further information about the research project. However, for the first few weeks, the caregivers attending the health centres and the hospital were not interested in the study. They received the information and the documents related to the study from the initial person (the psychiatric nurse) but they appeared to be reticent to participate in the study. Only a few people expressed their willingness to be a participant. This was perhaps because most of them were illiterate. Even though they were informed by the psychiatric nurse about the study, they appeared to be overwhelmed by the information and needed reassurance that the study would not affect them in any way. One participant told me that she took all documents for her niece to read and discuss with other relatives to ensure that the study was worth participating in. These challenges meant that it took five months to recruit sufficient participants to reach data saturation for the study.

After the initial period of reticence and once sufficient caregivers agreed to participate in the study, they proved to be very eager to be interviewed. Most shared their experiences willingly and felt that the tension of care giving had been relieved a little with the opportunity to tell their story. They talked at length telling me all about their
experiences. I just had to listen to them. Sometimes, it was difficult to keep the care
givers focused on the research questions as they talked randomly about their
experiences. The interview schedule was then used as a guide for me to return the
conversation to questions focused on the lived experience of care giving in crisis.

Another issue was the use of the term crisis. As already mentioned in Chapter 4, the
terms used instead of crisis were ‘difficulty’ and ‘challenge’. The intention was to avoid
bias in the participants’ telling of their stories. Before the data collection started, I was
worried about how the participants would respond to these terms. This feeling
disappeared after the first interview. The first participant responded quickly to the
research question and talked prolifically about her experience. She stated clearly that
her experience of caring for her son with a mental illness was a long term difficulty.
The feeling of shock continues to impact on her until the present day. Her story
changed my intention from exploring experiences of crisis to exploring experiences of
‘ongoing crises’.

This experience of ‘ongoing crisis’ for care givers providing care for relatives with
mental illness was confirmed by other participants. As I listened to their stories, I felt
overwhelmed by what they faced. I thought to myself that “This is an ongoing crisis
and it never ends.” I conducted a preliminary thematic analysis of the initial interview
of the first three participants and consulted one of my supervisors when she visited me
in Thailand during the data collection period. We discussed the preliminary findings
from these first three interviews and thought about how I might reflect back to
participants what I thought they were telling me. I decided to present this feedback as
a personalised letter to each participant.

I wrote a letter summarising the preliminary findings to each of the ten original
participants who agreed to meet with me for the follow up interview. During the
interview, all of participants were overwhelmed as they read or listened to the letter
that reflected their story. They were in tears and spoke of how very thankful they were
that someone understood what they were going through and recognised their efforts to
provide care for their loved ones with mental illness. Each of them agreed with the
summary and some of them repeated again what they had told me. I was happy that I could help them release the tension arising from care giving but sad to realise that they had been in a state of ongoing crisis for such very long periods of time. I felt sad and powerless to realise that their needs were so underestimated by mental health professionals who should have listened to them more carefully. When I told them that I had to terminate the interviews to go back to Australia to continue my study, they were sad because they did not want to end our interactions. I then had to remind them of the timeframe for my data collection and my role as a researcher. While they appeared to understand most of them sought to prolong the final session as long as possible finding it was very difficult to take their leave.

After the fifth month of my data collection, I myself experienced mixed feelings. On the one hand, I was glad the data had reached saturation within the set time period. I was proud of the participants who were informal experts in sharing their experiences of care giving for loved ones with mental illness. However, their experience of ongoing crises raised many concerns for me. I now realised how difficult their lives were, so much more difficult for them than what I had ever imagined. I was worried as I thought about how they live their lives in ongoing crisis with limited resources to help them deal with the difficulties and challenges they face every day. My most pressing concern about what I had heard was that most participants expressed a wish to die to escape from the care giving role.

I came back to Australia hoping that I could present the participants’ experiences clearly enough for others so that they would understand these experiences the way that I now do. However, the thematic analysis process was challenging. The English transcripts translated by a Thai professional translator were subjected to analysis. I selected the descriptions to support themes and sub-themes presenting the lived experience of care givers. The translated descriptions however were not accurate enough to enable me to portray the meaning of the lived experience of care givers. Thus, I took a considerable amount of time to retranslate all the English transcripts. I continuously consulted the Faculty of Health’s learning advisor, at the University of
Newcastle to check the correctness of the transcripts’ English expression. The tedious process of retranslating was done carefully as I attempted to remain true to the Thai culture and to the participants’ language. My focus was to ensure the experience of care givers was clearly presented. To my surprise and pleasure I found that when I presented the findings of the current study at the 1st European Congress for Social Society in Geneva, Switzerland, my audience seemed to understand my portrayal of the care giving experience.

These people had provided me with an insight into important issues that helped me understand a little about their experience of ongoing crisis during their care for their loved ones with mental illness. It had become very clear to me that they needed so much more than education. This was in stark contrast to my early ideas about what would be the best intervention for them. I now realise that they need constant support to assist them to deal with ongoing crises. At present, they live their lives with very little support from the people surrounding them, including family members, neighbours, health care providers, and the authorised persons involved directly in the crisis situations they face. This has helped me realise that there is a strong need to develop effective low cost interventions that the Thai government could provide to help such care givers. I have also thought deeply about how to build the knowledge of and promote understanding of the experience of care givers in ongoing crises during their care for relatives with mental illness by health professionals. I have used these thoughts as the basis to developing the implications of the study as presented in the previous section. The limitations of the study are addressed in the section that follows.

**LIMITATIONS OF THE STUDY**

This study has presented previously undescribed components of the lived experience of Thai family care givers caring for loved ones with mental illness, in particular identifying the nature of this experience as one of unrelenting crisis. It is important, however, to acknowledge the limitations of this study. A potential limitation in a qualitative study of this nature is the challenge of ensuring trustworthiness including...
dependability, credibility, confirmability, and transferability (Holloway & Wheeler, 2010; Lincoln & Guba, 1985).

For dependability, Holloway and Wheeler (2010) suggest that the findings of qualitative research depend on the researchers’ interpretation of the data as filtered through their personal and professional background, prior knowledge and experiences. Thus, it is possible that a different researcher using the same approach to investigate the experience of care givers in crisis may present different findings. Likewise, this experience could be explored and viewed in a different way with the use of an alternative qualitative research approach such as grounded theory or ethnography.

In this study, the researcher sought to address the challenges of ensuring dependability in the first instance through the employment of a qualitative methodology, i.e. hermeneutic phenomenology as outlined by van Manen (1990). This approach is underpinned by tenets which sit well with the aim of this study and provide an outline with a series of clearly defined steps designed to assist the researcher.

To further increase the dependability of this study, in-depth interviewing was chosen to explore the lived experience of participants so that they could share their experience in detail. During data collection, the researcher was able to draw on her professional training and experience as a Thai psychiatric nurse and nursing lecturer in mental health to engage more fully with the participants. The analysis of the data was undertaken with great care and in consultation with the researcher’s supervisors who read the transcriptions independently to cross-check the interpretation. As previously described, great care was taken to reflect the participants’ experiences through the use of verbatim quotes. Every effort has been taken to ensure that as far as possible the findings of the study have captured the meaning of the experience in respect to both the individual participants and the whole group’s experience of care giving.

Findings that fail to demonstrate credibility can be a further limitation in a study such as this. The extent to which the findings from a qualitative research study are credible
can be enhanced or diminished by the degree to which the participants are able to recognize their own experience in the findings. Credibility is enhanced when a researcher has presented the findings using the participants’ own words and the participants are able to recognize the truth of the meaning of the experience as reported by the researcher. In addition, the perceptions of the participants are attuned to the findings of the study presented by the researcher (Holloway & Wheeler, 2010).

To strengthen credibility in this study, a member checking technique was used to ensure the meaning of the lived experience was well captured and reflected the participants’ voices. Ten of the original participants agreed to attend for follow-up interviews. They were asked to validate the summary of the preliminary thematic analysis arising from the initial interview. As reported earlier, the themes were presented in a letter format using the participants’ own words. After reading or listening to the summary, each of the participants confirmed the veracity of the feedback, describing how well this had captured their experience. The extent to which participants were overwhelmed was moving and many of them cried as they reflected upon what they had faced in providing care for their loved one with mental illness. It is suggested that the response from participants indicates that the findings are strongly credible.

Qualitative studies also need to demonstrate an awareness of the need for confirmability, i.e. a focus on putting aside biases and attempting to appraise the results from a neutral perspective. To achieve this task, the researcher is required to demonstrate their thoughts using an audit trail. In the current study, the researcher maintained a reflective journal, sought to set aside her own thoughts, perceptions, and previous knowledge about the experience of care givers caring for loved ones with mental illness during times of crisis. During the research project, the researcher kept a detailed and extensive reflective journal recording her experiences as she conducted the interviews and the research project (See page 86). Contrary to initial concerns, the participants fluently and openly spoke of their experiences with the researcher during each interview. They talked at length and freely responded to the questions. The
interview transcripts provided an abundantly rich tapestry revealing the starkness of the experience of care givers in a state of unrelenting crisis.

During the data analysis process, the researcher sought to set aside her own background and previous knowledge attempting at all times to remain true to the participants’ words. Although the researcher is Thai and has been working in the field of mental health since 1991, her limited idea of what the participants might tell her proved to be far removed from what she heard from these care givers of their experience of unrelenting crisis.

In contrast to the participants, the researcher, while Thai born, is of a different cultural background to the participants. She has lived in an urban area of Bangkok for about 15 years but originally came from the north-eastern part of Thailand (about 700 kilometres north-east of the study site which is located in the central region of Thailand). As a practising Christian, her spiritual belief system differs greatly from that of her Buddhist participants. She has had no personal experience of needing to care for a loved one with a mental illness in crisis. The vast differences between the researcher’s background and life experiences and those of her participants meant that the experiences related were new and at times shocking. This led to an added passion and enthusiasm to ensure that the voices of these participants were reflected clearly throughout the project.

Another potential limitation of this study is the degree to which these findings may be transferable to other settings. Transferability is seen to be difficult to attain in a qualitative research project because of the often relatively narrow focus on specific situations and cases (Holloway & Wheeler, 2010). In keeping with other qualitative studies, this study focused on a specific research question designed to examine the experience of a specific group of people in a specific location. To this end sampling was purposive with participant numbers limited to 12 participants who were care givers of relatives with mental illness living in a rural-urban area of Nonthaburi Province in Thailand.
Although caution is required when considering applying the findings of this study to other populations in Thailand and other countries, it could be suggested that the findings from this study may indeed be relevant in other settings. The findings may be transferable to other care givers caring for relatives with mental illness in Thailand living in the same area, and having a similar cultural background and psychosocial circumstances to participants in the current study. It is likewise reasonable to argue that care givers in other rural-urban and remote areas of Thailand, and indeed similar settings within the Asia-Pacific region, where mental health services are extremely limited and stigma related to mental illness is high would likewise describe similar experiences.

In addition to the previously discussed limitations, the final potential limitation was that of capturing and translating into English the finer nuances of the Thai language. This study was conducted in Thailand and all participants spoke Thai as their ‘mother tongue’. None of the participants were able to speak English at all and they shared their experiences with the researcher in Thai. The interviews were recorded and transcribed directly in Thai before being translated into English.

The English transcripts as translated by the Thai translator were checked for accuracy by the researcher. They were then subjected to a further check by the Faculty of Health’s learning advisor at The University of Newcastle. This helped to improve the accuracy of the English transcripts. During the process of translation, the researcher sought to maintain the meaning of the experience using the participants’ direct words as well as attempting to incorporate the Thai cultural and contextual nuances into the English transcripts. Every attempt was made to ensure the experiences of care givers were presented without missing the finer nuances of the Thai language and to ensure that the English expression would enable readers to understand the experience of Thai care givers. It remains, however, a potential limitation that the finer nuances of the Thai language may not be totally visible to the non-Thai speaking reader.
CONCLUDING STATEMENT

The value of hermeneutic phenomenological research as an effective tool for deepening understanding and awareness of a specific experience has been demonstrated by this study which aimed to explore the lived experience of Thai family care givers in crises during their care for relatives with mental illness. The findings of this study provide a deeper understanding of the experience of participants. The difficulties and challenges that participants face led them to experience life as a series of ongoing crises. The major themes identified described this life as one where care givers felt that their lives were epitomised by being ‘Out of control’, feeling ‘So alone’, lost in a maze of ‘Confusion and chaos’, and seeing ‘No way out’ for themselves or their ill relatives. Viewing the lived experience of participants through these themes has enabled a greater recognition of the impact upon care givers of this state of ongoing crisis. These people experienced physical and mental illness including thoughts of self-destruction. The participants experienced their lives as unbearable. They wanted to die to escape from the care giving role but they felt that they had no option but to care for their mentally ill loved ones. For these participants, the centrality of their religious beliefs, focusing around ‘Karma’, reinforced the belief that they had to accept their ‘fate in life’ and the role of care giver and provide the care needed.

Many Thai people have a strong belief in Buddhism. They believe that doing good deeds will decrease ‘Karma’. Participants provided care for relatives with mental illness as a part of merit making with the hope that their life would improve. However, the continual difficulties and challenges that they faced over a long period of time left them to live their life and care for their loved ones with mental illness within a sense of hopelessness. One participant said, “I thought to myself, if it’s easy to die, let me die first”. (Samorn, p. 20)

The findings of this current study provided a deeper understanding of the lived experience of the participants. The findings can be used as a guideline for health workers, health/mental health professionals, and authorised people involved in helping care givers to cope effectively with difficulties and challenges during their care
for their ill loved ones. Moreover, health care providers who provide services to care
givers of relatives with mental illness need to be aware of and to not underestimate
caregivers’ needs in times of crisis.
References


WHO. (2007). Mental health at the primary care level. India: Regional Office for South-East Asia.


Conference presentation abstracts


OC202: Caring in crisis, the experience of family caregivers of people with mental illness in Thailand: A literature review

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Abstract

Relatives caring for a mentally ill family member face an often times arduous task in which periodic crises can add to what is already a heavy burden. While the experience of caregivers in Western countries has been increasingly described in the research literature, a limited number of studies have been undertaken in Thailand. A comprehensive online search on CINAHL, COCHRANE LIBRARY, MEDLINE, the Joanna Briggs Institute and Thailand’s Mental Health Department and Thailand universities’ websites was undertaken as well as a manual search using “crisis, caregivers, carers, caring, care giving, family, mental illness, and mental disorder”. All primary articles published from 2000-2010 were identified. Three main areas associated with crises experienced by caregivers of mentally ill relatives were identified: crises arising from behaviours associated with the mental illness; crises precipitated by the caregiver’s lack of knowledge and/or skills in coping with the mentally ill loved one; and those arising from problems accessing adequate support during times of relapse. Family caregivers identified precipitating factors for the crises associated with mental illness, including medication non-compliance, running away from the home, abuse of alcohol and drugs, suicidal ideation and behaviors, and violence. Difficulties dealing with psychotic symptoms with an inability to respond to such symptoms in a timely fashion may result in crises directly related to untreated psychosis. Importantly, family caregivers are also personally affected, at times facing their own crises precipitated by the difficulties faced by their loved ones. Contributing factors include the stress and distress of caring for a mentally ill relative; financial difficulties; social stigma; and legal concerns associated with the care giving role. Care givers also suffer from the distressing behaviours of their loved ones, such as social withdrawal, violence, and verbal aggression. This paper reviews the existing literature related to family care giving for relatives with mental illness, with particular emphasis on the situation in Thailand. The review identifies a gap in research regarding crises associated with the care giving role, and suggests directions for future research.

Keywords: Crisis, caregivers, caring, mental illness

**The lived experience of Thai family care-givers in a crisis during their care for relatives with mental illness**

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**Introduction:** The aim of this study was to explore family care-givers’ lived experience of the crises that periodically occur in the course of providing care and support for mentally ill relatives. The study was undertaken in a rural community in Thailand and many of the participants were involved in subsistence farming while also providing high levels of care and support for relatives with mental illness.

**Methods:** The study was undertaken using a hermeneutic phenomenological approach. In-depth audio taped interviews, using semi-structured open-ended questions, were conducted with 12 consenting participants. Follow up interviews were undertaken with 10 of the participants originally recruited to the study. Other data collection techniques included the use of note-taking during the interview and maintaining a reflective field journal. Data were subjected to thematic analysis.

**Results:** The results suggested that family care-givers in rural Thailand face a number of difficulties and challenges in providing care for their loved ones with mental illness: these include practical daily struggles, confronting relatives’ worrying and disruptive behaviours, unusual social and financial difficulties, and their own troublesome personal lives. The lived experience of care-giving for the participants was largely one of ongoing predicament, or crisis, which involved four main themes: ‘loss of control’, ‘no more heroes’, ‘confusion and chaos’, and ‘living in the dark’.

**Conclusions:** Consideration of the lived experience of the participants has highlighted the need for ongoing help and support for family care-givers in rural Thailand. It is important that health care providers can recognize and assess the significant burdens associated with family care-giving for a relative with mental illness. When care-givers face crisis situations it is important that practical help is provided in a timely fashion. Greater emphasis should be placed on improving the mental health literacy of village health care workers in Thailand, through training in basic mental knowledge and skills.
Appendices
Appendix One - Interview schedule

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Interview schedule for the Research project:

The experience of Thai family care givers caring for relatives with mental illness

Mrs Sudkhanoung Plangpongpan

Document Version 1; dated 10th August 2010

Examples of the conversations/questions are as follows:

A: Starting initial interview

Thank you very much for agreeing to participate in this study.
I would like to introduce myself. I am Sudkhanoung Plangpongpan, the researcher from the University of Newcastle, Australia.

I am doing the research about the experience of family care givers of people with mental illness in Thailand.

This study aims at exploring family care givers’ experience of the difficulties and challenges that occur in the course of providing care and support for your mentally ill relative.

After I interview you today, a further interview may be needed. This depends on whether when I have listened to our interview; I need to ask you to explain some of what we have talked about in more detail. If we need another interview, I will call you and make an appointment.

If you agree to a subsequent interview, I will summarise the key themes from this meeting and give it back to you to verify two - three days before the next interview.

It is anticipated that I will not interview you more than three times and each interview will be last for up to one hour.

This interview will be recorded. Following each interview the digital recording will be transcribed and any personal identifying information will be removed. Your name and your relative name will be replaced with false names instead (this will help to protect you and your relative’s privacy).

Please tell me if you feel uncomfortable with anything including questions and the interview process. The recording can be stopped at any time by your request.

Would you like to ask me any questions regarding the study, before we start?

May I start to talk with you about your experience now?
B: Initial interview questions

Could you please tell me about yourself: age, occupation, family and educational background?

How long have you been caring for your loved one?

Could you please tell me about your relative with mental illness?

What are his/her symptoms?

Could you please tell me about how you take care of him/her? What are the things you do to help him/her?

Can you tell me about a time that was difficult and challenging for you while providing care for your mentally ill relative at home?

Can you tell me about what this was like for you?

What were you thinking?

What were you feeling?

C: Subsequent interview questions

Thank you very much for making time to meet with me again.

Do the key themes of our previous interview reflect your experience?

Is there other information you would like to tell me about?

D: Closing interview

Thank you very much for participating in this study.

If you need the summary of this study, you can contact me via the address provided in the information statement.
Appendix Two – Thank you letter

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Dear ……… (Participant’s name) ……..

RE: RESEARCH – The experience of Thai family care givers caring for relatives with mental illness

I would like to thank you so much for sharing your experience of caring for your love one with mental illness. You made the data collection a great experience with a lot of valuable information to bring to the development of strategies that can be used by care givers to more effectively manage the difficulties and challenges associated with providing care and support for loved ones with mental illness. I truly appreciate the opportunity that you gave to me.

Once the thesis examination process has been completed (It may take around two - three years from now), participants who have requested a copy of a brief summary report on the project will be able to contact me on the following number and address: Boromarajonani College of Nursing, Chang Wat Nonthaburi Muang, Nonthaburi 11000, Telephone number: 0 2525 3136.

Again, thank you very much for the time you spent with me.

Sincerely,

Sudkhanoung Plangpongpan
Appendix Three - Reflective journal

Number of interview: 04011

Date of interview: November 9, 2010

Time of interview: 10-10.59 AM.

Place of interview: Health Centre

1. How do I think I did with the explanation of the research purpose?
   
   I explained the study very clearly following a prepared structure. However, I could not remember all the details and lacked confidence. Therefore, I looked at the document sometimes.

2. How did the interview context enable or constrain the interview process?
   
   I did the interview in a quiet, private and safe meeting room on the second floor of the Health Centre. There were two nurses and two workers working on the first floor. The weather was good. The participant concentrated on the interview process very well.

3. How did I do in building rapport with the participant?
   
   First, I greeted her and asked her about her food selling (barbeque pork and sticky rice). Secondly, I offered her refreshments. Thirdly, I introduced myself following the interview guide. Finally, I offered her an opportunity to ask me any questions she had about the study and myself. She had no questions and was willing to proceed with the interview.

4. What kind of questions did I ask in the interview?
   
   Most questions were open-ended questions focusing on difficulties and challenges experienced while caring for her son with schizophrenia. I used
prompting questions including elaboration probes: “Can you tell me more about that?”, and continuing probes: a raised eye brow, a nodding head. I also summarised her experiences and reflected on her words.

5. What kinds of responses did I get?

The interviewee responded to questions very quickly. She wept during most of the interview. She smiled when she told me about good behaviour on the part of her son.

6. How did my questions influence the participants’ responses?

The interviewee responded quickly to the questions focusing on her experiences. She explained clearly and did most of the talking.

7. Did I put possible responses into the questions?

I did pre-empt her responses to the questions.

8. Did I ask closed-ended questions or open-ended questions?

I mostly used open-ended questions.

9. Did I use more than one question at a time?

I mostly used only one or two short open-ended questions at a time.

10. How did I handle silence within the interview?

There was a short silence during the interview. I then reviewed the main points emerging during the interview to encourage her to talk more.

11. Was there overlapping talk or interruptions in the interview?

There were some interruptions. They were used to guide the interviewee to focus on the experience of interest.
12. Did I use continuers such as um, okay, mm-hmm?

I used a lot of continuers including um, mm-hmm, nodding my head, facial expressions for example smiling.

13. Do I treat interviews as conversation? If so, what was my input into the conversation?

I tried to treat the interview as a conversation. I listened to her and asked her to explain more about her experiences.

14. Did I evaluate the participants’ responses to my questions within the interview? If so, how did the participant respond to this evaluation?

I evaluated the interviewee responses’ to the interview by looking at her face, and listening to her answers. She responded directly to the questions very well.

15. Were my interview questions focused on the purpose of the research and my research questions?

The interview questions focused on the purpose of the research and the research question.

16. What would I do differently if I were able to do the same interview again?

I would try to conduct the next interview as a conversation as much as I could. I would like to explore this participant’s experiences much more in-depth in a future interview.

17. What suggestions for improvement do I have for my own interview techniques?

To improve my interview techniques, I will listen to this interview recording, read books, and consult my supervisors.
18. Other issues: She was an adult (56 years old), good hygiene, and wore appropriate clothes. She came to the health centre on her own. At the beginning of the interview, I was nervous and felt uncomfortable. I started the interview following the interview script. She cooperated with me very well. She expressed her experiences very clearly and mostly talked. I listened to her and asked her to clarify some unclear issues. Even though I sometimes felt as if her experience was similar to others, I let her tell me about it freely. Her experience of caring for her son with schizophrenia was very interesting and also unique. She was very emotional. I was emotional as well. I tried hard to concentrate on her story rather than my feelings. After the interview, she said that she felt as if she was in a therapy session. She was glad that there was someone who liked to listen to her story. Her tension in providing care for her son was relieved. She was willing to be interviewed again. I felt it was a great interview. It was not as hard as I had thought it would be. Sometimes I did not know what to ask and simply repeated her words and nodded my head to encourage her to speak continuously. I felt a little upset myself because of this. However, when I listened to the recording later, I found that repeating and nodding worked well. She had an opportunity to tell her experience freely. As a result, I gained richer and deeper information.
Appendix Four - Information statement

Professor Michael Hazelton
Dr Rachel Rossiter
Mrs Sudkhanoung Plangpongpan
School of Nursing and Midwifery
The University of Newcastle
University Drive Callaghan NSW 2308
AUSTRALIA
Tel: +61 2 49216770; Fax: +61 2 49216981
Email: Michael.Hazelton@newcastle.edu.au
Rachel.Rossiter@newcastle.edu.au
Sudkhanoung.Plangpongpan@studentmail.newcastle.edu.au

Care givers’ Information Statement for the Research Project:

The experience of Thai family care givers caring for relatives with mental illness

Mrs Sudkhanoung Plangpongpan

Document Version 2; dated 14th September 2010

We have asked the psychiatric nurse to distribute this invitation to people who care for a family member with a mental illness. As an eligible carer, we would like to invite you to participate in our research. This project is being conducted by Mrs Sudkhanoung Plangpongpan from the School of Nursing and Midwifery at the University of Newcastle. The researcher is conducting the research as part of her PhD in Nursing
under the supervision of Professor Michael Hazelton and Dr Rachel Rossiter from the School of Nursing and Midwifery.

Why is the research being done?

The purpose of this research project is to explore care givers’ experiences of the difficulties and challenges occurring as a result of caring for a loved one with a mental illness. This research is being done so that these difficulties and challenges experienced by family care givers of mentally ill relatives in the Thai community will be better understood. It is expected that the outcomes of the study will contribute to the development of strategies that can be used by care givers to more effectively manage the difficulties and challenges associated with providing care and support for loved ones with mental illness.

Who can participate in the research?

We are seeking care givers of people with mental illness who have experienced difficulties and challenges and are willing to tell these experiences to the researcher undertaking this project. If you are aged 18 or over, male or female, have lived with at least one mentally ill relative for a minimum of six months or more in the last year, and speak Thai, you are eligible to be involved in this study. Approval to conduct the study has been given by the University of Newcastle Human Ethics Committee and Nonthaburi Provincial Public Health Office.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether you decide to participate or not, you will not be disadvantaged in any way. Your relationship with staff and provision of services for your relative with a mental illness will not be affected. If you do decide to participate, you may withdraw from the project at any time without giving a reason. You may also choose to withdraw your interview data and any data identifying you.
What would you be asked to do?

If you agree to participate in the study you will be invited to attend an interview with the researcher which will be recorded. You will participate in a minimum of one interview lasting 45-60 minutes, at a mutually agreed and safe location. The researcher will ask you to tell her about your experience of the difficulties and challenges occurring while caring for your loved one with a mental illness. The interview will be recorded and transcribed. If another interview is needed for you to further explore the themes raised in your first interview, the researcher will make an appointment with you for a further interview. The subsequent interview will be held around one month after the first one. If you agree to participate in a subsequent interview, the researcher will summarise the key themes from the previous interview and give it back to you to verify two - three days before the next interview. It is anticipated that the researcher will not interview you more than three times. The researcher will turn off the digital recorder at any time during the interview at your request.

What are the risks and benefits of participating?

We cannot promise you any benefit from participating in this research. However, you will have a chance to tell the researcher about the difficulties and challenges you have experienced while caring for your loved one with a mental illness. If health policymakers and health professionals are better able to understand the experiences of family care givers, they can then develop effective ways of supporting family care givers undertaking this vitally important role. During interviews, you may experience some distress. If this does happen, the researcher will check to see if you would like to stop the interview. The researcher will also provide information for you to access support services such as a counsellor. If you travel to an agreed location for the interview such as the community hospital or the health centre, your travel costs will be reimbursed (up to 450 Baht per trip).
How will your privacy be protected?

You will not be personally identified in any of the documents used in or published from the study. As this research will use in-depth interviews, data will be transcribed and translated from Thai to English by a professional transcription service. The transcription typists employed for this purpose will sign a confidentiality agreement. They will be informed that they cannot save, keep or distribute any data from the study. False names and not yours and your relative’s real names will be used in the transcription of interviews. During the period of study, all information will be kept in a locked filing cabinet and will only be accessed by the researcher and supervisors. All data will be securely stored for a period of five years in a locked cabinet located in the School of Nursing and Midwifery, Faculty of Health, Callahan campus, the University of Newcastle.

How will the information collected be used?

The findings from this study will be presented in the form of a research higher degree thesis, and may subsequently be reported in conference presentations and/or journal publications. Once the thesis examination process has been completed, you will be able to request a copy of a brief summary report on the project. Should you wish to do so you can contact the researcher on the number and address included on this information statement.

What do you need to do to participate?

Please read this Information Statement and ensure you understand its contents before you consent to participate. If there is anything you do not understand, or if you have any questions about the project, please contact the psychiatric nurse. If you would like to participate, please complete the Consent Form and return it in to the labelled locked box at either the community hospital or the community health centre. Once you have placed your consent form in the box, the researcher will then contact you to arrange a time to meet with you for the interview. If you have consented to be involved you are welcome to ring the researcher directly (her details are below).
Further information

If you would like further information please contact:

Dr Rachel Rossiter  
School of Nursing and Midwifery  
The University of Newcastle, University Drive, Callaghan NSW 2308 AUSTRALIA  
Tel: +61 2 4921 6770 Fax: +61 2 49216981  
Email: Rachel.Rossiter@newcastle.edu.au

Mrs Sudkhanoung Plangpongpan  
School of Nursing and Midwifery  
The University of Newcastle, University Drive, Callaghan NSW 2308 AUSTRALIA  
Tel: +61 2 49216770 Fax: +61 2 49216981  
Email: Sudkhanoung.Plangpongpan@studentmail.newcastle.edu.au

Thank you for considering this invitation.

Professor Michael Hazelton  
Mrs Sudkhanoung Plangpongpan  
Project supervisor  
Research candidate

Complaints about this research

This project has been approved by the University’s Human Research Ethics Committee, Approval No. H-2010-1218. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The
University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email Human-Ethics@newcastle.edu.au.

Or contact the local contact person:

The Chief of International Affairs & Assistant Deputy Director in Research and Academic Service of Boromarajonani College of Nursing, Chang Wat Nonthaburi,

Telephone: 0 25253136.
Appendix Five - Consent form

Care givers’ Consent Form for the Research Project:

The experience of Thai family care givers caring for relatives with mental illness

Mrs Sudkhanoung Plangpongpan

Document Version 2; dated 14th September 2010

I agree to participate in the above research project and give my consent freely.
I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.
I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I agree to

☐ participate in a minimum of 1 one-on-one in-depth interview for 45-60 minutes;

☐ give permission to a nominee to read and write all documents for me;

☐ the data being transcribed and translated by a transcription service;

☐ give permission for the findings from this project to be published in a journal, a thesis, report, at an appropriate presentation and conference; and

☐ I would like to receive a summary of the results of the study.

I understand that my personal information will remain confidential to the researchers.

I have had the opportunity to have questions answered to my satisfaction.

Signature/fingerprint: __________________________ Date: _________________

Print Name: __________________________________________

Contact details:

Address___________________________________________________

Telephone number __________________________________________
Appendix Six – Ethics approval

HUMAN RESEARCH

ETHICS COMMITTEE

Notification of Expedited Approval

To Chief Investigator or Project Supervisor:  Professor Michael Hazelton

Cc Co-investigators / Research Students:  Ms Rachel Rossiter
                                           Mrs Sudkhanoung Plangpongpan

Re Protocol:  The lived experience of Thai family care givers in a crisis during their care for relatives with mental illness

Date:  16-Sep-2010

Reference No:  H-2010-1218

Date of Initial Approval:  16-Sep-2010

Thank you for your Response to Conditional Approval submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under Expedited review by the Chair/Deputy Chair.

I am pleased to advise that the decision on your submission is Approved effective 16-Sep-2010.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion
that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. *If the approval of an External HREC has been “noted” the approval period is as determined by that HREC.*

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal Certificate of Approval will be available upon request. Your approval number is H-2010-1218.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants. You may then proceed with the research.

### Conditions of Approval

This approval has been granted subject to you complying with the requirements for *Monitoring of Progress, Reporting of Adverse Events, and Variations to the Approved Protocol* as detailed below.

**PLEASE NOTE:**

In the case where the HREC has “noted” the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University’s HREC.

*Monitoring of Progress*

Other than above, the University is obliged to monitor the progress of research projects
involving human participants to ensure that they are conducted according to the protocol as approved by the HREC. A progress report is required on an annual basis. Continuation of your HREC approval for this project is conditional upon receipt, and satisfactory assessment, of annual progress reports. You will be advised when a report is due.

Reporting of Adverse Events

It is the responsibility of the person first named on this Approval Advice to report adverse events.

Adverse events, however minor, must be recorded by the investigator as observed by the investigator or as volunteered by a participant in the research. Full details are to be documented, whether or not the investigator, or his/her deputies, consider the event to be related to the research substance or procedure.

Serious or unforeseen adverse events that occur during the research or within six (6) months of completion of the research, must be reported by the person first named on the Approval Advice to the (HREC) by way of the Adverse Event Report form within 72 hours of the occurrence of the event or the investigator receiving advice of the event.

Serious adverse events are defined as:

Causing death, life threatening or serious disability.

Causing or prolonging hospitalisation.

Overdoses, cancers, congenital abnormalities, tissue damage, whether or not they are judged to be caused by the investigational agent or procedure.

Causing psycho-social and/or financial harm. This covers everything from perceived invasion of privacy, breach of confidentiality, or the diminution of social reputation, to the creation of psychological fears and trauma.

Any other event which might affect the continued ethical acceptability of the project.

Reports of adverse events must include:
Participant's study identification number;

date of birth;

date of entry into the study;

treatment arm (if applicable);

date of event;

details of event;

the investigator's opinion as to whether the event is related to the research procedures; and

action taken in response to the event.

Adverse events which do not fall within the definition of serious or unexpected, including those reported from other sites involved in the research, are to be reported in detail at the time of the annual progress report to the HREC.

Variations to approved protocol

If you wish to change, or deviate from, the approved protocol, you will need to submit an Application for Variation to Approved Human Research. Variations may include, but are not limited to, changes or additions to investigators, study design, study population, number of participants, methods of recruitment, or participant information/consent documentation. Variations must be approved by the (HREC) before they are implemented except when Registering an approval of a variation from an external HREC which has been designated the lead HREC, in which case you may proceed as soon as you receive an acknowledgement of your Registration.

Linkage of ethics approval to a new Grant

HREC approvals cannot be assigned to a new grant or award (ie those that were not identified on the application for ethics approval) without confirmation of the approval from the Human Research Ethics Officer on behalf of the HREC.
Best wishes for a successful project.

Professor Alison Ferguson
Chair, Human Research Ethics Committee

For communications and enquiries:

Human Research Ethics Administration
Research Services
Research Office
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 18999
F +61 2 492 17164
Human-Ethics@newcastle.edu.au

Linked University of Newcastle administered funding:

<table>
<thead>
<tr>
<th>Funding body</th>
<th>Funding project title</th>
<th>First named investigator</th>
<th>Grant Ref</th>
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Appendix Seven – Permission of data collection

Tuesday 14th September 2010

Chief
Nonthaburi Provincial Public Health Office
Moo 8 Muang,
Nonthaburi,
Thailand, 11000

Dear Chief,

RE: RESEARCH – The lived experience of Thai family caregivers in a crisis during their care for relatives with mental illness

Mrs Sudhakorn Plangoopan is a nurse educator at Boromarajonani College of Nursing, Chang Wat Nonthaburi. Currently, she is undertaking PhD studies under our supervision at the University of Newcastle, Australia. Her proposed research will explore the experience of Thai family caregivers at times of crisis occurring during their care of relatives with a mental illness. It is proposed that the participants in the study will be recruited from the caregivers of patients attending the mental health and psychiatric units of [Name of Hospital] Hospital and the health centres.

District and from those visited at home during home health care visits provided by the mental health teams. We are seeking your agreement to recruit participants to the study at the [Name of Hospital] Hospital and the health centres.

The intention is that nursing staff in the mental health and psychiatric unit will approach the caregivers of relatives with a mental illness attending the unit and caregivers encountered when making home visits to invite them to consider being participants in the study. Participants will be males or females, aged 18 or over, who have lived with at least one mentally ill relative for at least 6 months or more in the last year, can speak Thai language, and are willing to talk about their experiences of crises.

Potential participants will receive information about the purpose of the study and the nature of their involvement, and have an opportunity to ask questions or seek further information prior to deciding whether they wish to be involved in the study. Those who agree to be involved will be asked to sign a consent form.

Consenting participants will be invited to participate in a minimum of one in-depth interview. The interviews will be undertaken at a mutually agreed and safe location to ensure privacy and confidentiality. Participants will be able to withdraw from the study at any time without having to give a reason and the study will be conducted so that the data generated will not be able to be traced back to individual participants.

NEWCASTLE THE UNIVERSITY OF NEWCASTLE

The University of Newcastle
Newcastle, NSW 2308 Australia
Ph: +61 2 4920 5000
Fax: +61 2 4920 3992
www.newcastle.edu.au
It is expected that the findings of the study will contribute to knowledge about the lived experience of Thai family caregivers at times of crisis during their care for relatives with a mental illness in Thailand.

If you approve of this request we would ask that you sign in the space provided below and return this letter to the address provided below:

Professor Michael Hazleton  
Dr RachelRossiter  
School of Nursing and Midwifery  
The University of Newcastle  
University Drive Callaghan NSW 2308  
AUSTRALIA  
Tel: +61 2 4921 6770; Fax: +61 2 4921 6981  
Email: Michael.Hazleton@newcastle.edu.au

Should you wish to contact Mrs Sudkhanoun Plangpongpan, her contact details in Thailand are provided below:  
Mrs Sudkhanoun Plangpongpan  
Boromarajonani College of Nursing,  
Chang Wat Nonthaburi  
Muang, Nonthaburi,  
Thailand, 11000  
Tel: 0 2525 3136  
Mobile: 08 7327 0787  
Email: Sudkhanoun.Plangpongpan@studentmail.newcastle.edu.au

Yours sincerely,

---

Prof Mike Hazleton  
Professor of Mental Health Nursing  
School of Nursing and Midwifery  
University of Newcastle  
Phone: +61 2 4921 6770  
Fax: +61 2 4921 6981  
Email: Michael.Hazleton@newcastle.edu.au

Dr Rachel Rossiter  
Senior Lecturer  
School of Nursing and Midwifery  
University of Newcastle  
Phone: +61 2 4921 7708  
Fax: +61 2 4921 6301  
Email: Rachel.Rossiter@newcastle.edu.au
Approval

I give permission for Ms Sutikhamong Plangpongtran, a PhD student under the supervision of Professor Michael Hazelton and Dr Rachel Rossiter, University of Newcastle, Australia to conduct research for the project: The lived experience of Thai family caregivers in a crisis during their care for relatives with mental illness at the [blocked out] Hospital and the health centres.

Name and Signature: Chief of Nonthaburi Provincial Public Health Office:

Date: [blocked out]
Day/Month/Year

Researcher candidate Signature:

Supervisors' Signatures:

[Names of the hospital and health centres have been blocked out.]
Family care givers research study

Do you care for a relative with mental illness?

Do you think you face “difficulties and challenges” whilst caring for your relative at home?

**Difficulties and challenges may be caused by many different situations such as when:**

**Your relative with mental illness:** stops their medication against medical advice or abuses and alcohol or drugs, runs away from home, is experiencing suicidal feelings, attempts to kill or hurt themselves or starts to damage other people’s property, or is seeing or hearing things that are not real.

**You:** face the high cost of treatment, experience difficulties in accessing help for your loved one including hospital care, or because of the stresses and strains of dealing with the legal and criminal justice system, or when your relatives are discharged from hospital before they are well enough and because there is insufficient community support available for them and your family, or experience difficulties in your role as care giver because of community beliefs about mental illness.

If you would like to receive more information please ask to speak to the psychiatric nurse in the mental health and psychiatric unit.

This project has been approved by the University’s Human Research Ethics Committee, Approval No. H-2010-1218
Appendix Nine – English letter of preliminary thematic identification

Dear Aunty…,

Since I saw you at our first meeting, I have listened to our talk and read the transcript over and over. When I think about your story, I can see that things have been so difficult for you while caring for your husband with mental illness.

When your husband first became sick, it was very hard for you. He had been the breadwinner, and since then he has not been able to do anything to support his family. It was so difficult for you to accept the situation as you were used to him being the main provider since your first daughter was born. Currently, you have to do everything including taking care of him and earning money to support the whole family. I cannot imagine how hard it is trying to do everything on your own.

Some of what I can see is that perhaps you lived with fear. I imagine that you were frightened by his suicide attempts. He wanted to die because he felt sorry that he had not been able to do anything. Even though he could not walk, he crawled out of the house to try to kill himself as well as hurt his own body. He did not take any medicines prescribed by the doctor. He only wanted to die. It must be very difficult for you to live with feelings of great fear.

After I read what you told me about the things that happened to you, it was like you had to face difficulties almost continually, or we can say, every single day.

I think it must have been so hard for you to be patient with many things. You had to be patient with disgusting things like cleaning his excretions. Moreover, he always smeared stools on the floor. Even though you felt like you could not tolerate it anymore, you still cleaned it up. You had to be patient when he hurt you. He slapped and punched your face. He pulled your hair and you felt so hurt. You had to be patient when he reviled you with very rude words. This happened again and again. You also had to be patient in dealing with his unacceptable behaviours. He walked at night time
to collect things including garbage and brought them back home. You had to be patient living in a house which was like a rubbish heap. Being patient with his aggressive behaviours was another difficult issue for you. He destroyed the family’s belongings and the house. He was rude to neighbours and fellow villagers. He threatened everybody including you who had been caring for him. You could not say anything. You felt that you had to let him do whatever he wanted. Then, when he calmed down, you gently talked to him and asked him to behave but he never complied. In the meantime, you were diagnosed with cancer which was very painful for you. You were so tired and almost died twice. Your husband didn’t seem to have ever realised the gravity of the situation. He went to the hospital while you were an inpatient and behaved so badly and out of control towards you and the health professionals. You had to leave the hospital and return home to calm him down. Then, you went back to the hospital to get further treatment. In addition, you still had to work very hard to earn money. How difficult it was for you to be patient with these things.

It must have also been hard living with very little money. Sometimes, you were hungry since you didn’t have enough food to eat. You had to walk from the bus stop to the hospital which was very far to get treatment for the cancer. This was because you had to save the little you had for your husband’s treatments and for the things he wanted. It seems to me that it was difficult for you to work so hard but never to have enough money for even the basic necessities.

I have also thought about how difficult it was for you to live with conflicts. Even though you wanted him to get better, you feared that he would get hurt if he was admitted to the psychiatric hospital and you also feared that his sickness would get worse as it had been previously. So, you decided not to send him to the hospital again. As a result, you were criticized by the staff for that decision and they said that they would no longer provide him any treatment. It was hard for you to accept that they would not treat your husband any longer. You did not know what to do so you were disconnected from the hospital. Therefore, you had no modern medicine for him for
four years. Recently, the hospital has sent you his medicine. But, he has taken it irregularly and has not been well.

Another area of conflict and confusion for you was in regard to results of his out of control behaviours. It was also very hard for you when he behaved badly towards other people including family members and neighbours. So, you were confused at times when they hurt him back. Even though you felt that he deserved it, you thought that they should not hurt your beloved husband. It seems to me that it must have been very difficult for you to try and care for him in the midst of such chaos.

One more difficulty for you was feeling so sorry when he was harmed by the people whom he had hurt. And sometimes you also saw other people hurt him first. He also told you that he was hurt by the staff at the psychiatric hospital. You worried about him being hurt again. Even though your son wanted him to be admitted to that hospital, you did not do that because you thought that he might get hurt once more.

Living with so many demands was also so exhausting for you. You had to cook whatever or whenever he wanted. Even though you felt unwell because of your cancer, you cooked for him at midnight whenever he demanded it. Although you were so tired, to avoid an outburst, you gave him a shower immediately after work every day. I cannot even comprehend how hard it was for you to live with him and his constant demands.

I also guess that one thing making your life so hard was living your life with uncertainty. It was so very hard, not knowing what was happening to the husband that you love so much. You wondered what treatment he got at the psychiatric hospital that made him so unwell and you wondered why this happened. You had never been told about that treatment. Even now you still have questions about that and do not want to send him to that hospital again. As a care giver, you are so confused.

It also broke your heart to live with hopelessness. You sometimes let him do everything he wanted including hurting you because you thought you could not stop him. You tried to do the best you could and gave him folk medicine. But, bad things
still happened and he continued to destroy things as well as threaten your daughters’ lives. You had thought that you were ready to die if he wanted to kill you. You also wanted to leave him many times.

But do you know that I have also seen that you were very patient and kind? Even though you faced many difficult situations you had a strong will and persevered in taking care of him. I think that your sense of kindness and love helped you cope with the continuing despair and difficulties.

These are the issues that I have reflected on from reading your story on caring for your husband with mental illness. I would like to invite you to talk more with me in our next meeting about these things.

Thank you again for sharing your story with me.

Sincerely yours,

Sudkhanoung Plangpongpan
สวัสดีค่ะ
คุณป้า
ตั้งแต่ที่ฉันได้พบกับคุณป้าในการสัมภาษณ์ครั้งแรก ฉันได้สัมผัสกับความทุกข์ครั้งแรก คุณป้า
แม้จะสามารถทำอะไรเพื่อจะช่วยเหลือครอบครัวได้เลย ฉันจะเป็นเรื่องยากสำหรับคุณป้าที่จะต้อง
ยอมรับเรื่องนี้ เพราะฉะนั้น บุคคลชีวิตของคุณป้าในมิติของความรักที่มีต่อครอบครัว ดีนี่ไม่สามารถ
ที่จะต้องทำได้ ฉันไม่สามารถจินตนาการได้ว่า ฉันไม่สามารถจินตนาการได้ ที่จะรักษา
ความสงบของคุณป้าที่ต้องการพยาบาลที่ทุกอย่างด้วยทั้งนี้

บางอย่างที่มีนัยสำคัญอื่นๆอีกที่เป็นการที่บุคคลชีวิตที่มีชีวิตอยู่กับความทุกข์ ดีนี่จินตนาการว่าคุณป้าชีวิตก้าว
การที่เขาพยาบาลเพื่อดับดับ ฉันต้องการที่จะทำอะไรบางอย่างที่เขาไม่สามารถทำได้ ถึงแม้ว่าจะ
ไม่ได้ เขาเกลื่อนกางมือไปยังบ้านเพื่อที่จะพยายามเพื่อดับดับ เขาจะทำเรื่องที่ดีต่อเรา เขาไม่กินยา
ตามที่หมอสั่ง เขาต้องการเพื่อดับดับ ฉันจะต้องส่งแบบที่มีชีวิตอยู่กับความทุกข์แบบนี้

เมื่อฉันได้อ่านสิ่งที่คุณป้าได้บอกกับฉันถึงการเกิดขึ้นกับคุณป้าในเวลาต่อมา ฉันดูแลกันว่ามีความลำบาก
เกิดขึ้นกับคุณป้าเกือบทั่วไป บางที่ที่เรียกร้องเกิดขึ้นทุกวัน

ดีนี่อย่างดีกว่ามันจะเข้ากับลักษณะคุณป้าที่ต้อง คุณป้าชีวิต ซึ่งกลับกลับของคุณป้าตามลำดับ
ที่ต้องเจอในชีวิตที่ไม่สามารถอยู่กับคุณป้าไม่สามารถทำให้เกิดขึ้น แต่คุณป้าก็ยังคงคุณภาพและมาตรฐาน
คุณป้าห่างต้องหมู่บ้านที่เขาทำเรื่องคุณป้า เพราะ ซึ่งฉันได้เตรียมก่อนมัน เข้าร่วมสิ่งที่คุณป้า
ต้องทำในสิ่งที่เข้าร่วมกันก่อน แต่ที่ต้องการคุณป้าต้องทำที่ต้องการ ที่ต้องรักษาต้องทำ
เฉพาะกับพฤติกรรมที่ไม่เป็นที่ยอมรับของเขา ในตอนกลางคืน คุณป้ารู้สึกไม่สบายใจ ต้องอยู่ต้องอยู่
ต้องเสียหาย และต้องรักษาต้องอยู่ แต่คุณป้าต้องทำในสิ่งที่เรียกข้อความที่ต้องรักษาอยู่
อะไรได้เลย คุณป้าสรีระกายต้องปล่อยให้เขาจะอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างมุมครับและเข้าใจให้เขาประพฤติติดต่อกัน แต่สิ้นที่ไม่เคยเกิดขึ้นเลย ในขณะเดียวกัน คุณป้าก็ได้รับการบอกจากหมอว่าเป็นมะเร็ง ซึ่งมีช่วงเจ็บปวดที่รุนแรงกว่ามากส่งผลให้คุณป้ายิ่งลังเลและเจ็บปวดมากขึ้น การที่คุณป้ารู้สึกว่าต้องปล่อยให้เขาทำอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างนุ่มนวลและขอร้องให้เขาประพฤติตัวดีๆ แต่สิ่งนั้นไม่เคยเกิดขึ้นเลย ในขณะเดียวกัน คุณป้าก็ได้รับการบอกจากหมอว่าเป็นมะเร็ง การที่คุณป้ายิ่งลังเลและเจ็บปวดมากขึ้น การที่คุณป้ารู้สึกว่าต้องปล่อยให้เขาทำอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างนุ่มนวลและขอร้องให้เขาประพฤติตัวดีๆ แต่สิ่งนั้นไม่เคยเกิดขึ้นเลย ในขณะเดียวกัน คุณป้าก็ได้รับการบอกจากหมอว่าเป็นมะเร็ง การที่คุณป้ายิ่งลังเลและเจ็บปวดมากขึ้น การที่คุณป้ารู้สึกว่าต้องปล่อยให้เขาทำอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างนุ่มนวลและขอร้องให้เขาประพฤติตัวดีๆ แต่สิ่งนั้นไม่เคยเกิดขึ้นเลย ในขณะเดียวกัน คุณป้าก็ได้รับการบอกจากหมอว่าเป็นมะเร็ง การที่คุณป้ายิ่งลังเลและเจ็บปวดมากขึ้น การที่คุณป้ารู้สึกว่าต้องปล่อยให้เขาทำอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างนุ่มนวลและขอร้องให้เขาประพฤติตัวดีๆ แต่สิ่งนั้นไม่เคยเกิดขึ้นเลย ในขณะเดียวกัน คุณป้าก็ได้รับการบอกจากหมอว่าเป็นมะเร็ง การที่คุณป้ายิ่งลังเลและเจ็บปวดมากขึ้น การที่คุณป้ารู้สึกว่าต้องปล่อยให้เขาทำอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างนุ่มนวลและขอร้องให้เขาประพฤติตัวดีๆ แต่สิ่งนั้นไม่เคยเกิดขึ้นเลย ในขณะเดียวกัน คุณป้าก็ได้รับการบอกจากหมอว่าเป็นมะเร็ง การที่คุณป้ายิ่งลังเลและเจ็บปวดมากขึ้น การที่คุณป้ารู้สึกว่าต้องปล่อยให้เขาทำอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างนุ่มนวลและขอร้องให้เขาประพฤติตัวดีๆ แต่สิ่งนั้นไม่เคยเกิดขึ้นเลย ในขณะเดียวกัน คุณป้าก็ได้รับการบอกจากหมอว่าเป็นมะเร็ง การที่คุณป้ายิ่งลังเลและเจ็บปวดมากขึ้น การที่คุณป้ารู้สึกว่าต้องปล่อยให้เขาทำอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างนุ่มนวลและขอร้องให้เขาประพฤติตัวดีๆ แต่สิ่งนั้นไม่เคยเกิดขึ้นเลย ในขณะเดียวกัน คุณป้าก็ได้รับการบอกจากหมอว่าเป็นมะเร็ง การที่คุณป้ายิ่งลังเลและเจ็บปวดมากขึ้น การที่คุณป้ารู้สึกว่าต้องปล่อยให้เขาทำอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างนุ่มนวลและขอร้องให้เขาประพฤติตัวดีๆ แต่สิ่งนั้นไม่เคยเกิดขึ้นเลย ในขณะเดียวกัน คุณป้าก็ได้รับการบอกจากหมอว่าเป็นมะเร็ง การที่คุณป้ายิ่งลังเลและเจ็บปวดมากขึ้น การที่คุณป้ารู้สึกว่าต้องปล่อยให้เขาทำอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างนุ่มนวลและขอร้องให้เขาประพฤติตัวดีๆ แต่สิ่งนั้นไม่เคยเกิดขึ้นเลย ในขณะเดียวกัน คุณป้าก็ได้รับการบอกจากหมอว่าเป็นมะเร็ง การที่คุณป้ายิ่งลังเลและเจ็บปวดมากขึ้น การที่คุณป้ารู้สึกว่าต้องปล่อยให้เขาทำอะไรก็ได้ตามที่เขาต้องการ หลังจากนั้น เมื่อเขาสงบลง คุณป้าก็พูดกับเขาอย่างนุ่มนวลและขอร้องให้เขาประพฤติตัวดีๆ แต่สิ่งนั้นไม่เคยเกิดขึ้นเลย
เนื่องจากถูกสามีคุณป้าทำร้าย และบางครั้งคุณป้าถูกทำร้ายโดยที่คุณป้าไม่รู้เรื่อง การที่ต้องมีชีวิตอยู่กับการเรียกร้องอย่างมากก็เป็นสิ่งที่ทำให้คุณป้าเหนื่อยและอาจมีผมเรื่องพยาบาทได้ คุณป้าต้องท้องทาร้า ให้เขา ไม่ว่าจะเป็นอะไร เมื่อให้ก็ตามที่เขาต้องการ ถึงแม้ว่าคุณป้าจะรู้สึกไม่สบายเพราะโรคระเบิด และจะเป็นเวลาหลังๆก็ตามสิ่งนี้คุณป้าก็โดยทั่วไปก็จะท้องทาร้าที่เขาต้องการได้แม้จะมีไนฟ์ที่ทางาน ซึ่งมีความสามารถในการทำได้ตามที่เรา คำแนะนำที่ต้องใช้ชีวิตอยู่กับเขาและความต้องการที่ไม่สิ้นสุดนั้น

ด้วยเหตุผลที่ทำให้ชีวิตของคุณป้ายากลำบากมากก็คือการใช้ชีวิตอยู่กับความไม่รู้ มันลำบากมากที่จะรู้เกี่ยวกับสิ่งที่คุณป้าทำ ดิฉันไม่รู้เกี่ยวกับการทำงานที่เขาได้รับที่ทำกับสิ่งเหล่านี้ในโรงพยาบาลวันนี้คืออะไร สิ่งที่ทำให้เขาสามารถการทำมันได้ และคุณป้าเองก็ไม่รู้ว่าทำให้เกิดขึ้นอย่างนี้ คุณป้าไม่รู้ว่าการบอกเหตุการณ์ที่เขาจะทำในโรงพยาบาลวันนี้มีความสบายใจเพียงแค่การรักษาทางร่างกาย และไม่ต้องการที่เขาจะหันไปรักษาในโรงพยาบาลอีก แม้ว่าจะต้องอยู่กับสิ่งเหล่านี้ คุณป้าไม่รู้ว่าการบอกเหตุการณ์ที่เขาจะทำในโรงพยาบาลวันนี้มีความสบายใจเพียงแค่การรักษาทางร่างกาย และไม่ต้องการที่เขาจะหันไปรักษาในโรงพยาบาลอีก แม้ว่าจะต้องอยู่กับสิ่งเหล่านี้ คุณป้าไม่รู้ว่าการบอกเหตุการณ์ที่เขาจะทำในโรงพยาบาลวันนี้มีความสบายใจเพียงแค่การรักษาทางร่างกาย และไม่ต้องการที่เขาจะหันไปรักษาในโรงพยาบาลอีก แม้ว่าจะต้องอยู่กับสิ่งเหล่านี้ คุณป้าไม่รู้ว่าการบอกเหตุการณ์ที่เขาจะทำในโรงพยาบาลวันนี้มีความสบายใจเพียงแค่การรักษาทางร่างกาย และไม่ต้องการที่เขาจะหันไปรักษาในโรงพยาบาลอีก แม้ว่าจะต้องอยู่กับสิ่งเหล่านี้ คุณป้าไม่รู้ว่าการบอกเหตุการณ์ที่เขาจะทำในโรงพยาบาลวันนี้มีความสบายใจเพียงแค่การรักษาทางร่างกาย และไม่ต้องการที่เขาจะหันไปรักษาในโรงพยาบาลอีก แม้ว่าจะต้องอยู่กับสิ่งเหล่านี้ คุณป้าไม่รู้ว่าการบอกเหตุการณ์ที่เขาจะทำในโรงพยาบาลวันนี้มีความสบายใจเพียงแค่การรักษาทางร่างกาย และไม่ต้องการที่เขาจะหันไปรักษาในโรงพยาบาลอีก แม้ว่าจะต้องอยู่กับสิ่งเหล่านี้ คุณป้าไม่รู้ว่าการบอกเหตุการณ์ที่เขาจะทำในโรงพยาบาลวันนี้มีความสบายใจเพียงแค่การรักษาทางร่างกาย และไม่ต้องการที่เขาจะหันไปรักษาในโรงพยา...
ขอบคุณอีกครั้งค่ะ สำหรับการแลกเปลี่ยนเรื่องราวกับดิฉัน

ด้วยความเคารพ

ปลั่งพงษ์พันธ์

ตัวความเคารพ

ปลั่งพงษ์พันธ์