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The Needs of Thai Family Caregivers for Readiness to Provide Care for People With Psychosis: A Qualitative Approach

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Abstract

Background: After the implementation of the deinstitutionalization policy, the role of family caregivers has grown in importance and the caring responsibilities have shifted onto their shoulders. This study sought to better understand the Thai family caregivers' needs for readiness to care for people with psychosis.

Method: A total of 48 participants were enrolled in the study. A focus group discussion and in-depth interview were conducted with family caregivers of the people with psychosis at home, in an urban area of Chonburi province, Thailand. A content analysis approach was used to analyze the data.

Results: The findings revealed that caregivers' needs for readiness to care for people with psychosis encompassed two areas: 1) enhancing motivation to be a caregiver through encouragement, mental preparation, and community preparation, and 2) the need to be prepared and ready for psychiatric caregiving such as information, financial support, caregiving skills training, and self-stress management training.

Conclusion: This study offers a new understanding of the need for readiness in caring for people with psychosis. Moreover, healthcare providers can help provide basic information for formulating strategies to serve caregivers' needs and enhance readiness for caring for people with psychosis.

Keywords: Family caregivers, People with psychosis, Mental health, Thailand

1. Introduction

In Thailand, the number of people with psychosis attending public hospitals has dramatically increased. The number of people with psychosis hospitalized in public psychiatric hospitals increased from 50,123 in 2017 to 52,102 in 2020 [1]. The deinstitutionalization policy aimed to decrease the patient's length of stay in the hospital, decrease admission rates, and encourage them to live a normal life in society [2]. Since most people with psychosis symptoms return to their homes, a sudden responsibility is thrust upon family caregivers [2,3].

The caregivers' need and readiness to care for their family members with psychosis plays a crucial

role in the evolving health care system. As this current era is community-oriented, the primary caregiver is viewed as a significant person. The caregiving process for people with psychosis at home is tedious, and caregivers require specific skills to manage perplexing situations. Patients' cognitive deficit could lead them to exhibit problematic or harmful behaviors, especially in the acute phase of the illness. Hence, caring for people with psychosis increases the caregiver burden [4]. Previous studies regarding the caregivers' experience in caring for persons with schizophrenia reported that the caregivers struggled to cope with unstable psychotic symptoms by improving medication adherence, monitoring, and managing psychotic

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symptoms. They also prevented the relapse of symptoms and improved the patient's competencies for daily living [2,4]. Those difficult experiences have a negative impact on the caregivers' physical, mental, social, and spiritual health. It also leads to economic and financial burdens. Consequently, the caregiving quality becomes poor due to caregivers' inability to effectively deal with the impacts [5].

Furthermore, previous studies have predominantly focused on the impacts of illness on caregivers and focused less on caregiving tasks that are significant [4,6]. The recent study regarding caregivers' needs confirmed that the informal caregivers of persons with psychosis needed support, including economic, psychosocial, and informational support. However, these were the healthcare professionals' opinions as they were the study participants [7]. Since then, only limited studies have focused on the subjective feeling of the family caregiver's readiness to care for their mentally ill relatives in Thailand. This study consequently aims to understand the needs of caregivers to foster readiness in their caregiving roles.

2. Methods

This study is a part of the primary concurrent mixed-methods study exploring the readiness and needs for psychotic patient care of family caregivers and community networkers in Chonburi Province, Thailand. A descriptive design with a qualitative inductive interview approach was used since it focused on human experiences [8]. This qualitative part comprised only the information from family caregivers.

2.1. Key participants

Participants were recruited from the population of Thai family caregivers (TFCs) who cared for their psychotic relatives at home. They were recruited via primary contact from sub-district health promotion hospital staff, Chonburi province. Forty-eight participants were enrolled by purposive sampling. Forty caregivers for four focus groups and eight caregivers for in-depth interviews were selected. The inclusion criteria were primary caregivers, living and caring for the people with psychosis for at least six months; the caregivers had to be aged 18 years or older; and have the ability to communicate in the Thai language. Exclusion criteria were the caregivers who cared for other sick family members with other chronic diseases, and caregivers with mental illness.

2.2. Instruments

The interview guidelines comprised of open-ended questions that emphasized the caregivers' thoughts and needs regarding psychotic patient care. The sample questions included: "Could you please give me your idea; in what areas do you need to prepare for providing care for the psychotic patient? Or "What do you need the most for readiness to care for the psychotic patient? and Why?" When necessary, probing questions were used to clarify the question and foster a deeper exploration of the caregiver's needs. The interview guidelines were adapted based on a matrix of question options [8] and the interview preparation guidelines of Kvale and Brinkman [9]. The data collection was completed following data saturation and non-emergence of new themes.

2.3. Procedure

The data was collected using four focus group discussions with 10 participants per group. To ensure trustworthiness and gain in-depth data, in-depth interviews were conducted with 8 participants via the triangulation method. This study was conducted between October 2018 to March 2019, following the Helsinki Declaration Protocol. The participants were recruited via primary contact from Sub-district health promotion hospital staff, Chonburi province. They were asked for their willingness to participate in the study and informed about the objectives, methodology, benefits, risks, and their rights of participation. Written informed consent was obtained from the participants. The caregivers were interviewed in private meeting rooms. The duration of data collection lasted approximately 60–90 min (mean = 70) in focus groups and 45–70 min (mean = 60) for in-depth interviews. All the interview recordings were transcribed verbatim.

2.4. Data analysis

The first author was the investigator of this analysis. The textual data were analyzed in the Thai language using Colaizzi's seven-step method including [10] (1) reading the transcriptions thoroughly; (2) extracting significant statements; (3) significant statements were scrutinized to extract meaning; (4) codes and themes were generated; (5) formulated meanings were organized into clusters of themes; (6) The themes and subthemes were integrated into a detailed description of the caregiver's perception and needs of psychotic patient care; (7)

the findings were returned to the participants to check the researchers' findings. In terms of trustworthiness, this study used the triangulation method using focus groups and in-depth interviews, and reflexive journal writing. The researcher then translated the findings into English, back-translated the findings using a bilingual editor, and finally had it edited by a native speaker who works as an educational scholar in the university.

2.5. Ethical issue

The Ethics Committee of Burapha University, Thailand (IRB No. Sci 049/2018) approved this study.

3. Results

A total of forty-eight participants were recruited. The average age of caregivers was 58.65 years (SD = 10.66) of which the majority of them were above 60 years old (55%). Around 65% had a primary education level. Regarding the relationship status of caregivers, two-thirds of them (62.5%) were mothers, and 32.5% were siblings to the patients, with the rest 5% being fathers and couples (husbands). Their duration of caregiving role was more than 20 years, with a mean age of 16.32 years. The patients' ages ranged from 18 to 90 years with a mean of 45.96. Most of them were diagnosed with schizophrenia and substance-induced psychosis. Most of them were unemployed and lived together with their caregivers more than 20 years.

Following data analysis [10], the findings of needs for readiness to care for the psychotic patient culminated in the extraction of two main themes (i) needs for readiness to care for the psychotic patient, including the need for enhancing motivation to be caregivers, and (ii) the need to be prepared for the readiness for psychiatric caregiving. Six sub-themes emerged from the main themes as detailed below.

3.1. The need for enhancing motivation to be a caregiver

This was composed of two subthemes: mental preparation and social preparation.

3.2. Mental preparation

Mental preparation represents the psychological dimension of the caregivers. The caregivers verbalized the need for emotional support from their other family members which motivated them to optimally perform the caregiver role. A mother who cared for

her child during the critical phase of illness described, "At that time I could not control my emotions. I needed someone to touch my shoulder and tell me to fight for it. That's all I needed, not even money". The other caregivers' empathic understanding is a vital component of readiness for caring for the psychotic patient.

The motivation should not only be provided by family members but also by the health care providers, such as through home visits and telephone calls to follow-up. As a caregiver stated, "I need a nurse to call to know about patients' follow-up care and symptoms' progression. It is good for my mind to know that someone showed concern for us".

3.3. Social preparation

The caregivers perceive that people feel disgusted with people with psychosis. However, people with psychosis living in the community with other people will enhance their faster recovery. The caregivers felt discouraged when others rejected their loved ones. Healthcare providers should educate the public about psychotic disorders and develop cognizance, to promote compassion, and eradicate discrimination. As a mother explained:

... Now, social media portrays one side of the information. It makes people view the psychotic patient as a dangerous person who needs to be distanced. My son was chased by other people in front of my eyes. We got hurt His symptoms deteriorated after that.

3.4. The need to be prepared and ready for psychiatric caregiving

It comprised of the need for information, the need for financial support, the need for caregiving skills training, and the need for selfstress management training.

3.5. The need for information

The caregivers explained that the fundamental information necessary for the caregiving process should comprise the causes, pathologies, treatments, and guidelines to care for various psychotic symptoms. In addition, the caregivers also suggested education regarding each phase of the patient's illness. They expect the knowledge relevant to caregiving problems, as a caregiver mentioned "knowledge and skills should be provided corresponding to specific problems. Whatever you provide, we should be able to fulfill our caregiving

needs and manage our relatives' symptoms. Sometimes it is difficult for us to apply.”

Moreover, the caregivers needed to understand the patient's behaviors or symptoms in advance to prevent negative consequences. Most caregivers understood the patients' psychotic symptoms as inappropriate behaviors. Their misunderstanding made them respond negatively to the patients resulting in adverse clinical outcomes.

3.6. *The need for financial support*

The caregivers described that their stress was related to the family's financial status. It is an important aspect of patient care since some of the patients were unemployed and had to rely on the caregiver. Some caregivers had to quit working or could not work full time after taking on the caregiving role. Adequate financial support makes the caregivers feel secure. As a caregiver explained “I must have a job for financial security while taking care of him. Love and dedication alone are not enough. I must have money to buy food for him as well.”

Although the Thai government has a Disability Payment Act for people with disabilities, including mental disabilities [11], some caregivers are unaware of the registration procedures. They also lacked information about the pros and cons and the legal aspects of this Act. They eventually reported they had insufficient money.

It was interesting to find that nearly half of the caregivers negotiated with and paid money to the patients as a way to receive their cooperation. For example, they bought the patient tobacco or beverages such as coffee, coke, or even expensive notebooks or a mobile phone in exchange for medication compliance or other daily living activities.

The caregivers reported that they felt burdened and stressed due to their financial problems. Stressful situations with ineffective coping mechanisms may lead to severe consequences, as a caregiver mother stated, “... I spent all my money and didn't work for a year. I had suicidal ideations whenever I didn't have a solution for it.”

3.7. *The need for caregiving skills training*

The caregivers perceived that the caregiving process for people with psychosis was different from the patients with physical illness. They mentioned the three essential skills necessary for fostering their caregiving competencies: medication management skills, communication skills, and symptom management skills. In addition, all the caregivers had a

consensus about the training and continuous monitoring to enhance the caregiving competencies via the interactive process.

Most caregivers' experiences implied difficulties in managing the patient's medication adherence.

The most difficulty was related to an arrangement to promote the patients' medication compliance in each context of their real life. Some patients had irregular food intake. As a mother explained “If I call him to eat after he slept, he curses me which is a sign of medication non-compliance. Sometimes he didn't consume food for two days or three days.”

The caregivers have realized the importance of communication skills for making the patient's cooperation in both medication intake and controlling inappropriate behaviors. Most caregivers were aware that talking without coercion, threats or reproaches was significant since these could worsen the patient's psychotic symptoms. Therefore, they reported that early training in communication skills could aid them in getting accustomed to their role.

The caregivers must be educated about the ways of responding to psychotic symptoms when varied symptoms occur in patients. They took a long time to understand through the trial-and-error method. As a caregiver said, “The first time I couldn't understand. It's trial and error. Try it again and again.”

All the caregivers said that being prepared for readiness early could aid them in providing more effective care to people with psychosis.

3.8. *The need for self-stress management training*

Most caregivers experience the caregiving process for people with psychosis to be stressful. They felt it especially at the early stages of the illness when they did not understand the patient's behaviors. The caregivers sought help from a networking group to assess their mental health status. The caregivers from the focus group explained the reasons why they needed to be trained in stress management skills:

... You don't talk about caring for a bedridden patient that it is so much stress. It is also stressful if you can't live a normal life but live with a mentally ill person. The caregivers were likely to be depressed if they constantly lived with the psychotic patient.

Caregivers experienced stress or negative emotions due to worry about their relatives' illness. Sometimes they felt that they faced the suffering alone. They try to be patient and suppress their emotions. The caregivers felt their stress would alleviate if they had someone to consult especially in

a crisis, like a health care provider. As a father said “I think there is only one thing that will help me emotionally or whatever in a crisis. A health care provider is the one I need to consult about the caregiving.”

4. Discussion

This exploratory study provides a comprehensive understanding of the caregivers' needs for readiness to perform their caregiving roles. There was a complete consensus among the four focus groups ($n = 40$) and all participants ($n = 8$) regarding the caregiver's psychological preparation and their family's readiness to care for their relative with psychosis. They also required encouragement, understanding, and acceptance of the patient from other family members and society. The caregivers felt discouraged when others rejected their loved ones. In addition, caregivers suggested providing education to the people in the community to reduce discrimination against people with psychosis. The public rejection of the patients due to the fear of symptoms indirectly results in the caregiver's social isolation. These findings were consistent with the previous studies that found caregivers were neglected and often unable to participate in social activities due to the unpredictability of their relative's illness [12]. Stigma toward mental illness restrained the patients and their caregivers from participating in social events and resulted in inadequate social communication and support [13,14]. Nevertheless, social connection and support are considered protective factors against the caregivers' psychological difficulties. Transitioning from an ordinary person to a caregiver is not possible without emotional support [13].

To promote readiness for caring for people with psychosis, the caregivers need to possess knowledge about psychotic disorders and caregiving guidelines like medication management skills, communication skills with the patients, psychiatric symptoms management skills, and self-stress management skills. The findings are consistent with previous studies on the needs of caregivers who cared for people with psychosis at home that found caregivers had informational needs about mental illness and skills training in caring for psychiatric patients at a high level [15]. Caregivers often struggle due to their lack of knowledge and skills to manage the patient's medication non-compliant behaviors and side effects of antipsychotic drugs [2]. A prior study addressed the substantial role of psychoeducation in enhancing the caregivers' knowledge and their relationship with others. It also alleviated the

psychological distress resulting from caregiving [7,13]. The caregivers' misunderstanding of the illness led them to provide ineffective care to their relatives. Also, family caregivers experienced psychological discomfort with inadequate informational support and could not assist their mentally ill relatives [12,13,15].

The findings of this study highlight the critical issues for health care providers to provide knowledge about the disease and to train caregiving skills for the caregivers. Firstly, knowledge and caregiving skills should be specific for each stage of caregiving role development. Secondly, development in caregiving competencies should be continuously monitored to improve their caregiving skills related to the problem. These findings are consistent with a study that found caregiving demands to vary at different times during caregiving roles [16]. Hence, assessing the progression of the caregiving role and their competencies at each phase of their relatives' illness is critical. Besides, effective communication with the caregivers is required to understand their specific needs and provide adequate care to enhance their readiness. This was in line with another study that found the interactive process or training involving observation and reflection facilitated successful caregiving. It could also be fostered by understanding the caregivers' knowledge, attitudes, and skills [17].

The caregivers in this study expressed their need for financial support. This is consistent with many studies that indicated financial support to be crucial in caring for people with psychosis [3,13,18]. The caregivers quit their jobs and lost income in caring for their relatives. Even though they have to manage their daily life and treatment expenses. This financial burden led to stress, conflict, family discord, and low quality of life among caregivers [19,20].

It was surprising that nearly half of the caregivers reported that they spent money on negotiating with the patients' non-compliant behaviors. This in turn gradually leads to a financial drain and reflects an ineffective dealing with the patients' non-compliant behaviors. In agreement with earlier findings [18], our study provides strong evidence that family caregivers are inclined to use maladaptive coping strategies. They usually use emotionally focused coping strategies and avoid facing the problem by using the money to negotiate for the patients' compliance. Therefore, they need to use problem-focused coping and have negotiating skills training to enable them to face the patients' non-compliant behavior. Nevertheless, financial support alone is not adequate and practicable to solve the problem. The present study also suggests that the caregivers

need stress management skills training. Problem-focused coping skills training should be offered concurrently with emotional and cognitive-focused coping skills for the caregivers; to face their financial and other problems [8]. This was vital since the caregivers had to handle the complex nature of the illness and difficulties in dealing with their personal life. This was in line with many studies which indicated the caregiving effects on the mental health of caregivers [12]. In addition, if the caregivers coped with stress ineffectively, the patients might get affected due to their poor caregiving quality [2,3,14].

Moreover, caregivers viewed understanding the patient's abnormal behaviors as an essential factor for psychological readiness. The caregivers who had a positive attitude toward the patient could perceive the reason for the patient's inappropriate behaviors from mental illness. In addition, the psychotic symptoms must be explained to the caregivers following patient's diagnosis. This was consistent with a study on Thai parents' experiences caring for their child with early schizophrenia. It found parents have a negative attitude towards patients, faced difficulties, and had high stress levels during their child's onset of psychotic symptoms [4]. The possible reason could be caregivers' minimal understanding of the psychotic symptoms [3,4]. In addition, confusion and anxiety occur during the early phase of the illness that takes a long duration to learn about through trial and error [20]. These findings are consistent with previous studies that found that caregivers required information about the patient's symptoms, symptom monitoring, resources, access to care and hospitalization, and ensuring safety [3].

5. Conclusion

Two main themes emerged on caregivers' needs. There was 1) the need for enhancing motivation to be caregivers and 2) the need to be prepared for readiness for psychiatric caregiving. The caregivers of this study wanted their family members and community to understand them. This affects the quality of care for the people with psychosis at home. Family acceptance and a positive attitude towards the people with psychosis, emotional support for caregivers, and cooperation to solve problems are the vital components of caregivers' encouragement. In accordance with the findings, caregivers and family members should be prepared with various tools and methods that can be applied based on the context and situation of each family.

This study contributes to psychiatric nursing practice and offers a new understanding of the caregivers' needs in caring for the mentally ill in the community. Their caregiving experiences provide insight into the vital needs essential for caring for mentally ill relatives. The findings in this research provide direction at individual, family, and community levels. Early intervention programs can enhance the caregivers' readiness for transition to the caregiver role by providing them with appropriate psychoeducation and promoting their four essential skills: medication management skills, communication skills with patients, psychotic symptoms management skills, and stress management. In addition, clear and quick referral pathway should be established, such as an online platform, to help caregivers to access mental health services, especially in crisis [21].

In addition, caregivers should be encouraged to meet their peer groups both in the hospital and in the community to share and learn from other caregiving experiences. Also, caregivers need to be acquainted with helpful resources in both public and private sectors and organizations or foundations that provide financial support. Social media and online networks may be another option to find information and resources to evade difficulties while caring for people with psychosis. Family and community support can be fostered through understanding and compassion regarding caregivers' suffering and needs.

5.1. Recommendation

This study had some limitations. Since most of the participants in this study were females, the needs of male caregivers remain unclear. Therefore, our data could not be disseminated to male caregivers. The gender-specific caregiving needs further exploration. The findings suggested that the mean duration for the caregiving role was 16.32 years; and that reflects the necessity of focusing on the needs specific to the first five years in the caregiving process. In addition, future studies should shed light on the generalization to other cultural groups, as this study was conducted in the eastern urban part of Thailand. Research into the needs of caregiving at different levels of psychotic symptoms and severity levels are needed. Our finding reported the needs of the caregivers from a whole perspective.

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Conflict of Interest

This study has no conflict of interest.

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