Struggling to Restore Normalcy: Thai Parents' Experiences in Being Caregivers of Children with Early Schizophrenia

Pichamon Poonnotok, Wanlaya Thampanichawat, Autchareeya Patoomwan, Sopin Sangon*

Abstract: Although caregiving for persons with early schizophrenia is a difficult task, little is known about the caregiving process in early schizophrenia. This study explored the caregiving process for children with early schizophrenia. Twenty-five Thai parents of children diagnosed with schizophrenia within the last five years were interviewed indepth at outpatient clinics and wards of a large psychiatric hospital in Thailand. A Straussian grounded theory approach was used and data analysed using constant comparative analysis.

"Struggling to restore normalcy" emerged as the core category that comprised six sub-categories: *learning the diagnosis, facing shattered dreams, caregiving as an unavoidable role, struggling to control psychotic symptoms, struggling to deal with the illness impacts,* and *accepting a new normal*. The parents felt as if they were facing shattered dreams after learning the diagnosis. They viewed their caregiving as an unavoidable role, as they strived for their child's normalcy. They tried to control their child's unstable psychotic symptoms by maintaining medication adherence, monitoring and managing the symptoms, and preventing symptom exacerbation and relapse. They had to deal with the impacts of the illness including their child's poor decision-making, illness-related stigma, and their feeling of loss and difficulties. They gradually accepted the incurability of schizophrenia which was their child's new normal.

The unique study findings add to nursing's knowledge about caregiving for this group of children, and have implications for the development of an intervention program that nurses and others can use to help parents cope with caregiving challenges. Future studies should compare mothers' and fathers' experiences in caring for children with early schizophrenia.

***Pacific Rim Int J Nurs Res* 2016; 20(1) 71-84**

Keywords: Caregiving; Children; Experience; Grounded theory; Parents; Schizophrenia

Background

Schizophrenia is one of the most severe and chronic mental illnesses. The characteristics of the illness are disturbances of perceptual and thinking process, behaviors, and social function.[1] In Thailand, the numbers of person with mental illness including schizophrenia that attended at outpatient clinic of public hospitals increase from 1,076,155 in 2012 to 1,109,183, in 2013.[2] The prevalence of schizophrenia is approximately 8.8 per 1,000. The incidence rate

Pichamon Poonnotok, RN, Ph.D (Candidate) *Faculty of Nursing, Mahidol University* ***E-mail:*** *mouth.mind@gmail.com*
Correspondence to: Wanlaya Thampanichawat, RN, PhD *Assistant Professor. Department of Pediatric Nursing, Faculty of Nursing, Mahidol University, 2 Siriraj, Wang Lang Road, Bangkoknoi, Bangkok, Thailand 10700* ***Email:*** *wanlaya.tha@mahidol.ac.th*
Autchareeya Patoomwan, RN, PhD *Assistant Professor. Department of Pediatric Nursing, Ramamathibodi School of Nursing, Faculty of Medicine Ramathibodi Hospital, Mahidol University 270 Rama VI Road, Ratchathewi, Bangkok, Thailand 10400* ***Email:*** *autchareeya.pat@mahidol.ac.th*
Sopin Sangon, RN, PhD *Assistant Professor. Department of Mental Health and Psychiatric Nursing, Ramamathibodi School of Nursing, Faculty of Medicine Ramathibodi Hospital, Mahidol University 270 Rama VI Road, Ratchathewi, Bangkok, Thailand 10400* ***Email:*** *sopin.san@mahidol.ac.th*

was 0.3 per 1,000 with a peak at age of 15-24.[3] The estimate annual costs for the entire population with schizophrenia is high (THB 31,000 million or $US925 million). Hospitalization was the largest component of direct medical cost (50%). Additionally, 61% of the total economic burden is indirect cost of unemployment.[4] The majority of sufferers (98%) reside with their families and their parents were primary caregivers.[3]

The first five years after a diagnosis with schizophrenia is critical and sufferers need continuing care. The psychotic symptoms of early schizophrenia are particularly prominent, unstable, and marked by exacerbations, remissions, and relapse requiring rehospitalization.[5-6] Research evidence revealed that relapse rates were very high even after the first psychotic episode[6-8] and each subsequent relapse was associated with a poor response to treatment, a long time to remission, and a deterioration of functions.[8-9] Hence, caregiving in the early phase of schizophrenia is vital to prevent relapse and promote recovery.[10]

To date, the majority studies of caregiving in western countries has been focused on impact of schizophrenia on caregivers.[11-15] It is evident that caregivers faced multiple challenges to integrate caregiving into their lives and all aspects of their lives were impacted. The studies exploring caregiving process in chronic schizophrenia suggest that following a diagnosis of schizophrenia, caregivers struggle to understand what had happened to their loved ones.[10,12,16-17,20] They experience a sense of crisis and seek ways to solve unpredictable problems and to adjust emotionally to a demanding illness. There are many types of care that caregivers have to provide, including physical, psychological, medical, and social care.[11,16-18] Caregivers experience trial and error processes to overcome caregiving stress and to move toward a state of balance, normalcy, and mastery.[18-19]

In the Thai context, Buddhism has influenced people's perspectives of life and is an integral part of Thai culture.[21] Parental responsibility is culturally prescribed and centered on familial ethics and values which expect that caregiving for children is direct responsibility of parents.[22-24] Therefore, the majority primary caregivers of person with schizophrenia are parents.[10,25-27] Research evidence on parental caregiving support that parents utilized Buddhist principles in managing their feelings in caregiving.[23,26-27] Similar to western studies, caring for children with schizophrenia brings enormous impacts to families and parents' lives.[10] Parents have to adjust their lives in dealing with each phase of illness and the repetitive problems over time.[10, 26] They provide the close and thoughtful caregiving in managing the unpredictability psychotic symptoms and gradually develop caregiving skills and strategies for various circumstances by experiential learning.[10,25-27] Although informative, these studies provide information about caregiving experiences across a wide range of duration, from seven months to over 10 years, however caregiver's experience at the early phase of schizophrenia has been barely researched. Thus, little is known about how parents manage the challenges of being caregivers for their children with early schizophrenia in Thai context.

Study Aim

The aim of this qualitative study was to explore parental caregiving processes in Thailand during the early phase of schizophrenia.

Methods

Study design: A Straussian's grounded theory approach was employed to elicit parents' descriptions of dynamic process of managing caregiving in the early phase of schizophrenia.[28]

Participants and setting: Study participants were recruited from the outpatient clinic and wards of the largest psychiatric hospital in Thailand, initially through purposive sampling. The inclusion criteria were: 1) parents who served as primary caregivers and lived in the same household with the child since the first episode of schizophrenia: 2) had been informed by a psychiatrist that their child was diagnosed with schizophrenia no more than five years ago; and 3) spoke and understood Thai language. Parents who provided care for family members with chronic diseases in the same household and those who had been diagnosed with psychiatric illness were excluded from the study. Nurses in the clinic or wards were asked to approach parents who came with or visited their children with schizophrenia and asked if they were interested in participating in this study. If they indicated their interest, the researcher informed them about the nature and purpose of the study as well as their rights as research participants. The rest of the study participants were recruited through theoretical sampling, which based on emergent concepts from data analysis.

Ethical considerations: Approval for informed consent procedures and protection of human subjects was obtained from the Institutional Review Board of Nursing Faculty, Mahidol University and the selected hospital. Each participant was given monetary compensation of 200 Baht (US$6) for each interview.

Data collection and analysis: Data collection and analysis was conducted concurrently from August 2012 to July 2013. Indepth interviews ranged from 30 to 110 minutes. The general opening statement for all participants was "Tell me about your experiences since your child's illness begin." Additional questions were used to elicit more details about their experiences. Demographic data was completed after each interview using a brief paper and pencil survey.

Transcripts of the first three interviews were initially examined with open coding, by closely examining phrases or single words to identify types of specific events, activities, and behaviors.[28] Codes that shared common characteristics were grouped into concepts and categories. The beginning categories, and explanatory questions were used to refine the questions in the interview guide and to suggest comparative groups of further nine subsequent interviews. Early categories emerged from data analysis, and were elaborated and refined over the course of analysis through theoretical sampling. Then axial coding and selective coding were used.[28] The emerged concepts were compared against those emerging from eight subsequent interviews and linked to each other. At this point, data saturation was achieved, that is nothing new emerged from analysis. The categories were refined, compared, and linked; memos simultaneously recorded and diagrams representing the linkages were drawn. Writing a story line technique was used. Once the core category emerged, five further interviews were conducted to validate those relationships and hypotheses.

Trustworthiness: To enhance the credibility of the findings, each interview was audio-taped, then transcribed verbatim for analysis, checked the accuracy of transcriptions, and codes by the first author. Additionally, peer debriefing and member checking were used.[29] In peer debriefing, the analyses and conceptual abstractions of the data were presented to two experts in grounded theory approach to explore and shape the first author's interpretations. The preliminary findings were presented to five participants in the second interview for member checking.[29-30] Moreover, analyzing negative cases technique was used to increase explanatory power of the substantive theory. An audit trail including notes, field notes, transcribed interviews, and memos were recorded and reviewed by the second author, to enhance dependability of the findings.[29-30]

Findings

Characteristics of the study participants

The participants included 25 parents (17 mothers, 8 fathers). Their ages ranged from 44 to 77 years with a mean of 56.24. Duration of caregiving ranged from four months to five years with a mean of 3.20 years. None of them reported having any prior experience in caring for patients with mental illness. All participants were Buddhist and the majority of them were living in urban areas in the central region of

Thailand. The average age of children with schizophrenia when first diagnosed was 26.50 years (range 16-47 years). They had been first diagnosed for an average of 2.27 years. All of them were single, unemployed, and lived together with their parents. Half of them had 1-3 hospitalizations while the rest had more than 3 hospitalizations.

The grounded theory of struggling to restore normalcy

"Struggling to restore normalcy" emerged as a core category to describe the basic psycho-social processes of parents' experiences as they assumed roles of primary caregivers for their children with early schizophrenia and face their unstable psychotic symptoms, which was viewed as the basic social and psychological problems for the parents. The core category encompassed six sub-categories: learning the diagnosis, facing shattered dreams, caregiving as an unavoidable role, struggling to control psychotic symptoms, struggling in dealing with the illness impacts, and accepting a new normal, as described below (see in Figure 1).

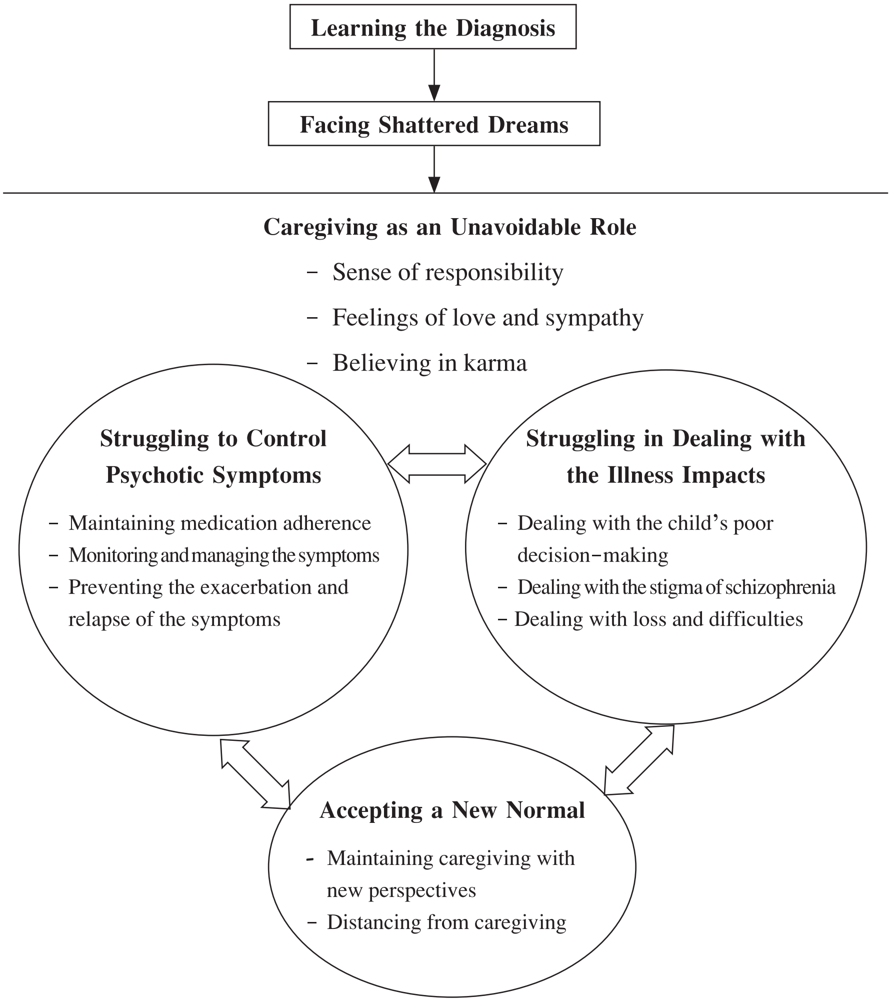

Figure 1. The grounded theory of struggling to restore normalcy.

1. Learning the Diagnosis: This was a process that began with noticing behavioral changes. The participants reported perceiving gradual changes in their child's behaviors such as increased social isolation or decreased daily activities. Most of them initially thought that those behaviors were normal or reflective of adolescent rebellion as most children first exhibited changed behaviors during their transition to adolescence. As the children's symptoms persisted and became more severe, they began suspecting the behaviors to be abnormal. After the diagnosis, participants reported responses as shock and disbelief at such an unexpected situation. One mother said: *It shocked us, unexpected. I couldn't believe, we brought her up so well.* These reactions were followed by feelings of guilt about whether they had caused or could have prevented the illness.

2. Facing Shattered Dreams: The majority of participants were aware that schizophrenia is both an incurable and highly stigmatized condition. Thus, they felt that the dreams that they had for their child and their future had been lost. They experienced anxiety when they thought about the future and their role as caregiver. One mother described:

> *Oh! It seemed that everything was ruined. All parents wish their children to have a prosperous future, to be a soldier, to be a police officer which is good for their lives. When he became like this, did not recover from the illness, could not do anything, he lost his future.*

3. Caregiving as an Unavoidable Role: After learning the diagnosis, the participants believed that they were obligated to fullfill the caregiving role for their child. This perception was associated with a number of feelings or reasons:

Sense of responsibility. Most participants perceived that caring for the children especially when they were sick was the direct responsibility of the parents. As one mother said,

> *I don't think anything....It's my duty. If I do not take care of him, who does? As mother, it does not matter if he is a child or an adult. He is our adult child.*

Feelings of love and sympathy. All participants engaged in caregiving with feelings of love and sympathy for their children. They experienced extreme pity for them especially when their children showed psychotic symptoms or had to be restrained or secluded in a hospital. As one mother described while she sobbed:

> *When I saw him while he was eating, I was sad and felt sympathy. 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].... He had not been ill since he was born.*

Believing in karma. Karma concerns intentional actions which have their consequences: good karma brings good consequences and bad karma brings bad consequences.[31] All participants believed that they were facing these current struggles because of their karma. They must have treated their children badly or committed a bad deed against someone in their past life. Therefore, they could not avoid repaying such karma. One mother mentioned,

> *I think that it is karma that I had to repay to him. Most of us think that karma involves something that we have done in the past.*

4. Struggling to Control Psychotic Symptoms: A primary caregiving task included managing their children's unstable psychotic symptoms. The participants used the following strategies in an attempt to control the illness:

Maintaining medication adherence. All participants understood that medication adherence could control the psychotic symptoms; therefore, they used various approaches to maintain their children's medication adherence. They *took control of medication adminstration* when they viewed that their child was unable to prepare and take medications by themselves. One mother explained:

> *I prepare the pills for him, put them in his hand, and ask him to take them immediately every meal time. I have to do this to make sure that he takes medication correctly and completely. I watch him swallow the pills.*

The participants began to *promote their children's self-responsibility for medication* when they noticed an improvement in symptoms. They gradually decreased their control. Though some of them still prepared medications for their children, they let them to take medication by themselves without observation. Some participants began to teach their children how to prepare the medication by explaining details of medication regimes, preparation, through testing their understanding, reminding their children to prepare and take medication, and re-checking whether the medication was prepared correctly.

In addition, the participants had to *deal with medication discontinuation.* They tried to persuade their children about the importance of medication adherence for recovery. They also used threats and force when their child spat out the medications. Some participants used deception such as crushing tablets and surreptitiously mixing them with food or drink without their children's acknowledge. One mother described her approach:

> *I will try to put it in "Birdy coffee" [an instant coffee beverage] that he likes. I thought he could not know because it is black, unlike "Ohishi tea" [a green tea beverage], he could see the powder left on the bottom of the bottle.*

The participants whose children were not compliant with medication duez to the side effects of the antipsychotic drugs consulted or asked for help from their psychiatrist and tried to diminish the side effects by themselves. For example, some participants provided natural laxatives or fiber foods for their child to alleviate constipation.

Monitoring and managing the symptoms. This approach was used to evaluate the treatment outcome and adjust their responses in managing their children's psychotic symptoms. The participants observed changes in psychotic symptoms from those their children expressed at the first onset of the illness. They determined the severity by comparing with the previous symptoms, in terms of the frequency and their effects on the child's daily activities and security. They additionally determined whether the changed behaviors were normal or were psychotic symptoms through considering the appropriateness of their child's thoughts and perceptions within the current context. The participants gradually comprehended their child's psychotic symptoms through a monitoring approach. A 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 wanted to brawl with her. Thus, she quarreled with it. That was her response to hallucination that I learned.*

They utilized accumulated knowledge for further observation and managing the psychotic symptoms. For example, they would make secret observations to prevent the escalation of their child's paranoia. If their child had a delusion or hallucination, they would redirect their children into reality by initially explaining the reality and giving logical explanations for reconsideration. If their child did not believe them, they expended more effort by presenting related evidences to prove the reality. One mother, whose son believed that he was the king's child, explained her strategy,

> *I showed him the picture of when he was a kid. 'Look! These are your pictures of when you were young.' ..... I rented a car three times and I paid a thousand each time for DNA testing.*

When their children expressed aggressive and violent behaviors, most participants used a complying approach to calm them down because they learned that such psychotic symptoms which may increase if they were forced to try to stop such behaviour. If such behaviours were harmless, they did what their child wanted or allowed them to continue their aggressive and violent behaviors.

Preventing the exacerbation and relapse of the symptoms. Most participants realized that their child was vulnerable to stress, anxiety, and to substance abuse which induced symptom recurrence and relapse. Therefore, they tried to prevent symptom exacerbation and relapse by comforting their child's mind, maintaining cheerfulness, and preventing substance abuse. For example, when their children were facing stress or anxiety, they tried to make the children felt better and realize that the situation was not so bad. As one mother described her response to her daughter's worrying about being admited into a psychiatric hospital:

> *'Mom, it 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 need to stay together with them in this hospital,'* I said.

When the child's distress was subsiding, the participants maintained their child's cheerfulness by pleasing them with their favorite foods, providing entertaining activities, and limiting stress in the environment. To prevent substance abuse, they convinced their child by refering to the psychiatrist's information that substance abuse could induce relapse of the psychotic symptoms. Some participants threatened their child that they would not take care of them if their symptoms were worsened by addictive substances. They tried to prevent access to substances by prohibiting their child to meet addicted friends. Some participants decided to take their children away from environments where there were drugs.

5. Struggling in Dealing with the Illness Impacts: The participants tried to lessen the impacts associated with schizophrenia, including their child's poor decision-making, the stigma of schizophrenia, and their feelings of loss and difficulties.

Dealing with the child's poor decision-making. This poor decision-making resulted in alterations in daily activities, such as staying in their room, not eating or not taking care of their hygiene as usual. They tried to encourage them. If their child did not comply, the participants would complete it by themselves, such as cooking for them or taking care of their clothes and hygiene.

The participants also thought that their child might harm other people or might be exposed to both physical and sexual harm as a result of their poor decision-making and vulnerability. To prevent their child from being harmed or harming other people, they kept an eye on them, watched carefully and did not leave them alone, and followed them everywhere. They also kept sharp materials away when their children were likely to harm themselves. As one mother narrated:

> *I keep observing him and being cautious. I usually stay with him, not to let him stay alone. He will not be surrounded with any sharp materials. I did not cook at home since cooking requires some utensils such as knives.*

When they perceived that the children were uncontrollable and might injure another person or damage property, they secluded their children in a locked room until they were able to take them to a hospital.

To protect their children from sexual harm, such as sexually transmitted diseases for the sons, or sexual abuse for the daughters, the participants tried to limit their child going outside by assigning them to do housework. Some participants cut the Internet signal at home to prevent them from contacting their boyfriend or girlfriend.

Dealing with the stigma of schizophrenia. The majority of participants concealed their child's illness to try to prevent negative consequences. Most were likely to conceal the schizophrenia from relatives and neighbours after learning the diagnosis as they still had hope for a cure. They did not mention the child's illness if symptoms were not severe enough to arouse neighbours' suspicions. They told a lie when the neighbours suspected and asked questions when the child showed more severe psychotic symptoms or changed their lifestyle due to their illness. Some participants told their neighbours that their child suffered with other conditions, such as tension or stress. The participants whose children ran away from home answered questions from others by giving such reasons that their children went to work somewhere else. Some others concealed the name of the hospital to prevent others from visiting and finding out about their child's illness.

However, after time passed and psychotic symptoms were still severe requiring frequent re-hospitalization, most participants could no longer conceal their child's illness. Some unavoidably disclosed the illness in the early phase, for example, when they needed to keep in contact with their relatives, lived nearby their relatives whom they could see regulary, or when their son needed a waiver for conscription for army service. A father explained, *It was because we needed to submit the medical certificate to waive conscription for an army service due to his being mentally ill, so the matter was known to all the villagers.*

Dealing with loss and difficulties. To be able to continue restoring normalcy for their children, the participants used various approaches to cope with their feeling of loss and difficulties, including *thum-jai*, searching for information about the illness, and gaining support from others. *Thum-jai* is a common approach that Thai people use when they face unpleasant situations and in order to overcome unpleasant feelings, calm their mind, and be able to accept them.[32] The strategies for *thum-jai* included being here and now, and thinking positively. These strategies related to the Buddhist principle regarding mindfulness, to be in the present time.[31] As one mother stated, *I had to be aware of every situation. I suffered whenever I saw my son as a mentally ill patient. .... Just only being here and now could enable me to restrain my mind.* Thinking positively was another way to *thum-jai* included finding existing good things and comparing themselves with other inferior persons.

Searching for information about the illness included the participants' actions in trying to understand schizophrenia, in terms of the course of the illness, symptom management, and sources of help. Some discussed this with relatives of the other patients, while the others read from books or pamphlets or watched some health programs on television. The knowledge that they acquired helped them to face the reality and deal with their child's symptoms more effectively, for example, one mother said:

> *I read from books 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 facing more difficulties.*

Gaining support from others. The majority of participants received financial, emotional, and informational support from their spouse, children, or partner. In addition, their family members or their child with schizophrenia assisted them to do household work. Two participants received both informational and emotional support from health care providers. Such support helped them to feel comfortable and made it easier to overcome their caregiving difficulties. One mother who lived alone with her son alone, and suffered from heart disease and hypertension, and used to have suicidal ideas, narrated about her experience:

> *Previously, I wanted to commit suicide. I felt discouraged .... When I saw he cleaned our house, 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 to clean up the house, whereas the dog just lay down and waited to be fed [laugh].*

6. Accepting a New Normal: Accepting a new normal is a consequence of struggling to restore normalcy. It refers to the participants' realization that the pre-illness normal state of their children would never be restored though they put so much effort to control their psychotic symptoms. Their child still would be a person with schizophrenia. Then, they began to adjust themselves in two ways: maintaining caregiving with new perspectives and distancing from caregiving.

Maintaining caregiving with new perspectives. When a child's psychotic symptoms were controllable for a period of time participants could maintain caregiving as usual with less emotional distress. They still had hope that it might be possible for their children to be better. They let things go, no longer worried about their child's future, and maintained caregiving as much as they could. They adjusted their previous expectation that their children would have a normal life, be self-reliant, have no violent behaviors, or adhere to their medications. Some participants gained optimistic views through a reciprocal relationship with their child while caring for them and living together. One mother, who divorced and let her son live with her husband since his childhood, noted about her optimism:

> *When my son lives with me, I gained opportunity to provide 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.*

Distancing from caregiving. Four fathers whose children's psychotic symptoms had not improved due to medication noncompliance, decreased the intensity of their struggle to restore the child's normalcy. Two of them cared for their child alone but they showed continual intense psychotic symptoms requiring frequent re-hospitalization. Another two participants shared the caregiving role with their wives for nearly five years. They reported that the long-lasting and frequent recurrence of their child's symptoms always disturbed their family's normal life. They adjusted to restore their normal life rather than their child's life. They no longer tried to maintain medication adherence and stopped searching for the strategies to manage psychotic symptoms. One father separated himself from his daughter, though he was in the same household, while another one moved away to live in another place and came back to visit his son occasionally. These fathers just waited to take their children to the hospital when the psychotic symptoms became severe. One father said:

> *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 .... I came back to see him occasionally and give him some food. If his symptoms became severe, I just took him back to the hospital.*

Discussion

While prior research has described the caregiving process in long-term care of schizophrena, the current study provided valuable data about the caregiving process in the early schizophrenia. Data analysis indicated that the children's unstable symptoms and the impacts of the illness were the basic psychosocial problems for their parents as caregivers. As a result, struggling to restore normalcy emerged as the core category describing the complex process of Thai parents' adaptations to their caregiving role in early schizophrenia. The findings shared some common attributes with "pursuing normalcy" in a study among family caregivers of severe mental illness.[18] Although that study demonstrated normalcy as a family caregivers' coping response to a chronic mental illness, the current study adds to body of knowledge that normalcy is also the goal of caregiving in the early schizophrenia. It indicates that, for parents, independence and productivity of their children are their optimal needs, regardless of where they were in the illness experience.

The participants in this study struggled with difficulties in dealing with their child's psychotic symptoms both before and after the diagnosis. Before the diagnosis, they experienced struggling in trying to understand and deal with things that happened to their children and which was consistent with findings from prior studies,[11,16-17,33] where caregivers recognized the abnormalities of their relatives, but they were unable to define them.

After diagnosis and treatment for schizophrenia, the participants struggled to restore normalcy for their children. Because of their lack of experience and caregiving skills, they experienced agony in controlling the unstable psychotic symptoms, especially in maintaining medication adherence, managing symptoms, and preventing the exacerbation and relapse of psychotic symptoms. This is similar to other studies,[16,18-19] where the researchers reported that caregivers experienced a cycle of instability and recurrent crises of care recipients' symptoms and they became aware of the chronic trajectory through the cycle of exacerbations and relapses.

Unlike findings of studies focusing on caregiving over a long-term period in which caregivers achieved mastery in caregiving,[10, 18-19,25-27] the participants in this study still struggled with uncertainty and wondered how to appropriately respond to the unstable and unpredictable nature of their child's symptoms. Previous studies supported that caregivers took a long time in adjusting themselves to living with and caring for people with schizophrenia.[10,15] Hence, it was impossible for them to reach a state of stability in caring for the early phase of schizophrenia. They still had to learn through trial and error to control unstable psychotic symptoms and the impacts of the illness.

It is evident that struggling to control psychotic symptoms and to deal with the impacts of the illness influenced participants' coping responses. These could be either adaptive or maladaptive. When a child's psychotic symptoms were controllable for some period of time, participants still had to maintain caregiving whilst developing new perspectives after accepting a new normal. This finding is consistent with other studies[17,22,34] where the researchers noted that most caregivers who experienced the positive side of caregiving usually were those who had hoped for improvement in their relative'condition. The caregivers' hopes and encouragement were maintained if their ill relatives had some signs of improvement or reciprocated their love. These encouraged the caregivers to continue their caregiving.

On the other hand, four fathers, whose children had never complied with medication and their psychotic symptoms had not improved, distanced themselves from caregiving. Two of them shared the caregiving role with their wives for nearly five years, while the others provided caregiving alone and their children showed continual intense psychotic symptoms requiring frequent re-hospitalization. This finding is consistent with previous studies[33,35-36] which noted that the 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. Another possible explanation for this issue concerns gender-specific behaviors associated with the Thai cultural values. Because Thai society expects women to be family caregivers,[23-24,26] these fathers might think that it was not their direct responsibility to be caregivers. A recent study supported that such thinking might be associated with family tradition that the main responsibility of child rearing and caregiving belonged to mothers.[37] Although they distanced themselves from caregiving, their wives still maintained a caregiving role. However, because of the limited number of fathers, it was not enough information to draw a conclusion and to compare with the mothers' experiences and this aspect of gendered caregiving needs further study.

The findings of the current study indicated that dealing with severe psychotic symptoms continuously is a barrier to the positive side of caregiving. Since the nature of psychotic symptoms in the early phase of illness is unstable, living with severe and unstable psychotic symptoms makes it very difficult for the participants to sustain their efforts to handle the illness over time. However, the majority of them could maintain caregiving 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.[22-23,26,32,34,36] This evidence suggests that caregiving is a strong cultural value and Thai culture and Buddhist principles have deeply influenced Thai caregivers and helped them to overcome distress in managing their children's conditions and their caregiving role.

Limitations of the Study

Although the study included both mothers and fathers, which seemed to be a strength of the study, there were limited numbers of the fathers. In addition, the study findings were based on interview only. As such, interpretation and conclusion about the differences between mothers' and fathers' experiences which were gender-specific should be undertaken with care. Recruiting larger number of fathers and obtaining data from medical records would enhance variation and saturation of the theory. Survey research may help to extend study findings, as would be a triangulation approach to data collection.

Conclusions

Our findings add to body of knowledge that normalcy is also the goal of parents in dealing with early schizophrenia. The experiences of caregivers provides more understanding to parents of children affected with schizophrenia, and to mental health care providers about the uniqueness of the caregiving in the early phase of the condition. It was a devastating experience for parents struggling to restore normalcy for their children. Caregiving in the early phase of schizophrenia has been demonstrated to be a critical period needing a high level of support from mental health care providers. In addition, Thai culture and Buddhist principles have deeply influenced Thai parents' responses to schizophrenia.

Implications for Nursing Practice and Research

Information from this study has implications for the development of effective and supportive services for parents of children with schizophrenia. Given the importance of the caregiving role, parents should be provided with systematic education to help them to deal with multiple problems of caregiving. This educational and support program should be started soon after the first diagnosis, and include providing information about schizophrenia, its prognosis, the nature of its symptoms and management, as well as side effects of antipsychotic drugs and management. Parents should be trained in caregiving skills, typically for monitoring the symptoms, maintaining medication adherence, and dealing with delusions, hallucinations, and aggressive and violent behaviors. Based on the study findings, of particular concern are the needs of fathers who are providing care for their children alone or who are faced with continual psychotic symptoms. Skill training for dealing their children's symptoms is essential for them to prevent maladaptive coping responses. A program could be implemented in a group format to promote the parents' learning from the others' experiences and for mutual support.

Acknowledgements

The authors gratefully acknowledge the funding support from the Thailand Nursing Council. We thank all participants for sharing their caregiving experiences.

References

1. World Health Organization. Schizophrenia. [cited 2015, June 08]. Available from http://www.who.int/mental_health/management/schizophrenia/en/.
2. Department of Mental Health. Rate of psychiatric patients: Annual report. [cited 2013, October 08]. Available from http://www.dmh.go.th/report/report1.asp.
3. Phanthunane P, Vos T, Whiteford H, Bertram M, Udomratn P. Schizophrenia in Thailand: Prevalence and burden of disease. Popul Health Metr. 2010;8(24):1-8.
4. Phanthunane P, Whiteford H , Vos T, Bertram M. Economic burden of schizophrenia: Empirical analyses from a survey in Thailand. J Ment Health Policy Econ. 2012;15(1):25-32.
5. Andreasen NC, Liu D, Ziebell S, Vora A, Ho BC. Relapse duration, treatment intensity, and brain tissue loss in schizophrenia: A prospective longitudinal MRI study. Am J Psychiatry. 2013;170:609-15.
6. Sariah AD, Outwater AH, Malima KIY. Risk and protective factors for relapse among individuals with schizophrenia: A qualitative study in Dar es Salaam, Tanzania. BMC Psychiatry. 2014;14:240-52.
7. Ascher-Svanum H, Zhu B, Fraies DE, Salkever D, Slade EP, Peng X, et al. The cost of relapse and the predictors of relapse in the treatment of schizophrenia. BMC Psychiatry. 2010;10(2):1-7.
8. Emsley R, Chiliza B, Asmal L, Harvey BH. The nature of relapse in schizophrenia. BMC Psychiatry. 2013;13:50-8.
9. Siegel SJ, Irani F, Brensinger CM, Kohler CG, Bilker WB, Ragland D, et al. Prognostic variables at intake and long-term level of function in schizophrenia. Am J Psychiatry. 2006; 163:433-41.
10. Tungpunkom P, Napa W, Srikhachin P, Chaniang S. Caregiving experiences of families living with patients with schizophrenia: A systematic review. 2013;11(8):415-564. Available from http://www.joannabriggslibrary.org/ jbilibrary/index.php/jbisrir/index. Doi: 10.11124/jbisrir-2013-881.
11. Caqueo-Urizar A, Miranda-Castillo C, Giráldez SL, Maturana SL, Pérez MR, Tapia FM. An updated review on burden on caregivers of schizophrenia patients. Psicothema. 2014;26(2): 235-43.
12. Mendenhall AM, Mount K. Parents of children with mental illness: Exploring the caregiver experience and caregiver-focused intervention. Fam Soc J Contemp H. 2011; 92(2):183-90.
13. Gater A, Rofail D, Tolley C, Marshall C, Abetz-Webb L, Zarit SH, et al. Sometimes it's difficult to have a normal life: Results from a qualitative study exploring caregiver burden in schizophrenia. Schizophr Res Treatment. [cited 2014, April 03]. Available from http://dx.doi.org/10.1155/2014/368215.
14. Negota AJ, Mashegoane S. Mothering children with schizophrenia in a village setting: A multiple case study. J Psychol Afr. 2012;22(2):259-62.
15. Mizuno E, Takataya K, Kamizawa N, Sakai I, Yamazaki Y. Female families'experiences of caring for persons with schizophrenia. Arch Psychiatr Nurs. 2013;27:72-7.
16. Muhlbauer SA. Navigating the storm of mental illness: Phases in the family's journey. Qual Health Res. 2002;12:1076-92.
17. Mcauliffe R, O'Connor L, Meagher D. Parents' experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: A qualitative study. J Psychiatr Mental Health Nurs. 2014;21:145-53.
18. Rose L, Mallinson RK, Walton-Moss B. A grounded theory of families responding to mental illness. West J Nurs Res. 2002;24(5):516-36.
19. Wynaden D. The experience of caring for a person with a mental illness: A grounded theory study. Int J Ment Health Nurs. 2007;16:381-89.
20. Janardhana N, Raghunandan S, Naidu DM, Saraswathi L, Seshan V. Caregiver, cargiving experiences, caregiver load, people with severe mental illness. Indian J Psychol Med. 2015; 37(2):184-94.

21. Sanseeha L, Chontawan R, Sethabouppha H, Disayavanish C, Turale S. Illness perspectives of Thais diagnosed with schizophrenia. Nurs Health Sci. 2009;11:306-11.
22. Thampanichawat W. Maintaining love and hope: Caring for Thai children with HIV infection. J Assoc Nurses AIDS Care. 2008;19(3):200-10.
23. Rungreangkulkij S, Chesla C. Smooth a heart with water: Thai mothers care for a child with schizophrenia. Arch Psychiatr Nurs. 2001;15(3):120-27.
24. Subgranon R, Lund D. Maintaining caregiving at home: A culturally sensitive grounded theory of providing care in Thailand. J Transcult Nurs. 2000;11(3):166-73.
25. Dangdomyouth P, Stern PN, Oumtanee A, Yunibhand J. Tactful monitoring: How Thai caregivers manage their relatives with schizophrenia at home. Issues Ment Health Nurs. 2008;29:37-50.
26. Sukmak V, Chockratnhirun U, Srijunlah A. Strategies used by caregivers in managing psychiatric patients at home. J Psychiatr Assoc Thai. 2001;46(2):107-16. [in Thai].
27. Tunkpunkom P. Staying in balance: Skill and role development in psychiatric caregiving [dissertation]. USA: University of California at San Francisco; 2000.
28. Corbin J, Strauss A. Basics of qualitative research: Techniques and procedures for developing grounded theory. 3rd ed. Los Angeles: Sage; 2008.
29. Lincoln Y, Guba E. Establishing trustworthiness. In: Bryman A, Burgess RG, editors. Qualitative Research, Vol III. Thousand Oaks (CA): Sage; 1999.
30. Bloomberg LD, Volpe M. Completing your qualitative dissertation: A roadmap from beginning to end. Thousand Oaks (CA): Sage; 2008.
31. Bhikkhu B. Handbook for mankind: Realizing your full potential as a human being. Bangkok, Thailand: Amarin Publishing; 2007.
32. Patoomwan A. Living with childhood cancer in Thai families: Stories of struggling with uncertaincy [dissertation]. USA: University of California at San Francisco; 2001.
33. Weimand BM, Hall-Lord ML, Sallstrom C, Hedelin B. Life-sharing experiences of relatives of persons with severe mental illness: A phenomenographic study. Scand J Caring Sci. 2013;27:99-107.
34. Huang XY, Hung BJ, Sun FK, Lin JD, Chen CC. The experiences of carers in Taiwanese culture who have long-term schizophrenia in their families: A phenomenological study. J Psychiatr Mental Health Nurs. 2009;16:874-83.
35. Wongsawang N, Lagampan S, Lapvongwattana P, Bowers BJ. Family caregiving for dependent older adults in Thai families. J Nurs Scholarship. 2013;45(4):336-43.
36. Yen WJ, Teng CH, Huang XY, Ma WF, Lee S, Tseng HC. A theory of meaning of caregiving for parents of mentally ill children in Taiwan: A qualitative study. J Clin Nurs. 2010;19:259-65.
37. West C, Honey A. The involvement of fathers in supporting a young person living with mental Illness. J Child Fam Stud. [cited 2015, June 06]. Doi 10.1007/s10826-015-0230-7.

การดิ้นรนต่อสู้เพื่อการกลับสู่ภาวะปกติ: ประสบการณ์ของบิดามารดาไทยในการเป็นผู้ดูแลบุตรโรคจิตเภทระยะแรก

พิชามญชุ์ ปุณโณทก วัลยา ธรรมพนิชวัฒน์ อัจฉรียา ปทุมวัน โสภิณ แสงอ่อน*

บทคัดย่อ: แม้ว่าการดูแลผู้ป่วยโรคจิตเภทระยะแรกจะซับซ้อนและยุ่งยาก ความรู้เรื่องกระบวนการดูแลในระยะนี้ยังมีจำกัด การวิจัยนี้จึงมุ่งศึกษากระบวนการดูแลบุตรโรคจิตเภทระยะแรก โดยการสัมภาษณ์เชิงลึกบิดามารดา 25 คนที่บุตรเป็นโรคจิตเภทได้รับการวินิจฉัยภายใน 5 ปีแรก ที่แผนกผู้ป่วยนอกและหอผู้ป่วยในของโรงพยาบาลจิตเวชแห่งหนึ่งในประเทศไทย วิเคราะห์ข้อมูลโดยการเปรียบเทียบข้อมูลอย่างต่อเนื่องตามวิธีวิจัยเชิงทฤษฎีพื้นฐานของสเตราส์

การดิ้นรนต่อสู้เพื่อการกลับสู่ภาวะปกติเป็นหัวข้อเรื่องหลัก ประกอบด้วย 6 หัวข้อย่อยคือ การรู้ว่าบุตรป่วยทางจิต การเผชิญกับฝันสลาย การดูแลเป็นบทบาทที่เลี่ยงไม่ได้ การพยายามควบคุมอาการทางจิต การจัดการผลกระทบของโรค และการยอมรับความเป็นปกติใหม่ หลังจากรู้ว่าบุตรป่วยทางจิต บิดามารดารู้สึกเหมือนกำลังเผชิญกับฝันสลาย จากการรับรู้ว่าการดูแลเป็นบทบาทที่เลี่ยงไม่ได้ จึงดิ้นรนต่อสู้ให้บุตรกลับมาเป็นปกติ โดยพยายามควบคุมอาการทางจิตที่ไม่คงที่ด้วยวิธีการต่างๆ ประกอบด้วย ดูแลให้ได้รับยาต่อเนื่อง เฝ้าระวังและจัดการกับอาการ และป้องกันการกำเริบและกลับเป็นซ้ำของอาการ อีกทั้งต้องจัดการกับผลกระทบของโรค ได้แก่ การตัดสินใจที่ไม่ดีของบุตร ตราบาปของโรค และความรู้สึกสูญเสียและความยุ่งยาก บิดามารดาค่อยๆยอมรับการรักษาไม่หายของโรคซึ่งเป็นความปกติใหม่ของบุตร

ผลการวิจัยเพิ่มองค์ความรู้ทางการพยาบาลเกี่ยวกับการดูแลบุตรในกลุ่มนี้ สามารถนำมาเป็นแนวทางพัฒนาโปรแกรมการช่วยเหลือบิดามารดาที่เป็นผู้ดูแล เพื่อให้ข้ามพ้นความยุ่งยากไปได้ การศึกษาต่อไปควรเปรียบเทียบประสบการณ์การดูแลบุตรโรคจิตเภทระยะแรกของบิดากับมารดา

Pacific Rim Int J Nurs Res 2016; 20(1) 71-84

คำสำคัญ: การดูแล บุตร ประสบการณ์ การวิจัยเชิงทฤษฎีพื้นฐาน บิดามารดา โรคจิตเภท

พิชามญชุ์ ปุณโณทก RN, PhD *(Candidate) คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล* ***E-mail:*** *mouth.mind@gmail.com*

ติดต่อที่: วัลยา ธรรมพนิชวัฒน์ RN, PhD *ผู้ช่วยศาสตราจารย์ สาขาการพยาบาลกุมารเวชศาสตร์ คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล*
Email: *wanlaya.tha@mahidol.ac.th*

อัจฉรียา ปทุมวัน RN, PhD *ผู้ช่วยศาสตราจารย์ สาขาการพยาบาลเด็ก โรงเรียนพยาบาลรามาธิบดี คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล 270 ถนนพระราม 6 เขตราชเทวี กรุงเทพฯ 10400*
Email: *autchareeya.pat@mahidol.ac.th*

โสภิณ แสงอ่อน RN, PhD *ผู้ช่วยศาสตราจารย์ สาขาการพยาบาลจิตเวชและสุขภาพจิต โรงเรียนพยาบาลรามาธิบดี คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล 270 ถนนพระราม 6 เขตราชเทวี กรุงเทพฯ 10400*
Email: *sopin.san@mahidol.ac.th*