

**THAI PARENTS' EXPERIENCES IN BECOMING CAREGIVERS
OF SCHIZOPHRENIC PATIENTS**

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THESIS ADVISORY COMMITTEE: WANLAYA THAMPANICHAWAT, Ph.D.,
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Although it is well document that caregiving for persons with early schizophrenia affects all aspects of the parents' lives, little is known about the caregiving process in caring for adult children with early schizophrenia. The purpose of this study was to explore basic social psychological process of being caregivers for adult children with schizophrenia among Thai parents. A grounded theory study was conducted. Twenty-five parents whose adult children were first diagnosed with schizophrenia within five years were interviewed, at the Outpatient (OPD) and Inpatient Departments (IPD) of the biggest psychiatric hospital in Thailand. The interviewed data were transcribed and analyzed using the constant-comparative method of the Straussian grounded theory approach.

Struggling to restore normalcy was the basic social psychological process of being caregivers for adult children with early schizophrenia. It began with causal conditions: learning the diagnosis and facing shattered dreams. Because of the unstable and unpredictable nature of psychotic symptoms and the lack of experience and caregiving skills to work with mental illness, the parents had difficulties achieving their children's normalcy. However, perceiving caregiving as an unavoidable role, a contextual condition which included a sense of responsibility, feelings of love and sympathy, and believing in karma helped the parents in continually provided caregiving for their children. In order to restore normalcy, the parents struggled to control psychotic symptoms, which involved monitoring the symptoms, maintaining medication adherence, managing the symptoms, and preventing the exacerbation and relapse of the symptoms; as well as struggling to deal with the impacts of the illness, including dealing with the children's poor decision making, dealing with the stigma of the disease, and dealing with loss and difficulties. As time passed, the parents began to realize and accept a new normal that they were unable to restore their children's normalcy. Their children still had to be the patients with schizophrenia who needed long term care. Once realized, most of the parents had maintained caregiving with new perspectives in being caregivers for their children, while some of them distanced themselves from caregiving.

These findings indicate that caregiving in the early phase of schizophrenia is a very difficult situation. In addition, the findings can be used as basis information for developing an early intervention program and for further study, to alleviate the parents' struggling, enhance their adaptive coping response and help them to overcome their difficulties.

**KEY WORDS: PARENTS / CAREGIVING EXPERIENCES / EARLY PHASE OF
SCHIZOPHRENIA**

173 pages

ประสบการณ์ของบิดามารดาไทยในการเป็นผู้ดูแลผู้ป่วยจิตเภท

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บทคัดย่อ

แม้จะเป็นที่ทราบกันดีว่า การดูแลบุตรโรคจิตเภทในระยะแรกมีผลกระทบต่อชีวิตของบิดามารดาอย่างมาก แต่ความรู้เกี่ยวกับกระบวนการดูแลของบิดามารดาในระยะนี้ยังมีจำกัด การศึกษาครั้งนี้จึงมีวัตถุประสงค์เพื่อศึกษากระบวนการพื้นฐานทางจิตสังคมของบิดามารดาไทยในการเป็นผู้ดูแลบุตรโรคจิตเภทระยะแรก โดยใช้วิธีการวิจัยเชิงทฤษฎีพื้นฐาน มีการสัมภาษณ์เชิงลึกบิดามารดา 25 คน ที่บุตรได้รับการวินิจฉัยว่าเป็นโรคจิตเภทครั้งแรกภายใน 5 ปี ที่แผนกผู้ป่วยนอกและหอผู้ป่วยโรงพยาบาลจิตเวช และวิเคราะห์ข้อมูลโดยใช้การเปรียบเทียบข้อมูลอย่างต่อเนื่อง ตามแบบของสตราสส์

กระบวนการพื้นฐานทางจิตสังคมในการเป็นผู้ดูแลบุตรโรคจิตเภทในระยะแรก คือการคืนชนทำให้กลับสู่สภาวะปกติ โดยเริ่มจากเงื่อนไขสาเหตุคือการรู้ว่าบุตรป่วยทางจิต และการเผชิญกับฝันสลาย บิดามารดาต้องใช้ความพยายามและประสพความยุ่งยากอย่างมากเพื่อให้บุตรกลับมาเป็นปกติ เนื่องจากบิดามารดาไม่เคยมีประสบการณ์และทักษะการดูแลผู้ป่วยจิตเวชมาก่อน อีกทั้งอาการทางจิตของบุตรมีการเปลี่ยนแปลงตลอดเวลาและไม่สามารถทำนายได้ แต่ด้วยการรับรู้ว่าการดูแลเป็นบทบาทที่หลีกเลี่ยงไม่ได้ ซึ่งเป็นเงื่อนไขเชิงบริบทประกอบด้วยรู้สึกดีกับผิชอบ ความรักความสงสารและความเชื่อเรื่องกรรม จึงทำให้บิดามารดายังคงให้การดูแลบุตรต่อไปได้ ในการทำให้กลับสู่สภาวะปกติ บิดามารดาต้องพยายามควบคุมอาการทางจิต ซึ่งประกอบด้วย การเฝ้าระวังอาการ การดูแลให้ได้รับยาอย่างต่อเนื่อง การจัดการกับอาการ และการป้องกันการกำเริบและกลับเป็นซ้ำของอาการ นอกจากนี้ บิดามารดาต้องพยายามจัดการกับผลกระทบของโรคไปด้วยพร้อมกัน ได้แก่ การจัดการกับการตัดสินใจที่ไม่ดีของบุตร การจัดการกับตราบาปของโรค และการจัดการกับความรู้สึกสูญเสียและความยุ่งยาก เมื่อระยะเวลาผ่านไป บิดามารดาเริ่มตระหนักและยอมรับว่าคงไม่สามารถทำให้บุตรกลับมาเป็นปกติได้ และบุตรยังเป็นผู้ป่วยจิตเภทที่ต้องการการดูแลระยะยาว หลังจากนั้น บิดามารดาส่วนใหญ่ยังคงดูแลบุตรต่อไปด้วยมุมมองใหม่ ในขณะที่บางคนเริ่มถอยห่างออกจากการดูแล

จากผลการวิจัยสะท้อนว่า การดูแลผู้ป่วยจิตเภทในระยะแรกเป็นสถานการณ์ที่ยุ่งยากมาก และผลการวิจัยนี้ สามารถใช้เป็นข้อมูลพื้นฐานในการพัฒนาโปรแกรม และเพื่อการวิจัยต่อไป เพื่อช่วยลดการคืนชนของบิดามารดา ช่วยให้มีการจัดการที่เหมาะสมและข้ามพ้นความยุ่งยากในการดูแลบุตรได้ต่อไป

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CHAPTER I

INTRODUCTION

Background and Significance of the Study

Schizophrenia is one of the most severe and chronic mental illnesses. In the context of Thailand, schizophrenia-associated problems are among the major causes of disability, accounting for 10.5% of the damage caused by the disease (Chakrabhand, 2005). The incident rate of schizophrenia in the Thai population is approximately 3 per 10,000 with a peak at the ages of 15-24 in both males and females (Phanthunane, Vos, Whiteford, Bertram, & Udomratn, 2010). The Department of Mental Health, Ministry of Public Health (2008) reported that the number of schizophrenic outpatients that attended public hospitals increased from 78,944 in 2006 to 86,105 in 2008. Since there is the deinstitutionalization policy which aims to decrease the hospital length of stay and decrease the number of patients in psychiatric hospitals, the majority of patients with schizophrenia (98%) resided with their families in the community (Phanthunane et al., 2010) and most of them returned home while still experiencing psychotic symptoms (Thongkhamrod, 2006). Parents are the majority group of primary caregivers for patients with schizophrenia at home (Wongchaiya, 2007).

The psychotic symptoms of schizophrenia are differentiated from other mental disorders by their severity which is characterized by the prominent structural deformities of thought and perception. The first episode of schizophrenia typically emerges in late adolescence or early adulthood (Corcoran et al., 2007; Reed, 2008). The course of schizophrenia is composed of prodromal, acute, and residual phase. In the early phase of schizophrenia, the families possibly face prodromal phase, then acute phase and eventually residual phase (Nevid et al., 2008; Pearson, 2006). The prodromal phase is the early signs which are vague and hardly noticeable. The main symptom is a slow change in behaviors and mood, such as social withdrawal and decline in function, as they enter the teen years (Corcoran et al., 2007). The vague signs make it difficult

for family members and professionals to differentiate between the normal struggles associated with adolescence and early warning signs preceding a first break or relapse (Norman, Malla, Verdi, Hassall, & Fazekas, 2004). At the acute phase of the illness, the patients can pose a threat to themselves, other people, animals, and properties due to their aggressive behaviors associated with delusions and/or hallucinations and poor cognitive functions (Corcoran et al., 2007; Payne, Malla, Norman, Windell, & Brown, 2006). They additionally express troublesome behaviors such as sleeping during the day and remaining awake at night, speaking aggressively, and acting out violently (Ferriter & Huband, 2003). After treatment, the patients possibly move to residual phase which psychotic symptoms are subsided with impairment of cognitive and social function (Messias et al., 2005).

Empirical evidence indicates that, during the first five years after diagnosis, the psychotic symptoms particularly prominent and unstable marked by exacerbations, remissions, and relapse; and became more stable after that time (Lieberman, 1999; McGlashan, 1998). Studies have found that the cumulative relapse rate was 70-82% for up to five years following the first admission or episode (Robinson et al., 1999; The Scottish schizophrenia research group, 1992). Some studies indicated that the most common cause of relapse during this phase of illness was medication non-adherence (Haywood et al., 1995; Lacro, Dunn, Dolder, Leckband, & Jeste, 2002). Adapting themselves to medication changing (Lambert, 2009; Robinson, Woerner, & Alvir, 2002) and suffering from antipsychotic drug side effects which are common happening in the early phase of illness (Lambert, Conus, Lambert, & McGorry, 2003) and having poor insight (Schultz, North, & Shields, 2007) lead patients to medication non-adherence. Lieberman (1999) indicated that patients had a poorer response to treatment, a longer time to remission, as well as a deterioration of functions with each subsequent relapse episode considered as the chronic state of the illness. Therefore, the early phase of schizophrenia is critical and substantial and continuing care is needed.

Caregiving in this phase of illness is a complex and troublesome process bringing enormous changes and impacts to parents in many aspects of their lives. Studies noted that caregiving for patients with schizophrenia required specific skills for dealing with patients' cognitive deformity and problematic behaviors (Mo et al.,

2008; Riebschleger et al., 2008; Sin, Moone, & Wellman, 2005). Unfortunately, the parents often do not have the knowledge or understanding about the patients' diagnosis, the available resources, the skills to manage difficult and embarrassing behaviors of the patients, as well as the way to deal with their own feelings. Mohr and Regan-Kubinski (2001) described that parents experienced grief from losing hope and their loved ones to the world of mental illness. They had to change their life plans to live with and care for the patients (Sin et al., 2005). Parents' relationship with the patients and their social relationship were disrupted causing by caregiving (Copeland, 2007; Ip & Mackenzie, 1998; Mavundla, Toth, & Mphelane, 2009; Mohr & Regan-Kubinski, 2001; Parker, 1993). In addition, they faced difficulties in managing the stigma (Liu, Lambert, & Lambert, 2007; Veltman, Cameron, & Stewart, 2002), the patients' symptoms (Ferriter & Huband, 2003; Parker, 1993), and dilemmas in the complex caregiving situations (Mavundla et al., 2009; Milliken & Rodney, 2003). Many studies have indicated that living with high stress and strain with little time to relax increased the risk of poor health in parents (Chaffey & Fossey, 2004; Dyck, Short, & Vitaliano, 1999; Greenberg, Greenley, McKee, Brown, & Griffin-Francell, 1993; Milliken, 2001) especially those who were living with the patients (Tennakoon et al., 2000).

The difficulties of caregiving affect the parental roles and family life. Milliken (2001) reported that parents had to provide full-time care for the patients, while maintaining multifaceted parental roles and other obligations in the family. Some studies described that parents faced difficulties in balancing the patients' demands with the needs of other children (Mendenhall & Mount, 2011; Nelson, 2002; Sullivan-Bolyai, Knafel, Sadler, & Gilliss, 2004). They had to have an awareness of and attention to the emotional reactions of other children and make sure that they did not feel overshadowed by caregiving role. However, studies indicated that parents experienced parental incompetence when they could not balance the illness demands with other children's needs (Chaffey & Fossey, 2004). They paid less attention to other children leading to frustration, guilt, and conflicts in the family. They additionally had to assure the economic stability of the family, as well as, maintain the household tasks and family activities (Mendenhall & Mount, 2011; Nelson, 2002; Sullivan-Bolyai et al., 2004). Furthermore, some studies indicated that several parents

had to change their paid work to part time or had to give up their paid work to provide care for the patients resulting in their families' financial hardship (Jungbauer, Wittmund, Dietrich, & Angermeyer, 2003; Milliken, 2001). It interfered with their ability to perform the breadwinner role, especially among fathers (Brandth & Kvande, 1998). Moreover, Brody (1995) noted that some of the parents, in their midlife were also providing care for their aging parents or in-laws. Therefore, they experienced being pulled in many directions by having to fulfill multiple roles (Milliken, 2001).

Empirical evidence indicates that parents' caregiving experiences are the crucial factor influencing patients' clinical outcomes. Addington, Collins, McCleery, and Addington (2005) found that if parents perceived sufficient support from health care providers, they could play a significant role in the patients' recovery from the first episode of psychosis. On the other hand, with insufficient support, parents experienced distress and burden and perceived a low quality of life which could affect the quality of care (Bull & Jervis, 1997; Seloilwe, 2006). Studies noted that parents were likely to have an increasing level of distress and behave in hostile, critical, or over-involved manners toward the patients' troublesome behaviors in an attempt to reduce the perceived stress of caregiving situation and loss (Bachmanna et al., 2002; Kuiper et al., 2006; Patterson, Birchwood, & Cochrane, 2005). Previous studies revealed that such expression of parents was associated with high levels of patients' anxiety and depression (Kuiper et al., 2006) preceding relapse (Bachmanna et al., 2002; Freeman & Garety, 2003; Gleeson, Linszen, & Wiersma, 2009).

Although caregiving for patients with schizophrenia in the early phase of illness is difficult and brings enormous impacts to families, parents' lives, and patients' clinical outcomes, the study concerning parents' experiences in dealing with changes and impacts in this phase of illness is rare. In the Western context, most studies reflected the concern about the impacts of caregiving on caregivers in this phase of illness (e.g., Addington, Coldham, Jones, Ko, & Addington, 2003; Corcoran et al., 2007; Reed, 2008; Tennakoon et al., 2000). Some phenomenological studies described caregivers' perceptions and responses to their relative's mental illness (McCann, Lubman, & Clark, 2011; Sin et al., 2005). There were grounded theory studies shedding the light on the process of providing care for psychotic patients (Rose, Mallinson, & Walton-Moss, 2002; Wynaden, 2007). The findings of these

studies revealed that before the diagnosis, caregivers were in a stormy period. They experienced psychological distress as they struggled to understand what had happened to their loved ones. They experienced a sense of crisis and had to seek ways to solve the unpredictable and uncontrollable problems, restore normalization, and adjust their coping to take each day as it comes. After the diagnosis, it was an unacceptable situation for them to have mentally ill children. They encountered the sense of uncertainty, the possibility of making major changes in their usual routines to accommodate illness demands, and the possibility of radically altered future. They tried to find for the possible ways through using trial and error to overcome their difficulties before moving to a state of balance and gaining a sense of mastery (Rose et al., 2002; Wynaden, 2007). However, these studies have focused on the caregiving experience with a wide range of duration from 1 to more than 20 years in which the experience in the early phase of illness was a part (Rose et al., 2002; Wynaden, 2007). The prominent information is the caregivers' dealing with the illness. Additionally, caregivers in these studies had various relationships with patients, including parents, children and siblings, and the patients had various psychotic disorders, including schizophrenia, bipolar, and depression. Thus, these studies lack homogeneity of parents' experience in caring for patients with schizophrenia and little is known about the parents' responses in adjusting their personal and family lives amidst the chaos of being caregivers.

In Thai context, there were two phenomenological studies concerning lived experience of caregivers who cared for relatives with schizophrenia who had been diagnosed from 3 to 13 years (mean = 6.5, SD = 4.27) (Rungreangkulkij & Chesla, 2001) and had lifetime hospitalizations ranged from 1 to 12 times (Sethabouppha & Kane, 2005). These studies provided knowledge about Thai caregivers' perceptions and responses in particular to their relatives' mental illness which was captured from the wide range of caregiving duration. Some grounded theory studies explored the process of dealing with schizophrenia, such as managing caregiving tasks and developing skills and caregiving role (Dangdomyouth, Stern, Oumtanee, & Yunibhand, 2008; Tunkpunkom, 2000) and coping process of caregivers (Sukmak, Chockratnhirun, & Srijunlah, 2001). The findings of these studies provided understanding that caregivers' coping responses were changed over time (Sukmak et

al., 2001). Caregivers had to adjust their lives in dealing with each phase of illness and the repetitive problems. They had to provide the close and thoughtful caregiving in managing the unpredictability of the patients' psychotic symptoms, as well as manage their own feelings (Dangdomyouth et al., 2008). In dealing with the difficulties of caregiving tasks, they gradually developed caregiving skills and strategies for various circumstances by experiential learning (Dangdomyouth et al., 2008; Tunkpunkom, 2000).

However, these studies provided information about caregiving experiences with a wide range of duration, from seven months to over 10 years, but the experience at the early phase of illness was only slightly touched upon (Dangdomyouth et al., 2008; Rungreangkulkij & Chesla, 2001; Sukmak et al., 2001; Tunkpunkom, 2000). In addition, these studies included mothers, spouses, and siblings as participants (Dangdomyouth et al., 2008; Sukmak et al., 2001; Tunkpunkom, 2000). Little is known about the parents' experiences in becoming caregivers of their adult children with schizophrenia in the early phase of the illness.

The issues needed to be extended for better understanding are Thai parents' meanings attached to the experiences in having children with schizophrenia and being caregivers, the changes and impacts happened in their lives, and their actions/interactional responses to those changes and the conditions influencing such responses, from the first episode of the illness to within five years after the first diagnosis. Understanding the parents' problems and their responses in being caregivers for their children with schizophrenia in this early period is crucial for psychiatric nurses in learning from them in what responses are effective or ineffective. It is important in identifying the nursing therapeutics based on knowledge derived from parents' perspectives to help them learn about ways to deal with changes and impacts and gain a sense of readiness to be caregivers, to prevent the adverse consequences of both parents and the patients' clinical outcomes, and to facilitate a sense of mastery in being caregivers of their children with schizophrenia at the early phase of illness.

Purpose of the Study

The purpose of this study was to explore the experiences of Thai parents in being caregivers of their children with schizophrenia within five years after the first diagnosis. A substantive theory was developed to describe the conditions influencing the process of being caregivers from the perspectives of Thai parents.

Research Questions of the Study

A major research question of this study was:

What were Thai parents' experiences in being caregivers for their children with schizophrenia within five years after the first diagnosis?

More specific research questions were:

1. How did Thai parents perceive the illness of their children and their caregiving role?
2. How did Thai parents deal with the changes and impacts happened in their lives?
3. What were the conditions influencing the parents' experiences?

Definitions of Terms

The keywords for this study are:

Parents refer to fathers or mothers, or both of them who are the primary caregivers of their children with schizophrenia.

Schizophrenia refers to a mental illness which changes in behavior due to the deviation of thought and perception diagnosed by a psychiatrist. The diagnosis is based on criteria of the Diagnostic and Statistic Manual of Mental Disorders, 4th edition-Text Revision (DSM-IV-TR) (APA, 2002) or the Tenth Revision of the International Classification of Disease (ICD-10) (WHO, 1992).

The early phase of schizophrenia refers to the duration from the first episode of schizophrenia that parents become aware that the changes are taking place

in their children to five years after the first diagnosis with schizophrenia is confirmed by a doctor. This information is obtained from the parents.

Summary

Schizophrenia is one of the most severe and chronic mental illnesses. Most of the patients dwell in the community. The schizophrenic symptoms during the first five years after the diagnosis are unstable or unpredictable alternating between exacerbations and remissions and gradually impair functions that precede the state of chronic illness. As a consequence, the patients with schizophrenia need substantial and continuing care and most of the care responsibilities fall on their parents. Having children with schizophrenia and giving care for them in this phase of illness is a complex and troublesome situation bringing about enormous changes and impacts to many aspects of parents' lives and families. Parents experience the difficulties in learning to adapt and incorporate their new caregiving circumstances into their lives and families. They, at the beginning of the illness, struggle to understand what has happened, and suffer with the changes of their children's behavior. In taking care of their children, they encounter the difficulties in dealing with loss, stigma, and their children's psychotic symptoms, and in balancing their caregiving roles with parental roles. However, little is known about Thai parents' experiences in being caregivers for their children with schizophrenia in the early phase of the illness. This study aimed to describe how Thai parents perceived their children's illness and their caregiving role and dealt with the changes and impacts in being caregivers of their patients with schizophrenia from the first episode of the illness to five years after the first diagnosis, as well as the conditions influencing their experiences.

CHAPTER II

LITERATURE REVIEW

This chapter provides information to understand the broad context of parents' experiences in being caregivers for patients with schizophrenia from the first onset of the illness through five years after the first diagnosis. The selected literature that is relevant to this study is reviewed and organized into eight sections: schizophrenia, transition into becoming caregivers, impacts of schizophrenia on a family unit, impacts of caregiving on parents' lives, caregivers' experiences in the context of other countries, caregivers' experiences in the Thai context, grounded theory, and trustworthiness of qualitative study. A review of schizophrenia is aimed to describe the nature of the disease which involves the caregiver's experience. Transition into being caregivers is proposed to enhance an understanding about its meaning and its nature and present knowledge relating to transition in the area of caregiving for schizophrenic patients. A review of family types is aimed to describe the characteristics of family functioning under difficult situations. The literature about the impacts of schizophrenia on the family and parents' lives are reviewed for understanding of how schizophrenia affects the family unit and parents' lives. In addition, the literature on caregivers' experience is intended to show empirical evidence related to caregivers' experience in being caregivers of patients with psychotic disorders, including schizophrenia in other countries and Thailand and how caregivers perceive and deal with the impacts and changes happened in their lives. The grounded theory and trustworthiness is intended to provide an understanding of the methodology adopted in this study and trustworthiness of qualitative research, in terms of its principle.

Schizophrenia

Schizophrenia is a severe and chronic mental illness. Although it affects 1% of people, its prevalence rate is high by its chronicity (Mueser & McGurk, 2004). The first expression of psychotic signs and symptoms begins earlier in men than women with a peak at age of 15-25 years and 25-35 years, respectively (Aleman, Kahn, & Selten, 2003; Varcacolis, Carson, & Shoemaker, 2010) and most persists the whole time of the patient's life (Mueser & McGurk, 2004).

Causes of schizophrenia

Although extensive studies on the etiology of schizophrenia have been done, the cause of schizophrenia is unknown. However, previous studies consistently noted that a combination of biological and environmental factors increases susceptibility to schizophrenia (Mueser & McGurk, 2004; Owen, Craddock, & O'Donovan, 2005; Tandon, Keshavan, & Nasrallah, 2008). Biological perspective focuses on genetic as it is an important factor of schizophrenia (Hall et al., 2007; Sullivan, Kendler, & Neale, 2003). The biological relatives of Patients with schizophrenia have a more elevated risk of developing schizophrenia (Gottesman, 2001). Abnormality of brain structure and chemicals are also considered as biological contributors of schizophrenia (Sadock & Sadock, 2009). The result of schizophrenic patients' brain scan via magnetic resonance imaging (MRI) showing enlargement of the cerebral ventricles and decreasing gray matter indicated the nerve damage and disconnections in the pathways that carry brain chemicals especially dopaminergic pathway (Freedman, 2003). The evidence supports that schizophrenia involves hyperactivity of dopamine (Mueser & McGurk, 2004). The disconnection in brain circuits could additionally impair information processing and coordination of mental functions involving psychotic symptoms (Mueser & McGurk, 2004; Sadock & Sadock, 2009).

According to a view of the stress - vulnerability model, a person with schizophrenia has an underlying psychological vulnerability, determined by genes and environment in the early of an individual's life. Studies indicated that the risk of developing schizophrenia was increased by prenatal and perinatal event, including maternal viral infection, malnutrition, diabetes mellitus, smoking during pregnancy,

and an obstetric complication such as hypoxia (Thomas et al., 2001). The other factors involving increase risk of schizophrenia include socioeconomic factors such as poverty and lower social class (Mueser & McGurk, 2004). The disturbed family interaction is as environmental factors of schizophrenia. Mother's characteristic precipitating schizophrenic child has been focused for a long time. Sadock and Sadock (2009) indicated that mothers of Patients with schizophrenia behaved in ways that they speculated caused the schizophrenic breakdown (e.g., over protecting or rejecting, over hostile or subtly hostile, unduly restricting or insufficiently restricting). Furthermore, family double-bind family communication, a problematic style of communication created conflicting messages of verbal and nonverbal content, is one of the factors involving the development of schizophrenia (Mueser & McGurk, 2004; Sadock & Sadock, 2009). The onset and the course of the illness is determined by biological and psychological factors which interplays dynamically with each other. Stress and substance abuse can be viewed as a trigger of symptoms recurrence and relapse. Nonetheless, coping skills and social support can diminish the adverse effects of stress (Mueser & McGurk, 2004). The mechanisms of biological vulnerability and environmental factor may interplay in developing schizophrenia through a person's life span.

Symptom of schizophrenia

Clinical characteristics of person with schizophrenia are marked by fundamental disturbances in thought, speech, and perceptual process, as well as disturbances of behavior, mood, and interpersonal relationships. These disturbances cause a variety of symptoms and disrupt a person's functioning in all areas that are essential to human adaptation. The pattern and severity of schizophrenic symptoms vary with each person. In general, The earlier schizophrenia is more severe, particularly in men. The symptoms of schizophrenia are divided into two forms: positive and negative symptoms.

Positive symptoms are characterized by the more bizarre symptoms involving the loss of contact with reality, including delusions, hallucinations, and disorganized speech (Mueser & McGurk, 2004). Delusions are common symptoms of the person with schizophrenia involving the deviation of thought contents. A person

has false beliefs that have no basis in and are not influenced by reality (Nevid, Ratus, & Green, 2008). Delusions often appear complicated and difficult to understand which tend to center around themes of persecution, grandiosity, sex, and religion (Barry, 2002). Hallucinations are perceptual disturbance involving both the accuracy of perceptions and cognitive operations in making sense of them. Hallucinations are characteristics of sensory stimulation when no such stimulation is present. The schizophrenic persons may report hearing voices that talk to or about them, that tell them what to do or that analyze and criticize their actions (Jones & Fernyhough, 2007). They may see persons or objects perceived to be present. They sometimes report feeling or seeing tiny bugs crawling all over the skin or bodily fluids oozing from their pores. Some patients with schizophrenia report their feeling that their insides are rotting away or they are empty inside (Nevid et al., 2008). Disorganized speech is caused by thought and association. Loose association of speech is the symptom that the persons speak without any apparent connection between topics. Though the words may be real words, grammar may seem normal, but the associations fail to hold together in an understandable train of thought. Schizophrenic speech may also include clang association, the use of words that are associated merely because of the way of sounding rather than by their meaning. In addition, the person with schizophrenia can make-up words called neologisms which are difficult to understand and may have poverty of speech that is adequate in form, but conveys little information (Nevid et al., 2008).

On the other hand, negative symptoms are deficit states. The basic emotional and behavioral processes are diminished or absent, including symptoms of affective disturbances and behavioral and psychomotor dysfunction (Mueser & McGurk, 2004). Symptoms of affective disturbances can exhibit as *flat affect* which persons show no facial expression and speak in a monotone voice. The affect disturbances may take the form of difficulty in controlling emotions or inappropriate emotions (e.g., laugh in responding to a sad situation or cry in responding to a funny story). They can be irritable, sensitive, and moody which are inexplicable. Their emotional expression may alter rapidly for no apparent reason (Nevid et al., 2008). For symptoms of behavioral and psychomotor dysfunction, they often exhibit particular mannerisms, gestures, and facial grimaces. Patients may show little spontaneity of

movement or responsiveness to environment changes. They may sit for hours staring at the wall or repeat a complex series of hand signals (Nevid et al., 2008). In addition, persons with schizophrenia may express social withdrawal behavior due to retreating into a private fantasy world called *autism* and may interact with other people inappropriately or intrusively, such as make unreasonable demands on others, and fail to accurately interpret other people's feelings and rights. The patients may also lack enjoyment of social relations and of pleasure in any activity called *anhedonia* led them to a lack of motivation, interest, or energy to pursue meaningful tasks (APA, 2000; Mohr, 2006). Negative symptoms are more pervasive and fluctuate less over time than positive symptoms (Fenton & McGlashan, 1991) and are strongly associated with poor psychosocial functioning (Sayers, Curran, & Mueser, 1996) which make relatives perceive them as lazy (Weisman, Nuechterlein, Goldstein, & Snyder, 1998).

Diagnosis of schizophrenia

Unlike other mental illnesses, the psychotic symptoms of persons with schizophrenia are characterized by prominent deformities of thought and perception, and by unapt feelings. The two major diagnostic systems for schizophrenia in common use are the Tenth Revision of the International Classification of Disease (ICD-10) (WHO, 1992) and the Diagnostic and Statistical Manual of Mental Disorders, 4th edition-Text Revision (DSM-IV-TR) (APA, 2000). According to DSM-IV-TR, schizophrenia is a disturbance that lasts at least six months and includes at least one month of two or more active symptoms such as bizarre delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behavior, and negative behavior. These symptoms interfere markedly with patients' social and occupational functioning (APA, 2000). The ICD-10 defines symptoms and impairment features of schizophrenia in the same way as DSM-IV-TR does. However, there are two major differences between the systems. While the DSM-IV-TR requires of social or occupational dysfunction, it is not included in the ICD-10. In addition, the DSM-IV-TR requires duration of illness of 6 months, whereas the ICD-10 requires just only 1 month (Mueser & McGurk, 2004).

There are many mental disorders differentiated from schizophrenia. Some signs and symptoms of schizophrenia are similar to substance abuse. Therefore, a history of drug use should be taken as a part of a drug screening in the patients who show psychotic features. Additionally, some psychotic symptoms can be displayed in the patient with severe depression or bipolar disorder, but the mood disorders are prominent and occurred before the psychotic feature. Some characteristics of delirium are similar to the active symptoms of schizophrenia, such as hallucinations, delusions. Nonetheless, its etiology is wide and usually caused by many medical illnesses. In addition, signs and symptoms of delirium usually have a much rapid onset, whereas schizophrenia generally develops over weeks to months (Schultz et al., 2007). Moreover, delirium shows severe alteration of cognitive function and consciousness which are not the main symptoms of schizophrenia (Stuart, 2009). Therefore, assessment of clinical and personal history of people from significant family members is a crucial part of diagnosis. The biography that is essential for diagnosis as well as predicting psychosis and acute psychosocial problems includes development and past psychiatric history, and the family history (Maki et al., 2005; Mueser & McGurk, 2004). Additionally, Harrow, Sands, Silverstein, and Golberg (1997) found that schizophrenia was different from the other psychotic disorders by not only its nature of symptoms, but also its outcomes. Patients with schizophrenia present poorer functional outcomes and slower recoveries from episodes than other psychotic disorders.

Treatments for schizophrenia

Typical treatment of schizophrenia is antipsychotic medications. There are two generations: neuroleptics and atypical antipsychotics. Neuroleptic is the first generation antipsychotics such as phenothiazines, thioxanthenes, and haloperidol. These medications have been found to have antipsychotic properties particularly helpful in sedating and reducing the intensity and frequency of positive symptoms and preventing relapse. However, the negative symptoms seem to be remained. In addition, the patients typically need to remain on medication to avoid relapses and they are at risk of extrapyramidal side effects such as acute dystonia, the tightening of muscle, especially the neck and jaw and parkinsonism, Parkinson's like syndrome

(e.g., rigidity, bradykinesia, shuffling gait, tremor), and akathisia, the state of inability to sit still, motor restlessness, and tapping of feet (Schultz et al., 2007). The most severe and even fatal side effect is called neuroleptic malignant syndrome in which the patients develop fever and muscle rigidity and rapid pulse and must be treated immediately. Additional common side effects are sedation, dry mouth, blurry vision, constipation, weight gain, sexual dysfunction, hypothyroidism, hepatic toxicity, and impaired memory (Newcomer, 2006). The potentially disabling side effect of long-term treatment is tardive dyskinesia (TD), involuntary facial movements such as grimacing, tongue thrusting, lip smacking, and eye blinking (Nevid et al., 2008).

The antipsychotic medication known as atypical antipsychotics such as perphenazine, fluphenazine, haloperidol decanoate, loxapine, risperidone, and clozapine have been used later to decrease negative symptoms. The atypical antipsychotics have low rates of extrapyramidal side effects which helps medication adherence (Schultz et al., 2007). However, they are more expensive than traditional medications so that their availabilities are limited. Some of them such as clozapine can cause a potentially fatal blood disease called agranulocytosis; thus, patients need to have their white blood cell counts monitored weekly which increases cost (Friedman, 2005). It additionally carries risk of substantial weight gain and potentially serious metabolic problems that can double or even triple the likelihood of death from cardiovascular disease (Remington, 2006). According to side effects, a meta-analysis study found that drop-out rates and relapse prevention were not better with atypical antipsychotics than with neuroleptics (Leucht, et al., 2003).

There are arguments that medications alone are not enough especially for residual or negative symptoms of schizophrenia. Behaviorally based programs in hospital to teach patients to improve their self-care and interpersonal behavior and to acquire work skills are conducted and lead patients to better and longer functioning outside the hospital (Mohr, 2006; Penades et al., 2006). Furthermore, treatment involves psychoeducation and family therapy for families has been developed to help them more understand about illness, cope with their high stress resulted from their relatives' illness, learn realistic expectations about schizophrenia, and facilitate patients' improvement and offer options for reducing hostile, critical, and emotional over-involved behaviors toward the patients to prevent relapse (Askey, Gamble, &

Gray, 2007; Falloon, 2003; Jeppesen et al., 2005; McFarlane, Dixon, Lukens, & Lucksted, 2003).

Onset and course of illness

The first onset and acute phase of schizophrenia typically emerges in the late adolescence or early adulthood (Corcoran et al., 2007; Reed, 2008) and infrequently occurs after the age of 45 years (Almeida, Howard, Levy, & David, 1995). It begins with the prodromal phase, the period when the process of disease begins but without any prominent psychotic symptoms (Corcoran et al., 2007) for which the early signs may be vague and hardly noticeable. Typical symptoms include behavior changes such as deterioration in role function and withdrawal from social interaction into a private world of fantasy and personal preoccupation (Corcoran et al., 2007; Nevid et al., 2008). Cognitive symptoms, including poor problem-solving, poor decision-making and illogical thinking are general and relatively severe at the early phase of the illness. The active phase of schizophrenia or the onset of the illness is the period that positive symptoms are prominent (Kaplan & Sadock, 2005) and its severity is an important reason for the first or subsequent contact to psychiatric service (Hann, Welborn, Krikke, & Linszen, 2004). The patients then enter the residual phase, in which their behavior returns to the level of the prodromal phase. Obvious psychotic symptoms are not present, but their cognitive and social functions are still impaired (Messias et al., 2005) which affect their effectively social living (Barch, 2003).

Although the course of schizophrenia varies greatly from person to person, it is generally chronic with acute psychotic relapses requiring frequent hospitalizations. Approximately 20% to 30% of patients with schizophrenia can lead somewhat normal lives. Another 20% to 30% continue to have moderate symptoms, whereas the illness significantly impairs 40% to 60% (Mohr, 2006). Over time, psychotic symptoms are unstable characterized with recurrence and relapse oftenly involved with a potential risk to self or others (Mueser & McGurk, 2004). However, several empirical studies suggest that the course of illness is most stormy at the early phase of illness and usually present some impairment throughout their lives though many of them experience remissions of symptoms later in life (Eaton, Thara, Federman, & Melton, 1995; Harrow, Grossman, Jobe, & Herberner, 2005). The long-

term poor outcome of illness course is also predicted by male gender, early age of onset, prolong the period of untreated illness, severity of cognitive and negative symptoms, and the outcome of treatments of the early phase of illness (Mohr, 2006; Tandon et al., 2008).

The early phase of illness

According to the definition of the early phase of schizophrenia, Birchwood, Todd, and Jackson (1998) pointed out that the early phase of schizophrenia was the period when most deterioration occurs and may represent a critical period for determining long-term outcome. In a study reviewing the treatment of early psychosis, Ehmann, Yager, and Hanson (2004) determined a five-year period following the first episode as the early phase of psychosis, including schizophrenia. However, Browne, Larkin, and O'Callaghan (1999) suggested that it is difficult to determine the period from the first onset to the time of the first diagnosis because it depended upon the families' awareness in the irregularities of their ill family member. Previous studies (e.g., Addington & Burnett, 2004; Addington et al., 2003; Addington et al., 2005; Addington, McCleery, & Addington, 2005; Barrowclough, Tarrier, & Johnston, 1996; Butzlaff, & Hooley, 1998; Eaton et al., 1992; The Scottish schizophrenia research group, 1992; Shiers & Lester, 2004) concerning the outcome of early stage of treatment and the early intervention for patients with schizophrenia and their families usually used the diagnosis made at the first contact as the starting point in the research methodology. The ranges of the patients' illness duration in these studies were varied within five years. Thus, it is reasonable to define the early phase of schizophrenia as the period from the first episode of schizophrenia that parents become aware that the changes are taking place in their children to within five years after the first diagnosis.

Unlike the other psychotic disorders, the outcome of the early phase of illness is a predictor of long-term outcomes. At the early phase of schizophrenia, psychotic symptoms are often relapsed. Studies indicated that the first relapse and the first readmission always occurred within five years of the onset but subside somewhat after five to 10 years (McGlashan, 1998; Robinson et al., 1999). Furthermore, a recent study indicated that brain volume was decreased of approximately 3% and lateral

ventricle was enlarged of approximately 7% during the first year of illness and significantly associated with functional outcome two years after the initial treatment (Cahn et al., 2006). Shiers and Lester (2004) suggested that the treatment outcomes at 2 years after symptom onset could predict illness severity 15 years later. Some studies found that after the first diagnosis, patients with schizophrenia showed an increase in relapse rate from 24% to 40% from two-year and three-year follow-up (Linszen, de Hann, Dingemans, & Wouters, 2006) despite the best treatments and attempts to intervene early (Leucht et al., 2003). Studies indicated that the patients had poorer response to treatment and longer remission in each subsequent episode (Lieberman, 1999; Lieberman et al., 1993). Studies supported that at five years after diagnosis, only 9-14% of the patients were in full remission (Robinson, Woerner, Delman, & Kane, 2005; Svedberg, Mesterton, & Cullberg, 2001), while 39% of the others were no longer to get further treatment (Svedberg et al., 2001). The remaining patients with schizophrenia continued to have moderate symptoms and significant social function impairments (Robinson, et al., 2005).

Empirical evidence indicates that there are multiple factors influencing relapse in the early phase of schizophrenia. Lacro et al. (2002) indicated that medication discontinuation was the prominent factor associated with relapse of patients with early phase of schizophrenia. A prominent reasons of patients' poor adherence indicated in some studies (e.g., Kazadi, Moosa, & Jeenah, 2008; Lacro et al., 2002) included factor of the patients and medication regimen.

It is evident that the patient's poor insight into illness, lack of motivation, poor memory, low education, and lower parental social class are the cause of medication nonadherence. Other predictors of medication noncompliance involved the patients' negative attitude toward taking medication, previous poor adherence, and substance abuse. The patient's factors sometimes associate with medication regimens. The complexity of the medication regimen, excessive cost or lack of access to medication, lack of social support, and perceived inadequate efficacy can also contribute substantially to medication noncompliance. In addition, Lambert et al. (2003) point out that, in the early phase of schizophrenia, patients are also more responsive to antipsychotic drug side effects than patients who have experienced multiple episodes. Suffering from these side effects of antipsychotic drugs led to

medications nonadherence among patients (Schultz et al., 2007). Besides, taking antipsychotic drug involve with perceiving stigma (Lambert et al., 2003). Furthermore, the psychiatric and mental health services such as inadequate discharge planning and poor therapeutic alliance are the factor related nonadherence.

The other significant factor involving relapse is environmental factor, including family and/or social supports. Though it is considered as the protective factor for the patients' course of illness, it can be a factor influencing patients' relapse. Studies indicated that at the early phase of mental illness, caregivers often had high express emotion (e.g., critical, hostile, and over-involved expression) (Bachmann et al., 2002; Patterson et al., 2005). Nuechterlein, Snyder, and Mintz (1992) suggested that such high emotional expression, attitude of significant others which had developed mostly if patients had more severity of illness and lived in the same household, also plays an important role in influencing the psychotic relapse. Kazadi et al. (2008) supported that patients with relapse had more frequent interpersonal stress and life-stress events than patients who had no relapse. Therefore, relapses in the early phase of schizophrenia can occur from a variety of causes.

In summary, schizophrenia is a chronic mental illness characterized by thought and perception disorder which typically occurs in adolescence and early adulthood with complex causes. The diagnosis is made through the continuous presence of two or more active psychotic symptoms such as bizarre delusions, hallucinations, disorganized behaviors, and negative symptom for at least six months and impairment of social functions. The treatments of schizophrenia are medication and psychosocial treatments. Schizophrenia is different from the other psychotic disorders by its psychotic symptoms, poorer functional outcomes, and slower recoveries from the episode. In the early phase of illness, patients' symptoms are often recurrent or relapse caused by multiple factors. The outcomes of treatments in the early phase of illness are also important for determining on the illness prognosis. These are the reasons why a course of schizophrenia is generally chronic presenting some impairment throughout patients' lives, though varied from person to person and why the early phase of illness is a critical period requiring substantial care.

Transition into Becoming Caregivers

Meleis, Sawyer, Im, Messias, and Schumacher (2000) defined transition as the passage or movement from one state, condition, or place to another triggered by critical event and changes in individual or environments. It connotes both of time and movement and can be thought of as linking change with experienced time (Meleis, 2010). It can also be both the process and the outcome of changes (Kralik, Visentin, & van Loon, 2006). Types of transitions which nurses encounter in working with patients and families include developmental transition, situational transition, health/illness transition, and organizational transition (Meleis et al., 2000). In a variety of transitions, people may undergo more than one transition at any given time. Moving from a parent of a normal child to a caregiver of a child with schizophrenia is a situational and health/illness transition. The diagnosis of schizophrenia makes unplanned changes in parents' lives and unexpected transition for them in being caregivers. Additionally, it is an unavoidable situation for parents to respond to their children's illness.

The pattern of transition in being caregivers can also be considered as a simultaneous and related transition (Meleis, 2010). Schumacher (1995) noted that transition into caregiving role simultaneously happen with the health and illness transition. While children are experiencing the transition in becoming mentally ill persons, parents are experiencing the transition in being caregivers. Additionally, while parents are experiencing the transition in becoming caregivers, they may be in midlife transition or becoming the elderly which is a developmental transition (Meleis et al., 2000). Although such transitions are not directly related at first, they may interrupt each other over time. During such transitions, their life structure usually comes into question and become a time of crisis in meaning, direction, and value (Meleis, 2010). Turner, Killian, and Cain (2004) described that in midlife transition, women usually faced the change in marital status, the change to a parental caregiving role, and the change in health status and those changes significantly increased depressive symptoms of them. Besides, Brody (1995) noted that it was common for midlife adults to make the transition to provide care for their aging parents. Therefore, being caregivers means parents have to deal with multiple changes such as the change of their children's health, the change of their role, and the change of their lives and

families. It also signifies making the choices that must be made, which may lead to forming a new life pattern, a commitment to new tasks, or interruption of their developmental tasks.

Studies concerning transition in becoming caregiver have mostly focused on the experience of caregivers who care for physically ill persons. Some studies examined the effects of transitioning into caregiving role (Mark, Lambert, & Choi, 2002; Skaff, Pearlin, & Mullan, 1996). The findings showed that parents in becoming new caregivers for children with a disability reported a significantly greater increase in depressive symptoms and fathers also reported a lower level of personal mastery. In addition, Skaff, Pearlin, and Mullan (1996) found that caregivers who continued to care for Alzheimer's patients at home over the 3-year period experienced the feeling of being trapped and having lost a sense of their own identity. These experiences were related to a decrease in a sense of mastery which involved with limited income and insufficient of emotional support. A grounded theory study explored the process of preparing for and beginning a new caregiving role following a family member's stroke (Silva-Smith, 2007). The investigator reported the dynamic process of restructuring life for caregiving. At the beginning of the new caregiving role, caregivers experienced waiting for information and a new better signs of stroke. Close to discharge, caregivers rearranged home environment, usual daily routine, employment situation, and other roles responsibilities to hold a new caregiving role. The rearranging phase of the experience continued through the first weeks to 4-week of caregiving after discharge. After that, caregivers, especially who cared for the patients with mild cognitive impairment marked a shift to feeling a sense that routines and care needs were stabilizing. On the other hand, caregivers who cared for the patients with severe cognitive impairment did not report reaching a point of increased stability. However, during the state of stability, a complication or new medical problem requiring medical care triggered a return to a reduce state of stability and thus, increased rearranging and additional waiting (Silva-Smith, 2007).

In addition, Herr (2010) explored the patterns of adaptation to caregiving role among caregivers who were spouses, mothers, and daughters of persons with physical disability. The major findings of this study revealed three collective patterns of movement. The beginning is characterized by both emotional and reactive

responses of caregivers. Emotional responses included denial, doubt, anger, and ambiguity. Then, caregivers began sacrificing his/her own needs to provide care for the care recipients through identifying resources for caregiving. In the middle journey, they moved to role accepting by working with previously identified support resources. They found that it became easier to identify and act upon care recipient needs. However, because of the main priority was caregiving, they experienced loss of dreams. It was a critical foundation for transitioning to the future, which was the end point. In the long term journey, the awakening of new self began to emerge. It was characterized by new perspectives, the process of grief, and the open sharing of the experience of others. These characteristics involved the loss of care recipient or in case that care recipient had experienced remission.

Correspondingly, the other qualitative study (Sherwood et al., 2011) exploring change in caregivers' perception in providing care for a primary malignant brain tumor over 4-month follow-up reported that after the patient's functional and behavioral changes, they experienced shock and fear. They felt emotionally closer to the patients shortly after the diagnosis. Relationships within family improved involving shifting priority to value personal time. Then, they had to reestablish family routines to accommodate the patient's changes. It took a long period of time for establishing the new normal of family routine. They also continued to additional responsibilities in balancing the family normalization. Four months later, they reported that they needed to be supported from family members, friends, or others who have been in similar situations.

The study actually focused on parents' experience of being caregivers of psychotic patients is rare. In a grounded theory study, Milliken (2001) explored the changes of parental role in caring for children with schizophrenia. The findings of this study revealed that parental identity was redefined over time. It involved an adaptation of their parental care involving four parental identities and three transitional states. At the initial stage of illness, they perceived their children's early deviant behaviors as normal, without any indication of impending mental illness. Therefore, they perceived themselves as *parent of a teen or young adult* (p. 152). When their children had excessively bizarre behaviors and then were diagnosed with schizophrenia, the parents faced the transition in *becoming marginalized* (p.152) involved becoming alarmed and

assuming responsibility for their children. This stage, parents perceived that no one appears to listen to them, to understand their experience and viewpoint, or to provide them with any useful information. Therefore, they defined themselves as *disenfranchised parent* (P. 152). Next, parents encountered *embracing the collective* (p. 153) involved connecting with others to overcome facing mental illness alone. This period, they entered to *re-enfranchised parent* (p.153) involved regaining their rights and responsibilities by taking on the mental health care system. After many years and the achievement of some benefits for their children, parents moved to the stage of *evaluating my life* (p. 153) They began to reassess how they wished to spend their remaining years and focused more on themselves or long ignored interests and moved towards mutual independence between themselves and their ill children. At this point, their parental identity was *emancipated parent* (p. 154). The other study explored the process of finding meaning in response to the diagnosis of a family member with mental illness among caregivers (Burrelsman, 2010). The major findings were categorized into stages of experience that became the journey of searching meaning. The findings revealed that caregivers moved to acceptance or found meaning in the midst of familial mental illness through a process that incorporates the succinct concepts of emotion, resources, knowledge, strategies, process, and coming to terms.

In Thailand, the study about parents' responses during the transition from being parents of normal children to caregivers of patients with schizophrenia in the early phase of illness has not been found. There was a grounded theory study exploring experience among 10 mothers in taking care for asthmatic children who were diagnosed in 1 to 6 years (Santati, Ratinthorn, & Christian, 2003). The findings revealed the process of struggling to take control the patient's symptoms. The mothers experienced six phases of passage from novices to experts, including searching out, seeking help, trying out and making changes, dealing with changes, never giving up, and finding ways to take control. When mothers experienced early symptoms of asthma, they tried to find meaning for their children's symptoms. As the process of asthmatic attack continued, mothers experienced more anxious and frustrated and tried to seek help. After their children's symptoms were diagnosed as asthma, mothers had to learn to provide the complicated care with less confidence due to insufficient or unpractical information. In providing care for their ill children, they had to change

their lifestyle to fit with caregiving demands. They not only had to manage the asthma, but also maintain household activities and their paid work. The mothers developed the strategies to control the symptoms as well as their own normal lives. However, they did not give up and tried to do the best from day to day. As time passed, mothers discovered their own ways and gain mastery in controlling all of their children's asthmatic symptoms.

These studies provided important information that transition in being caregivers has certain hallmarks. It is a slow process of recovery, with specific stages and reflected changes throughout the years. At the beginning, most of caregivers experience emotional distress. Then they try to seek help to reorganize their normal before moving to the state of balance that they experience a sense of mastery. Each stage of transition is dynamic. It can move back and forth triggered by the change of the patients' illness conditions.

The Impacts of Schizophrenia on Family Unit

The family is a critical resource for delivering health care to both individuals and families. Family members' health/illness status and the family mutually influence each other. Having a family member with schizophrenia impacts many areas of family, such as family financial security, psychological well-being of other family members, and all family relationships. Many studies noted that taking responsibility for the patients with schizophrenia at home affected parents' abilities for full-time employment (Chaffey & Fossey, 2004; Ip & Mackenzie, 1998; Mavundla et al., 2009; Wynaden, 2007). Although parents usually are the breadwinners in families, some of them had to give up paid work or reduce the length of their work hours to have more time to provide care for the patients and it affected family incomes (Chaffey & Fossey, 2004; Jungbauer et al., 2003). The previous studies also pointed out that at the early stage of illness, parents usually expected a cure; thus, they sought several treatments for the patients (Chen, Dunn, & Miao, 2005; Sanbrook & harris, 2003). Another source of financial burden is associated with patients' behavior. Mavundla et al. (2009) described that the patients sometimes destroy or sell household

properties. Parents reported that they had to spend much money on repairing or replacing such properties. In addition, Muhlbauer (2002) described that families experienced difficulties in gaining financial support because the existing governmental entitlement programs were complex and difficult to access. As a consequence, families experienced the financial burden of having and caring for the patients with schizophrenia at home.

Another area that schizophrenia evidently affects is family relationships. Previous studies supported that after parents made major changes in their lifestyles for full time care for their adult children, they provided less attention and isolated from other family members (Rose et al., 2002; Wynaden, 2007). In addition, they did fewer activities together as a family, and sometime mentioned disagreeing opinions with their spouses or within families about how best to care for the patients (Johansson, Anderzen-Carlsson, Ahlin, & Andershed, 2010; Saunders & Byrne, 2002), inducing the disruption in family routine and family conflicts (Provencher, 1996; Shyu, 2000). Chaffey and Fossey (2004) described that parents' routines be changed to meet the needs of the patients leading to some dissatisfaction of other family members. Mendenhall and Mount (2011) stated that parents faced difficulties to meet the needs of their entire family by balancing the need of the patients and other family members, and themselves. They also experienced difficulty to negotiate or communicate with other children when they did not accept the patients' problematic behaviors and sometime parents experienced loss of their mentally well children and grandchildren as a consequence of unresolved conflicts (Saunders & Byrne, 2002).

In addition, other family members were also affected by having family relatives with schizophrenia. Friedrich, Lively, and Buckwalter (1999) reported that living with patients with schizophrenia influenced on siblings' psychological well-being. They experienced anxious, chaos, and psychological distress from psychotic symptoms of the patients and fear regarding the potential for abuse when patients posed violent behaviors. In a phenomenological study, many siblings of individuals with first-episode psychosis described resentment against their ill brothers or sisters for taking so much of their parents' time (Sin, Moone, & Harris, 2008). They also experienced feelings of being overwhelmed by their brothers' or sisters' onset of psychosis. They talked about shame and embarrassment of having siblings with the

mental illness at home and concealed the illness of their siblings. Johansson et al. (2010, p.696) described that some siblings ignored their own need to support the patients on the attitude that if the whole family applied for care, they would be considered as a “madhouse.” On the other hand, Sin et al., (2008) noted that some siblings worried about the stress and strain faced by their parents and their own future lives; thus, they tried to support their parents, such as sharing the caregiving with their parents and had to be more supportive of the family as a whole. They also had to be as their ill siblings’ social companion through concerning its importance and therapeutic for them. Rungreangkulkij, Chafetz, Chesla, and Gilliss (2002) found that the psychological status of the family members was affected by stress of family life resulting from caregiving, rather than from the mental illness itself.

In summary, adjusting parents’ work life to take responsibility as primary caregivers for children with schizophrenia affects family financial security. The changes of parents’ lifestyle and family chaos resulting from having and caring for children with schizophrenia affects family relationships, as well as family members’ psychological well-being.

The Impacts of Caregiving on Parents’ Lives

Empirical evidence supports that caring for persons with mental illness brings about impacts to parents’ lives in multiple aspects. After their children were labeled by a mental illness diagnosis, parents experience a feeling of loss. Karp and Tanarungsachock (2000) described the reaction of parents to mental illness diagnosis that though they relieved after having an explanation for previous inexplicable behaviors, they also concerned over the long-term consequences of the illness and perceived loss and grief. In terms of loss, many studies described that it was as losing the person they once knew (Champlin, 2009; Parker, 1993; Wynaden, 2007). The grief for losing the children to the mental illness was unlike the general grief. Parents did not receive the comforts that society provided for death. There was no funeral, no flowers, no note of condolence, no gathering of friends and family (Muhlbauer, 2002; Parker, 1993). Additionally, feeling of loss, grief, and worry were constantly recurring and rarely resolved because the patients were always there (Muhlbauer, 2002; Pejler,

2001; Rose, Mallison, & Gerson, 2006). Muhlbauer (2002) described that loss additionally associated with patients' symptoms. Loss and grief were intense if the patients' symptoms were not responded to medication or parents realized that relapses or exacerbations were the norm of their loved ones' illness. Jungbauer et al., (2003) described that the parents always experienced feelings of sorrow and bitterness when they compared the patients with former classmates or with their siblings.

Empirical evidence suggests that parents have to adjust their lives to care for their adult children. In a phenomenological study, McCann et al. (2011) described parents' experience in living with children with first episode schizophrenia that they worried that the patients might never manage to live independently; hence, they had to live together with them and delay their leaving home, change their retirement plans, and prolong gainful employment to sustain the running of the family home and the prolong active parenting role. Studies indicated that parents perceived their caregiving role as an extended parenting role and a burdensome and endless responsibility (McCann et al., 2011; Sin et al., 2005). They also perceived as it was emotional distress and as if they were on a steep learning curve in taking on the role of caregivers in addition to their parental role. It is very difficult for them in accepting their caregiving role considered as the dealing with a complex and multifaceted problem. They also had to take other responsibilities in the family. Milliken (2001) reported in responding to meet the completion of other obligations, such as jobs, elderly parents, and family members led parents experienced being pulled in many directions, leading to frustration, guilt, and conflicts. However, they sustained their caregiving role through a sense of love and obligation to their children (McCann et al., 2011; Sin et al., 2005).

In addition, several parents perceive burden from adjusting their work life. In difficulties of caregiving, some parents had to stop their paid work (Chaffey & Fossey, 2004; Jungbauer et al., 2003). Many caregivers who were seeking to remain gainfully employed experienced difficulty in balancing their paid work and caregiving needs. These caregivers felt drawn in conflicting directions: being good employees, good parents, and good caregivers. They had repeatedly demonstrated that they may need flexible working hours, a paid leave of absence, resource information, and other assistance to effectively perform their responsibilities both at home and work (Keene

& Prokos, 2007). Pruchno and Patrick (1999) found that levels of burden and difficulties were high among parents who dealt with the difficulties of caregiving alone.

Furthermore, empirical evidence suggests that parents encounter the change in relationship with the patients. Studies indicated that after hospitalization, parents perceived loss of trust from the patients because of taking them to receive treatment (Ip & Mackenzie, 1998; Miliken, 2001; Parker, 1993). Additionally, parents were often afraid that the patients might harm them or other family members; hence, they distanced from them. Unlike spouses' responses, Jungbauer, Wittmund, Dietrich, & Angermeyer (2004) described that spouses often conflicted with their ill partners and perceived the emotional burdens in everyday life caused by declining in sexual activities and reducing the physical attraction of the ill partners. These causes were the consequences of the negative side effects of their medication, such as sexual dysfunction and weight gain. Such burdens were the sources of their potential conflict resulting in relationship changes. Several studies indicated that parents experienced disruption of social relationships caused by spending most of their time for caregiving and could not attend social activities (Mavundla et al., 2009; Rose et al., 2002; Velman et al., 2002; Wynaden, 2007). Mavundla et al. (2009) described that change in relationship with others was associated with parents' involvement in caring for the patients. They could not attend church services, funerals, and other important tradition functions. It was also associated with the stigma of disease (Champlin, 2009; Phelan, Bromet, & Link, 1998).

It is evident that parents conceal their adult children's mental illness in dealing with stigma. Studies pointed out that parents perceived they were unappreciated, blamed, misunderstood by the general public and sometimes by mental health professionals (Velman, et al., 2002), and shunned away by society (Wade, 2006) and revealed feelings of guilt as they seem to be viewed as the cause of illness confirmed by some forms of psycho-education (Karp & Tanarungsachock, 2000; Pejler, 2001). Johansson et al. (2010) indicated that single parents, especially mothers experienced a feeling of being exposed as mothers of patients with schizophrenia leading to mistrusting other people. They feared and worried that their friends and neighbors would avoid them and treat them differently (Thara & Srinivasan, 2000),

and gossip about them (Ip & Mackenzie, 1998). As a consequence, they responded to their perceptions by concealing and avoiding talking about the patients' mental illness. Lui et al. (2007) supported that some parents stated reluctance to invite friends into their home since their loved ones had become the patients with schizophrenia. Similarly, Chang and Horrocks (2006) also described that parents tried to confine the information about their adult children's mental illness to protect their family name and to avoid losing face to relatives or friends. Phelan et al. (1998) found that half of parents reported concealing the hospitalization at least to some degrees. They were more likely to conceal the mental illness if they did not live with the patients, if the patients were female, and had less severe positive symptoms. They, sometimes, deliberated to keep the patients away from other people because of stigma. The investigators of this study noted that the sense of being stigmatized of parents may have constricted them in using effective coping patterns or seeking social support inducing greater distress and burden.

Some studies reported that parents, in living with chronic stress and strain of taking care for the mentally ill adult children, were more likely to have health problems (Dyck et al., 1999; Greenberg et al., 1993; Turner et al., 2004). Schene, van Wijngarden, and Koeter (1998) found that most parents who cared for children during the early phase of schizophrenia spent more times per week for direct contact with their ill children than those who cared for children with chronic schizophrenia. Chaffey and Fossey (2004) also reported that parents had little time for themselves to chores, to relax or concentrate on things they would like to do and also perceived loss quality of time with other family members or friends resulting in a sense of being trapped. They also experienced less satisfaction with their lives (Foldemo, Gullberg, Ek, & Bogren, 2005) and perceived the caregiving role as a burdensome responsibility (McCann et al., 2011). Milliken (2001) described that most parents reported some difficulty with sleeping because of worrying through the night. Some parents developed some physical problems such as periodic tightness in the chest, severe and early osteoporosis, hypertension, heart attack, and weight gain. Similarly, Upasen (1998) found many physical problems among parents providing care for children with schizophrenia, such as tiredness, headaches, high blood pressure, and sore throat. Correspondingly, Turner et al. (2004) found the increasing of depressive symptoms

among parents who cared for children with schizophrenia. In addition, Tennakoon et al. (2000) found that parents who were living with patients had more frequent visits to their general practitioner than those who were not living with the patients.

In summary, being caregivers of children with schizophrenia, parents are affected in several aspects of their lives. Most of parents experience loss and grief for children they once knew. They have to adjust their lives and face with difficulties in balancing their work life and meeting the needs of the children with schizophrenia and the other family members. They additionally experience a change of relationships with their ill children caused by loss of trust from them and their troublesome behaviors. They also experience a change of relationships with communities because almost of their time is spent in providing care. Stigma of disease makes them additionally loss of relationships with communities. Parents are likely to conceal and avoid giving information of their adult children's mental illness to others. Living with a chronic strain of caregiving and having little time for taking care of themselves consequently affects their health status.

Caregivers' Experiences in Context of Other Countries

This section is an organization of several qualitative studies relating caregivers' experience which mostly focusing on a wide range of caregiving duration and the experiences at the early phase of illness is a bit part. The caregivers' experiences are grouped into five parts running from the period before the patients' diagnosis to turning points, including the perceptions and reactions before the diagnosis, the difficulties of caregiving tasks, transcending the difficulties, support from the mental health care system, and turning points.

Perceptions and reactions before the diagnosis

Empirical evidence suggests that before the diagnosis, parents experience psychological distress as they struggle to understand and deal with things happened to their adult children. Corcoran et al. (2007) noted that the early signs of schizophrenia were hardly noticeable. The main symptom was a slow change in behaviors and mood as they entered the teen years; hence, it was not easy for parents to detect the psychotic

symptoms. Muhlbauer (2002) defined the initial phase of illness as “the storm warning” (p.1082) which parents had an awareness of something wrong with their adult children, but they were unable to define that wrongness. The previous studies indicated that parents felt utterly bewildered by their adult children’s behaviors and did not know how to react behaviorally and emotionally (Karp & Tanarugsachock, 2000), and felt as if they were floundering in the dark until the confirmed diagnosis was made (Jeon & Madjar, 1998)

Studies in caregivers with other relationships with patients reported the caregivers’ responses in similar ways. In a grounded theory study exploring 52 spouses’ experience in living with partners with schizophrenia, Jungbauer et al., (2004) also described that spouses could not interpret their partners’ psychotic symptoms as an expression of mental illness. Seloibe (2006) described that when relatives first became ill and caregivers noticed changes in their relatives’ behaviors, they were shocked, wondered in disbelief what may have happened to their loved ones, why them, and what may be the causes of the changes. They searched for help based on their beliefs in attempting to know what an actually going on was. Some studies reported that families often thought that drugs or stress was the cause of their relatives’ changes (Haan et al., 2004). The other studies described that they initially tried to compensate and dreaded making decisions because of fear for mistaken actions (Mohr & Regan-Kubinski, 2001). They had to adjust their coping to take each day as it comes (Jeon & Madjar, 1998). In addition, Muhlbauer (2002) and Haan et al. (2004) described that families tried to manage the difficulties and delayed seeking help from psychiatric services until their relatives’ troublesome behaviors became evident in the form of bizarre behaviors which were uncontrollable. This reason led them to take their ill relatives to the mental health care system to receive the diagnosis and treatments.

The difficulties of caregiving tasks

It is evident in the literature that caregivers experience difficulties in dealing with a wide range of caregiving tasks. Studies noted that because deinstitutionalization attempted to decrease the hospital length of stay, most of mentally ill patients returned home while still experiencing psychotic symptoms; thus,

dealing with difficulties of patients' behaviors in a new circumstance was a vital task of caregivers (Guarnaccia & Parra, 1996; Thongkhamrod, 2006; Valfre, 2001). Ferriter and Huband (2003) described that caregivers had to deal with patients' troublesome behaviors, such as sleeping during the day and remaining awake at night, speaking aggressively, and acting out violently. Parker (1993) described that caregivers had difficulties in interacting with their ill relatives when they demonstrated the psychotic symptoms. They wondered what reactions could be effective for controlling their ill relatives' symptoms. Some studies suggested that caregivers, especially parents and those who were living with the patients, always behaved in hostile, critical, or over-involved manner toward patients' troublesome behaviors in an attempt to reduce the perceived stress of caregiving and loss (Bachmanna et al., 2002; Bentsen et al., 1998; Patterson et al., 2005). Such expressions of caregivers have been considered as a disturbed family environment influencing patients' relapse (Freeman & Garety, 2003; Gleeson et al., 2009; Kuiper et al., 2006). Some studies supported that the patients from high EE families stand a higher risk of relapsing than those with low EE families (Kopelowicz, Liberman, & Zarate, 2006; Van Humbeeck, Van Audehove, de Hert, Pieters, & Storms, 2002).

Empirical evidence reveals that caregivers face not only the difficulties of patients' behaviors, but also their unpredictable symptoms. In a phenomenological study exploring the experiences of caregivers of the patients with first episode schizophrenia, McCann et al. (2011) described that caregivers perceived caregiving as a roller coaster because of an unstable of psychotic symptoms. Copeland and Heilemann (2011) reported that parents of children with mental illness and a history of violence perceived their lives as going around the circles resulting in harassing and frustrating. In dealing with unstable situations, Rose et al. (2002) described that caregivers were uncertain to let them take care of themselves. They had to keep watching patients' behaviors and try to understand their symptoms. They felt being consumed by the illness and the feeling of anger at the health care system for poor treatment and lack of clear information. They described a sense of crisis and needed helps, especially during many repeated hospitalizations.

In addition, the other important task is stabilizing the patients' illness. Studies reported that the hardest task was having the patients to take medication

regularly at home (Huang, Hung, Sun, Lin, & Chen, 2009; Mavundla et al., 2009). Mavundla and colleagues (2009) described that caregivers needed to supervise their daily administration of their medication because the patients had poor insight and their comprehension of treatment regimens was inadequate. Patients often stopped or refused to take their medication, especially when they developed side-effects or became discouraged when they did not feel better. The other study described that caregivers also faced the difficulties in taking the patients to the hospital to regular follow-up of their treatment (Champlin, 2009). It is very hard when their symptoms were uncontrollable. They had to call authorities such as the police to assist them, which was complex and never easy because the psychotic symptoms were unpredictable. Muhlbauer (2002) reported that in doing this task, caregivers struggled with ethical dilemmas related to control, autonomy, independence, privacy, and freedom of their loved ones.

Empirical evidence shows that caregivers have to additionally provide endless basic supports for their loved ones. Studies suggested that caregivers' major concern of their relatives was about their social function impairment; thus, they had responsibilities for providing basic supports for their ill relatives (Mavundla et al., 2009; Muhlbauer, 2008). Chaffey and Fossey (2004) described caregivers' responsibilities, including household chores, getting prescriptions, monitoring medication, doing banking and shopping, providing transport, and running general duties. Similarly, Jungbauer et al. (2004) described that many spouses had to take on additional duties in the partnership and family, involved unfamiliar or gender specific tasks which had been the duty of the patients before the illness. Mavundla et al. (2009) reported that caregivers also had to provide psychological support by engaging their ill relatives in many social activities to increase their self-esteem and self-worth. When the patients' symptoms were worsened, caregivers additionally provided complete care for their relatives' personal hygiene, diet, and medication. Even though their mentally ill relatives were able to function quite independently, Chang and Horrocks (2006) reported that caregivers needed to regularly provide them with food and shelter and occasionally check or supervise their mentally ill relatives' medications and behaviors. These tasks were difficult and challenge when the mentally ill relatives refused to cooperate. In dealing with such caregiving tasks, Veltman et al. (2002) described that

caregivers perceived that they were everything in 24- hour caregiving, such as a nurse, a social worker, a psychiatrist, a cook, but nobody recognized their efforts.

Transcending the difficulties

Research evidence shows that caregivers seek for the suitable different ways to overcome their difficulties of caregiving. Many studies noted that caregivers went through a period in which they actively learnt to save or cure their loved ones (Harden, 2005; Karp & Tanarugsachock, 2000; Seloibe, 2006). They became more aware of any information about the illness and sought in several ways to know more. They learnt how to survive amid all problems. They found some strategies that worked for them in coping with day-to-day situations, including being compassionate, playing tricks, being dishonest, being manipulative, and accepting and negotiating the situation (Karp & Tanarugsachock, 2000; Seloibe, 2006). Correspondingly, Chang and Horrock (2006) described that caregiving skills and tacit knowledge that caregivers had acquired through experience and learning to accept the disabilities of the ill relatives and their caregiving situation were invaluable for them to cope with the day-to-day caregiving.

In grounded theory study, Rose et al. (2002) described that the normalcy process including confronting the ambiguity of mental illness, seeking for control impact of illness, and seeing possibilities for the future was used as a central concept for caregivers of the person with severe mental illness. Muhlbauer (2002) described the caregivers' experience as phases in a journey, using the metaphor of *navigating* (p.1802) through a storm in perilous sea with few experienced guides. They mastered the navigational skills which were necessary for enduring this storm by seeking knowledge from self-help groups, learning methods to get desperately needed information from health professionals, developing expertise in managing the illness and supporting their loved ones, as well as discovering personal strengths in the process by using religious supports and adjusting their perceptions on the illness. Another study noted similarly that caregivers employed positive thinking, acquisitive knowledge, and the direction received from their religious support to rearrange their life and re-start a new better way in dealing with difficult circumstances (Huang et al., 2009).

Empirical evidence notes that parents have to adjust themselves to accept their caregiving role. McCann et al. (2011) described that parents had to accept firstly the changes in their ill children that were not a temporary phenomenon, but required long-term role change. They additionally necessitated accepting their circumstances, maintaining hope, and coming to terms with the change in their role of normal parenting to parental caregiving. Similarly, Pejler (2001) reported that concentrating on positive aspects of life and being involved in one's own interests, accepting the illness, and maintaining hope for a better lifestyle for the children were revealed as being helpful in coping with difficulties of parents. In addition, Milliken (2001) described that parents fought for their *suffrage* (p.153) to take care of their ill children by engaging in volunteer works, advocating for mentally ill adult children, and improving public education and knowledge about schizophrenia.

Supports from mental health care system

Research evidence supports that in dealing with difficulties, caregivers need information and help from health care providers on how to take care of the patients and need to be accepted as a part of caring for their ill relatives; however, their needs were unmet. Many studies reported that, in the first few years of contact with psychiatric care, families perceived that they were excluded and their suffering was not in health care providers' awareness (Copeland & Heilemann, 2011; Doornboss, 2002; Harden, 2005; Pejler, 2001; Rose, Millinson, & Walton-Moss, 2004). Milliken (2001) described that, in dealing with the mental health care system, they had to redefine their parental identity over time. Perceiving the loss of their rights to care for their ill adult children, parents redefined their identity from parents of teens or young adults through *disenfranchised parents* (p.152).

In addition, studies asserted that caregivers experienced greater psychological distress because the post-hospital care and the supports for families were limited (Noh & Turner, 1987; Veltman et al., 2002). Studies that included parents of children with bipolar or schizophrenia showed consistent findings of inadequate patterns of supports in the health care system (Moore & Beckwitt, 2003; Pejler, 2001; Veltman et al., 2002). Veltman et al. (2002) described that the legal and medical system cared for patients only, not for caregivers. They were very eager to

talk about their struggle for system, including hospitalization needs, treatment concerns, financial oversights, and changes they would like to see in the system. Ip and Mackenzie (1998) asserted that caregivers needed emotional support in handling the ill relatives' affairs; however, they perceived they were alone in their situation, nothing could be done to change things, and nobody could help them out of their caregiving situation. Some studies described that caregivers desired respite care, assistance, and affirmation and validation from the mental health community for their sacrifices and caregiving efforts. Nonetheless, caregivers felt voiceless when they attempted to communicate their concerns with mental health providers (Copeland & Heilemann, 2011; Veltman et al., 2002).

The other studies suggested that caregivers faced the difficulties in dealing with mental health providers and they could not utilize social support of the mental health care system as a consequence (Doornboss, 2002; Muhlbauer, 2002). Harden (2005) and Mavundla et al. (2009) described parents of young people with mental health problems that they experienced discriminating by the medical profession. They were given unclear information about the initial diagnosis and the development of treatment regimens, making them frustrated. Wade (2006) noted that parents perceived health care practitioners as unknowledgeable, uncaring, and inattentive, which was incomprehensible for them. Psychiatrists were unable to spend more than a few minutes with them every few months, and consequently little education was provided to them. Some of parents relayed stories of feeling mistrust in psychiatrists' knowledge of their adult children's illness and its medications and feeling abandoned. These experiences left them the feeling of helplessness and unable to fulfill their caregiving role.

Turning points

It is evident that caregivers, in long-term care, find themselves being at the turning points to rearrange their new lives from caregiving role. Many studies described that caregivers felt as if they were cheated out of the life they had expected for themselves; thus, they had more inclination to allow themselves to do what they had wanted to do even though those made them felt guilty (Copeland & Heilemann, 2011; Huang, Sun, Yen, & Fu, 2008). Milliken and Rodney (2003) described that

parents emancipated themselves from caregiver role when they realized that they grew older, they may have some health problems, and their ill children may function better. On the other hand, in a phenomenological study which included caregivers with different relationship with patients, such as spouses, adult children, and siblings, Karp and Tanarugsachock (2000) described that when caregivers realized that their relatives' illness was chronic and was well beyond their control, it was their turning point to allow themselves to withdraw from the caregiving role without guilt. Similarly, Jungbauer et al. (2004) described that for spouses of the mentally ill persons, although at immediately after onset of the illness they showed great solidarity with the ill partners and strongly rejected the thought of separation, they decided to choose their new better lives when they felt that taking care of the patients permanently demands large personal sacrifices but limited chances of restoring a satisfactory coexistence.

In summary, being caregivers is a process that involves devastation. It is accompanied by uncertainty, emotional distress, interpersonal disturbance, and turmoil. It involves burdensome responsibility as a result of trying to regain control following the disruptive event. Before the adult children's diagnosis, it is difficult for parents to recognize what has happened to their loved ones; hence, parents experience psychological distress by the dazed behaviors of their ill children and wonder how to react appropriately. They initially try to manage the difficulties by themselves until the psychotic symptoms are prominently occurring and uncontrollable then they seek help from the mental health care system.

In being caregivers for mentally ill persons, caregivers face with the difficulties of patients' symptoms. Most of them experienced the strain of managing the patients' troublesome behaviors in a new circumstance. Because of stress, they are likely to behave toward the patients with hostile, critical, or over-involvement manners which have been considered as a disturbed family environment preceding patient's symptom relapses. Under unstable symptoms of the patients, caregivers have to closely live with the patients to monitor their symptoms, provide basic supports for them which are burdensome and endless responsibilities. They additionally have to manage the patients' medication for stabilizing the illness and preventing relapse, which is difficult to handle because the patients usually refused to cooperate. Amid

their chaotic lives, they seek the appropriate strategies to cope with the day- by- day, including accepting the illness and their caregiving role, seeking knowledge and developing needed skills for managing the illness, and maintaining possible hope and the normalization of their families' life. They perceive a lack of supports and abandonment of the mental health care system in mastering their difficulties of Caregiving role. Finally, when they realize that their lives are swindled, they are too old to do caregiving role, in particular parents, the patients can function better, or their hope that the patients should be cured is impossible, caregivers are likely to let themselves to live free from the difficulties of caregiving.

Though the previous studies provide information which enhances understanding about a sequential progression of caregiving experience running from the period before the diagnosis through a turning point in a long-term care, these studies have a primary concern in caregivers' responses in dealing with their relatives' illness. In addition, the caregiving experiences were captured from the wide range of caregiving duration for over ten years (e.g., Muhlbauer, 2002; Seloibe, 2006; Rose et al., 2002; Rose et al., 2006; Wynaden, 2007). The relationships with patients were various including parents and others (e.g., Jungbauer et al., 2003; Karb & Tanarugsachok, 2000; Muhlbauer, 2002; Pejler, 2001; Rose et al., 2002; Rose et al., 2006; Seloibe, 2006). In addition, care recipients in each study were variably diagnosed, such as schizophrenia, schizophrenia related disorders, and mood disorders (e.g., Copleland & Heilemann, 2011; Muhlbauer, 2002; Karb & Tanarugsachok, 2000; Rose et al., 2002; Rose et al., 2006; Wynaden, 2007). Some studies did not indicate the duration of caregiving (e.g., Copleland & Heilemann, 2011; Karb & Tanarugsachok, 2000; Milliken, 2001) and the actual diagnosis of the patients (e.g., Mohr & Regan-Kubinski, 2001; Pejler, 2001). It reflects the rare attention on the homogeneous caregiving experience of parents who are the majority group of primary caregivers and have a very close kinship tie with patients, in being caregivers for the patients with schizophrenia, particularly in the early phase of illness which is the critical period for both patients and parents. There is no clear cut about the experience in the first five years after the diagnosis—how parents deal with the difficulties over time and what conditions influencing the dealing process in this period are. In addition, parents' responses in adjusting their personal and family lives amidst the

chaos of being caregivers for patients with schizophrenia in the early phase of illness are also little known.

Caregivers' Experiences in Thai Context

To understand the experience of caregivers in Thai context, Buddhism and Thai context is essential to present in the first section. The following sections are conceptualization of Thai previous researches composed of perspective on mental illness and caregiving, responses of caregivers on mental illness and caregiving role, and utilizing mental health care service.

Buddhism and Thai context

Available evidence indicates that Thailand is a predominantly Buddhist country. Buddhist teaching has influenced Thai people's perspective on life and has been an integral part of Thai culture (Sanseeha, Chontawan, Sethabouppha, Disayavanish, & Turale, 2009). The important feature of Buddhism is the notion of *karma*. It is an absolute theory about cause and effect indicating that individuals may come into the world with consequences of *karma*, intentional actions. The present life is a consequence of the cumulative deeds of the past life and the present deeds determine the future (Payutto, 1993, 1994). Therefore, Thai people emphasize making merit or *kusala* for accumulating good karma in their present lives (Chunuan, Vanaleesin, Morkruengsai, & Thitimapong, 2007). *Kusala* can be a calmness or pure body and mind including *sati*, mindfulness or recollection; *metta*, goodwill or a desire to make others happy; non-greed, absence of desire and attachment (including altruistic thoughts); *karuna*, a compassion or sympathy toward those who need help; *mudita*, a zeal or contentment with the good, a desire to know and act in accordance with the truth, and a gladness at the good fortune of others; *ubekha*, an impartiality or equanimity toward others; and *wisdom*, a clear understanding of the way things are (Bhikkhu, 2007; Mererk, 1994).

Making merit is also involved with the concept of *bunghun* and *katanyu katavedi* of Thai culture. *Bunghun* is defined as good things, favors, or meritorious help (Subgranon & Lund, 2000). Once individuals receive good things, favors, or

meritorious help from others, it is their long-term obligation to pay back (Podhisita, 1998). The repaid actions are related to *katanyu katavedi* or a gratitude that one has toward *bunkhun* of the others and an obligation actions for paying back in interpersonal relationship which is a social expectation in Thai society (Kespichayavatana, 1999; Subgranon & Lund, 2000).

In addition, Buddhism teaches about the causes of suffering and solution existed in the *Four Noble Truths* and the *Noble Eightfold Path*. The Noble Truths composes of suffering/uneasiness (*dukkha*), cause of suffering (craving), the cessation of suffering or a liberated state of enlightenment (*bodhi*); and the path leading to the cessation of suffering (Bhikkhu, 2007; Mererk, 1994; Payutto, 1993). *Dukkha* is as in the condition of being disturbed. It can be a sorrow, an affliction, an anxiety, a dissatisfaction, a discomfort, an anguish, a stress, a misery, and a frustration induced by several causes including birth, old age, illness, death, lamentation, resentment, being associated with the non-beloved situations or even with the loved things, not to get what is wanted, and even get too much of what is wanted. To reach this liberated state, Buddha provided direction for happy living, the *Noble Eightfold Path*: right understanding, right thought, right speech, right action, right livelihood, right effort, right mindfulness, and right concentration (Bhikkhu, 2007; Payutto, 1993).

Buddhist also influences in shaping certain Thai characteristic traits and perspective of the harmony and smoothness of interpersonal relationship. Cultural hierarchy identifies respective positions of Thai people and influences the types and forms of appropriate and harmonious behaviors (Knutson, 2004). Thai society requires people to behave in ways of politeness, avoid bothering or imposing on others, and avoid confronting and conflict. Children are taught to be obedient, docile, and submissive towards their parents. They have to express loyalty and compliance to elders and authority figures, such as teachers, Buddha, and other religious symbols (Chunuan et al., 2007).

Thai characteristic traits involve the use of word *heart* or *Jai* which is the most frequent metaphor in the Thai language (Knutson, 2004, p. 151). Thai people use the word *Jai* for the meaning of both heart and mind (Moore, 1992). *Jai yen* is characteristic of remaining calm required in behavioral pattern in the difficult situation of everyday life (Komin, 1991). *Jai dii* is the other Thai heart expression referred to a

state of goodness and performing tasks for others before a request is made. In relationships, Thai people usually use the word *Kreng Jai*, the desire to avoid embarrassing others or creating discomfort or annoyance for other people. In addition, *Thum-Jai* is the word often used when Thai people face with an unchangeable situation to make a calm mind. It represents a combination of accepting, understanding, reasoning, and having patience and a sense of obligation (Rungreangkulkij & Chesla, 2001). Such characteristics have often been explained by Buddhist teaching of *Middle Path*, *Detachment*, and *Equanimity* (Komin, 1991). It is a path of moderation away from the extremes of self-indulgence and self-mortification (Payutto, 1993). Buddhist teaching influences Thai's worldviews and their ways of lives.

Perspective on mental illness and caregiving

Empirical evidence suggests that Thai people view mental illness, including schizophrenia based on superstition and Buddhist belief. Super natural beliefs which are the principles of Hinduism and inherited through Indian influence are constantly present in Thai society (Ratanatikanon, Assanangkornchai, & Tanchaiswad, 1997). Ghosts were viewed to be a cause of mental illness for a long time (Suwanlert, 1976). Even in a previous study, Burnard, Naiyapatana, and Lloyd (2006) reported that even though Thai people had gained scientific knowledge, they had still believed in ghost as a cause of mental illness. Correspondingly, Sanseeha et al. (2009) described that even though most of Thai caregivers believed in other causes of mental illness such as stress and gene, the black magic was viewed as a cause of mental illness of their loved ones. In addition, Burnard et al., (2006) reported that *Kwan*, a concept usually mentioned as life spirit or life force, was a cause of mental illness especially when it leaves the individuals' body.

Based on Buddhist teaching, most of Thai people perceive mental illness and caregiving for mental illness patients as *karma*, the effect of bad deeds in a past life (Burnard et al., 2006; Sanseeha et al., 2009; Subgranon & Lund, 2000). If one makes merit, one can take a pleasant consequence in the future (Payutto, 1993). As such belief, Thai people also perceived caregiving as a good karma or making merit returning a good result in their present or next life (Wongchaiya, 2007). Caregiving is

a social expectation that it is obligation of family to take care of the ill relative (Wongchaiya, 2007). Caregiving also represents another aspect of Buddhism, the gratitude to parents, siblings, teachers and those who provided support and care known as *katanyu katavedi* (Subgranon & Lund, 2000). In addition, because of Thai cultural value, though caregivers have a great deal of suffering, they should not express their frustration at the responsibility of being caregivers (Wongchaiya, 2007).

Responses of caregivers on mental illness and caregiving role

Data from Thai studies which capture a wide range duration of caregiving experience of caregivers who had a variety of relationships with mentally ill patients suggests that Thai caregivers' responses to mental illness are based on their belief. Because of the belief of a ghost as a cause of sickness, they firstly took the ill person to see the monk or spiritual healer to release the ghost out of the body (Burnard et al., 2006). In addition, empirical evidence indicates that Thai people use Buddhist teaching to overcome their difficulties of caregiving. A phenomenological study in parents, grandparents, siblings, spouses, and a daughter caring for schizophrenic relatives who were hospitalized for 1 to 12 times revealed that caregivers responded to their relatives' illness by practicing their Buddhist beliefs such as *matta* (caring) and *karuna* (support) to generate compassion in giving care. They also practiced *The Noble Eightfold Path* in managing their caregiving tasks (e.g., stress management, symptom management, and treatment management). Additionally, they practiced *ubekkhā* (equanimity) to promote acceptance for caregiving (Sethabouppha & Kane, 2005).

The other phenomenological study in 12 Thai mothers of adult children who had been diagnosed with schizophrenia for 3 to 13 years revealed that Thai mothers used practicing *Thum-Jai* in dealing with the patients' symptoms and responding to social values that parents must care for their adult children. Parents also created a calm family environment by being highly patient with patients' behaviors and responding to them in gentle, supportive, and non-confrontational manners to avoid an escalation of their psychotic symptoms (Rungreangkulkij & Chesla, 2001).

Additionally, it is evident that in caregiving process, Thai caregivers develop their repertoire of management skills for caregiving tasks through direct

experiential learning and their caregiving experiences are changed over time. In grounded theory study, Sukmak et al. (2001) explored coping response process among 14 caregivers, including mothers, siblings, and wives who cared for patients with schizophrenia for 5 to 40 years and found that coping responses were changed over time. There were four stages of coping responses. At the early phase of illness, caregivers experienced confusion. Expecting cure led them to later seek help in several ways. During the treatment course, caregivers had to adjust their lives by living together with the patients to monitor their symptoms and check medications, being the informant for health care providers, seeking helps from other sources, and planning for the patients' future. In the long term of illness, they faced with the repetitive problems and moved to stage of exhaustion. As a consequence, they tried to leave their responsibilities because of hopelessness.

In other grounded theory study, Dangomyouth et al. (2008) discovered the process of giving care for patients with schizophrenia among 17 family members who had caregiving duration of 1 to 15 years. The findings showed the nature of caregiving for the patients with schizophrenia. The researcher identified caregiving strategy called *tactful monitoring* (p. 42) representing awareness in treating patients respectfully. Their strategies included unobtrusive observation and strategies for calming to avoid psychotic episodes. They managed the patients' symptoms by keeping eyes on and questioning and asking them about their symptoms, and sometimes they had to restrain the patients to control their severe disturbing behaviors. They also had to manage medication by checking, monitoring, and reminding the patients for taking their medication.

Similarly, Tunkpunkom (2000) explored the role and skill development process among 30 mothers who lived with and cared for the patients with schizophrenia or related disorders for 7 months to 10 years. The findings revealed that mothers had to both manage their tasks and adapt themselves in doing their caregiving role to maintain a balance of their lives. The three major care tasks were identified, including normal parenting, psychiatric symptom management, and medication management. Mothers tried to develop their repertoire skills for managing caregiving tasks for various circumstances through direct experiential learning. Although mothers can sustain their caregiving by using Buddhist belief and Thai culture awareness, they

experienced exhaustion, tiredness, and suffering from providing care with inadequate supports from the health care system.

Utilizing mental health services

Health care services in Thailand comprise the modern and the traditional treatment. Burnard et al. (2006) pointed out that Thai people use a mixture of the modern and the traditional treatment for mental illness. The treatment in the urban area tended to be more modern, while those in rural area often use traditional treatment (Burnard et al., 2006; Rungreangkulkij & Chesla, 2001). Burnard et al. (2006) reported that the reasons why Thai people chose monk or spiritual healer instead of modern medicine because they had time to talk with, advise, and bless for them more than modern medicine does. The findings from some studies showed that Thai caregivers lacked support from health care providers, especially information about how to care for the mentally ill relatives (Ratanatikanon et al., 1997; Tunkpunkom, 2000). Though there are family support groups, they are usually provided in hospital located in urban areas. Thus, it is difficult for caregivers who reside in rural areas to access to such activities (Tunkpunkom, 2000).

In addition, although the community mental health services such as home care have also been integrated into health services in order to serve the deinstitutionalization policy, the capacity of such services was questionable and the integration of services was criticized as superficial and inefficient (Tunkpunkom, 2000). Dangdomyouth and colleagues (2008) also noted that, in home care services, there was no provision for family support, no visiting nurse service, no respite care, and minimal caregiver education. Besides, Chunuan et al. (2007) noted about the interaction between the health care providers and clients that the relationship between them, in particular urban areas, was normally formal and they did not share common interests with clients. However, Thai people have respected health professionals as they assist clients to improve their health and be healthy (Chunuan et al., 2007; Ekintumas, 1999).

In summary, Thai studies provide understanding about Thai caregivers' perspective on mental illness that the superstition and Buddhist teaching has a huge influence on their perspective and their responses to mental illness and caregiving.

They seek help from both spiritual healers and mental health system. In providing care for their loved ones, Thai caregivers face with difficulties in managing caregiving tasks and their lives with inadequate supports from the mental health system. Their caregiving experiences change over time. They have to manage both their relatives' illness and their own feeling of staying in balance. In dealing with difficulties, they gradually develop caregiving skills and strategies for various circumstances by experiential learning. They learn to provide the close and thoughtful care in managing their adult relatives' psychotic symptoms. Although practicing Buddhist teaching and maintaining social value can help them to overcome their difficulties, most of them experience exhaustion and suffering in their caregiving process.

However, all of these studies provided the information about caregiving experience specifically about caregivers' responses in dealing with schizophrenia, such as managing caregiving tasks and developing skills and caregiving role captured from a wide range of caregiving duration, from one to over 10 years in which the experience at the early phase of illness was slightly touched upon. Their findings did not focus on homogeneity of parents' experience because they included caregivers with different relationships with patients, such as mothers, spouses, and siblings (Dangdomyouth et al., 2008; Sukmak et al., 2001; Tunkpunkom, 2000). The little known is about Thai parents' dealing with the changes, either in their children or in their lives and with impacts happened in their lives amidst chaos of being caregivers, their integration of caregiving role in their normal lives, as well as the change of parents' perceptions and responses from the period before the diagnosis when they recognized that the changes had taken place in their children to the first five years after the diagnosis, which is the critical period.

Grounded Theory

Grounded theory (GT) is an approach for collecting and analyzing data in qualitative research. It is appropriate for a study in complex areas of human behavior and social life processes where little research has been done or few adequate theories concerning a phenomenon of interest exists (Cheniz & Swanson, 1986). The GT method has been developed initially by the two sociologists Barney G. Glaser and

Anselm L. Strauss in the 1960s as a result of their research program on dying. The explicit goal of theory development that moves qualitative inquiry beyond descriptive studies into the realm of explanatory theoretical frameworks makes GT unique among qualitative methods (Glaser & Strauss, 1967; Charmaz, 2006).

Philosophical underpinning

Grounded theory is derived from the insights of symbolic interactionism which spotlights on the process of interaction of people in exploring human behaviors and social roles (Blumer, 1969). Symbolic interactionism is a perspective in social psychology in studying the human group life and human conducts (Blumer, 1969). Symbolic interactionists view the reality as a physical object existing independently out there. It is defined by individuals influenced by their social life in relation to the situation as it exists (Charon, 1998). In addition, they assume that society, reality, and self are constructed through interaction and, thus, rely on language and communication (Blumer, 1969).

Historical background of symbolic interactionism is usually traced back to the work of George Herbert Mead, a philosopher and psychologist of the University of Chicago. The other pioneered symbolic interactionists include John Dewey, William James, Charles Price, William Thomas, and Charles Cooley Herbert. Blumer, Mead's student, integrated the work of Mead and the pioneered symbolic interactionists and wrote primarily about symbolic interaction in the 1950s and 1960s.

Symbolic interaction rests on three basic premises. First, human beings act toward things on the basis of meanings that the things have for them. These things may be objects, other human beings, institutions, guiding ideas, activities of others and situations, or a combination of these. Second, the meaning of such things is derived from or arisen out of social interaction that one has with other people. Communication is symbolic, and language is an essential mechanism for meaning to be shared. Third, these meanings are handled and modified by each person through an interpretative process in dealing with situations (Blumer, 1969).

The methodological position of symbolic interactionism is that a social action must be studied in terms of how it is formed. Therefore, interactionism requires that the inquirers actively enter the worlds of people being studied, not to a contrived

laboratory setting, to see the situation as it is seen by the actors, not by the outside scholars, to observe what the actors take into account, and to observe how they interpret what is taken into account. The process of actors' interpretation is an intelligible rendering not merely through the description of words and deeds, but by taking rich description as a point of departure for formulating an interpretation of what the actors are up to (Blumer, 1969; Denzin & Lincoln, 2011). In addition, in order for the knowledge to be understood and accepted by the researcher's discipline, the researcher, as an observer, must translate the meaning derived from the researcher as a participant into the language of the research discipline (Blumer, 1969).

Because symbolic interactionism focuses on the meaning of events to people in natural or every day settings (Chenitz & Swanson, 1986), it is concerned with the study of inner or experiential aspects of human behaviors; that is how people define events or reality and how they act in relation to their belief. In addition, the reality or meaning created by people guides behaviors and consequences of actions (Chenitz & Swanson, 1986). In other words, symbolic interactionism holds that people are in a continual process of interpretation and definition as they move from one situation to another. Blumer contributed symbolic interaction to GT since 1969 through the idea that human beings are active participants in their situation rather than passive respondents (Blumer, 1969).

Evolution of grounded theory

The two co-originators of GT, Glaser and Strauss came from different backgrounds. Glaser's background was associated with quantitative methodology. He was trained in quantitative methodology and qualitative mathematics at Columbia University by the innovator of quantitative methods, Paul F. Lazarsfeld (Glaser, 1998; Strauss & Corbin, 1998). On the other hand, Strauss was trained in symbolic interaction by Herbert Blumer, Evert Hughes, and Robert Park at the University of Chicago, where he was also influenced by pragmatic philosophical tradition. During the early 1960, they worked together and combined their distinct backgrounds to produce the constant comparative method later known as grounded theory (Glaser & Strauss, 1967). It is considered as the first generation of GT methods (Creswell, 2013). The basic research process includes gathering data, coding, comparing, categorizing,

developing a core category, and generating a theory. In addition, the fundamental procedures are coding, constant comparative, and theoretical sampling (Glaser & Strauss, 1967).

Because of the different backgrounds, they then continued to develop the method over years independently of each other. Strauss and coauthor, Juliet Corbin, have contributed to GT separately from Glaser since 1990. It turns into the second generation of Glaser's and Strauss' former doctoral or postdoctoral students. At present, there are several versions of GT; however, the three popular versions considered as the closest to this study are Glaserian, Straussian, and Charmaz (Creswell, 2013). Although the three versions of GT have the same purpose to generate theory, their worldviews—assumptions regarding the nature of reality are different. The positivist tradition is the stance of Glaserian. Glaserian believes that reality already exists in the world; as a result, Glaserian assumes that the data represent the objective facts about a knowable world waiting for discovery. The central issue of Glaserian version is “to know what informants' main concern is and how they seek to resolve it” (Glaser, 2001, p. 177) and the continual resolving is “designated by a category called core category” (Glaser, 2001, p. 199).

Straussian's position moves into postpositivism which believes that the world is complex, and reality can be reached imperfectly. Because Strauss was trained in symbolic interaction and was influenced by pragmatism which focuses on action, the problem situation, and conceptualization of a method within the context of problem solving, he views human beings as active agents in their lives and in their world rather than as passive recipients of larger social forces. He assumes that process, not structure, is fundamental to human existence. Human beings create structures through engaging in social interaction and social processes. Indeed, people are also in a continual process of interpretation and definition as they move from one situation to another. Their responses create conditions influencing restructuring the variety of action and interaction. Because of such belief, he values the great varieties of human action, interaction, and emotional responses that people have to events and problems they encounter (Charmaz, 2000; Corbin & Strauss, 2008; Strauss & Corbin, 1990; Strauss & Corbin, 1998; Walker & Myrick, 2006).

For Charmaz, she believes in the relativism of multiple social realities. She recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward an interpretive understanding of subjects' meanings (Charmaz, 2006). Her belief lies between postmodernist and postpositivist approaches to qualitative research and relies on interpretive tradition. The focus of constructivist GT is about learning the experience within embedded, hidden networks, situations, and relationships in terms of how, when, and to what. It also focuses on making visible hierarchies of power, communication, and opportunity that maintain and perpetuate the differences and distinctions between people (Charmaz, 2006).

Because of the disparities of their worldviews, the ways they do grounded theory are slightly different. One obvious difference is the relationship between the researchers and the world they study. Glaserian researchers treat data as something separated from them and imply that data are untouched by their competency of interpretations (Glaser, 2003). The role of researchers becomes more of a conduit for the research process rather than the creator of it or forcer of the data. They enter the field with only a broad topic area of interest in mind, without specific preconceived research questions and the detailed reading and understanding of the extant literature in the area (Jones & Noble, 2007).

On the contrary, Straussian allows a much more provocative, interventionist, and interrogationist researchers to influence over the data (Corbin & Strauss, 2008; Jones & Noble, 2007; Straus & Corbin, 1998). They suggest that the researchers should develop theory through intimate relationship with data while being aware of themselves as instruments of theory development. Moreover, the temporal features of the inquiry process and of the phenomenon being studied should be used as a part of the analysis (Strauss, 1987). Straussian's techniques encourage researchers to use their own personal and professional experience and acquired knowledge as a positive advantage to enhance theoretical sensitivity rather than obscuring vision. Strauss noted, "If you know an area, have some experience...you don't tear it out of your head, you can use it" (Strauss, 1987, p. 84).

While Glaser and Strauss talk about discovering the theory as emerging from data separated from scientific observers, Charmaz (2006) assumes that neither data nor theories are discovered. She deems in that we are a part of the world we study

and the data we collect. Thus, researchers construct their grounded theories through their past and present involvements and interactions with people, perspectives, and research practices. In addition, she assumes that any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it (Charmaz, 2006). The research is the process of reality construction which both data and analysis are created from sharing meanings, experiences, and relationships among researchers, research participants, and other sources of data.

The other area of differences among the three versions of GT is about the different terms and some techniques used in the data analysis process. Glaserian uses simple and quite focused coding procedure (Heath & Cowley, 2004; Walker & Myrick, 2006; Urquhart, 1014). Coding comprises two procedures: substantive coding and theoretical coding. Substantive coding composes of two sub-coding, open coding and selective coding. However, Straussian uses three phases of coding: open coding, axial coding, and selective coding. The key difference between Glaserian and Straussian is the dimensionalizing which is the core task for Straussian researchers to develop the category in terms of its properties and the dimensions of the properties (Corbin & Strauss, 2008; Strauss & Corbin, 1990).

In addition, Strauss and Corbin emphasize sorting memos in weaving theory and create specific tools such as questioning, using flip-flop technique, making close-in and far-out, and waving the red flag for enhancing researchers' theory sensitization (Strauss, 1987; Strauss & Corbin, 1990; Strauss & Corbin 1998; Walker & Myrick, 2006). Moreover, because Strauss emphasizes conceptual development and the density of theory that comprises many concepts and many linkages among them, the Straussian uses a condition matrix as an extension of coding paradigm and as an analytic aid that sensitizes the researchers to a variety of conditions and consequences that surround the actions/interactions.

For Charmaz, she places more emphasis on the views, values, beliefs, feelings, assumptions, and ideologies of individuals than on the methods of research. The data analysis process comprises four phases of coding: initial coding, focus coding, axial coding, and theoretical coding (Charmaz, 2006). She advocates using active codes, such as gerund-based phrases, and subsequent categories to preserve images of the experience. Although the Glaserian, Straussian, and Charmaz GT

versions have the same purpose to generate theory, they have the disparity of their worldviews. As a result, they use basic GT strategies in their own way for reality inquiring.

Using symbolic interactionism perspective, GT provides a way to study human behaviors and interactions in complex situations, to understand unresolved or emerging social problems, and to understand the impact of new ideologies. A research question that fits with GT is a statement that identifies the phenomenon to be studied oriented toward action and process. It can be an interactional question focused on human interaction in somewhat conditions, an organizational question focused on the broader organizational responses to situations, and biographical question focused on both present and past of person's responses to situations (Strauss & Corbin, 1990). Hence, in nursing, GT research is applicable for study human behaviors related to health issues, transitions, and situational challenges (Williams & Vogt, 2014; Wuest, 2007).

Procedures of grounded theory

Because Straussian GT version is chosen as a methodology for this study, procedures of GT described below are based on Straussian version. The fundamental procedures compose of coding, making comparison, theoretical sampling, and memo and diagram writing (Corbin & Strauss, 2008; Strauss & Corbin, 1990; Strauss & Corbin, 1998).

1. Coding procedure. It is an organizing of the raw data into meaningful categories. It is used to uncover constituents of experience that emerge from the data, and eventually is clustered into common categories. Data collection and analysis are tightly interwoven processes, and must occur alternately because the analysis directs the sampling data (Strauss & Corbin, 1990). Coding procedure of Straussian GT comprises open coding, axial coding, and selective coding (Strauss & Corbin, 1990).

Open coding aims for generating categories and their properties and then seeks to determine how categories vary dimensionally. The researchers will break the interviewed data down into discrete incidents, ideas, events, and acts and give a name which may be taken from the words or phrase of informant

called *in vivo codes* to keep it close to data or from researcher's conceptualization suggested by the context in which the event is embedded. While reading transcriptions, the researchers can ask the explanatory questions through thinking about the data, for example, "What does... mean?" "What if...?" "Then...?" "How...?" Thinking about the range of the possible answers can also help the researchers to think about what ideas needed to be looked for in the data in order to probe deeper into the data. When the concepts emerge, they are grouped around particular phenomena called category. The emerged categories are then be named which might stand out as broader and more abstract terms than the concepts grouped under it or its sub-categories. To indicate the actions in the process, coding with gerunds, words in noun-form ending with "-ing" are used (Hutchinson, 1993). The researchers then go back to data and do a more detail analysis to determine how categories vary dimensionally. The researchers generate properties which are the characteristics of a category. The locations of a property along a continuum called dimensions are also generated (Strauss & Corbin, 1998).

Axial coding aims to relate more specific categories and subcategories emerged during open coding and to define evidence of variation and process referring to them. Strauss and Corbin call linking subcategories to its category in a set of relations the "paradigm model" (Strauss & Corbin, 1990, p.90). Its main components include causal conditions, phenomenon, context, intervening conditions, actions/interactional strategies, and consequences. Phenomenon is the central idea, event, or happening to which a set of actions/ interactions is related. Causal conditions refer to the events or incidents that lead to the occurrence or development of a phenomenon. Context refers to a specific set of properties or conditions within which the action/interaction strategies are taken to manage in responds to a specific phenomenon. Intervening conditions are broad and general conditions that facilitate or constrain action/interaction. Actions/interactional strategies are the responding of individuals or groups directed at managing, handling, carrying out a phenomenon as it exists in context, and consequences are the outcomes of those actions/interactions. Using the paradigm model enables the researchers to think systematically about data, relate them in highly complex ways, and enhance density and precision of theory (Strauss & Corbin, 1990).

In doing this, the sensitizing questions such as who, what, when, where, how, and with what consequences are used to tune the researchers into what the data might be indicated and lead the researchers to new discoveries by using theoretical sampling. The category is compared against another to see how they are clustered or connected. The theoretical connections of each comparison that integrate different categories and their properties are made. To verify the statement of relationship, the researchers return to data and look for evidence, incidents, and events that support or refuse such statement. This strategy also helps the researchers to add density and variation to theory. Then the researchers have to give the more abstract terms or phrases of the category that seems more logically related to its properties and dimensions and take them into memos (Strauss & Corbin, 1990).

Selective coding is the process of integrating and refining the theory of fitness, completeness, congruence and harmony in the phenomenon. The researchers have to select the core category, systematically relate it to other categories, validate those relationships, and fill in categories that need further refinement and development (Strauss & Corbin, 1990). Core category is the central concept identified by its centrality, a frequent occurrence, good connections to other categories, and implications for more general theory (Flick, 2014; Strauss & Corbin, 1998). When the core category is identified, the researchers do focus on selectively coding around the core category by means of the paradigm (Strauss & Corbin, 1990; Walker & Myrick, 2006). The main categories are compared with the data to determine under what conditions they are likely or unlikely to occur, and if they are central to the emerging theory. The theoretical sampling is still used to fill in poorly developed categories. Memos constantly noted through the analytic process are sorted into piles and examined to discover how the categories come together around the core category. Diagrams that illustrate categories and their relationships are drawn through the sorting process. The final process is integration through telling or writing a storyline by using a diagram and sorting and reviewing memos (Strauss & Corbin, 1990).

2. *Making comparisons.* Making comparative analysis is an adjunctive procedure in the data analysis process. It is performed through open coding, axial coding, and selective coding and involves constant comparison and theoretical comparison (Strauss & Corbin, 1998; Corbin & Strauss, 2008). For *constant*

comparison, incidents are compared to previous incidents and categorized according to whether they fit with existing incidents or warrant new codes, properties or categories. Then emergent concepts derived from the analysis are compared to more incidents to generate new theoretical properties of the concepts and more hypotheses in order to bring out different aspects of the same phenomena. They are also compared with the properties of the category in order to reach theoretical elaboration, saturation, and densification of concepts.

When the researchers come across an incident because they are unable to further define the incident in terms of its properties and dimensions, it is time to make the *theoretical comparison*. It is a tool designed to assist the researchers arriving at a definition or understanding of some incidents by looking at the property and dimensional level to discover what is similar and different about each incident. The incidents, objects, and actions that the researchers use to make theoretical comparisons can be derived from the literature and experience to give the researchers the ideas of what to look for in the data. The theoretical comparison leads the researchers to reach thick descriptions, conceptual levels, and integration into hypotheses to become a theory (Corbin & Strauss, 2008).

3. *Theoretical sampling*. It is described as “a method of data collection based on concepts derived from data” (Corbin & Strauss, 2008, p. 114). Theoretical sampling in GT is not planned before starting the study, but it continues throughout the study, which makes it unlike the other sampling. It aims to maximize opportunities to discover the variation among concepts and to make the density categories in terms of their properties and dimensions. During analysis, concepts emerge, and these concepts generate the questions which become the directions leading to places, persons, and situations that will provide more information under different condition of those concepts. Therefore, data collection and analysis go hand in hand until reaching the point of saturation that the same ideas arise over and over again (Corbin & Strauss, 2008; Strauss & Corbin, 1990).

4. *Memo and diagram writing*. Throughout the data analysis process, the researchers have to write memos and diagrams to help with the development and formulation of theory. Memos represent the written forms of abstract thinking about data, such as thoughts, interpretations, questions, and directions for

further data collection. Writing memo requires several stages and becomes gradually complex in the process. Diagrams are the graphic representations or visual images of the relationships between concepts. They are important elements of analysis, as if working and living documents that grow and accumulate theoretically in complexity, density, clarity, and accuracy as the research and analysis are progressing, while maintaining its grounding in empirical data. Memoing and diagram writing force the researchers to work with concepts rather than raw data. They function as the reflection and analytic thoughts that help the researchers to quickly see the logic and coherence of thoughts (Corbin & Strauss, 2008; Strauss & Corbin, 1990).

Strauss and Corbin (1990) mention three kinds of memos: code notes, theoretical notes, and operational notes. Code notes represent the memos about concepts being discovered. Theoretical notes theoretically sensitize and summarize researchers' ideas about what is going on in the text. Operational notes are the memos containing directions for the researchers regarding sampling, questions, possible comparisons to further data collection.

In summary, grounded theory (GT) is an approach for data collection and analysis in the qualitative research based on the philosophy of symbolic interactionism. Symbolic interactionism emphasizes the interactional process of people in exploring human behaviors as well as social life processes which is little known. Straussian GT is developed by Strauss and Corbin, and postpositivist is its stance. Its fundamental procedures are composed of coding, making comparison, theoretical sampling, and memo and diagram writing. Coding procedure of Straussian GT comprises open coding, axial coding, and selective coding. During analysis process, when concepts emerge, the constant comparison and theoretical comparison is made to generate the categories, properties and their dimensions until core category is formulated. The emerged concepts generate the questions which direct further data collection. Because data collection and analysis are tightly interwoven process and must occur alternately, comparison making and theoretical sampling are used throughout the process until the saturation of data is reached. The memos and diagrams are written throughout the data analysis process to help in the development and formulation of theory.

Trustworthiness of Qualitative Study

In qualitative research, trustworthiness is an effort of researchers to address the traditional quantitative issues of validity and reliability. Lincoln and Guba (1985) offers aspects of trustworthiness which consists of *credibility*, *dependability*, *confirmability*, and *transferability*. There is a set of procedures to establish each aspect of trustworthiness, as follows.

Credibility

The credibility is defined as the way to prove whether the findings are accurate and credible from the standpoint of the researchers, the participants, and the readers (Bloomberg & Volpe, 2008). There are many ways to demonstrate the credibility as follows.

1. *Ensuring an accuracy of collected data.* It is a basic element of finding accuracy. All of the interview documents must be guaranteed for accuracy. Digital recorder or other mechanical device that is used to record the interviews are essential. All interviews have to be checked for gaps to identify the information that has been omitted. The researchers have to check all transcriptions while listening to the tapes to ensure that the typing has been corrected, included notations for all pauses and exclamations, and otherwise has indicated as many of the participants' expressions as possible (Morse & Field, 1996). In addition, the field notes should be written immediately after the interviews or observations to increase an accuracy of recalling (Beck, 1993).

2. *Prolonged engagement.* It is the investment of sufficient time to achieve certain purposes by spending enough time on the site to understand the context of phenomenon. It helps the researchers to be accepted as a member of the group of studies and to build adequate trust. It also helps the researchers to detect both personal and participant distortion that might otherwise creep into the data. This technique can enhance credibility of the findings and the interpretations (Creswell, 2013; Denzin & Lincoln, 2011).

3. *Persistent observation.* It aims to identify characteristics and elements of the situation that are most relevant to the problem or issue being followed and focus on them in detail. It goes along with prolonged engagement. While

prolonged engagement provides scope, persistent observation provides depth of the situation. The researchers have to explore the dimension of salience and crucial atypical happening to what might to be erroneous at the initial assessment. Additionally, the researchers must be able to describe in detail just how this process of tentative identification and detailed exploration are carried out (Denzin & Lincoln, 2011).

4. *Triangulation technique.* It is the technique to improve credibility of the findings and the interpretations. There are basically four kinds of triangulation strategies: methods triangulation, data sources triangulation, investigator triangulation, and theory triangulation (Creswell, 2013; Holloway & Wheeler, 2002; Denzin & Lincoln, 2011). Methods triangulation is used when the researchers aim to check out the consistency of findings by using two or more methods, such as observations, interviews, document analysis, and questionnaire using, simultaneously or sequentially in one study to answer a similar question. It helps the researchers to verify particular details captured from participants. Data sources triangulation is done for comparing or checking out the consistency of different data sources by using the same methods. Though it cannot be expected that everything will turn out the same or totally consistent, it enhances the researchers' opportunity to study and understand when and why there are differences. Investigator triangulation involves using two or more researchers in analyzing the same qualitative data set. They analyze data independently and then compare their findings to reduce the potential bias that come from a single researcher. The last strategy is theory triangulation involving using different perspectives or theories to interpret the same data. The point of theory triangulation is to understand how findings are affected by different assumptions and fundamental premises. All different types of triangulation are strategies for reducing systematic bias in the data which enhance the credibility of the findings.

5. *Peer review or debriefing.* This technique involves a process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise continue to be only understood within the researcher's mind. A peer may be someone who is competent in qualitative research procedures and in that area of study, and is willing to re-analyze the raw data, listen to the researchers' concerns and discuss them. They

might share alternative explanations to the researchers which enable them to recognize their bias or inappropriate interpretations and to modify their interpretations and explanations which best describe the experience of the participants (Creswell, 2013; Denzin & Lincoln, 2011).

6. Negative case analysis. In theory building, the researchers may find negative cases, deviant cases, which fall at either extreme dimensional range of a concept or that seem quite contrary to what is going on. The outliers and all exceptions or the events that do not fit into the emergent theory will be revised by constantly reworking the hypothesis at issue until the fitness is perfect. In doing this, the researchers have to think about the reasons why deviant cases do not fit within the dominant patterns and provide alternative explanations via exploring whether conclusions from them are appropriate. In the final report, the inclusion of the discrepant data and negative or alternative cases shows the complexity of the research and intellectual honesty (Creswell, 2013; Denzin & Lincoln, 2011). Discovering the negative cases and building explanations into the theory increase theory generalizability and explanatory power (Strauss & Corbin, 1998).

7. Member checking. It is the process whereby data, analyzed categories, interpretations, and conclusions are checked by members who were studied. The main reasons for member checking are to gain the feedback of participants and to check their reaction to the data and findings. The specific purposes of member checking are: 1) to find out whether the reality of the participants is presented, 2) to provide opportunities for them to correct mistakes which they feel they might have made and give additional information, 3) to evaluate the researchers' understanding and interpretation of the data, and 4) to give the participants opportunity to challenge the ideas of the researchers (Flick, 2014; Holloway & Wheeler, 2002). This procedure helps the researchers avoid misinterpretation or misunderstanding of participants' words or actions. It represents the participants' perspective that makes sure the trustworthiness of the research findings. To carry out the member checking, the researchers can present participants with interview summarizing, interpretation of participants' words, phrases, and field notes. They then ask whether or not the participants find the interpretation is a true and fair representation of their perspective.

However, member checking is seen as problematic and complex (Sandelowski, 1993). The researchers and participants come up with different agenda. The researchers are looking for the multiple realities, while the participants are concentrating on their own experience. In addition, the participants' perception can change over time. Hence, they may view the researchers' interpretations as an inaccurate work, or they might hesitate to disagree with researchers' interpretations because of social norm concerning politeness. As these reasons, when the discrepancy occurs in member checking, this does not mean that it is not a valid theoretical interpretation. May and Pope (2000) noted that member checking may be better suited as being identified as a tool for error reduction, rather than a verification protocol. Therefore, when the discrepancy occurs, the researchers should go back to the data for checking ponderingly on the issues given by the participants. Although it is not essential to rip the whole down, it allows the researchers to re-evaluate within the study, implement changes, and conduct further interviews in areas where the study is weak.

Dependability

Dependability is the degree to which the findings of study would repeatedly transpire if the study is replicated with the same or similar participants in the same or similar context (Denzin & Lincoln, 2011). To establish dependability, the researchers have to document the procedure and demonstrate that coding schemes and categories have been used consistently (Bloomberg & Volpe, 2008). In addition, the audit trail must prompt to be examined. It is the detailed record of the entire researchers' thought and rationale for all choices and decisions made during the research process which can be laid open to external scrutiny (Creswell, 2013; Denzin & Lincoln, 2011). The original transcripts and memos are available for audit trail and clarification. Since the uniqueness of the human situation and variation in the participants' experience are emphasized in qualitative research, the detailed description of participants' characteristics, contexts related to the study, and methods used in the study are provided in the final report of the study, so that readers and other researchers are able to clearly follow the progression of events in the study and understand their logic.

Confirmability

Confirmability is the proof that the findings are the results of the research, rather than an outcome of the biases and subjectivity of the researchers (Bloomberg & Volpe, 2008). According to Denzin & Lincoln (2011), confirmability is established when dependability is demonstrated. To put it simply, it needs an audit or decision trail where readers can trace the data to their sources to follow the path of the researchers arrived at the constructs or interpretation. For this, the contextual documents containing the description of setting, people, and location are needed. The process notes, the notes about procedures, designs, strategies, and rationales, trustworthiness notes, and audit trail notes, should be prompt to be accessed. Because the researchers act as the human instrument, they may be tainted with biases, assumptions, and impressions. Thus, the reflexive journal of self-awareness should be kept and recorded for external scrutiny. In addition, the technique of checking or confirming data with the informants or member checking as mentioned above is a critical way to establish confirmability. Moreover, excerpts of the participant's statements should be quoted appropriately and adequately to assert that the findings are grounded in the event rather than in the researchers' personal constructions (Chiovitti & Piran, 2003).

Transferability

Transferability is the way in which the readers determine whether and to what extent this particular phenomenon in this particular context can be transferred to another particular context. The researchers have to give enough information to the readers to judge the applicability of the findings to other contexts (Denzin & Lincoln, 2011). Thus, the thick description about the setting, participants' characteristics, methods and techniques used in the study will be provided in the final report (Creswell, 2013; Denzin & Lincoln, 2011).

In summary, to enhance the trustworthiness of qualitative study, the credibility, dependability, confirmability, and transferability are deserved attention. The credibility of the study is demonstrated by enhancement of data accuracy, prolonged engagement in the study field, persistent observation in situation of study, using triangulation technique, peer review or debriefing, negative case analysis, and

member checking. To establish dependability, the documentation of the procedure, the report demonstrating the consistency of coding schemes and categories and the audit trail must prompt to be examined. The confirmability is established when dependability is demonstrated. Thus, the audit trail, including the contextual documents, the research process notes, and reflexive journal of self-awareness of researcher, as well as member checking is needed to confirm that the findings are the results of the research, rather than an outcome of the biases and subjectivity of the researchers. The thick description about the setting, participants' characteristics, methods and techniques used in the study should be provided in the final report to help the reader to judge the transferability.

CHAPTER III

RESEARCH METHODOLOGY

The chapter described research design, setting, and participants. The procedure of data collection and data analysis, rigor of the study, and protection of human subjects were also presented.

Research Design

This was a qualitative study that employed grounded theory methodology. The purpose of this study was to understand Thai parents' experiences in becoming caregivers for schizophrenic patients. The ultimate goal was to generate theory that explains how parents define events or reality and how they act in relation to their belief in dealing with the changes and impacts of being caregivers for schizophrenic patients and what conditions influencing their experiences within five years after the first diagnosis. Caregiving for schizophrenia in the early phase of illness is complex and dynamic. It depends on the meaning they construct through social interaction which guides their appraisal and response. This phenomenon is little known in the stage of present knowledge in caregiving area. The research question of this study is a biographical question focusing on human responses to situation from past to present in which the changes of response pattern can be revealed. Thus, grounded theory methodology was chosen as most appropriate for this study because it emphasizes action and the process of human behaviors in context to generate a theory (Strauss & Corbin, 1990).

The Straussian GT approach was employed in the current study to explore the great varieties of human action and interaction that people respond to events and problems (Strauss & Corbin, 1990; Strauss & Corbin 1998; Corbin & Strauss, 2008). It can be used to answer the research questions of this study. In addition, its technique as well as procedure gives direction for data collection and analysis process step by

step which is clear for a novice researcher to pursue. It additionally enables the researcher to think systematically. Moreover, the researcher believes that the reality is imperfectly reached because human beings continuously undergo the process of interpretation based on their prior knowledge or experiences; hence, it is impossible for researchers to perfectly treat data as something separated. This belief is compatible with the Straussian GT approach that allows researchers to influence over the data and be intimate with data in the process of theory development by concerning that the prior knowledge and experiences can be used to enhance their theoretical sensitivity (Strauss & Corbin, 1990; Strauss & Corbin, 1998; Corbin & Strauss, 2008).

Setting

The settings for this study were Outpatient Department (OPD) and Inpatient Department (IPD) of the biggest psychiatric hospital located in Nonthaburi province, Thailand. The settings have provided mental health and psychiatric services for, but are not limited to, the population in eight provinces in the central region of Thailand: Nonthaburi, Ang-Thong, Ayuthaya, Chainart, Saraburi, Singburi, Lopburi, and Pathumthani. For the OPD, the service hours are from Monday to Friday, 8:00 a.m. to 4:00 p.m. Staff of the OPD consists of psychiatrists, psychologists, social workers, psychiatric nurses, and nurse aides. There were more than 500 patients visiting the OPD each day. The patients coming to the OPD had been diagnosed with various disorders, such as schizophrenia, depressive disorder, bipolar disorder, anxiety disorder, drug induced psychosis, and organic psychosis. They came to obtain medication refills and received regular follow-up treatment every one to three months. When they arrived at the OPD, they had to get the queue number to meet with the psychiatrist.

The medication treatment is the major services provided for the patients. After meeting with the psychiatrist, the patients or their caregivers would take a prescription to a pharmacist and waiting for receiving medication. Individual or group psychoeducation was provided to caregivers by a nurse while caregivers were waiting for the prescription. Psychoeducation focused on providing information about the

importance of medication adherence, their side effects and management, as well as psychotic signs and symptoms and management. However, because of time limitation and a huge number of the clients, it was not a routine service and training caregiving skills were not included.

For the IPD, psychotic patients, including patients in the early phase of schizophrenia with severe or uncontrollable psychotic symptoms threatening the security of the others or themselves had been admitted into several wards. The researcher contacted for some wards of male and female patients. More than half of all patients in these wards were diagnosed with schizophrenia. In the early phase of admission, the medication was a major treatment in order to stabilize psychotic symptoms. Because of de-institutionalization policy, patients were discharged from hospital when their psychotic symptoms were able to be controlled. They were provided the psychosocial treatments in addition to medication treatment to enhance their social skills and prepare them for discharge from the hospital. However, most of them were re-hospitalized because of medication nonadherence. In each ward, patients' relatives or parents could visit the patients in the visiting area every day from 10:00 a.m. to 4:00 p.m.

In both of the OPD and IPD settings, parents constituted the majority of primary caregivers for the patients. After their children received treatment or before their discharge from the hospital, the psychiatrist or nurses provided them with important information that their children's psychotic symptoms could be controlled by constantly taking the antipsychotic drugs and by coming to follow up regularly. An additional service was one follow up telephone call one week after discharge. The nurse asked the caregivers about the patients' symptoms, gave them information to solve their problems, and remind them of their follow-up appointment at the hospital. If the patients and caregivers had complex problems, the nurses would refer to the community psychiatric setting of the hospital to plan for community-based care. However, there were some barriers to maintaining contact with caregivers and the patients, such as change of address or telephone number or unavailability to receive a call. Because of these barriers, most patients is lost from the continuing care system.

Participants

The participants of this study were Thai parents, either mothers or fathers, or both, of schizophrenic outpatients and inpatients who were diagnosed within five years. These parents took main responsibility for their children's illness, provided direct care such as maintaining medication adherence and managing psychotic symptoms and other impacts. The parents were initially recruited by the purposive sampling with following criteria: 1) were primary caregivers and live in the same household with the patients since the first episode of their illness, 2) had been informed by a psychiatrist that the patients are suffering from schizophrenia for no more than five years, 3) speak and understand Thai language. Exclusion criteria for this study were the parents who provided care for additional family members with chronic diseases in the household and had been diagnosed with any psychiatric illness.

Procedures

Recruiting participants

The participants were recruited while they came to accompany with their schizophrenic patients at OPD and while they visited their children at psychiatric wards. After the study was approved by the Institutional Review Board (IRB) of the Faculty of Nursing, Mahidol University and the selected hospital, the researcher contacted head nurses of both the OPD and IPD to gain access to the participants. The nurses who had been working at both the OPD and wards were asked to initially approach the participants who came with or visited patients with schizophrenia and invite them to meet with the researcher in a private room. The researcher introduced herself to potential participants as a doctoral student and asked them to ensure that they qualified as the study's participants by using the screening interview guide. The detail of the study was explained to the parents who met the inclusion criteria. These parents were invited to participate in the study. The participant information sheet was read to the parents who were illiterate while who were literate were asked to read the participant information sheet. They were encouraged to ask questions and discuss any concerns they may have before making the decision. The parents who were willing to participate in this study were asked to sign the informed consent form.

In grounded theory studies, the sample size was not determined ahead of time but grows as data collection and analysis continued and data saturation was used to determine an adequate sample size. Twenty-eight parents were approached, with 25 of them deciding to participate in this study and willing to be interviewed in the same day. One of the potential participants was not available at that time of approaching, but was willing to be interviewed and gave the telephone numbers to the researcher to make an appointment with her for the next follow-up. The other two of them refused to participate in the study because they did not want to tell anyone about their children's illness and their experiences. Most parents lived in the same household with their ill children since the first episode of the illness. Only one mother who provided care for her son for nearly four years reported that her son returned to study and lived separately from her for only one semester. During that period, she had daily contact with him, to monitor his symptoms and remind him to take medication regularly. She contacted him by telephone and met with him at home weekly. After that, her son stopped studying caused by symptom relapse and lived in the same household with her until the time that she was interviewed.

Data collection

This study used in-depth-interviews for data collection. For GT approach, data collection and analysis were conducted simultaneously until reaching the point of saturation that the same ideas arise over and over again (Corbin & Strauss, 2008; Strauss & Corbin, 1990).

Interviewing. To ensure the confidentiality and privacy of participants, all of the interviews were conducted in the private room or area of both settings. At the OPD, the parents who had enough time to complete the interview were interviewed before the patients' meeting with the psychiatrist. The nurse of this setting ensured the participants that they would be called immediately when their queue numbers were reached. On the other hand, some parents, whose patients' queue numbers were in the line that the time for completing the interview was impossible, were interviewed after the patients' meeting with the psychiatrist. For the IPD, the participants were interviewed in the private rooms or area. The fathers and mothers who were both primary caregivers were interviewed individually.

The data was collected through unstructured interviews with open-ended questions. All interviews were taped-recorded in Thai language. The first three interviews were conducted. A relaxed atmosphere was created at the beginning of each interview by making a small talk and allowing a smooth transition between topics. The general statement “Tell me about your experiences since your children’s illness begin.” Then, the researcher encouraged the participants to clarify and elaborate the details of their experiences by using probed questions listed in the interview guide.

During the interview, the researcher used active listening techniques by listening to both feeling and meaning of what the participants said without assuming that the researcher had already known the meanings of their words and statements. Then probed questions were used to encourage the participants to clarify and elaborate the details of their experience. Examples of probes were: Could you explain what you mean by...? Could you tell me more about...? Could you tell me why...? Or, when was that? The researcher also observed nonverbal behaviors of the participants and their interaction with the researcher during the interview.

At the end of the interview, the researcher responded to participants’ questions and concerns, although they were not directly related to the research questions. In addition, the participants’ background information which was not mentioned in the interview was obtained and recorded in a demographic data form. All participants were interviewed only once. Only five participants were interviewed twice for member checking.

After the interview, the researcher immediately recorded all of the interactions and observations during the interview in field notes, including descriptions about the general appearance of the participants, their nonverbal behaviors, the overall flow of the interview, location and structural situation, the researcher’s thoughts and feelings, working hypothesis, and any problems happened. The researcher transcribed all of the interviews into written form.

The length of the interview ranged from 30 to 110 minutes with an average of 70 minutes ($SD = .26$). Its variations were based on the participants’ communication ability. Most participants needed more time to talk about their experiences. A few participants, especially fathers were less fluent and open

about themselves. Although there were three interviews made before the patients' meeting with the psychiatrist, all of them were completed for analyzing. None of the interviews were interrupted. Although the research assistant was ready to provide the relaxing activity for the patients while their parents were interviewed, all patients had other relatives to take care of them. However, the researcher provided them fruit juice to drink and cartoons or magazines to read while they were waiting for their parents.

Data analysis

The researcher examined and coded the data in Thai language from the initial three interviews through line-by-line data inspection. The researcher closely examined phrases or single word to identify the type of specific events, activities, and behaviors. In attempting to understand how parents were interpreting their experiences, the researcher, while inspecting the data, asked these analytic questions: What were the parents saying? What had been going on here? Who were the actors involved? To label phenomena, the researcher took apart sentences or paragraphs, analyzed the major idea brought out in these sentences or phrases, and gave ideas or events the names or codes which represented such phenomena. During doing this, the researcher asked the explanatory question such as What does... mean? When it happens?

For example, the words of the participants were: "I prepared the pills for him, put it in his hand, and asked him to take them immediately every meal time. I have to do this, and to make sure, I watched him swallow the pills." The code assigned to these statements was "making complete involvement in medication." Another example was "I crushed the tablets and secretly mixed them with their food." The code assigned to these statements was "deceiving" subsumed under a category of "dealing with medication noncompliance." A third example was "I taught him how to prepare his medication, which pills after breakfast and before bed, something like this. I had to be sure that he could do it correctly." The code assigned to these statements was "teaching about medication preparation" subsumed under a category of "promoting self responsibility for medication."

All interviews were coded in this manner. Memos to record the ideas related to the data, analytic schemes, explanatory questions, and hypothesis in forms of code notes, theoretical notes, and operational notes were also made simultaneously. The following examples were excerpted from the analysis of the first three interviews:

**Date.....Code notes:
Properties and dimensions of medication management**

The parents' approaches to manage medication were varied based on different conditions. The first two mothers made complete involvement in medication ranging from preparation and gave them by hand to observing their swallowing. Because their children did not comply with medication. The first mother also used a deceiving approach to make her son take medication as prescribed, while the second mother did not use deceiving approach. For the third mother, she taught her son for medication preparation because she was not sure that her son could prepare medication correctly by himself.

Date..... Theoretical Notes:

As the code notes, I made an assumption that the different conditions influenced the different actions of the parents in managing medication. The main condition may be the severity of the children's psychotic symptoms. The parents reported that when their children's psychotic symptoms were severe, their children rejected taking medication. I also would like to know how the parents manage their children's medication in different severities of the children's psychotic symptoms and what about the outcomes of those management.

Date..... Operational Notes:

For the subsequent interviews, I have to ask the parents about their actions in the different children's conditions. The question I have to keep in mind is that "do they act as the same manner as the first three parents in the same conditions?" I also have to examine the other conditions influence on the parents' action in managing medication, such as the severity of the children's psychotic symptoms, the duration of caregiving. Moreover, the outcome of each strategy should be examined in the next interviews.

After the nine subsequent interviews, the researcher then grouped the codes or concepts that seem to pertain to the same phenomena by using question such as “What are these?” Then, the researcher gave the conceptual name, which more abstract explanatory terms, for the group of concepts called “categories.” The open codes in the previous demonstrating, such as making complete involvement in medication, deceiving, and teaching about medication preparation were clustered along with similar codes and conceptualized as maintaining medication adherence and subsumed under the category of struggling to control psychotic symptoms.

The researcher then built up code cards. They included information about the definition of a gerund code, examples of behaviors described in the interviews, conditions under which the behaviors happened or did not happen, and relationships between codes. In addition, the beginning categories were used to direct the focus of study or suggest comparative groups in order to discover their properties and dimensions. The following example was about the code card of maintaining medication adherence:

Date..... **Code card:** Maintaining medication adherence

Definition: It refers to the parents’ actions in trying to ensure that their children took antipsychotic drugs regularly as prescribed in order to control psychotic symptoms. The parents used different approaches, including making complete involvement in medication, promoting self responsibility for medication, monitoring medication adherence, and dealing with medication noncompliance.

Conditions under which it happens:

- After their children received psychiatric treatment.
- The parents’ perception that medication adherence is an important factor in controlling their children’s psychotic symptoms.

The analysis of twelve interviewed data confirmed that the perception that children were abnormal, included having unstable psychotic symptoms and the deterioration of their self-care abilities, was the basic psychosocial problems for Thai parents in caring for schizophrenic patients in the early phase of the illness. All of them tried to bring the normalcy to their children. Therefore, the researcher decided to

focus the study on exploring the processes through which the parents moved as they try to restore their children's normalcy.

The several categories were identified from the twelve initial analysis. These concepts were compared to generate categories and their properties. Based on these categories, the interview guide was revised for using in the subsequent interviews. However, the main question was used and the probes were adjusted and altered along with the emerged categories and developing theory (Appendix F). The researcher then moved to axial coding and eventually selective coding with the eight more interviews. The researcher explored more deeply to identify and confirm categories, their properties, and dimensions. The researcher compared the categories and examined their linkages by means of coding paradigm of conditions, context, action/interactional strategies, and consequences (Strauss & Corbin, 1990).

The categories were elaborated and refined over the course of analysis through theoretical sampling. For example, to refine the category of maintaining medication adherence, the researcher decided to additionally interview with the parents whose children complied with medication to compare with those whose children had not complied with medication. The reason for the theoretical sampling decision was based on the assumption that children's medication compliance influence the parents' struggling in controlling their children's psychotic symptoms and the strategies they used. The sampling with these parents helped the researcher to clarify and test the conceptual linkages of theory development. The parents were more likely to struggle in controlling their children's psychotic symptoms if their children had not complied with medication, especially when their children's psychotic symptoms were severe. They eventually used deceiving approach, after other approaches were ineffective.

Struggling to restore the normalcy was selected as a core category as it provided the most fruitful explanation for the phenomenon under study. Five more interviews were conducted to fill in categories that need further refinement and development, to elaborate the properties and relationships among categories, and to validate those relationships and hypotheses. Data collection and analysis continued until there was no new information about categories from the analysis. The researcher related the component categories around the care category by the coding paradigm and

writing a story line. To shape the story line, the researcher used the questions; for example, What is the main story of the study? Recording memos and drawing the logical diagrams that represent the linkages were made simultaneously. They represented the evolution of the logical relationships between categories and subcategories continued all over the process of constant comparative analysis.

Rigor of the Study

In all steps of data analysis, the researcher made the appointments with major advisor for peer debriefing. Twelve meetings were scheduled throughout as 12 months period of data collection and analysis. The major advisor and the researcher independently coded the first three interviews and then made the appointment for the discussion about the interviewing and open coding. The following meetings were arranged for the discussion about the emerging categories and their properties, linkages among categories, and theoretical sampling. Transcripts, memos, and diagrams derived from the analysis were provided for the major advisor to review. After she agreed with the revised axial coding analysis, core category was selected in the next session. The last three meetings were arranged with co-advisors for the discussion about the theory and conceptual model. They gave the researcher feedback on the theory after examining the accuracy of codes, categories, and their relationships.

Member checking was conducted in the late stage of data collection when a tentative theory was developed. The researcher contacted five participants and made an appointment with them on the day they came accompany with their children to follow up at the OPD. Because of the follow up date was not on the same day, it's difficult to conduct a group interview for member checking. Thus, the second interviews were conducted with five participants individually for member checking. The researcher described the tentative theory representing the overall perceptions and experiences of Thai parents in being caregivers for schizophrenic patients in the early phase of the illness. Then they were asked if they agreed or disagreed with such descriptions. All of five participants actually agreed with the tentative theory.

Although most of them gave more information about their caregiving experiences to the researcher, the information was redundant with the existed data.

Writing and translating a grounded theory

The tentative theory was initially written in Thai language. After the major advisor who is an expert in grounded theory methodology confirmed the accuracy of codes and categories, the researcher then revised the theory based on her feedback. After that, the researcher translated it into English and asked a bilingual translator, who has worked in Australia for more than five years, to confirm the equivalent meanings of both Thai and English quotations represented in the findings. Then, the researcher revised the English quotation after considering the translator's comments and suggestions.

Protection of Human Subjects

Protection of human subjects for this study was carried out by obtaining the approval from the Institutional Review Board of Faculty of Nursing (IRB-NS), Mahidol University and the Institutional Review Board (IRB) of the selected hospital before starting the data collection process. The research process involved requesting voluntary participation. The researcher provided each participant the information about the purpose of the study, the nature of the study and his/her rights as a subject. Each participant was asked to read the participant information sheet and the informed consent form. The researcher read it to a mother who was illiterate. A written consent was obtained when he/she decided to participate in the study. The researcher gave a copy of the consent form to each participant and kept the original one.

The researcher realized that the name of the illness could hurt the participants' feeling, hence, the researcher avoided using the word "schizophrenia" in the participant information sheet and replaced with the word "person with mental health problem". In addition, the researcher realized that an interview on sensitive topics could provoke painful and emotional experiences. Hence, the interview questions were carefully asked to imply no judgment or blame. The participants were informed at the beginning of each interview that they could stop the interview at any

time or refused to respond to a specific issue that they did not want to talk about with no negative consequences on them and their children. Additionally, there were some participants very emotional during the interview. The researcher gave them a time for composing themselves and asked if they wanted to stop or continue the interview. However, nobody decided to discontinue the interview, but reported that they felt relieved from emotional tension after talking with the researcher. Additionally, each participant was given monetary compensation of 200 Baths (\$6) for each interview. It was offered to compensate for their time and transportation and to express the researcher's appreciation for their contribution to the development of nursing knowledge.

To ensure the privacy and confidentiality of the participants and the data, the interviews were conducted in a private room or area of the settings. In addition, the researcher transcribed all the audio taped interviews by herself and replaced the participants' names in the transcriptions and consent forms with code numbers and the code numbers were also used on the demographic data forms. Other identifiers such as location or institution referred in their experiences were removed from the transcripts. The duplicated tapes were erased after transcription. The original tapes were secured in locked cabinets and later destroyed at the completion of the study. Following the completion of the study, all of the written data, including memos and transcribed data were kept by the researcher in separated secure files and printed out to be stored in a locked cupboard in the researcher's office for five years and destroyed after that. Only the researcher and research committee of this study could access to these data.

Summary

This chapter provides a detailed description of the research methodology. The Straussian grounded theory approach was employed to explore Thai parents' experiences in being caregivers of the schizophrenic patients in the early phase of illness. Twenty-five Thai parents recruited from the OPD and IPD of the selected psychiatric hospital. Twenty of them were interviewed only once and another five were interviewed twice for member checking. All interviews were taped-recorded and transcribed into Thai language by the researcher. The data collection and analysis were

simultaneously conducted until data saturation was achieved. Memos were maintained throughout the process of analysis to document the ideas and insight. A constant comparative method and theoretical sampling were used to identify properties and dimensions and their relationships with the core category. All steps of the data analysis were reviewed and discussed with the major advisor and co-advisors. Throughout the process of data collection, the human rights of all participants were protected. The privacy and confidentiality of the participants and the data was a major concern. All participants were able to handle stress and discomfort during interviews. A tentative theory was written in Thai and then translated to English by the researcher. A bilingual translator was asked to confirm the accuracy of the translations. A detailed description of the findings is given in the next chapter.

CHAPTER IV

RESEARCH FINDINGS

The purpose of this chapter is to present the empirical grounding of the research findings. The first section describes characteristics of the study participants. The substantive theory of “Struggling to restore normalcy” will be presented in the second section.

Characteristics of the Participants

The demographic information of the participants is shown in Table 4.1, while the demographic information about their children with schizophrenia is shown in Table 4.2.

The participants in the study were 25 parents from 22 families, three families of which had both fathers and mothers as primary caregivers. Two thirds of the participants (68%, $n = 17$) were mothers. The age of the participants ranged from 44 to 77 years with a mean of 56.24 ($SD = 8.75$). Six of them (4 mothers, 2 fathers) were older than 60 years of age. The majority of the participants were married. Ten participants (40%) had primary school education and lower, one of them was illiterate. Only one father had completed a doctoral degree. More than half of the participants were working, eight of them were employees and seven of them were merchants. The majority of the participants reported that their family incomes were enough for their living expenses. All participants were Buddhist. The majority of the participants were living in urban areas. Two thirds of them had more than one child. Duration of caregiving, the duration of time from the parents' first noticing their children's changed behaviors to the time that the parents were interviewed, ranged from four months to five years with a mean of 3.20 years ($SD = 1.52$). None of the participants had experience in caring for the mentally ill patients. More than half of the participants had a duration of caregiving in the first three years (Table 4.1).

Of 22 children, 13 were male, while 9 were female. All of them were unemployed and lived together with their parents. The majority of them were single. Their age at first diagnosis ranged from 16 to 47 years with a mean 26.50 years (SD = 8.46). The duration of illness, the duration from the first diagnosis to the time that the parents were interviewed, ranged from 0 to 4.9 years with a mean of 2.27 years (SD = 1.57). The frequency of hospitalization ranged from 0 to 6 times with a mean 1.95 times (SD = 1.47). Three of them had never been hospitalized and only one of them was hospitalized six times (Table 4.2).

Table 4.1: Summary of Demographic Characteristics of the Parents (N=25)

Demographic characteristics	Frequency	Percentage
Relationship with the patients		
Father	8	32.0
Mother	17	68.0
Age (years)		
41-50	5	20.0
51-60	14	56.0
> 60	6	24.0
Range = 44-77, Mean = 56.24, SD = 8.75		
Marital status		
Married	20	80.0
Widowed	3	12.0
Divorced	2	8.0
Educational level		
Primary and below	10	40.0
Secondary	11	44.0
Diploma	1	4.0
Bachelor's degree and higher	3	12.0

Table 4.1: Summary of Demographic Characteristics of the Parents (N=25) (Cont.)

Demographic characteristics	Frequency	Percentage
Working status		
Housewife	10	40.0
Employee	8	32.0
Merchant	7	28.0
Family income		
Enough	21	84.0
Not enough	4	16.0
Religion		
Buddhism	25	100.0
Living area		
Urban area	21	84.0
Rural area	4	16.0
Number of children		
1	8	32.0
2	8	32.0
>2	9	36.0
Range = 1-6, Mean = 2.16, SD = 1.14		
Previous experience of caregiving		
No experience	25	100.0
Duration of caregiving (years)		
<1	3	12.0
1-3	12	48.0
>3	10	40.0
Range = 4 months-5 years, Mean = 3.20, SD = 1.52		

Table 4.2: Summary of Demographic Characteristics of the Children with Schizophrenia (N=22)

Demographic characteristics	Frequency	Percentage
Gender		
Male	13	59.1
Female	9	40.9
Marital status		
Single	20	91.0
Married	1	4.5
Divorced	1	4.5
Working status		
Unemployed	22	100.0
Age at first diagnosis (years)		
< 21	4	18.2
21-30	13	59.1
31-40	3	13.6
> 40	2	9.1
Range = 16-47, Mean = 26.50, SD = 8.46		
Duration of illness (years)		
< 1	2	9.1
1-3	11	50.0
> 3	9	40.9
Range = 0 months- 4.9 years, Mean = 2.27, SD = 1.57		
Number of hospitalizations		
0	3	13.6
1-2	12	54.6
3-4	6	27.3
5-6	1	4.5
Range = 0-6 times, Mean = 1.95, SD = 1.49		

Struggling to Restore Normalcy

A substantive theory “Struggling to restore normalcy” is presented to explain a basic social psychological process of being caregivers for children with schizophrenia in the early phase of illness among Thai parents. It was defined as any action of the parents in making an effort in a midst of difficulties to pull their children with schizophrenia back to the normal conditions as in the pre-diagnosis state. The process begins with learning the diagnosis and facing shattered dreams, the causal conditions leading to the phenomenon of struggling to restore the normalcy. “Learning the diagnosis” is triggered by the parents’ noticing changes of the children’s behaviors and suspecting the changed behaviors to be abnormal. After they took their children for diagnosis and treatment and were informed by the psychiatrist that their children suffered with schizophrenia, they felt as if they were facing shattered dreams. The parents perceived that their hope and dreams about their children were ruined before their eyes, since they viewed suffering with schizophrenia as facing an incurable and stigmatized disease, and facing loss and difficulties. All of them had high expectations that their dreams would be returned. They strongly desired to see their children recover from schizophrenia. They expected that the children return to be ones they once know and could have a normal life as others, such as to complete their education, to get a job, or to have a new family and be independent from the parents.

Perceiving caregiving as an unavoidable role comprising a sense of responsibility, feeling of love and sympathy, and believing in karma, they made a strong attempt to bring their children back to normalcy before the parents passed away. Unfortunately, they had to put much effort into trying to meet their expectations because of their lack of professional skills for caregiving, as well as the nature of the symptoms of schizophrenia, which is unstable and characterized by recurrences and relapses. Schizophrenia also comes with other impacts, such as the children’s poor decision making, the stigma of the disease, as well as the parents’ feeling of loss and difficulties.

In restoring normalcy, the parents struggled to control psychotic symptoms by monitoring the psychotic symptoms, maintaining medication adherence, managing the psychotic symptoms, and preventing the exacerbation and relapse of psychotic symptoms. At the same time, they struggled to deal with the impacts of the illness,

including dealing with the children's poor decision making, dealing with the stigma of the disease, and dealing with loss and difficulties.

However, most of them eventually learned, through the passing of time, that their children's illness would never recover the normalcy they initially expected. Therefore, they began to accept a new normal. "Accepting a new normal", thus, is viewed as a consequence of struggling to restore normalcy. Most of the parents still had maintained caregiving with new perspectives and some of them distanced from caregiving.

A summary of the categories and subcategories is presented in Table 4.3 and the substantive theory of struggling to restore normalcy is shown in Figure 1.

Table 4.3: Summary of Categories and Subcategories

Paradigm model	Categories	Subcategories
Causal condition	Learning the diagnosis	- Noticing changes of the children's behaviors and interpreting them to be normal - Suspecting the changed behaviors to be abnormal
	Facing shattered dreams	- Facing an incurable and stigmatized disease - Facing loss and difficulties
Phenomenon	Struggling to restore normalcy	
Contextual condition	Perceiving caregiving as an unavoidable role	- Sense of responsibility - Feelings of love and sympathy - Believing in karma
Actions/Interaction strategies	Struggling to control psychotic symptoms	- Monitoring the symptoms - Maintaining medication adherence - Managing the symptoms - Preventing the exacerbation and relapse of the symptoms
	Struggling to deal with the impacts of the illness	- Dealing with the children's poor decision making - Dealing with the stigma of the disease - Dealing with loss and difficulties
Consequences	Accepting a new normal	- Maintaining caregiving with new perspectives - Distancing from caregiving

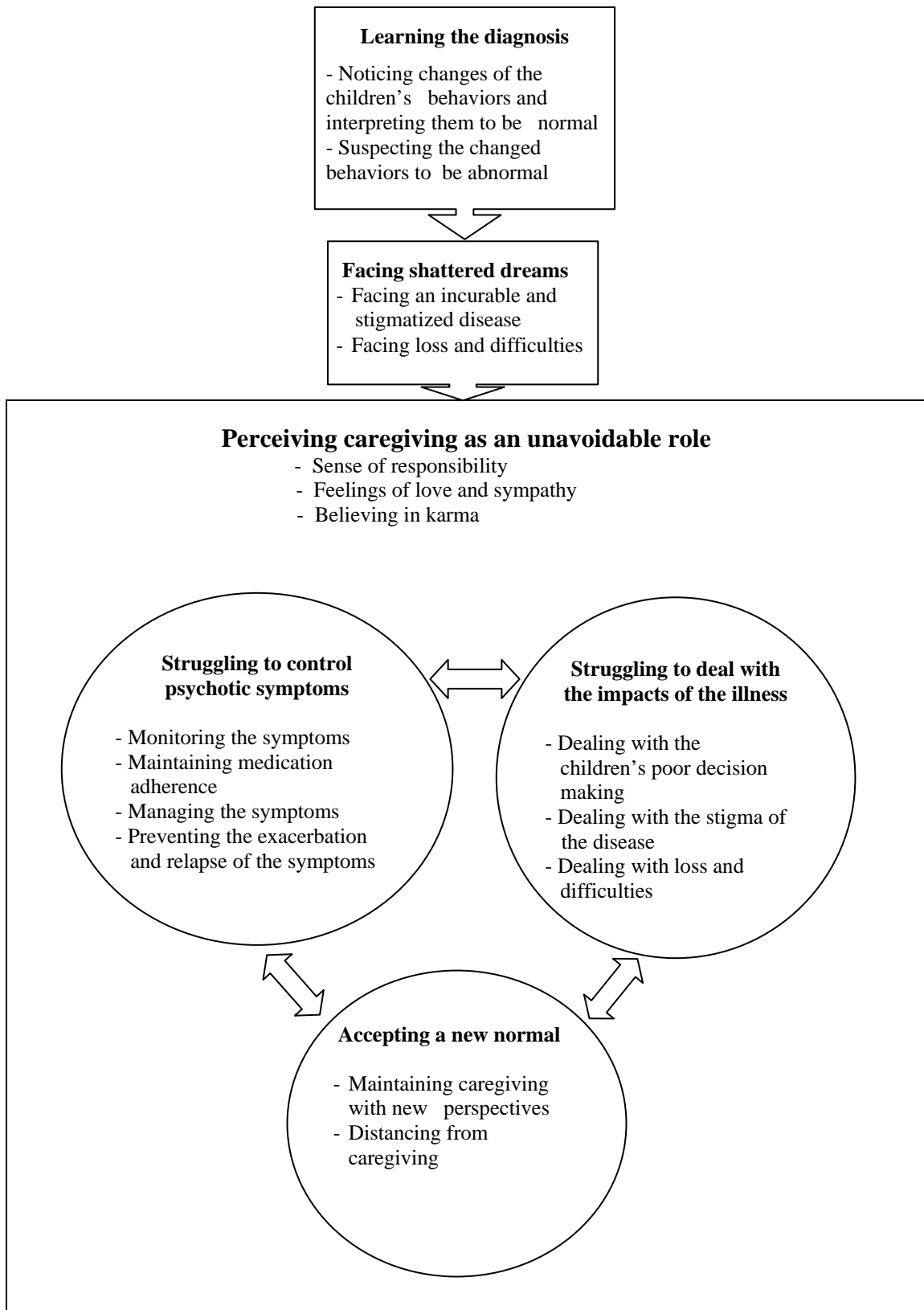


Figure 4.1: The Grounded Theory of Struggling to Restore Normalcy

Learning the Diagnosis

Learning the diagnosis is a process wherein the parents try to understand and interpret their children's changed behaviors and respond to them from the first notice of the changed behaviors until the children were diagnosed. Each parent took a different amount of time in this process, possibly months or years. It depended upon the parents' awareness of children's changed behaviors. The process is composed of two components: a) noticing changes of the children's behaviors and interpreting them to be normal and b) suspecting the changed behaviors to be abnormal.

Noticing changes of the children's behaviors and interpreting them to be normal

Before the diagnosis, each parent noticed the changes of their children's behaviors differently. More than half of the parents who lived together and had a close relationship with their children could notice gradual changes from their usual behaviors, such as increased social isolation or decreased daily activities. These parents reported that their children's changed behaviors happened from occasionally to frequently, and had a long-lasting effect on their daily functions. On the other hand, the rest of the parents who had to work outside or who took care of other ill family member at that time could notice sudden changed behaviors which were severe, such as bizarre behaviors, hallucinations, delusions, or aggressive and violent behavior. In addition, some of them began to notice or acknowledge the changes in their children's behaviors when the others, such as teachers or relatives mentioned them. The pattern of behavioral changes of each child may be similar or different as described below.

Increased social isolation behaviors. Some parents noticed that their children had more withdrawal behavior, refused to go to school or work, or hardly talked. If the social isolation behavior was the usual behaviors of the children, the parents would notice the changes when such behaviors occurred more often. One mother whose son had withdrawal behaviors as his usual behaviors stated about the teacher's mention the changed behaviors of her son:

The teacher phoned and asked if [name of the patient] was talkative at home. I replied that he hardly talked to others

and rarely went outside. [He] just stayed in the room more than he did before, but I didn't think it was abnormal.

Changes of daily activities. Most parents noticed, in the early stage of the illness, the changes of their children's daily routines. Some parents reported that their children could not sleep or did not sleep at night but slept during the day. Some of them noticed the changes of their eating behaviors, such as using chopsticks instead of a spoon as usual, eating less food, or refusing to eat and drink. In addition, some of their children neglected to take care of their personal hygiene. As one mother described:

... He did not want to take a shower... He did not take care of himself as before. He did not wash his clothes; he put on unwashed clothes. He wore them, took them off, hung them and wore them again; he did not wash them. His behavior changed, but not much.

Bizarre behaviors. Some parents noticed their children's behaviors were bizarre. They expressed inappropriate, repetitive, and confusing behaviors, such as washing all of the clothes in their house, eating in the same unwashed dish, or showering repetitively even when the weather was cold. Some parents reported that their children expressed purposeless movements such as stopping in some gesture for a long time, climbing, tearing down some parts of the house, or playing with swords alone. Moreover, some parents reported that their children presented a poor appearance, including wearing disheveled and dirty clothes, wearing the same clothes, or wearing many ornaments. As one father described:

Two or three days ago, he went out of the house and stayed still like a ghost. I followed him and wanted to know what he did. There were a lot of mosquito bites on his back and he behaved strangely. He walked to the wall and used his finger to poke at the wall and pressed his finger against the wall for a long time.

Auditory/visual hallucination. Most parents reported that their children often experienced hallucinations and only one mother reported that her daughter experienced visual hallucination. These parents acknowledged the children's auditory/visual hallucination from their behaviors. They reported that their children

sometimes stayed inattentive and talked or smiled/laughed to themselves. Some of them noticed that their children grumbled, and seemed to respond to someone else, whereas nobody was there and the topic was impossible and illogical in that context. Some children perceived superstitious things which were unprovable. For example, they said that they were talking to God or going to kill someone. As one mother stated, “He said he would kill the others, talked about impossible things, he would shoot someone. He said he was annoyed by someone who was saying something in his ears.”

The parents whose children had auditory hallucination reported about hallucination that it ranged from the sound without content to voices with clear contents. Some of the children said that someone was gossiping in their ears, while some of them heard voices from an amplifier or television. The voice may have been in the form of blaming or criticizing them, or commanding them to do something. In addition, the parents noted that their children often expressed emotions or behaviors corresponding to their hallucination. The most common behavior, responding to the voice, was talking to that voice in form of grumbling or complete conversation or angry outbursts and scolding. One mother whose daughter heard a commanding voice and talked to herself stated, “She said that someone talked to her. I don’t know, whispered in her ears. She talked to herself, saying ‘don’t talk to me; I know what I’ll do.’”

For visual hallucination, the mother reported that this symptom usually came along and was associated with auditory hallucination, as well as paranoid delusion. As one mother, whose daughter had visual hallucination, described:

She thought that her senior at the university gossiped and intended to harm her. Sometimes she told me that those seniors came to harm her at home. I said there is nobody here but she told that she saw them in front of our house.

Delusion/paranoid. Some parents noticed that their children began to think without a basis of reality. They noted that their children had a fictitious belief about a power or authority. For example, some children believed that they were a rich man or a king’s child. Additionally, some parents noticed that their children had the false belief of being harmed or persecuted by a particular person or group. The

parents reported that their children initially often had negative views against others, thought that other people intended to abuse them or their family members, or were afraid that their spouses would be unfaithful, resulting in frequent stress. Eventually, these negative views became fixed false beliefs. Some children responded to their distorted thinking, such as hiding from persons who would hurt them, becoming agitated, or becoming vigilant and hostile. The parents acknowledged that such paranoid behaviors could occur simultaneously with hallucination or emerge alone. One mother mentioned about her son's paranoid behaviors:

He told me someone tried to attack him. When he was sitting in the car, he was agitated and vigilant like he felt afraid of something, but there was nobody there. He asked his dad to park the car. It seems like he was afraid of someone in his paranoid.

Aggressive and violent behaviors. Some parents noticed that their children were easily irritated. When they got irritated, they could not control themselves, and would be stubborn. They also expressed hostile behaviors and extreme uncontrollable aggression. The parents reported that their children sometimes scolded and argued even though other people spoke to them nicely. They also destroyed properties or hurt their parents. As one father said about his daughter's behaviors:

At that time, she expressed her resentment to the person who was dissatisfying her. In addition, if her mom made more complaints, she would destroy things. Sometimes she threw the pictures of her mom away. That was one of her changes.

Most parents had little knowledge about schizophrenia, when they initially noticed some of their children's changed behaviors, including increased social isolation behaviors, changes of daily activities, auditory hallucination, or paranoid, they perceived such behaviors as normal. The parents' reasons for perceiving the changed behaviors as normal included a) the behaviors were slight changes and b) the changed behaviors happened during the transition to adolescence.

The behaviors were slight changes. Although the parents could notice something wrong happening with their children, they did not recognize psychotic symptoms if those behaviors slightly changed from their usual behaviors. For example, one mother whose son had social withdrawal as his usual behaviors said, “I thought it was normal because he was the same as when he was in high school, he hardly went outside.” Some parents perceived that their children’s changed behaviors were not severe, because such behaviors did not occur frequently and were not prominent. For example, the parents might think that their children’s talking to themselves was normal behavior because their children just moved their mouth without speaking out and the children refused to answer their questions. They thought that since people may talk/smile or laugh to themselves or hear faint voices occasionally, their children’s behaviors might be normal. In addition, during that period, their children performed their daily functions normally. As one father said, “He said he heard faint voices, and sometimes I did too, but I did not pay attention and I thought it would be the neighbors’ voice or the noise from a fan.”

The changed behaviors happened during the transition to adolescence. The majority of the parents noticed their children’s changed behaviors during the transition to adolescence. The parents thought that their children were exposed to many stressful events, such as entering university, preparing or starting their career. Some parents reported that their children were disappointed with their study or love, faced a troublesome work situation, had an interpersonal conflict, or had excessive concerns over their own appearance. They interpreted that the children’s changed behaviors were caused by these stressful situations or by the transition to adolescence. One mother whose son had a paranoid described her perception:

... I didn’t think he would be sick. I wonder if it’s about love. He talked like he was afraid as he was fighting with someone. He told me that a guy and his friends would hurt him. He was an adolescent at that time. Somebody attempted to harm him too, so he became paranoid.

Because of perceiving the children’s changed behaviors as normal, the parents did not make any decision. They thought that their children’s changed

behaviors might go away by themselves. Additionally, if the changed behavior occurred when the children nearly finished a training program, or a school test, parents would wait for their children to complete such tasks since they thought that their children's symptoms were not severe. As one mother stated, "I looked at her and continued waiting because I sometimes talked to myself and I thought it was normal."

During this period, most parents warned their children about their inappropriate behaviors in order to enhance the children's awareness. If the children continued their troublesome behaviors, such as complaining about their conflict with others or refusing to prepare or eat food, the parents perceived that their children were stupid, impatient, irresponsible, or demanding. Some parents would punish their children by criticizing, blaming, or hitting them. As one mother stated about punishing her daughter who refused to eat, "She looked sarcastic, and I told her she was an adult. I got very angry at her; as a result I hit her and stomped on her leg."

Suspecting the changed behaviors to be abnormal

Most parents became suspicious when they noticed a greater intensity of the children's changed behaviors, in terms of duration and frequency. They noticed that their children displayed prominent psychotic symptoms marked by delusion, hallucination, and bizarre behaviors. Some parents noted that their children showed increased numbers of problematic behaviors, such as aggressive and violent behaviors. Some of them realized that their children's perceptions and thoughts were not real when they knew precisely the content of the voices or the objects. For example, their children told them that someone was talking to them or they were seeing something, but there was nothing in that context. One mother who could no longer think that her son's paranoid was normal, talked about her reason that, "... Nearly two months after his symptoms became severe, he had paranoid. He thought that someone cheated his dad. I asked his dad and knew that it was not real, so we thought that was not normal."

The parents' suspicion was divided into two distinctions: a) acknowledging abnormality and b) suspecting the changed behaviors to be mental illness.

Acknowledging abnormality. It refers to the parents' awareness of the abnormalities of their children's behaviors, but could not define what they were.

If the parents had never seen a mentally ill person expressing the same symptoms as their children, they would not be aware of mental illness. As one mother described, “I never thought he was mentally ill. I did not know. I could not tell because I had never seen this kind of symptom before. I had no idea.”

Suspecting the changed behaviors to be mental illness. Most parents were likely aware of the mental illness when their children had prominent auditory or visual hallucination, delusion or paranoid, bizarre behaviors, or aggressive and violent behaviors. These parents used to see the mentally ill persons in their community expressing these symptoms which were similar to their children. They also learned from various media, usually portraying aggressive or violent behaviors of persons with mental illness which threatened the security of other people and properties. One mother who learned about psychotic symptoms from the media stated that, “He asked me if there was something in his ears, ‘Mom, please drop some water into my ears.’ I began to wonder because I had seen this symptom on TV.”

However, some parents whose relatives were mentally ill would initially be suspicious of mental illness because such behaviors were similar to their relative’s behaviors. These parents perceived mental illness as a genetic disease; thus, they thought that their children’s changed behaviors might be caused by mental illness. One mother noted about her initial perception when her relative mentioned her son’s changed behaviors to her:

I think it is genetic because his uncle was a mentally ill person and used to be admitted here [psychiatric hospital]. He had the same symptoms, talking to himself. When his grandma mentioned, I suddenly thought that was sure. I suspected because I had realized that mental illness is a genetic disease.

To confirm what went wrong with their children, the parents took their children for diagnosis and treatment from various sources, including 1) taking them to see a physician, 2) taking them to get alternative therapies, and 3) taking them to see a psychiatrist.

Taking them to see a physician. The parents who just acknowledged the abnormality would go directly to see a physician at a local hospital

near their home. They may have thought the physician could tell them the diagnosis. As one mother who lives in Chonburi province described:

First, we went to Chonburi Hospital... Before going to see the doctor, he was very strange. It seemed like he talked to someone that he saw and I thought it was quite strange. Then I took him to see the doctor at Chonburi Hospital.

Furthermore, there were some parents who suspected the mental illness also took their children to see the physician firstly to prevent stigmatization. They perceived that the physician could help them to solve their children's problems since the children's symptoms were not severe. One mother said, "I did not want her to go to a psychiatric hospital. Nobody wanted her to be there, so I took her firstly to a general hospital."

Taking them to get alternative therapies. Some parents took their children to get alternative therapies, such as energy healing or holy water from a monk to get rid of the black magic. These parents considered the temple and monk as the source of their mental and spiritual support and believed that their children's changed behaviors might be caused by superstition. These parents were also concerned about medical expenses if they chose modern treatment. One father who first took his son to see a monk for holy water sprinkling said:

I consulted his mom's siblings.... They suggested sprinkling him with holy water to get rid of the black magic. We also took him to get energy healing. We did not have much money, so we tried this first. It's better if he didn't need a medical treatment.

Taking them to see a psychiatrist. The parents who first took their children to see a psychiatrist at a psychiatric hospital were those who had mentally ill relatives. They realized that long-term untreated psychotic symptoms could lead to adverse treatment outcomes. One father who had a mentally ill relative said, "Because it is genetic... When my daughter had these symptoms, I did not leave it for long. When it seemed worse, we took her to the doctor immediately, and took the medicine."

Additionally, some parents who initially suspected that their children may be suffering with mental illness and other people also remarked on their suspicion, would directly take their children to see a psychiatrist. One mother whose son had bizarre behaviors as the initial symptoms said, “We went directly to the psychiatric hospital because we thought that our son was not afflicted with a common disease.”

The parents who took the children to see the physician or get alternative therapies eventually took their children to see a psychiatrist when their children’s symptoms did not improve. Though their children were treated with antipsychotic drugs, they refused to take medication. As a result, their behaviors became more aggressive and uncontrollable so that parents could no longer handle them. These parents were also recommended by the physician and the monk that they should take their children to receive psychiatric treatment directly from a psychiatric hospital. The monk also confirmed that there was nothing to do with black magic. One mother stated about the reasons why she decided to take her son to get psychiatric treatment at the psychiatric hospital after going to see the physician:

I decided because I could no longer control him. He didn’t comply with treatment; he grumbled and held a knife. He would attack his stepfather with a bottle and we tried to hold him. Oh! It was such chaos when we had finally held him; we rented a car to go to the psychiatric hospital; it was no longer tolerable.

After the parents took their children to the hospital, either a psychiatric or general hospital, the physician or psychiatrist informed them that their children suffered with schizophrenia. Thus, they realized that all of the changed behaviors of their children were the signs and symptoms of schizophrenia.

The parents’ initial responses to learning the diagnosis were shock and disbelief. Most parents were shocked because it was an unexpected situation. Though some parents had suspected the mental illness, they did not really believe it and it was difficult for them to accept the painful reality. In addition, although some parents had mentally ill relatives and perceived mental illness as a genetic disease, they did not expect that their children would have this disease. Some parents believed that they had provided good child rearing, so the disease was not

likely to occur. As one father said, “It was unbelievable. It should not happen to us because we brought her up so well. We gave her what she wanted and she graduated.”

Facing Shattered Dreams

After the process of learning the diagnosis, the parents felt as if their dreams were shattered, dreams which had nearly come true disappeared in front of their eyes. For parents, their children are their dreams and hope. At least, they expected that their children could have a normal life and be independent when they grew up. At the time of the first onset of their children’s illness, they were mostly in their adolescence and early adulthood. The parents perceived that their children were in good developmental stages; for example, they were studying in high school or university. Some of them had nearly finished their education and were getting a job. Thus, the parents felt as if they were awakened from a sweet dream to face an agonizing reality. Facing shattered dreams was derived from two components: 1) facing the incurable and stigmatized disease and 2) facing loss and difficulties.

Facing an incurable and stigmatized disease

More than half of the parents realized the difference of schizophrenia from a physical illness. In their opinion, schizophrenia is a defect of the individual’s mind caused by stress, whereby its abnormalities were invisible and unpredictable. Hence, the duration of treatment could not be exactly determined. Some of these parents whose relative was mentally ill learned that mentally ill patients had to continue the medication for a lifetime. Their understanding was confirmed by the psychiatrist. As one mother who had a mentally ill relative said, “In my mind, it is difficult to recover. Our relative had been like this, not getting better. It is hereditary.” Another example is one mother’s statement, “I understand that this illness is associated with the subconscious which is inside and invisible. Heart disease can be operated on, but this is invisible. Thus, it is difficult to cure, I thought at that time.”

In addition, all parents acknowledged that the public generally view mental illness as heritable and associated with poor parenting; therefore, they felt

embarrassed to have children with schizophrenia. The parents, especially those who had higher education and social status, felt the others could look down on them. Additionally, the embarrassment derived from the fact that a mentally ill person is called “insane,” loses consciousness and has uncontrollable and shameful behaviors, such as undressing and acting in bizarre manners. One father, a lecturer in the university who holds a Ph.D., described his perception of his daughter’s illness:

The patient was not normal. For example, she walked naked. How would it be normal? This behavior is shameful. Other people think that person is insane and view their parents as inferiority. It represents poor parenting and the child is deranged. I’m a teacher. I can teach others, but I cannot teach my own child. People might question how I bring up my kid to be mentally deranged. People think like that and it is shameful.

Facing loss and difficulties

According to the parents’ understanding that schizophrenia is an incurable and stigmatized disease, most parents felt that they faced the total loss of their dreams about their children. They thought that their children might lose their opportunity for a normal life in society, such as getting a job and getting married. They reported that their dreams about their children’s future were ruined. They also experienced loss of the children they once knew to mental illness, especially when their children expressed psychotic symptoms. It was difficult for parents to accept that many of their wishes, expectations, and dreams about their children would never come true. One mother described her feeling after she knew definitely that her son suffered with schizophrenia:

Oh! It seemed that everything was destroyed. All parents wish their child to have a prosperous future, to be a soldier, to be a police officer or something like that which is good for their lives. When he became like this, he cannot do anything and his future is lost.

At that time, they felt as if they were staying in darkness alone. Their reaction to loss was grieving. They cried and were sorrowful and preoccupied with thinking about the time when their children were normal. They also lamented over

their children's expected accomplishments. One mother described her feelings and reactions, "We have seen him since he was born. We looked at his pictures when he was young [tears in eyes and voice shaking]. He is very handsome and cute. Now, he is older, it is miserable."

Furthermore, the parents experienced the feeling of difficulties when they thought about the future, which various obstacles might lie ahead. They realized that they would have to take care of their grown-up children and control their psychotic symptoms without professional skills. None of them had ever taken care of a patient with schizophrenia, though some of them had relatives with mental illness. They did not know how to handle their children's psychotic symptoms. Some parents who lived alone and had to work were likely to have extreme worry about their caregiving. As one mother who was divorced and lived with her son alone, explained her feelings:

I don't know how to handle the situation. How can I help my son to be normal as before. I think repeatedly. My head seemed to be exploded. I had never taken care of such patient. I also have no more time to care for him because I have to go to work.

Perceiving Caregiving as an Unavoidable Role

Perceiving caregiving as an unavoidable role was the contextual condition within which the process of struggling to restore normalcy was taken. It refers to the parents' perception that they could not refuse to provide care for their children with schizophrenia. Their perception was derived from their sense of responsibility, feelings of love and sympathy, and believing in karma.

Sense of responsibility

All parents perceived that taking care of their children, especially when they were sick was their direct responsibility. They also perceived that it was a social expectation. Some parents engaged in caregiving to avoid accusation by others. In addition, when the parents began to ponder the causes of their children's illness, they experienced feelings of guilt for doing or not doing something which could possibly be the cause of their children's illness or worsen their symptoms. For example, when

parents learned that early diagnosis and treatment are associated with the successful treatment outcome, they felt guilty for failing to recognize the symptoms sooner. Some parents were ashamed that they had ignored their children's complaints, got angry with them, or punished their children at the early phase of the symptom expressing. Therefore, the parents felt that it was their responsibility to restore normalcy to their children and this would release them from guilt. They had tried to take care of their children as much as they could although they faced a threatening situation and experienced feelings of loss and difficulties in taking care of their adult children. Most parents reported that they would never abandon their ill children, though they had to care for them for their whole lives. They viewed that others would never be able to provide as good care as they did. As one mother said about her willingness to care for her son:

I don't think anything.... It's my responsibility. If I do not take care of him, who does? As a mother, it does not matter if he is a child or an adult. He is our adult child. If I abandon him, the public will blame me and wonder what kind of mom as I am.

Feelings of love and sympathy

All parents viewed their children as belonging to themselves, the representation of their love, dreams, and hopes. Their children are important to fulfill their lives. They reported that the feeling of love and sympathy for their children had stayed in their heart forever though everything else could be changed. They still had love regardless of whether their children were mentally ill, though sometimes their children displayed aggression and stubbornness. Their sympathy involved not only the feeling of extreme pity for the children, but also concern about their children's future, especially when they perceived that their children were threatened with an incurable and stigmatized disease. They still wished their children to have a prosperous future, to complete a high education level, to have a career, and to have a new family and a normal life as others did. As one mother said, "I always love him, my son, and I wish him a happy life, to complete his education, and to have a normal life."

Furthermore, the parents experienced tremendous sympathy, especially when their children were admitted to the psychiatric hospital. They felt as if the pain

went deeply through their heart when they saw their children being restrained or secluded in a room, or when they saw that their children showed psychotic symptoms which differed from the behavior they once knew and from the others in their age group. A mother sobbed out while she was describing her feelings when her son displayed psychotic symptoms:

... When I saw him while he was eating, I was sad and felt sympathy. At home, he used chopsticks instead of a spoon, wore trousers backwards, took a shower many times a day, and scratched his foot with a brooch [wipe her tears and stop for a while]. Anyone who did not experience this would never understand how it is. He is a child that we brought up since he was young. He had not been ill since he was born.

Believing in karma

The law of karma, the law of cause and effect, relates to Buddhist philosophy and influences the Thai Buddhist's way of life. Karma concerns intentional actions, including both bad and good actions that were done physically, verbally, and mentally. All actions have their consequences: good karma brings good consequences and bad karma brings bad consequences (Payutto, 1993). Therefore, Buddhist people believe that present actions lead to future consequences, meanwhile, the present happening is the consequence of actions in the past or present life. In addition, "karma" has been additionally used synonymously with "Babb (demerit)" which is a negative meaning and refers to a bad deed. On the other hand, "Boon (merit)" is a good deed. According to the belief of karma, the Buddhists attempt to perform Boon and avoid Babb (Podhisita, 1998, p. 43).

The parents in this study perceived that it's all about karma determining their children to be mentally ill and themselves to be caregivers of their grown-up children. Most parents thought that they might treat their children badly in a past life or do bad deeds against human or other living creatures in the past. Therefore, they realized that they could not avoid repaying such karma. As one mother mentioned about her perception of being a caregiver for her son, "I think that, I don't know, it is karma that I had to repay through him. Most of us think that karma involves something that we used to do which we cannot know."

Struggling to Control Psychotic Symptoms

Struggling to control psychotic symptoms refers to the parents' difficulties in pulling their children's psychotic symptoms down to the normal state when they were expressed prominently, and in suppressing them so that they would not re-emerge when they were subsiding. Most parents noticed that their children's psychotic symptoms were unstable and unpredictable in the following ways: occasionally subsiding, occurring more frequently, and eventually being uncontrollable, particularly in the first one to three years of treatment. They reported that the psychiatrist needed to adjust the types and dosages of medications in alignment with their children's symptoms. In addition, the parents reported that their children were also unable to return to study or work. The parents thought that their children could live a normal life if their psychotic symptoms were absent. Without professional skills in caregiving, the presence of the children's psychotic symptoms posed enormous challenges for the parents. They tried to control their children's psychotic symptoms through trial and error by using these strategies: a) monitoring the symptoms, b) maintaining medication adherence, c) managing the symptoms, and d) preventing the exacerbation and relapse of the symptoms.

Monitoring the symptoms

This refers to the parents' actions in using multiple strategies to monitor the changes of their children's psychotic symptoms after treatment. The parents' aims were to report the changes in their children's psychotic symptoms to the psychiatrist, as well as to deal with such symptoms to help their children to be normal as much as possible. The strategies for monitoring the symptoms included a) observing behaviors and emotions, b) raising inquiries about the changed behaviors and emotions, and c) detecting the severity of the symptoms.

Observing behaviors and emotions. The majority of the parents would observe their children's changed behaviors expressing at the first onset of the illness. Simultaneously with observation, most parents gradually acquired more knowledge and understanding that the unusual behaviors and emotions of their children were their psychotic symptoms. They utilized an accumulated knowledge for further observation. For example, some parents acknowledged that their children

would talk to themselves if they had auditory hallucinations. Hence, the parents would make observations while the children were staying alone. The parents, whose children had paranoid as an additional symptom, would make secret observations to prevent the escalation of their children's paranoid. One mother whose son had paranoid and just stayed in his room and talked to himself explained her observation:

[I] Had glanced, when I walked past his room, I glanced. He used to tell me that someone was looking at him. He took it for granted that someone was looking at him, so I was afraid that he would be more paranoid if I made direct observation.

In addition, some parents learned that their children's facial expression was an indicator of psychotic symptom. For example, if their children preoccupied with something else, they would show excessive blinking during a conversation. The parents would aware that their children had poor attention at that time. As one mother said:

Oh yes. There is a way to detect. While I was talking to him, I had to observe his behavior. I looked at his eyes. Eye contact is an important thing for a mentally ill person. The nurse also told me like that. When he had symptoms, he blinked his eyes frequently; I knew that he was thinking about something else.

Moreover, most parents perceived that their children would not be able to perform their daily activities well or would not perform them at all if their psychotic symptoms did not improve. Thus, some parents would observe the changes of their children's daily activities. Most parents perceived deviated behaviors, such as not sleeping, not taking care of their own hygiene, or not eating, as the signals of the existent psychotic symptoms. One mother, whose son believed that his head was implanted with a microchip by someone who wanted to read his mind, described her observation of her son's daily activities:

For example, if I tell him to wash hair, he would not. He did not shampoo his hair, no matter how I told him. His father had to take him to hair salon when his symptoms

remained. Normally, he can do it; he would take a bath and shampoo his hair by himself without having to be reminded. I have to watch him.

In observing the children's emotions, the parents also utilized their past experience in interpreting the emotional changes. The parents learned that the children's emotions usually changed in line with hallucination or paranoid. The changes of the emotions might range from stress, frustration, dissatisfaction, and anger, to expression of the aggressive behaviors. The parents perceived that those emotional expressions were the signs of psychotic symptoms. As one father, whose daughter had auditory hallucinations, stated:

If she had auditory hallucinations, her emotion changed. She would rebuke people. I used to ask why and she said that she heard something. Sometimes it was like someone scolded her and she wanted to scold back and argue. It was like someone wanted to brawl with her. Thus, she quarreled with it. That was her response to hallucination that I learned.

On the other hand, if the children had not expressed such emotions, parents would perceive that the children's psychotic symptoms were improved. As one mother stated, "... There was no expression of paranoid. I noticed that he was not stressful and frustrated, and he did not complain same stories."

Raising inquiries about the changed behaviors and emotions.

The parents would ask their children about what they were doing or ask them the reasons when they expressed unusual behaviors. They then determined whether the children's behaviors or emotions were normal or were psychotic symptoms through considering the appropriateness of their children's thoughts and perceptions within the current context. In addition, the parents learned that delusion or hallucination might be difficult to assess if they were not clearly expressed through behaviors. Therefore, the parents keep monitoring their children's delusion/hallucination by asking them directly. Some of them asked their children indirectly because their children avoided telling them about their symptoms. As one mother whose son used to express paranoid and hallucination stated:

He never replied to my direct questions. Thus, I told him that, in the past, he used to think about this and that. He remembered it. 'It was really like this, but it has stopped now' he said. I mean the voice he used to hear.

Detecting severity of the symptoms. While observing the children's behaviors and emotions, the parents assessed psychotic symptom severity. In doing this, they compared the present symptoms with the previous symptoms, in terms of their frequency and their effects on the daily functions of their children and the safety of themselves and others. The parents would perceive that the symptoms were severe if they occurred frequently, threatened the safety of the children, others, and property. If the parents considered that their children's symptoms were severe, they would take their children to the hospital. One father described his son's behaviors that he interpreted them as severe psychotic symptoms:

I knew that his symptoms were severe which began by going outside and being stubborn. I sometimes scolded him, since I was stressed. He was also stressed. He threatened to hurt his mom, so [I] just took him to see the doctor.

Maintaining medication adherence

Maintaining medication adherence was defined as the parents' actions in trying to ensure that their children took medications correctly, completely, on time as prescribed, and continuously in order to control the psychotic symptoms. All parents realized the importance of medication adherence as it could control their children's psychotic symptoms. Most parents were emphasized by a psychiatrist that mental illness requires continuous medication. They also learned through sharing experiences with other psychotic patients' relatives when they visited their ill relatives in the hospital. They noticed that their children's psychotic symptoms would return, occur more frequently and for longer durations, and eventually be uncontrollable after their children discontinued medications. The parents reported that the treatments would be re-started and the course of treatment was extended with each subsequent relapse. To maintain their children's medication adherence, each parent used different approaches based on their children's conditions, including a) making complete involvement in

medication, b) promoting self responsibility for medication, c) monitoring medication adherence, d) dealing with medication discontinuation.

Making complete involvement in medication. The parents practiced complete involvement in medication when they noticed that their children's psychotic symptoms were severe. They noticed that their children had insufficient awareness and had the poor decision making ability. They thought that their children might not have an effective self-care, forget to take medication, might prepare medication incorrectly, or take repeated doses of medication. These parents prepared and gave medication to their children at each mealtime and watched over their medication taking until the pills were swallowed. As one mother said:

I prepared the pills for him, put them in his hand, and asked him to take them immediately every meal time. I have to do this to make sure that he took medication correctly and completely. I watched him swallow the pills.

Promoting self responsibility for medication. More than half of the parents who perceived that their children's psychotic symptoms were improved and controllable—for example, their children began to comply with the parents, hardly displayed or complained about their symptoms, and performed their daily functions normally—tried to promote their children's self responsibility for medication.

These parents were those who realized, after their children's re-hospitalization, that the treatment for their children would be extended. They thought that their children would not be a burden on others if self responsibility of their children was promoted.

In doing this, the parents were gradually decreased their involvement on their children's medication. Because they could not trust that their children could prepare medication correctly by themselves, therefore; they still prepared medications for their children but let them take medication by themselves. Some parents prepared medications by placing them in a medicine box for each meal time. If their children had to work outside, the parents gave them the prepared medication and warned them to take on time at the workplace. One mother whose son's psychotic symptoms improved and went back to work, mentioned about preparing the medications for her son:

When it was medication time, I would prepare and put them in the little sachet for morning and evening. [I] Looked for the little sachets to put the pills on each time and gave them to him at medication time. I put the sachet in his bag for taking to the workplace. I was afraid that he would take the wrong pills, or take the same pills repeatedly.

In addition, some parents began to teach their children how to prepare the medication. They explained details of medications to be taken each time, such as the types of medicines and the number of pills, and demonstrated medication preparation to their children. After that, they reminded their children to prepare and take medication at each medication time. To ensure that their children could prepare medication by themselves correctly, some parents tested their understanding and memory for details of medications. Additionally, some other parents re-checked whether the medication was prepared properly after their children had finished the preparation. One father stated about how to test whether his son properly prepared medications as prescribed:

He knows everything, these pills for this time. Sometimes, I pretended to give him the wrong ones, but he knew that was in the evening. This makes me quite sure that he would not take the wrong pills.

Monitoring medication adherence. When the parents let their children take medication by themselves, they were not sure about their children's responsibility. They, therefore, monitored their children's medication adherence. Some parents, who spent a whole day with their children, would monitor their children's medication taking directly and completely. They could monitor both their children's medication preparation and medication taking. On the other hand, some parents thought that their children might be in compliance only when their parents observed them. To ensure their children's responsibility, these parents made secret observations while their children were preparing and taking the medication. Some parents put the plastic bag containing their children's medication in an area where the parents could see their children clearly. If they could not see their children's preparing and taking the medication, they tried to listen and ask their children at that time. For example, one mother listened and asked her son who was in his room to ensure that he was

preparing and taking the medication. She mentioned about the conversation between her son and herself:

I asked him to prepare medication by himself. When it was time to take medication, I heard the sound of plastic bags *kobkapkobkap* [the sound from the plastic bags] and I asked ‘What are you doing [Patient’s name]?’ I asked him when I was in my bedroom. ‘Are you taking the medications?’ ‘Which tablets, for the evening or before bedtime?’ He replied, ‘Before bedtime, the evening tablets were taken already’ ‘How do you take the evening pill?’ I asked. ‘Half a tablet.’ Something likes that.

Furthermore, if the parents prepared medication for their children to take by themselves, they would check the remaining medication in order to ensure that their children had already taken them. Some parents checked them from the medicine box, while some of them counted the remaining tablets in the sachets. For the parents whose children took medication at the workplace, they asked their children to return the sachets or wrappers to them. As one mother said:

I told him these were the pills. ‘Give me back the foil wrap, give it back to mom, baby. I will reuse the sachets to refill the pills in.’ I told him like this and he gave it back to me to ensure that he had taken the pill already.

The parents whose children had paranoid against them would secretly check the remaining medication in the medicine bag. They experienced more difficulties because their children mistrusted them. They had to prevent their children from becoming increasingly resentful or paranoid at the same time. One father, whose son felt paranoid against him and did not allow him to involve with his medications, mentioned about his attempt to check the remaining medication:

I used to keep the pills with me and prepared them for him. However, he never let me do it. He was stubborn and told us not to get involved with his stuff. He kept the medicine bag in his room secretly. When he went to study, I counted the remaining pills to see if he took them or not. It was difficult to find them because he kept them hidden.

Dealing with medication discontinuation. The majority of the parents reported that their children discontinued medication. Most children refused to take medication because they rejected their illness, while some of them did not take medication as prescribed, for example, refused to take some tablets that made them suffer from side effects. The parents realized that medication discontinuation was an important cause of psychotic symptom recurrence and relapse. They tried to manage the problems by using various approaches, including 1) persuading, 2) threatening, 3) deceiving, and 4) reducing the side effects of antipsychotic drugs.

1) *Persuading.* Although the parents understood the reasons for their children's medication noncompliance, they kept trying to persuade their children to realize the importance of medication adherence. They tried to explain the nature of schizophrenia based on their understanding that it was difficult to cure and required continuous medication. The parents emphasized the advantages of medication adherence and the disadvantages of discontinuing medication. One mother presented her persuading her teenage daughter to take medications:

‘... If you don't take the medication, you'll be a psychotic person. Don't be stubborn. You must complete the medication and you'll be normal and you will have a boyfriend.’ I talked to her nicely. ‘[Patient's name] You have everything, don't be stubborn. If you get a job, there will be lots of people who would like to be your boyfriend.’

2) *Threatening.* When the parents failed at the approach of persuading, some parents used a threatening approach. In doing this, they warned of unfavorable conditions for their children if they did not take the medications. For example, the children would look like a psychotic patient walking along the street, or they would have to go back to the hospital and could not study or work like a normal person. Some parents warned their children that they would not provide care anymore if the psychotic symptoms were recurrent because of their medication discontinuation. Meanwhile, some parents would force the children to take medication again after spitting them out. They forced their children to open their mouth and lift their tongues. These approaches were likely to fail if the children had severe psychotic symptoms.

One father talked about the moment when he forced his son after spitting medication out:

I told him to take the tablets. [I] Put them in his hands. He sometimes put them in his mouth and held them under his tongue and spit them out later. When I saw this, I forced him to take them again but he did not comply. He thought he was normal. My wife and I asked him to take the pills, but he refused as he thought he was not ill.

3) *Deceiving*. After using other approaches, but the children still refused all medication or complied only with some tablets, most parents would inform the psychiatrist. Then, the psychiatrist would change from pills to liquids and the parents secretly dropped such drugs into drinking water for their children. However, some parents considered that it was difficult to control the drug dosage resulting in ineffective clinical outcomes. Some children received an overdose if they often drank water. As an illustration by one father:

The doctor prescribed medication for him, but he didn't take them. Then, the doctor recommended taking liquid medication.... I put it in drinking water for a year, but it did not work. I put it in water bottles which were in the refrigerator, and sometimes he drank a lot of water.... My son did not know that I put it in his drinking water.

In addition, if the children had to take medication in the form of pills, some parents crushed the tablets and secretly mixed them with food or drink without giving notice. This approach was mostly ineffective if the children hardly ate any food. Besides, the children refused to eat when they knew that the pills were mixed with food or drink. Some parents have lost the trust of their children and their children's paranoid symptoms increased. Nevertheless, some parents continued finding new approaches. They crushed the pills and mixed them with a beverage where it was difficult for the children to notice. One mother, who crushed the pills and mixed them with a kind of clear drink where her son could notice the pills and refused to drink any more, mentioned about her attempt to find other approaches:

There is another solution. I will try to put it in “Birdy coffee” [an instant coffee beverage] that he likes. I thought he may not know because it is black, he cannot see the medicine. Unlike “Ohishi tea” [a green tea beverage], he could see the powder left on the bottom of the bottle.

Moreover, some parents tried to request the psychiatrist to write on medical zipper bags that the medication were the type of dietary supplement, in order to encourage their children to take them. As one mother stated, “Could I deceive her by requesting the psychiatrist to write on medical zipper bags that it was a type of vitamin or dietary supplement for brain?”

4) *Reducing side effects of antipsychotic drugs.* More than half of the parents noticed that, after taking antipsychotic drugs, their children suffered with some conditions such as muscle pain, constipation, drooling, weight gain, and tongue rigidity. They acknowledged later that those conditions were side effects of antipsychotic drugs. These symptoms made their children complain about their physical discomfort, or embarrassment of their own image, or difficulties in studying and living. These parents noticed that their children would then stop taking medication. However, because the parents realized the importance of medication adherence, they tried to diminish their children’s suffering from such side effects in order to help their children adhered to medication. They firstly reported to the psychiatrist and the psychiatrist would adjust their children’s drug regimens. According one father’s description, “... I reported to the doctor that he discontinued some pills because he suffered with constipation. The doctor said that my son had to take medication continuously and he adjusted the medicine for my son.”

In addition, some parents used their personal knowledge and experiences to solve their children’s problems simultaneously with reporting to the psychiatrist. For example, some parents provided natural laxatives or fiber foods for their children to alleviate constipation. Some of them gave their children a massage to release muscle pain. If the side effects were diminished, some children returned to take medication and the parents continued adopting such approaches. One father, whose children stopped taking medication due to constipation, mentioned about utilizing his existing knowledge and experiences to help his son to alleviate constipation:

... He did not defecate for seven days, did not defecate like this. The doctor said that he was constipated from the pills and food he was eating. Thus, I force him to eat more fruit and vegetables. Then, he adjusted the excreted within a few days and did not wait until seven days. Sometimes if he didn't defecate just for two days, I might give him "YaknomTrabaihor" [a Thai herbal laxative] that I usually take to make defecate, about six to seven tablets....Wait for a couple days, then he defecates.

Managing the symptoms

It refers to any actions of the parents in dealing directly with their children's psychotic symptoms, including delusion, hallucination, and aggressive and violent behaviors. The parents noticed that when their children displayed these symptoms, their normal daily functions were disrupted. They were preoccupied with their distorted thinking and perception and sometime displayed bizarre behaviors. In addition, they expressed aggressive and violent behaviors threatening the security of the family members or others. At that time, the parents felt as if their children were strangers who were not the children they once knew. Therefore, the parents tried to bring the children they once knew back by dealing with these symptoms through various approaches divided into two groups: 1) dealing with delusion and hallucination and 2) dealing with aggressive and violent behaviors.

Dealing with delusion and hallucination. When the children expressed delusion and hallucination, the parents tried to use many approaches, comprising 1) explaining reality, 2) disputing distorted thinking and perception, 3) presenting related evidence, and 4) distracting preoccupied thinking. The parents' aim was to redirect their children into reality; to change their children's distorted thinking and perception and make them stop performing abnormal behaviors resulting from delusion and hallucination.

1) *Explaining reality.* The parents gave the children the reasons why their thinking and perceptions were not real. When the children expressed intense emotions or behaviors responding to hallucination or paranoid, such as excessive fear, anxiety, frustration, aggression, or hiding themselves when having paranoid that someone would assault them; the parents would explain to their children

in a consoling manner to assure them that this was not the case. As one mother narrated about her explaining the reality to her daughter when she expressed abnormal behaviors resulting from her paranoid delusion and hallucination:

Yes, she was frustrated and cursed someone who criticized her [with her auditory hallucination]. She said the janitor at school always rebuked her. She sometimes ran to me and told me that the janitor rebuked her in front of our home, and she rebuked him back. I tried to explain her that nobody rebuked her. I didn't know what to do because nobody did anything.

Furthermore, if the children did not believe them, some parents asked the psychiatrist to explain the reality to their children. They thought that their children might believe an authoritative person such as the psychiatrist. As one mother whose son believed that there was something in his abdomen and tried to get an operation said:

... [He] had wanted to get an operation. The doctor said, 'What an operation!, you are all right.' He said his abdomen needed to be operated on and it was not cured by medication. He always talked like this and went to see many doctors to get an operation. I asked [a doctor] to help me to confirm that his abdomen problem was nothing.

2) *Disputing the distorted thinking and perception.* When the children expressed delusion or hallucination without irritability, the parents perceived that the children could be reached with logic. Therefore, they tried to give them different perspectives. Some parents tried to give logical explanations to their children. One mother, whose son was paranoid that drinking water was poisonous and refused to drink it, narrated her statement, "I said, 'there was nothing. I did not put anything poisonous in what you drink. If it is poisonous, you would have died by now.'"

3) *Presenting related evidences.* After the parents used the strategies mentioned above, but their children did not believe them, the parents expended more effort to redirect their children to reality by presenting related evidence to prove the reality. The evidence they used were varied based on their children's

delusion. For example, if the children believed that they were adopted, the parents would show them old photographs or take them to have DNA testing. One mother, whose son believed that he actually was the king's child and she had adopted him, tried to prove reality by presenting existing evidence or testifying to make her son believe and return to the real world. She said:

I showed him the picture when he was a kid. 'Look! These are your pictures when you were young.' That time he was not normal [laughing]. I rented a car three times and I paid a thousand each time for DNA testing.

4) *Distracting preoccupied thinking.* If their children's symptoms were severe, the parents noticed that their children were unable to understand reality and were preoccupied with faulty beliefs or auditory or visual hallucination leading to the disruption of their children's daily functions. Therefore, the parents tried to distract their distorted thinking by changing their attention to something else, or they told their children to stop such thinking. As one mother whose daughter was preoccupied with paranoid delusion and hallucination stated:

I took her to [the shopping mall] and she said 'The next table, they are university students and they hear what I think. Look! They are gossiping about me and blaming me.' 'It is not real, they are other people, don't pay attention to them.' I said. 'Eat, come on eat, and then we will buy something to eat at home.' I tried to change her attention to something else.

Dealing with aggressive and violent behaviors. When the children displayed aggressive and violent behaviors, the parents understood that those behaviors were their children's psychotic symptoms which were uncontrollable. To calm their children's behaviors down, each parent used different approaches, including 1) complying and 2) giving a warning.

1) *Complying.* Some parents learned about the nature of the psychotic patient from the media, such as books, and television that reasonable explanations or disputes to stop behaviors would not be successful, when psychotic symptoms were severe. In addition, they learned that their children were vulnerable to tension. When being offended or forced to do something, the children might be

resentful, stressful, or have more severe psychotic symptoms. Thus, they avoided forcing their children at that time, allowed them to continue their aggressive and violent behaviors if they were harmless, and agreed to do what their children wanted. As a mother mentioned about her complying with her daughter's aggressive behavior:

Whenever her symptoms showed up, I needed to do what she wanted me to do, not to be against her. Sometimes she forced me to pour water, and I always did anything that she needed. I had to act as mentioned earlier so that she would not be emotional and calm down. If she was moody, it seemed like she was beaten and would be uncontrollable.

2) *Giving a warning.* Though the parents acknowledge that such behaviors were their children's psychotic symptoms, they would give them a warning that they behaved with improper manners to their parents and others. They asked them not to do such behaviors again. The parents also explained that such behaviors made the parents' embarrassed and that others could view them as abnormal. Some parents used this approach alone, while others used this approach after the children were calm down. As one mother narrated about her response to her son's aggressive behaviors:

When he was irritated, he started shouting at me. At the market, 'I have to go home, walk quickly' he shouted to order me. When we arrived home, I warned him, 'You shouted at me, don't do that. It is not good for you. Other people look at you and think that you were abnormal. It was embarrassing.' He then apologized to me.

Preventing the exacerbation and relapse of the symptoms

This refers to the parents' actions when they noticed that their children's psychotic symptoms were subsiding whether during hospitalization or after discharge from the hospital. Most parents perceived that mental illness is related to the mind and the patients are vulnerable to stress or anxiety which could induce symptom escalation. In addition, nearly half of the parents learned that substance abuse was one of the major causes of recurrence and relapse of their children's psychotic symptoms. Therefore, the parents tried to prevent their children's symptom exacerbation and

relapse by using the following strategies: a) comforting their mind, b) maintaining cheerfulness, and c) preventing substance abuse.

Comforting their mind. When the children were faced with stress, anxiety, and any upset feeling, the parents thought that these situations could induce an escalation of their psychotic symptom. Therefore, they used multiple strategies varied upon the situation, including consoling, ensuring, and offering help, to make their children feel better.

When the parents noticed that their children were anxious, they tried to console their children to feel calm, to relax, and to realize that the situation was not so bad. The parents sometimes agreed not to tell the truth to their children and talked about positive things in their future lives. As a description of one mother whose daughter worried about being admitted to the psychiatric hospital:

‘Mom, it [name of psychiatric hospital] is written on the pillow.’ Then, I said, ‘That’s right, this is the hospital. But you are not mentally ill. You have a chance to recover because you are simply stressed, but you need to stay together with them in this same hospital.’ I said.

When the children were hospitalized, the parents perceived that the children might be afraid of being abandoned; they assured their children that they would never leave them at the hospital. They also paid more attention to their children, as well as engaged in caring conversation and hugged them in an attempt to make their children realize that they had always loved and cared about them. As one mother said, “I said, ‘I will never leave you and I will be back to visit you frequently. I will pick you up when you recover’.... I have attempted to make him feel warm and not to be lonely.”

In addition, when some parents perceived that their children were nervous because of their paranoid that someone was persecuting them; they reassured their children that they would protect them. As one mother, whose daughter had paranoid, said, “...‘what do you fear? I will protect you, stay with you and won’t let anybody hurt you.’ Something like that.”

When the parents realized that their children faced some problems and stress, they tried to help their children to solve those problems. One

mother whose daughter went back to work after being discharged from the hospital, tried to make her felt more comfortable by offering help. She said:

She might be stressed since her performance was not as satisfactory as others'. That's what she thought. I said, 'Although your performance is not good, you can resign whenever you wish.'.... I tried to help her. As for her car payment, I told her that I would make payment for her as the amount is 4,000 Baths only. If I had enough money, I would repay the whole remaining amount for her.

Maintaining cheerfulness. The parents understood that good emotion was essential for their children's condition and resentment could make their children's psychotic symptoms recur or relapse. They tried to maintain their cheerfulness by using various strategies comprising a) pleasing them with their favorite foods, b) providing entertaining activities, and c) limiting exposure to stressful environments.

Most parents perceived that their children would be in a bad temper or frustrated when they were hungry. While visiting their children at the hospital, the parents brought their favorite foods for them. When the children stayed at home, the parents attempted to serve them their favorite food on time. One mother mentioned about how to please her son with food:

I noticed that food is important.... I had tried to serve him with healthy food that he likes. I'm aware that he will get frustrated when he is hungry. In contrast, if he was provided with his favorite food on time, he would be cheerful.

Some parents were informed by the psychiatrist that the children would get worse if they had nothing to do. They could become preoccupied with their delusion and hallucination. Thus, the parents tried to provide their children with entertaining activities, such as travelling, watching enjoyable television programs, or exercising which could enhance their relaxation and cheerfulness. Some parents adopted some activities that they remembered from group activities that nurses provide for the patients, such as drawing, painting, or molding. As one mother said, "... [I] looked for something entertaining such as watching television, watching

comedy to make him relaxed.... He also exercised such as doing pushups; he would be preoccupied with his delusion if he had free time.”

Some parents perceived that the environment had an influence on the children’s emotions. If the children were in an unpleasant environment, such as a noisy place or a crowded and confusing environment, they would become easily stressed and frustrated. In addition, the parents perceived that their children could experience stress caused by a pressured environment. For instance, staying with his successful peer might make the children feel inferior and stressed. Thus, parents tried to limit exposure to such environments by taking him to live in a peaceful environment which was not noisy or crowded, or minimizing their meeting with peers. One mother mentioned about her attempts to limit his meeting with his peers:

I can’t let him meet with any friend for a long time because he can make a comparison that his friends could flirt with the girls but he couldn’t.... I have to be careful about this matter, and I could not permit him to go out with friends for a long time.

Preventing substance abuse. The parents whose children were adolescent also perceived that their children had a strong sense of belonging to a group. They thought that their children, especially the son could be persuaded to use addictive substances. In addition, nearly half of the parents acknowledged that their children had a substance abuse history. Therefore, these parents tried to prevent substance abuse by prohibiting the use of addictive substances, bargaining, and preventing access to substances.

The parents whose children had a substance abuse history and had addicted friends felt that the children had an inclination to use addictive substances again; therefore, they tried to prohibit their children from using them. Some parents made the prohibition simultaneously with threatening that they would not take care of him if the symptoms were worsened by using addictive substances. Some other parents would claim that it was the psychiatrist’s order, and the children usually obeyed the parents if his psychotic symptoms were not severe. One mother mentioned about claiming the physician’s order and threatening her son to prevent substance abuse:

... I threatened him that the doctor ordered him to take medicine, not to drink coffee and M100 [a kind of stimulant drink], stop all of these things, such as cigarettes, cannabis, and amphetamines. 'If you are not obedient and your symptoms were exacerbated by using them again, I will leave you and no longer take care of you.' I said. Then, he seemed to be frightened of what I said.

Some parents reported that if they could no longer prohibit their children to use drugs, they tried further as much as they could by using the bargaining approach. They offered favorite things in return for their children to delay using addictive substances. One mother mentioned about her bargaining with her son to delay his alcohol drinking:

He told me that he would like to have a notebook computer and would not go out to drink.... 'I promise, but you don't go out' I told him. He agreed, and then I bought him a notebook computer and internet hours for him to play. He could stay for an hour.

If the children lived in a community which had many drug dealers, the parents thought that it was easy for their children to access drugs. In addition, some parents perceived that their children had poorer decision making than normal, which might allow them to be persuaded to use drugs. Therefore, the parents not only prohibited using addictive substances, but also prevented their children from access to substances. Some parents prohibited the children to go outside. The parents noticed that their children tried to go out to meet with their addictive friends when they had free time. Therefore, the parents tried to keep their children busy with household chores in order to divert the children's interest in substance abuse, or not allow them to go out. As one mother whose son had substance abuse history described:

He had too much free time, so he went out to see his friends. I did not want him to go out, so I tried to assign him to do household chores. I requested him to do several things for me. I was worried that he would smoke cigarettes or cannabis.

Struggling to Deal with the Impacts of the Illness

This refers to the parents' trying to lessen the other impacts which came along with schizophrenia, including the children's poor decision making, the stigma of the disease, as well as their feeling of loss of their children and the difficulties of caregiving. The presence of their children's psychotic symptoms posed enormous challenges for the parents to restore normalcy. The following subcategories were identified: dealing with the children's poor decision making, dealing with the stigma of the disease, and dealing with loss and difficulties:

Dealing with the children's poor decision making

While their children displayed their symptoms, the parents noticed that their children's decision making was poor, which impacted their self-control and daily functions. The parents reported that their children did not perform their daily routines as usual. In addition, the parents understood that their children's poor decision making might lead their children to harm other people. Their children also were vulnerable to be exposed to harm. To deal with these impacts, these parents utilized strategies, including a) completing the children's daily routines and b) shielding from harm.

Completing the children's daily routines. When the parents noticed that their children lost their motivation to perform their daily routines—for example, some children only stayed in their room, refused to go out to eat, or did not cook for themselves or wash their clothes as before—the parents initially tried to encourage their children to perform their daily routines by themselves, such as reminding them to cook, eat, or take a shower. If their children did not comply, the parents complete it by themselves. They had to cook for them or take care of their clothes and their hygiene such as washing, or taking them to a hairdressing shop for shampooing. The parents whose children displayed severe withdrawal behavior, such as refusing to go outside, had to cook for them and bring food into their room for three mealtimes. If the parents needed to go out, they would prepare food for the children before leaving. One mother whose son had withdrawal behavior explained about providing care for her son, “About food, I had to bring it into his room. [He] did not go out, [I] brought into him.... He stayed in his room without doing anything. I had to bring him his breakfast, lunch, and dinner.”

Shielding from harm. As the parents perceived that their children were likely to harm others and vulnerable to be exposed to harm, they shielded both their children and others from harm.

1) *Shielding the children from harm.* The parents thought that their children might be exposed to both physical harm and sexual harm when displaying severe psychotic symptoms. Most parents identified physical harm as physical injury from a variety of causes. For example, their children could wander the streets because of their lack of awareness and expose to a car accident. They also may be attacked by other people because of their aggressive appearance. Therefore, the parents stayed closely with their children and followed them wherever they went, for prompt prevention of any harm to them. As one mother whose son displayed bizarre behaviors said:

Sometimes when I saw him going out, I wondered where he was going, and I would follow him while carrying my grandchild as I was afraid he would be “Puang” [Northeastern dialect refers to being insane and lack of awareness], and wander.... I’m afraid he will be attacked outside. His eyes look aggressive.... If people did not know that he was ill, they might punch him. I’m worried.

Furthermore, some parents worried that the children could possibly injure themselves when they complained that they did not want to live any more. Some children used to attempt suicide when their psychotic symptoms were severe. In addition to staying closely with their children, the parents also hid sharp household utensils that the children might use to injure themselves. Some parents decided to stop cooking in order that the knife would not be used. One mother stated about her attempt to prevent her son from injuring himself:

I keep staying closely with him and being cautious. I usually stay with him, not to let him stay alone. He will not be surrounded with any unsafe household instruments. It is necessary to buy food since cooking requires some utensils such as knives.

Since their children had poor awareness, self-control, and judgment and more than half of the children were adolescent who were interested in sex, the parents were concerned about sexual harm. The parents who provided care for a son viewed that their son might be exposed to a sexually transmitted disease caused by unsafe sex, while the parents who provided care for a daughter thought that they might be a victim of sexual abuse, including rape of which unwanted pregnancy was a possible result. Therefore, the parents tried to limit their children's going outside to prevent them from being exposed to those harms. Some parents kept assigning their children's activities at home so that they did not have time to go outside. If the children were not in the parents' control, some parents hid the car keys so that their children could not go out in their vehicle. As one mother stated about shielding her son from sexual harm, "I don't want him to go outside. I'll hide his car keys when he is unaware. If I let him go, he may get something at a price of twenty bath [buying sexual services]. It's not worth doing this."

Besides, the parents realized that their children could interact with others via Internet without going outside. Thus, some parents cut the Internet signal at home to prevent their children from contacting their boyfriend/girlfriend. They provided other activities for the children so that they would not be preoccupied with sex. One mother, whose daughter was deceived by a man contacting her via the Internet before the first onset of schizophrenia, said:

I try my best. The Internet was removed, and I told her that the signal was weak. Then, I said that I had no money to renew the Internet service. This is an attempt to prevent her from returning to the same problem.... I took her to join some occupational training courses [occupational group therapy in psychiatric hospital] with hopes that she would be distracted from thinking about that man.

2) *Shielding others from harm.* This approach was adopted when the children expressed violent behaviors threatening the security of others, as well as the parents. The strategies they used included keeping their distance and secluding them from others. When the parents acknowledged that their children might harm them, they needed to keep their distance from their children and keep watching

the children until they calmed down. One father mentioned about keeping his distance from his son when he had violent behaviors from paranoid:

... Well, another thing is that I can't stay at home with him as he may hurt me some day. Therefore, I have to get away. I feel stressed when I struggle to escape from him. He seems to be a stranger to us. He is suspicious of me, and may kill me like the cases in the news report.

Some parents used secluding if they could not take the children to the hospital at that time. They thought that they and their children might be injured from physical restraint. They secluded their children in a locked room alone until their children were calm enough to take to the hospital. One mother whose aggressive son threatened to injure his stepfather needed to seclude her son in the room so as to ensure the safety of his stepfather. She said:

... I was always suspicious that he would come to kill his stepfather. The door had been locked. It would be opened during mealtimes to serve the food. Then, it would be closed. When his symptoms became severe, he was taken there.

Dealing with the stigma of the disease

This involves the parents' actions to conceal their children's illness to protect their family from the loss of a good reputation and prevent negative consequences to their children's lives. The parents perceived that revealing the children's illness may bring loss of social opportunities for their children. Besides, some parents also considered that any damages or loss of a good reputation might induce their children's distress. The parents may also be humiliated for giving poor parental care causing the mental illness of their children. The majority of the parents were likely to conceal their children's illness at the initial period of the illness as they still had hope for a cure. They thought that after their children recovered, they should have social opportunities like the others. Each parents concealed their children's illness differently depending upon the severities of their children's psychotic symptoms, including a) not mentioning the children's illness and b) telling a lie.

Not mentioning the children's illness. If their children's symptoms were not severe enough to make others suspicious, more than half of the parents would not mention their children's illness to the others, especially those who they mistrusted and even their relatives. The parents who lived in an urban area were more likely to ensure that they could cover up their children's illness since their children stayed at home and their symptoms were controllable. In addition, people in their community had less involvement with each other. As one father mentioned, "Mostly we did not bother one another. People usually went out to work and returned home at night. We did not socialize with one another, so there's no chance to know if we did not mention it."

Telling a lie. This refers to the parents' actions in trying to hide their children's illness. When their children showed more severe psychotic symptoms or had prolonged illness, or needed to change their lifestyle due to their illness—such as stop working, stop studying, or wandering from home—the neighbors would suspect and make inquiries. Some parents told them a lie or provided evasive answers. For example, they told the others that their children suffered with other conditions, such as often being forgetful, experiencing tension or stress. Additionally, some parents whose children ran away from home answered the others' questions that their children went to work somewhere else. Some other parents also concealed the name of the hospital to prevent them from visiting and finding out their children's illness. As one mother narrated about her telling a lie to her daughter's friends, "Her friends also asked what hospital to make a visit. I replied that it's around here and she was nearly discharged from the hospital, and would further travel with her boyfriend."

However, when the children's illness was prolonged and their psychotic symptoms were still severe, requiring frequent re-hospitalization, most parents could no longer to conceal their children's illness. The parents perceived that others could realize that their children were mentally ill by themselves. The parents additionally were accustomed to their children's psychotic symptoms and unsure about a cure. Thus, they decided to reveal their children's illness. One mother whose son was diagnosed for nearly 5 years stated her reasons for revealing the truth to others:

They asked whether my son went to see the doctor.... I honestly answered the question as I was not embarrassed any more due to the prolonged existence of his symptoms. I used to be embarrassed at the early stage, and gave evasive answers that my son had a stomach condition and heart disease so he did not go to work.

Furthermore, the parents might disclose their children's illness in the early phase of illness if they faced an unavoidable situation. Most parents revealed their children's illness to relatives of their husbands/wives because they needed to keep contact with them. In addition, if those relatives lived nearby and could see each other every day, the parents could not avoid revealing their children's illness. As one mother stated about her reasons for revealing it:

All of our relatives knew the truth as I had to take my son to visit them. For example, I took him to our relative's wedding party. At the party, my son sat silently and did not give any response to the others' questions. As a result, I had to tell the truth to all of them. Both my relatives and my husband's relatives acknowledged the matter. They all knew at an early stage as I took my son with everywhere and I could not conceal his illness.

Moreover, some parents were forced to reveal their children's illness to others when their children expressed violent behaviors against neighbors, or when their sons needed to waive conscription for an army service. One father stated about the situation forcing him to reveal his son's illness, "It was because we needed to submit the medical certificate to waive conscript for an army service due to being mentally ill, so the matter was known to all villagers.

Dealing with loss and difficulties

The parents' feeling of loss emerged when they acknowledged their children's diagnosis had existed and changed dynamically in line with changes in their children's symptoms. They also felt the loss of hope for a cure after they noticed the prolonged illness of their children, which required frequent re-hospitalization. They additionally experienced difficulties in trying to handle their caregiving through trial and error. They faced difficulties in dealing with the patients' troublesome behaviors,

such as sleeping during the day and remaining awake at night, just laying down like a lazy person or lacking enthusiasm, speaking aggressively, and acting out violently. They often experienced frustration and bitterness at taking care of the children at an age where should be independent. Sometimes they felt as if the destination of normalcy became distant from them over time. Nevertheless, because of perceiving caregiving as an unavoidable role, the parents needed to deal with their feeling of loss and difficulties through these approaches: a) Thum-jai, b) searching for information about the illness, and c) gaining support from others, in order to be able to continue restoring normalcy for their children.

Thum-jai. Thum-jai is a Thai word which literally means “managing the mind.” Thum-jai is a common approach used by Thai people when they face unpleasant situations in order to overcome unpleasant feelings, calm their mind, and be able to accept the unpleasant situations (Patoomwan, 2001, p. 96). Thum-jai was both a process and an outcome. When the parents talk about Thum-jai, it represents that they could accept their children’s illness and their caregiving role to some degree. Besides, Thum-jai as the outcome could change over time. Although some parents could accept the truth about the situation for some period of times, it was unsteady. Most of them felt loss, confusion, distress, and experienced difficulties whenever their children expressed episodes of crisis and acute exacerbation which required them to adopt Thum-jai strategies repeatedly. In the process of Thum-jai, the parents adopted Buddhist principles to perform since all of them are Buddhists. The Thum-jai strategies included 1) being here and now, 2) thinking positively.

1) *Being here and now.* This refers to the parents’ actions for controlling their mind and feelings so as not to be dominated by grief from loss, through being aware and awake to the present moment. Being here and now is related to the Buddhist principle regarding mindfulness, to be in present time, not concerned about the past or the future (Bhikkhu, 2007; Payutto, 1993). One mother mentioned about her attempt to be here and now since she faced suffering from the loss of her son to schizophrenia:

Like Thum-jai, I tried to be here and now, from the beginning until now. I had to be aware of every situation. Sometimes I suffered either in the past or the present

when I saw my son as a mentally ill patient. Although he looked better, I still realized that he was sick and that made me suffer. Just only being here and now could enable me to restrain my mind. Only Dhamma could help me to restrain my mind and not be sunk into suffering. I should do my best at the present as I am doing.

2) *Thinking positively.* Some parents restrained their mind from the feeling of loss, and the difficulties by always thinking positively. Looking for good things instead of disappointment and feeling loss is one way of positive thinking. The other way was to compare with the others who were in worse situations than themselves, in terms of either the children's symptoms or the family's financial support, so as to have encouragement in restoring the normalcy of their children. Some parents thought it was better that they did not have only one child, but other children who could be relied on. The other parents, who had only one child, would view that they were lucky as their children were not physically disabled and could not be self-reliant, or be confined to bed. Some parents accepted that although their children could not study or work as expected, their family did not have financial problems. One mother who had three children stated that:

I never thought that I would rely on him as he was the youngest child. I could rely on my two elder children. The youngest one was not my expectation. If I had only one child with schizophrenia, I might be unable to Thum-Jai.

Searching for information about the illness. Some parents perceived that information about the illness could help them cope with the difficulties of caregiving. They began to search for information on schizophrenia, in terms of the course of the illness, symptom management, and sources of help. In searching for information, some parents discussed with relatives of other patients, when they visited their children at hospital. Some parents asked for information about sources of help from other people, while some parents read books or pamphlets, or watched some health programs on television. The knowledge that they acquired in this way was

helpful as it helped them to face the reality and deal with their children's symptoms more effectively. As an example of one mother's description:

I read from books described that we have to comply with the patients. I did not fight against her symptoms especially when she showed aggressive behaviors. I let her to do what she wanted so I could avoid the difficulties.

Furthermore, some parents gained more knowledge from their direct experience. For example, when some children used something to block their ear canals or avoided going to areas where there were amplifiers or television, the parents gradually learned from their observations or inquiries that their children performed those strange behaviors in order to stop hearing voices. As one mother stated about her son's behaviors:

His eyes looked aggressive. He said someone will hurt him. He heard a threatening voice in his ears. He looked like a mad dog in an irritated mood, showed aggressive eyes. So I asked him what's wrong and he told me. After that I was not angry at him anymore.

Gaining support from others. More than half of the parents received much support including financial, emotional, and informational support from their significant others, such as husband/wife, son/daughter, or their partners. In addition, some parents reported that their family members, such as their husband/wife, even their children with schizophrenia, helped them by sharing the household routine. The parents reported that such support helped them feel comfortable and encouraged them to easily overcome their caregiving difficulties. As one mother who lived with her son alone, suffered with hypertension and heart disease, and used to have suicidal ideas, narrated about her experience when her son helped her with housework:

Now I feel easier in providing care for my son. Previously, I wanted to commit suicide. I felt discouraged. Both my son and I were sick. I had no idea who would be a caregiver. I used to think about ending both of our lives. I could not fight any more. However, after that, when I saw he cleaned our house while I was tired, I came up with an idea that I could take care of a

dog even though it could not talk to me. My son could talk to me and help me clean up the house, whereas the dog just lay down and waited to be fed [laugh].

Besides, some parents received emotional and financial support from other family members or partners. Gaining that support helped them to realize how lucky they were not to struggle alone as several others did. As one mother who provided care for her son alone said about gaining support from her partner:

He always suggested me to use Buddhist practice. He always supports me with some money, five hundred or one thousand Bath per month. It helped relieve me from my distress. If we have someone who is always willing to support us, our mental state will be better. Having him, my difficulty situation is better.

Moreover, there were two parents who received both informational and emotional support from health care providers. These parents described that such support brought hope to them and encouraged them to overcome their feeling of loss and difficulties from caregiving role. As one mother stated:

I needed to consult with [a nurse's name]. It was the first time for me for having a son with schizophrenia; while she had been highly experienced with taking care of 2,000 patients.... We had some conversation for half a day. I felt relieved and encouraged as if she had provided treatment for me as well. She helped me relieve my concerns when she listened to me and understood me. She helped me to be able to live with my children's illness and my caregiving role.

Accepting a New Normal

Accepting a new normal is a consequence of struggling to restore normalcy. The parents gradually learned through the passing of time that the pre-diagnosis normal state of their children would never be restored and their dreams might not be able to be fulfilled. Not all parents reached this point at the time of being interviewed because some of them were in the initial stage of being caregivers and

their children were first hospitalized. The parents who reached this point took a different amount of time and typically were those whose children had never complied with medication and their symptoms had changed over time.

The parents realized that their children's normalcy was beyond their ability to restore. Even some parents, whose children complied with medication, thought that their children's psychotic symptoms were controllable because they could maintain medication adherence. These parents had never been sure that their children's psychotic symptoms would not relapse if the medication was discontinued. Eventually, most parents began to revise their perspectives of what it meant to be normal and concluded that the new normal was that their children still had to be the patients with schizophrenia who needed long term care. They began to accept a new normal and adjusted themselves to live with a new normal divided into two sides a) maintaining caregiving with new perspectives and b) distancing from caregiving.

Maintaining caregiving with new perspectives

Most parents whose children's psychotic symptoms were controllable for some period of time, though occasionally relapsed, could reaffirm their hope that it might be possible for their children to be better than the present time. Such hope, as well as the sense of responsibility and the sense of love and sympathy motivated them to maintain caregiving with new perspectives. Though the parents still had to control psychotic symptoms as usual, their emotional distress was released.

While caregiving was maintained, the parents adjusted their initial expectation that their children would have a normal living like others, to just having self-reliance, without being a burden on anybody. Some other parents lowered their expectations to accept only that their children had no violent behaviors, or just complied with medications. One mother whose son had been diagnosed for nearly 5 years mentioned about diminishing expectations, "Initially I had some expectations. However, after taking medicine for several years, I could Thum-jai I just wanted him to take medications and see the doctor in order not to become aggressive."

Besides, the reciprocal relationship in living together with and caring for their children helped them to gain optimistic views. Some parents who did not live with their children before they became ill felt that they were compensated and

complemented with what they used to miss in their lives. One mother, who divorced and let her son live with her husband since his childhood, noted about recovering what her son and herself used to miss after living together and taking care of him:

It was better than before. When my son lives with me, I have acquired what I used to lack. I make compensation by providing him with warmth. He used to live with his father when we were separated. I experience good feelings. He also looks so happy and is very close to me.

Moreover, the parents realized that their children could not go back to the pre-diagnosis period. Therefore, they let things go and maintained caregiving for their children as much as they could. They reported that they let their emotional tension go and no longer worried about their children's future. As one mother whose son was diagnosed for over three years and re-hospitalized three times mentioned:

At first, it's hard to Thum-jai [accept]. Then, I could Thum-jai after experiencing prolonged symptoms. It was acceptable for us. So, I was not too worried about that like I was before. Whether he was employed or unemployed was not my concern. I was still thinking about it, but not taking it seriously. I just had to do my best in taking care of him as much as I could.

In addition, some parents tried to seek other options for treatment, such as using Thai herbs as a complementary therapy. One mother whose son had not totally complied with medication as prescribed for over three years, tried to seek Thai herbs to complement modern medicine. She said:

I sought Thai herbs. I didn't know at first. I heard from the other so I tried to find out and got it. Oh! So many people in queue [laugh]. I boiled them for him to drink and maintained medication just only tablet and he complied.

The parents were more likely to maintain caregiving with new perspectives if they gained both financial, emotional, and informational support from their significant others and health care providers.

Distancing from caregiving

It is the parents' actions in decreasing the intensity of their striving to restore the children's normalcy after they perceived that their children could not recover, and that they themselves could not control their children's psychotic symptoms anymore. Though they perceived that their children's psychotic symptoms were still severe needed close care, they detached themselves from caregiving. The parents' distancing varied upon different conditions which were possible to be intentionally and unintentionally, as well as physically and emotionally distancing.

There were four fathers who intentionally distanced themselves from caregiving. They also intensely distanced themselves from caregiving both physically and emotionally. These fathers were those whose children had never complied with medication and their psychotic symptoms had not improved over time. They reported that they eventually realized that it was not up to them to do everything to restore normalcy, but also up to their children themselves. They described that their children had never taken care of themselves and done nothing to recover.

Two of them had shared caregiving role with their wives for nearly five years and their sons expressed additional negative symptoms such as laying down like a lazy person, or lacking enthusiasm. The other two fathers were those who provided care for their children alone and their children showed continual intense psychotic symptoms requiring frequent re-hospitalization. One widowed father provided care for his daughter for nearly four years and had previous conflict relationships with his daughter. He separated his living from his daughter, though he lived in the same household with her. Another one was a father whose son expressed violent behaviors toward family members overtime and his wife had to move other children to live in another place and he provided care for his son alone for nearly two years. He then moved away from his son to live with his wife in another place. These fathers reported that non improvement and the frequent recurrence of their children's symptoms always discouraged them and disturbed the normal life of their families. They sometimes felt as if the illness tore their family apart. They began to think that it was time to restore their normal life rather than their children's lives.

All of them no longer tried to maintain medication adherence. They thought that since the children did not comply with medication, they could do nothing.

They also stopped searching for a variety of strategies to manage their children's psychotic symptoms as they had done before. However, these fathers still had provided food for their children. The father who moved away from his son came back to him once a week to give him some food. They occasionally had monitored their children's psychotic symptoms and just waited to take their children to the hospital when the psychotic symptoms became severe. One father who provided care for his son nearly two years and his son was hospitalized repeatedly for four times within one year, said:

... His illness made my family broken. His mom and his brother could not live with him since his first episode of the illness. He was also paranoid about me and tried to injure me. I had to go away to have a normal life and I left him to stay alone. It was just like staying without peace. I eventually gave up; what happens, happens. He had never taken care of himself, no one could help him. We are parents, though we felt pity on him, we could no longer care for him as we did before. I came back to him occasionally to give him some food. If his symptoms became severe, I did nothing, just took him back to the hospital.

On the other hand, there were three mothers who unwillingly and physically detached from their caregiving for a daytime. These mothers were those who stayed alone with their children due to their husband's death or because they were divorced and their family income was insufficient. These mothers had to return to their paid work in the daytime with strong concerns about their children. They reported that it would be harder for them to balance their caregiving and their living demands without other financial support for a long time. They had to earn money for their children's treatment and for their living. However, though they left their children to live alone at home, they kept contacting their children by telephone and provided caregiving for them after their working hours. As an example of this mother's statement:

I suffered a lot. It was difficult to control my mind. I kept thinking too much and lost my appetite. I wondered how my son and I could go on without money and how could I help him to be better while I had to work. Without jobs, I had no money. I left him alone to work. I could take care of him after my work hours.

In summary, in struggling to restore normalcy, the parents faced difficulties controlling their children's psychotic symptoms and the impacts of the illness. They used various strategies through trial and error, but they found that their children's psychotic symptoms were unstable. They finally learned that their children could not recover completely and return to be normal children as before. They began to accept a new normal.

Summary

In this chapter, the background of the participants, as well as categories generated from grounded theory analysis is presented. The majority of the participants were mothers who were middle aged, had more than one child, had not higher than secondary education, and lived with their current partners. More than half of them were working. The majority of the participants had sufficient income. All of them were Buddhist. More than half of them had a duration of caregiving within the first three years. According to grounded theory analysis, struggling to restore normalcy was derived as a basic social psychological process of being caregivers of children with schizophrenia in the early phase of the illness. Struggling in restoring the normalcy, as a core category, was linked to several subcategories. Learning the diagnosis and facing shattered dreams was seen as causal conditions leading to struggling to restore normalcy. Perceiving caregiving as an unavoidable role helped the parents to maintain the process of restoring normalcy. Struggling to control psychotic symptoms was the parents' actions, including monitoring the symptoms, maintaining medication adherence, managing the symptoms, and preventing the exacerbation and relapse of the symptoms. Struggling to deal with the impacts of the illness was one of the parents' actions comprising three properties: dealing with the children's poor decision making, dealing with the stigma of the disease, and dealing with loss and difficulties. Accepting a new normal was viewed as a consequence of the process. It consisted of maintaining caregiving with new perspectives or distancing from caregiving.

CHAPTER V

DISCUSSION AND CONCLUSION

This chapter aims to discuss the findings of this study. The research findings will be compared with current knowledge in the area of caregiving for a psychotic patient including schizophrenia and other related area. Limitations of this study, as well as implications for nursing practice and future research will be presented.

Comparison of the Findings

Struggling to restore the normalcy as a central concept in the process of being caregivers among Thai parents who care for adult children with schizophrenia is added to the body of knowledge of caregiving in the early phase of schizophrenia. It describes the process of coping responses with the psychotic symptoms and the impacts of the illness which is complex, difficult, and needs special skills. The parents desired to restore the normalcy of the children's lives since they viewed their children's illness as facing shattered dreams. They needed their children to live a normal life as in the pre-diagnosis stage: recovering from schizophrenia, having employment or going back to work, having a new family, and being independent.

The struggle to restore normalcy described in this study shared some common attributes with "pursuing normalcy" in a study among family caregivers of severe mental illness (Rose et al., 2002). The investigators defined pursuing normalcy as "a perspective or a general attitude characterized by thoughts, actions, and emotional responses centered around that patients' achievement of normative goals in a manner that would be expected if the illness had not occurred." (p. 525). In living with the ambiguity of mental illness, those family caregivers tried to manage the crisis and contain and control psychotic symptoms to restore normalcy to their ill relatives and their families by using the strategies of confronting ambiguity of the illness,

seeking control over the illness, and adopting a stance of possibilities and realities. Although the study of Rose et al. (2002) demonstrated normalcy as a family caregivers' coping response to a chronic mental illness, the current study adds to that body of knowledge that normalcy is also the goal of the parents who are trying to handle the early phase of schizophrenia.

The parents in this study struggled with difficulties in dealing with their children's psychotic symptoms both before and after the diagnosis. Before the diagnosis, the parents struggled to understand and deal with the changed behaviors of their children. They often underestimated the seriousness of the symptoms when they began to notice the changed behaviors of their children. This evidence is similar to the concept "confronting ambiguity" (p. 525) of Rose and her colleagues' study. This concept was defined as the family response to the onset of the psychotic symptoms and the diagnosis, comprising keeping watch/losing trust, being consumed by the illness, and making sense of behaviors as illness symptoms. This evidence is also consistent with other previous studies which noted that family caregivers often experienced extreme difficulties because they did not know how to react behaviorally and emotionally to their relatives' changed behaviors (Jeon & Madjar, 1998; Karp & Tanarugsachock, 2000; Mohr & Regan-Kubinski, 2001; Rose et al., 2002). Muhlbauer (2002) identified this phase of illness as "the storm warning". The caregivers recognized the abnormalities of their relatives, but they were unable to define them. The other study identified the concept, called "early nightmares," illustrating the caregivers' awareness of their relatives' abnormalities ranging from a gradual perception to a sudden realization of the wrongness (Mohr & Regan-Kubinski, 2001).

After the diagnosis and treatment, the parents struggled to restore normalcy for their children. They had to put much effort into controlling the unstable psychotic symptoms, especially in maintaining medication adherence, managing the children's symptoms, and preventing the exacerbation and relapse of psychotic symptoms. Similar to other studies (Muhlbauer, 2002; Seloibe, 2006), the authors reported that caregivers experienced a cycle of instability and recurrent crises of care recipients' symptoms in the early phase of the illness and they became aware of the chronic trajectory through the cycle of exacerbations and relapses. They had to cope with the day-to-day situation because planning for the future was difficult. Other

studies (Junbauer et al., 2004; Lacro et al., 2002) also indicated that medication discontinuation was the prominent factor associated with relapse of patients in the early phase of schizophrenia. Some studies (e.g., Kazadi et al., 2008; Lacro et al., 2002) revealed the reasons for patients' poor adherence, including poor insight into the illness, negative attitudes toward medication, previous medication nonadherence, substance abuse, inadequate discharge planning, and poor therapeutic alliances. Most parents in the current study also reported that their children discontinued medication because they denied their illness and because of the side effects of antipsychotic drugs.

The findings of this study are also consistent with a grounded theory study exploring the caregiving process (Dangdomyouth, et al., 2008). The authors reported that to avoid psychotic episodes, participants used various strategies through the process of "tactful monitoring," including keeping an eye on, checking medications, and calming. In addition, in a grounded theory study exploring the process of skill and role development among Thai mothers, Tungpunkom (2000) identified caregiving tasks similar to those identified in the current study. They included maternal care, managing psychotic symptoms, and medication management. Most parents in the current study had to deal with hallucination, delusion, and paranoia, disturbance and violent behaviors, as well as their children's stress. This evidence supported those described in previous studies (Junbauer et al., 2004; Milliken & Northcott, 2003; Tungpunkom, 2000). The investigators reported that the majority of parents struggled to manage their children's positive symptoms. The parents also had to keep stress and burdens away from their ill child. They tried to motivate their ill child to pursue pleasant activities in everyday life in order to prevent their children from psychotic symptom exacerbation.

However, it is noticeable that the findings of the previous studies (Muhlbauer, 2002; Rose, et al, 2002; Tungpunkom, 2000; Wynaden, 2007) showed a state of increasing success in symptom management and personal growth among caregivers which was not found in the current study. Instead, most parents in the current study still struggled with controlling the psychotic symptoms and the impacts of the illness after the diagnosis. It might due to this study focused on the parents' experience in the early phase of illness which the nature of the psychotic symptoms is unstable and unpredictable, while the others focused on caregiving for chronic mental

illness. Thus, the major task for the parents of the current study was to control their children's psychotic symptoms and its impacts. None of the parents had experience in caring for mentally ill persons. Thus, they learned through trial and error to control the cycle of exacerbations and relapses of their children's psychotic symptoms. It was impossible for them to have reached a state of stability or mastering the caregiving role. This evidence indicated that taking care of children with schizophrenia in the early phase of the illness was the critical period needing a high level of support from mental health care providers.

It is evident that struggling to control psychotic symptoms and to deal with the impacts of the illness influenced the parents' coping response, which could be either adaptive or maladaptive. Most parents still had to maintain caregiving with new perspectives after accepting a new normal, while some of the parents distanced themselves from caregiving. This finding is consistent with those identified in other studies (Chen & Greenberg, 2004; Jungbauer, et al., 2004; Karp & Tanarugsachock, 2000). Most caregivers who experienced the positive side of caregiving usually were those who had hoped for the improvement of the relative's condition (Chen & Greenberg, 2004; Jungbauer, et al., 2004). Thampanichawat (2008) noted that maintaining hope for the child's survival helped caregivers to continue their caregiving role. Additionally, the finding also supports the claim of the reciprocal relationship in the role acquisition process which was described by other studies (Tungpunkum, 2000; Schumachers, 1995). Some parents in the current study gained optimistic views of their caregiving role through a reciprocal relationship, between their ill children and themselves. When their children's conditions improved, some of them showed empathy for their parents and tried to repay their parents by sharing some household chores as much as they could. This eased the parents' feeling of difficulties in caregiving.

For negative side of caregiving, there were four fathers intentionally distanced from caregiving which was maladaptive coping response. These fathers had children who had never complied with medication and their psychotic symptoms had not improved. Two of them provided care for their children alone and their children showed continual intense psychotic symptoms requiring frequent re-hospitalization. The other two of them had shared caregiving role with their wives for nearly five years

and their sons expressed additional negative symptoms such as laying down like a lazy person, or lacking enthusiasm. As several studies (Huang et al., 2009; Magliano, Fiorillo, De Rosa, et al., 2005; Saunders & Byrne, 2002; Sukmak et al., 2001) noted, caregivers responded in a negative way if they did not experience the recovery of their care recipients in long-term care. After they experienced failure in trying to control the psychotic symptoms, they felt exhaustion, boredom, and hopelessness. The findings of the current study indicated that dealing with severe psychotic symptoms continuously is a barrier for reaching to the positive side of caregiving, in the early phase of schizophrenia. Since the nature of psychotic symptoms in the early phase of illness is unstable and also develops new features, living with severe and unstable psychotic symptoms makes it very difficult for parents to sustain their efforts to handle the illness over time. Even in short-term caregiving with continual intense psychotic symptoms, they could reach the state of exhaustion as experienced by the parents in this study.

Another possible explanation for this finding is about gender associated with Thai cultural context. Because Thai society expects that women should be family caregivers (Rungreanhkulkij & Chesla, 2001; Subgranon & Lund, 2000; Wongchaiya, 2007), it might be possible for the fathers who shared caregiving role with their wives to think that it was not their direct responsibility to be caregivers. When they encountered difficulties in caregiving situation, they gave up sooner than the mothers did. In addition, the fathers who shared caregiving role with their wives might have thought that although they distanced themselves from caregiving, their wives still maintained a caregiving role for their children. However, because of the limited number of fathers, it was not enough to draw a conclusion and to compare with the mothers' experiences. Thus, it was just a hypothesis and needs further study to confirm.

It is evident that the majority of the parents could maintain the process of struggling to restore the normalcy because they perceived caregiving as an unavoidable role. It is a positive appraisal of the caregiving role which is in line with many studies, in Asian culture, focused on the caregiving area and not only in psychiatric nursing. In a grounded theory study exploring the meaning of caregiving among the parents who cared for children with schizophrenia, in Taiwan, Yen et al.

(2010) identified “responsibility” as the core category. They documented that responsibility was culturally prescribed and centered on familial ethics and values. It also involved their feeling of guilt for the possibility of being a cause of their children’s illness, and believing in karma and the challenges from local gods and fate. Especially the parents, they viewed responsibility as the rule and principle of their lives. Their sense of responsibility and feeling of love and sympathy also were based on blood relationship and attachment with their children. Thus, they engaged in the caregiving role willingly.

Similar to previous studies in Thailand (Karp & Tanarugsachock, 2000; Sethabouppha & Kane, 2005; Subgranon & Lund, 2000; Thampanichawat, 2008; Tungpunkum, 2000), the authors indicated that Thai family caregivers were able to continue providing care to their ill relatives because they viewed caregiving as karma, felt honest love and compassion, and had sense of obligation which derived from Thai culture and Buddhist belief. This evidence validates that Thai culture and Buddhist principles have deeply influenced Thai caregivers and helped them to overcome the distress in managing their children’s conditions and their caregiving role. Additionally, it indicates that the positive appraisals about the caregiving role helped the caregivers to accept their role and motivated them to maintain caregiving. Therefore, understanding caregivers’ belief system is essential for mental health care providers to assist caregivers to search for positive meaning in caregiving.

In summary, the findings of this study represent the uniqueness of the caregiving in the early phase of schizophrenia. The parents had struggled in the midst of the chaos of the caregiving resulting from the unstable psychotic symptoms. The Thai culture and Buddhist belief influenced their responses throughout the process of struggling to restore normalcy. The consequence of struggling to restore normalcy process, in this phase of the illness could possibly be both positive and negative sides.

Limitations of the Study

Two limitations of this study are associated with the participants’ characteristics and the lack of use of triangulation. The participants were limited to the

parents of children with early phase of schizophrenia. The findings of the study might not be transferable to those who care for children with chronic schizophrenia. Although the study included both mothers and fathers, which seemed to be a strength of the study, there were limited numbers of the fathers. Interpretation and conclusion about the differences between mothers' and fathers' experiences which were gender specific should be undertaken with care.

The second limitation involves the lack of use of triangulation, such as methods or data sources triangulation. The findings of this study are mainly derived from the interview data obtained from the parents who care for their children with schizophrenia. Gathering data from multiple sources, such as from other family members, who are involved in caregiving might enhance the credibility of the findings. In addition, because the study was not designed for gathering data from medical records, there were limitations in developing theoretical sampling to compare the parents' experiences in caring for children with various severities of the psychotic symptoms. More variation and saturation of the sub-categories such as maintaining medication adherence and managing the symptoms might be added to the theory if the data from medical records were obtained. Moreover, observing the parents' actions while they were visiting their children in the hospital, might be an additional source of data for checking the consistency of the findings regarding the parents' reactions after the diagnosis and while visiting their children at the hospital.

Implications for Nursing Practice

A major contribution of this study to nursing practice is that it offers mental health care providers a new understanding about the phenomenon of struggling to restore normalcy among Thai parents who care for their children with schizophrenia in the early phase of the illness. It is evident that the parents struggled to control their children's symptoms through the cycle of exacerbations and relapses. They strived for their children's normalcy through trial and error with great difficulties and simultaneously dealt with the impacts of the illness. Their struggling in the midst of difficulties influenced their coping response. Thus, an early intervention program should be developed based on information from this study to enhance their adaptive

coping response and help them to overcome the struggle in restoring normalcy for their children and to move to state of mastery in caregiving sooner.

Guidelines for an early intervention program should be as follows:

1. Since the findings of this study showed that the parents had to search for information about the illness to cope with their difficulties in caregiving, the program should be started soon after the first diagnosis. The program should include providing information about schizophrenia, its prognosis, the nature of its symptoms and effective management, side effects of antipsychotic drugs and their management, as well as the available resources to enable them to provide proactive caregiving. However, learning the diagnosis is a crisis situation for the parents, the mental health care providers should be sensitive and provide proper support for the parents at that time to enhance their ability to face the reality.

2. It is evident from this study that the parents struggled in controlling psychotic symptoms which required special skills. Thus, information in the form of psychoeducation might not be enough. The parents should be trained in effective caregiving skills, typically for monitoring the symptoms, maintaining medication adherence, and dealing with delusion, hallucination, and aggressive and violent behaviors. Besides, since it is evident that positive appraisals about the caregiving role helped the parents to accept and maintain their caregiving role, assisting the parents to search for a positive outlook on caregiving should be added to the program.

3. This study showed that the fathers especially who faced continual intense psychotic symptoms and provided care for their children alone were more likely to quickly distance themselves from caregiving. Therefore, these fathers should be given more attention to prevent maladaptive coping responses. Training in effective strategies for controlling the psychotic symptoms and to deal with loss and difficulties should be provided to them individually and intermittently. In addition, the training should be integrated into a supportive group by adding both sharing experiences of caregiving and demonstrating effective strategies. This may lead them to learn from others and apply effective strategies in taking care of their children. Sharing painful experiences, understanding, and gaining supporting from persons having similar experiences may help them to realize that they are not alone in this agonizing

experience. Gaining support from the group and gaining reinforcement from health care providers may empower parents to release their grief from loss, maintain hope, and get new optimism quickly.

4. It is evident in this study that the parents misinterpreted or struggled to understand the changed behaviors of their children before the diagnosis was made. This information could help mental health care providers realize that knowledge about prodromal psychosis, as well as effective responses to it should be provided to the public, especially to the parents of adolescents and young adult since schizophrenia commonly emerges during this period. Additionally, since the stigma of the disease is the pivotal issue that the parents have to deal with, de-stigmatization of mental illness should be the health care providers' concern. Basic knowledge of schizophrenia and families' experiences should be provided to the public through a variety of media in order to enhance their understanding and compassion. Practical strategies to live with mentally ill persons in the community should be provided to decrease discrimination and fear of mentally ill patients. Furthermore, the threatening behaviors of the psychiatric patients should be carefully portrayed through the media.

Implications for Future Research

Based on the findings and limitations of this study, suggestions for further studies are as follows:

1. The findings of this study are mainly derived from the interview data obtained from the parents who care for their children with schizophrenia. To enhance the validity of the findings, further studies should gather data from multiple sources, such as from other family members who are involved in caregiving. To enhance the variation and saturation of the theory, further studies should obtain data from medical records. Method triangulation should be adopted, such as obtaining data from observation of the interaction between the parents and their children when they visit their children at the hospital or at home setting if it is possible.

2. Further studies should include the parents who distance themselves from caregiving to explore more deeply the caregiving experience in this group. More

understanding may help the mental health care providers to develop an intervention appropriate to this group of parents. In addition, further study should include a greater number of fathers to compare with mothers' experiences in order to confirm the hypothesis of this study that distancing from caregiving was gender specific.

3. This study explored the parents' experiences in which family was a context. The unknown knowledge is about the impact of early schizophrenia on the family unit which needs further study. The further study may be a mixed method study gathering data from multiple sources.

4. The findings of this study suggest that struggling to control psychotic symptoms, struggling to deal with the impacts of the illness, and accepting a new normal may have an influence on each other. A quantitative study should be developed to test this hypothesis and to examine the influence of the parents' struggling to control psychotic symptoms and to deal with the impacts on their adaptive coping response.

Conclusion

The aim of this study was to expand our understanding of Thai parents' experiences in being caregivers for children with schizophrenia in the early phase of the illness. The perspective of symbolic interaction underpinned the grounded theory methodology and the research process of this study. Struggling to restore normalcy, a substantive theory grounded in the perceptions and experiences of the twenty five parents, was developed. It indicates that caregiving in the early phase of schizophrenia is a hardship and a devastating experience. It requires intensive support to help caregivers to overcome the crisis of the instabilities of psychotic symptoms and the impacts of the illness. It is crucial for psychiatric nurses to learn from the parents in what responses are effective or ineffective. An early intervention program based on knowledge derived from parents should be developed. It might help them learn about effective ways to deal with changes and impacts of the illness, gain a sense of readiness to be caregivers, and have a sense of mastery in their caregiving earlier. Several implications for nursing practice and further research were derived from the

study findings. Two limitations of the study are related to the characteristics of the participants and the lack of use of triangulation.

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APPENDICES

APPENDIX A
EXAMPLE OF SCREENING INTERVIEW GUIDES

Thank you for your interest in this study. My name is Pichamon Poonnotok All of your responses will be confidential. Nobody except me will have access to the information you share today. Do you have any questions before I continue?

1. Do you know your child’s diagnosis, if so who informed you and when?
 - I have known my child was suffering with schizophrenia from the psychiatrist for not more than five years.....(Yes)
 - I have known my child was suffering with schizophrenia from the psychiatrist for more than five years.....(No)
 - I known my child was suffering with other psychotic disorder.....(No)
 - I don’t know/ I am not sure.....(No)
 - .
 - .
 - .
 - .

6. Do you have any health problem?
 - No.....(Yes)
 - Yes.....(No)

If yes, which hospital/department do you receive treatment?

 - If they were suffering with physical illness(Yes)
 - If they were suffering with mental illness.....(No)

EXAMPLE OF SCREENING INTERVIEW GUIDES (THAI):**ตัวอย่างแนวคำถามในการคัดกรองผู้เข้าร่วมการวิจัย**

คุณมากะที่ให้ความสนใจต่อการวิจัยครั้งนี้ ดิฉันชื่อ พิชามณัฐ ปุณโณทก สิ่งที่เราพูดคุยกันในวันนี้ และคำตอบของคุณ นอกจากดิฉันแล้วจะไม่มีคนอื่นที่จะสามารถล่วงรู้ข้อมูลที่คุณให้ ก่อนที่ดิฉันจะเริ่มสัมภาษณ์เบื้องต้น คุณมีคำถามหรือข้อสงสัยอะไรไหมคะ

1. คุณทราบไหมว่าผู้ป่วยเป็นโรคอะไร ทราบจากใคร ตั้งแต่เมื่อไหร่
 - () ทราบว่าเป็นโรคจิตเภทจากจิตแพทย์มาแล้วไม่เกิน 5 ปี..... (ตรง)
 - () ทราบว่าเป็นโรคจิตเภทจากจิตแพทย์มานานกว่า 5 ปี..... (ไม่ตรง)
 - () ทราบว่าเป็นโรคจิตชนิดอื่น ที่ไม่ใช่จิตเภท..... (ไม่ตรง)
 - () ไม่ทราบ/ไม่แน่ใจ..... (ไม่ตรง)
6. ปัจจุบันคุณมีโรคประจำตัวหรือการเจ็บป่วยอะไรหรือไม่
 - () ไม่..... (ตรง)
 - () ใช้ ระบุ.....รับการรักษาจากโรงพยาบาล/แผนก.....
 - (ตรง) (กรณีที่เป็นการเจ็บป่วยทางกาย)
 - (ไม่ตรง) (หากระบุว่ามีการเจ็บป่วยทางจิตและอยู่ระหว่างรับการรักษา)

APPENDIX B

EXAMPLE OF INTERVIEW GUIDES

General / Opening Statement

Tell me about your experiences since the first onset of your child's illness

Specific / Focused questions

Specific aims	
1. To describe Thai parents perceptions of their children's illness and their caregiving role.	-What were the changes at the first episode of the illness?
.	- What did those changes mean for you and how did you respond to them?
.	- How did you think and feel when you were informed about your child's diagnosis from a doctor?
.	
.	

Questions Asked

Example of Probes

- Could you explain what you mean by.....?
- What does..... mean?
- Why?
- When was that?
-and then?
- Could you tell me why.....?
- How do you feel about.....?
- I don't quite understand?, you said earlier.....

EXAMPLE OF INTERVIEW GUIDES (THAI)

คำถามทั่วไป

กรุณาเล่าให้ดิฉันฟังถึงประสบการณ์ของคุณนับตั้งแต่ที่บุตรเริ่มป่วยจนถึงปัจจุบัน

คำถามเฉพาะเจาะจง

จุดประสงค์ของการวิจัย

- เพื่ออธิบายการรับรู้ของบิดามารดา
- ไทยต่อการเจ็บป่วยของบุตรและต่อ
- บทบาทการเป็นผู้ดูแลของคน
- .
- .
- .
- .

คำถามที่ถาม

- ในช่วงแรกที่บุตรเริ่มป่วย คุณสังเกตเห็นว่าเขามี
- การเปลี่ยนแปลงอะไรบ้าง อย่างไร
- คุณคิดหรือรู้สึกอย่างไร และคุณทำอะไรบ้างในช่วง
- นั้น
- ในครั้งแรกที่แพทย์แจ้งการวินิจฉัยโรคของบุตรให้คุณ
- ทราบ คุณคิดหรือรู้สึกอย่างไรบ้าง

ตัวอย่างคำถามเพิ่มเติม

- กรุณาช่วยเล่ารายละเอียดให้ดิฉันฟังเกี่ยวกับ-----
- -----หมายถึงอะไร
- เพราะอะไร
- เหตุการณ์นั้นเกิดขึ้นเมื่อไหร่
- -----หลังจากนั้นคุณ-----
- กรุณาอธิบายให้ดิฉันฟังว่าเพราะอะไรคุณจึง-----
- คุณรู้สึกอย่างไรเกี่ยวกับ-----

APPENDIX C
DEMOGRAPHIC DATA FORM

Demographic Information of Parents

1. Sex Male Female
2. Age.....years
3. Marital status Married Widowed Divorced Separated
4. Education Not attend any school Primary Secondary
 Certificate Bachelor's others.....
5. Incomes Enough Not enough
6. Family members include (relationship with the patient).....

Demographic Information of Patients

1. Sex Male Female
2. Age..... years
3. Marital status Married Widowed Divorced Separated
4. Education Not attend any school Primary Secondary
 Certificate Bachelor's others.....
5. Setting OPD IPD, ward.....
6. Number of hospitalizations.....

APPENDIX D

EXAMPLE OF REVISED INTERVIEW GUIDES

Major Themes	Questions Asked
<p>Managing the children’s symptoms</p> <p>•</p> <p>•</p> <p>•</p> <p>•</p>	<p>1. How did you take care your child when:</p> <ul style="list-style-type: none"> - your child was first admitted and the next time? - your child was discharged from the hospital? - your child expressed delusion and hallucination? - your child expressed aggressive and violent behaviors? - your child did not perform daily routines - your child’s symptoms did/ did not improve
<p>Dealing with loss and difficulties</p>	<ul style="list-style-type: none"> - How did you manage your feeling of loss and difficulties? - What did you find most helpful?

EXAMPLE REVISED INTERVIEW GUIDES (THAI):

ตัวอย่างแนวคำถามในการสัมภาษณ์ (ปรับปรุง)

ประเด็นหลัก	คำถามที่ถาม
<p>การจัดการกับอาการของคุณ</p> <p>.</p> <p>.</p> <p>.</p> <p>.</p>	<p>1. คุณดูแลคุณอย่างไร</p> <ul style="list-style-type: none"> - ช่วงที่คุณได้รับการรักษาในโรงพยาบาลครั้งแรก และครั้งต่อมา - เมื่อกลับจากโรงพยาบาลครั้งแรกและครั้งต่อมา - เมื่อคุณมีอาการหลงผิด ประสาทหลอน - เมื่อคุณมีพฤติกรรมก้าวร้าว รุนแรง - เมื่อคุณไม่ทำกิจวัตรประจำวัน - เมื่อคุณอาการดีขึ้น/เมื่อคุณอาการไม่ดีขึ้น
<p>การจัดการกับความรู้สึกสูญเสียและความยุ่งยาก</p>	<ul style="list-style-type: none"> - คุณจัดการกับความรู้สึกสูญเสียและความยุ่งยากอย่างไรบ้าง - วิธีไหนใช้ได้ผลมากที่สุดในการจัดการกับความรู้สึกสูญเสียและความยุ่งยาก

BIOGRAPHY

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