RELATING, REALIZING, REPEATING AND REINVENTING: EXPERIENCES OF PSYCHIATRIC PATIENTS AND FAMILY CAREGIVERS IN A THAI RURAL COMMUNITY

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Abstract

Patients with psychiatric illnesses require a long-term management; however, disruptions in care and resultant relapse are often expected. Family caregivers of psychiatric patients often experience anxiety and stress related to caregiving and lack of appropriate understanding and skills to care for the patient. This qualitative research aimed to explore experiences of psychiatric patients and their caregivers. The participants included 8 patients and 9 family caregivers who were purposively recruited into the study. The authors conducted in-depth interviews and thematic analysis. Four themes reflected the experiences of the participants: 1) surviving family and social relationships, 2) never again slip away, 3) repeated daily routines, and 4) searching for a new me. Based on these themes, the authors formulated a model of culturally sensitive care for psychiatric patients represented in a 4 R’s model, that is, Relating, Realizing, Repeating and Reinventing. Relating deals with the relationships between patients and significant others which change over the course of illness and care management. Realizing reflects the patients’ awareness of their own illness as incurable and thus requiring continuous medical treatment. Repeating describes day-to-day routines including self-care and household chores. As a result of the changing self and landscape, some patients attempt to reinvent different aspects of their lives. This model guides culturally sensitive humanistic care of psychiatric patients and their family.

Keywords: Psychiatric patients, care givers, qualitative research, culturally sensitive care

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Background

Data from around the world show that 26 million people suffer from psychiatric illnesses at a rate of 7 per 1,000 in the adult population (Health Promotion Fund Office, 2014). Psychiatric patients in Thailand have also increased. During 2010-2011, patients receiving psychiatric treatment increased from 70,717 to 88,432 accounting for 25% increase in number (Department of Mental Health, 2015).

Psychiatric illnesses are considered chronic illness. Mental disorders comprise a broad range of problems, with different symptoms. However, they are generally characterized by a combination of abnormal thoughts, emotions, behaviors, and relationships with others. These are for example schizophrenia, bipolar, depression, and drug abuse. Most of these disabilities can be successfully treated and treatment at the beginning of the disease will make it more effective. Though medication does not cure mental illness, it may help with the management of symptoms. Medication when combined with psychotherapy is the most effective way to promote recovery. That explains why many people diagnosed with mental illness achieve better outcomes and recovery through participating in individual or group treatment. Although patients have improved symptoms, they often have problems with their lifestyle, adaptation to society and life skills (Holmberg & Kane, 1999). Mental illness economically affects the patients and their family. Patients require complex care and lose almost every aspect of their self-care ability. It also reduces social skills and community living (Seo, Ahn, Byun, & Kim, 2007).

Patients with psychiatric illnesses require a long-term management. Family caregivers of psychiatric patients often experience anxiety and stress related to caregiving and lack of appropriate understanding and skills to care for the patient. Caregiving activities include management of personal hygiene, food preparation, sleep and rest, and encouraging patients to participate in community activities (Tungpankham, 2013).

Thai National Health Development Plan No. 10 (2012-2016) has focused on patient’s competency of rehabilitation in community to reduce the cost of medical treatment and recurrence rates. To achieve this, patients are encouraged to adhere to medical regimens, follow their daily lives, and to engage with families and communities (Ministry of Public Health, 2012). This plan complies with the direction of mental health development and the Strategic Plan for the Department of Mental Health (2012 - 2016) that aims to educate the public about understanding and attitudes towards mental health and capability to care for their own health (Department of Mental Health, 2015). Self-care aims to maintain daily life, health and well-being. Self-care and dependent care are behaviors learned within a socio – cultural context. Self-care concept addresses the general self-care needs in normal situations such as maintaining the basic needs, keeping balance between activity and leisure, life-threatening protection, and self-care in health deviations (Orem, 1991).

Psychiatric patients often have multiple impairments that reduce their ability to self-care, social skills, and the ability to work or live in the community. Most patients lose interest in themselves and their environments. Specifically, the necessary self-care, continuous medication management were also ignored. The illness also reduces their adaptability in the family and community. As a result of psychiatric patients not being able to take care of themselves, follow
medication management and lack of social support, these patients will experience relapse and require hospitalization (Pongsuksri, Phusopa, & Samutthiya, 2009). Therefore, continuous care and rehabilitation at home are essential.

Recovery from mental illness can be defined differently. On the other hand, psychiatric patients define recovery as the attainment of meaningful and valued life, rather than the absence of symptoms (Deegan PE., 1988). Mental health professionals such as psychiatrists have developed a “medical” model of recovery placing the emphasis on elimination of symptoms and return to normal functioning (Zipursky RB., 2014). At present, psychiatric and mental healthcare providers have adopted proactive multidisciplinary care to guide their practice and services. The role of psychiatric nurses in the community focuses on encouraging patients to care for themselves and support their families to care for patients appropriately and to prevent recurrence. In order to work with families, nurses will need to have understanding of how psychiatric patients and their families experience the illnesses and how care is being approached in their contexts. This study therefore aimed to explore experiences of psychiatric patients and their caregivers in one semirural community in Thailand. The results of this study will be used as a guideline or strategy for health personnel and agencies involved in the provision of health services to psychiatric patients and their families suitable with their needs and respective contexts.

**Objective:**

This study aimed to explore experiences of psychiatric patients and their caregivers and construct a model for family caregiving of mentally ill patients.

**Participants:**

Purposive sampling was used in this study. The participants consisted of 8 patients with mental health illness and 9 family caregivers. The participants lived in a rural community in Lampang province, Thailand. The participants had been diagnosed by ICD-10 for at least 3 years prior to the study. The patients were 4 males and 4 females aged between 38 to 69 years. They were diagnosed with schizophrenia, mood disorders, depression, and anxiety disorders. All of the patients were considered able to communicate with the researchers. The family members were parents, husbands, wives, aunts, sons and daughters who had cared for the patients for 2 years to 8 years.

**Methods: Data collection and analysis**

This qualitative research used semi-structure in-depth interviews for data collection. Data collection took place between October 2015 and April 2016. The researcher explained the objectives of the research to the participants. Then we requested the consent from the participants to participate in the research. Interviews were arranged at the participant’s
convenience. The researcher established relationships with the participants before conducting the interview. We visited each informant 2-3 times. The first visit focused on general inquiries. Later, in-depth interview was conducted with tape recordings.

The thematic analysis was used in this study. The researchers read through each transcript to get the whole picture of each participant’s experiences. Following this, the researchers identified words or open coding. The researchers then grouped these coding into different categories. The categories were then thematically names. The researcher examined the trustworthiness of the findings or themes through peer checking.

Findings

Thematic analysis identified four themes that reflected the experiences of the participants. These include: 1) Surviving family and social relationships, 2) Never again slip away, 3) Repeated daily routines, and 4) Searching for a new me. These findings are presented below.

1) Surviving family and social relationships: Relating

Psychiatric patients and families learned that relationships were important in managing and maintaining health of the patients and wellbeing of the family. Good family relationships helped promote the recovery of the patients and prevent recurrence. Relationships could be good or bad. Good interactions with individuals in the community make psychiatric patients feel acceptable, reduce the feeling of being stigmatized, and promote adaptation to living with others. In contrast, some patients and relatives experienced poor relationships that made them feel lonely. Some patients refused to participate in the community because they felt unsafe and uncomfortable. These are illustrated from the participants’ narratives below.

“My husband is very kind. When I felt not comfortable, he tried to take me to see the doctor.”

“My descendants often visit me.”

“Sometimes I told the neighbors about the problem. He listened to me.”

“My mother, she was ok. I would take care for her about taking medicine and driving her to see the doctor then she would not stress.” The relative said.

In the otherwise, poor relationships can lead to stress. If stress management is not appropriate, it can result in relapse. Examples of poor relationship experience included;

“I worried about annoying children. I often talk, be said that I was complaining.”

“I was tired of chatting.”

“I often argue with my husband. I didn’t dare tell anyone. I stuck feeling alone.”

“I did not want to talk to anyone. They did not understand. They said we were sick.”

“Sometimes when I was stressed from hard working, I might make her stressed. If I didn’t drink, she wouldn’t stressful.”
Psychiatric patients and their relatives learned from their experiences that if they had good relationships, they will continue to build relationships. In the other hand, when they were not accepted, they would separate and isolate from the society that the way of self-care to protect themselves from relapse.

2) **Never again slip away: Realizing**

Psychiatric patients and families learned that mental illness was incurable, and that this illness had negative impacts on family and required continuous care. As mental illness requires continued medication to prevent recurrence. Both patients and relatives came to the realization that prevention of relapse was at utmost importance as relapse could produce profound impacts on the family as a whole. Here are the stories.

2.1 schizophrenia as incurable disease,

“I do not know how long to take the drug.”

“I've been very sick I do not want to take medicine.”

2.2 impacts of relapse and hospitalization

“Previously, the patient did not take the medicine; we went to the hospital very often.”

“Patients and relatives do not want to go to hospital again.”

2.3 continuing medication treatment

“I need to take medicine all the time, stopping medicine, not taking medicine will be stressful.”

“I took medicine but also noticed that there was a tremor. If I stopped taking medicine I would not go to work.”

Based on findings, psychiatric patients and families learned about the benefits of each issue. They would try to find their ways to prevent recurrence.

3) **Repeated daily routines: Repeating**

At some stage, daily routines must be established for both the patients and their caregivers. This could happen sooner or later. Daily routine activities reduced stress and anxiety of the patients as they minimized the use of complex thinking and skills required to perform new tasks. Relatives played a significant role in making decisions about what routine activities were. Psychiatric patients would automatically repeat that activity. Routine activities involved: self-care routines, and household chores and responsibility. Patients and families recounted these routines below.

3.1) self-care routines,

“My mom told me to take medicine, I did then I felt better.”

“I try to take medicine myself every day.”

“I had to tell her to take medicine every day. If I didn’t tell her, she doesn’t take it. Now a day, she can do everything herself.”
3.2) household chores and responsibility,

“I always wake up early to do my household work myself.”

“I do washing clothes and cook for my brother and sister because they go out to work.”

“I ask my employer for doing my work at home.”

As results, relatives and patients have attempted to adapt both to patient-based activities and self-care by being ordered to do.

4) Searching for a new me: Reinventing

At one point after patients established their routines, patients might seek new things in their life. This was to deal with boredom and stress-related to repeated routines. This also reflected the need for patients and families to adapt their lifestyle and adopt some changes surrounding them. If new things became new stressors and caused stresses, the patients would discard them and resume the routines. The process of searching for new me is echoed in the following accounts.

4.1) boredom and stress,

“I’m bored. I do not want to talk anymore.”

“I do not want to take medicine.”

“I was wondering why I was not getting well? I don’t know what to do.”

“I was so stressed I thought of suicide. But I can deal with it, now.”

“I went to work with my neighbor and then stressed. I change to work at home alone.”

“I went out cycling when I was angry.”

4.2 trialing the new me,

“At first, I did not talk to anyone. Then the neighbors asked me about my illness. I talked with some people who I trusted on.”

“My cousin used to take me on a trip and I did not feel comfortable. I have not been far away from home for 2 years.”

“Previously, I did not want to take medicine. I thought that’s ok after I took it and I’ve been continuing taken medicine until now.”

4.3 my true self,

“I try to keep going. I do not think so much.”

“I will keep continuing take medicine, I think it’s okay. My health is not too bad.”

“If someone talks to me, I’ll talk. But sometimes being alone is more comfortable.”
“My husband is so kind. He goes to work every day. When I feel irritated him, I will go to another place to relax, then just fine.”

“My mom bored with long time taking medicine, we let her as she need. Then she got panic symptom, so we returned to take the medicine again.”

Searching for a new me was essentially a process of reinventing for both the patients and their families. This process was associated with patient self-worth.

**Discussion and Conclusion:**

Based on these themes, we formulate a model of culturally sensitive care for psychiatric patients. This model is entitled “Patient-caregiver in tandem relationships”. This model involves four concepts derived from the original themes, that is, relating, realizing, repeating and reinventing. Relating indicates the relationship between the patient and their family as well as with other people in the community. These relationships often change with the progress of the disease. Realizing represents the understanding of the patient and the caregiver towards the actual state of the disease and the care required, which changed over time. Repeating refers to the fact that patients need to repeat their daily routines. Reinventing describes the needs of patients and families to find new identities for both patients and their families. As a result of the changing self and landscape, some patients attempt to reinvent different aspects of their lives. Upon closely examining these concepts, we discovered the relationships between them. The relationships between these concepts are depicted in Figure 1. This model explains how the care of patients with psychiatric illnesses unfolds in the studied context.

![Figure 1: Patient-caregiver in Tandem Relationships: A Model of Collaborative Family Care for Psychiatric Patients.](image-url)
The tandem relationships between patient and family caregivers convey the caregiving practices undertaken by the family. Effective family caregiving of psychiatric patients requires that caregivers develop healthy relationship and understanding with the patients. For the healthy relationship and understanding to be attained, caregivers first need to have realization about the illnesses and the patients. Family caregivers need to understand that psychiatric illnesses are long-term conditions and that, in most cases, cure is not possible. Further, they need to have the understanding that these long-term conditions need long-term continuous treatment and care, and that family support is a necessity throughout the continuum of care. Once the caregivers have the realization, they know what they can expect from the patients in terms of what they patients can or cannot do. They become more realistic about the outcomes of care. Importantly, they know what they should do for the patients at different stages or situations. For example, when the patients do not accept their illness during an early stage of the illness, caregivers realize that it is their duty of care to make sure that the patients follow prescribed regimens. When experiencing patient non-adherence, family caregivers experience less stress because they have already expected the non-adherence. Over time, patients will improve and become more realized about their illnesses and the care needed to sustain outcomes. They establish routines, contribute to family functioning, and regain their self-worth. Once the patient symptoms are sustained, family can then focus on their day-to-day routines. Caregiver with correct understanding often relates very appropriately and effective with the patients. This is a situation described as “relating with realizing”. Some patients may go on seeking for new things in life such as work and relationships. This, however, does not happen often.

Unfortunately, this realization may not happen in all families. When it does happen, it may not arrive timely. When family does not have realization about the illnesses and the care, the quality of family-patient relationship often falls short. “Relating without realizing” can lead to conflicts between caregivers and patients, sometimes resulting violence, non-adherence to treatment regimens, and stresses on both parties. Unhealthy relationship as a result of poor realization serves as a barrier for improved patient’s outcomes. This often hinders the patient’s journey to healing. Patients may spend longer time to achieve realization or may not achieve this at all as a result of poor cooperation with care regimens. They may fail to establish routines and remain dependent on family for self-care and treatment management, as a result, experience relapse. In this scenario, family can expect high level of stresses related to caregiving. The relationship may be abusive and negligent in nature. The “relating without realizing” is often noxious and follows a vicious cycle.

It is clear from the above that healthy relationship between caregiver and patient is instrumental in family caregiving of psychiatric patients. The family caregiving is therefore very collaborative. It requires that both parties have correct understanding about the situations and each other, and work in tandem throughout the expected and unexpected changes. In summary, the psychiatric patient care model requires collaborative efforts between patients and families. It starts with the management of family relationships between patients and caregivers. Good relationships between patients and their families have resulted in continuous and quality care. The tandem relationships can be illustrated through the case below.
Exemplars:

Mrs. Noi, 69 years-old, was diagnosed with anxiety disorders. She denied the illness and refused the treatment. Her son tried to convince her to begin treatment. Eventually she agreed to go to the hospital and received medication. She got better and soon stopped the treatment. Her family could not force her to continue the treatment and later gave in. Noi later got panic and could not work. After that, she resumed her medical treatments, and got better again. She learned that continuous treatment was needed to prevent relapse. Her family learned that too, and realized that mental illness required long-term medication to control the symptoms. This family kept continuing the treatment plan and follow-ups with doctors.

Miss. Tim, 50 years-old, had her schizophrenia treated since she was 16. Her family (brother and sister) tried to support her by urging her to follow daily routines care, taking medicine every day until she could manage it by herself. Even though she got better, she did not prefer going out anywhere. She used to go out working with neighbors, but she felt uncomfortable, stressed, and later decided to work at home. She preferred staying alone or conversing within family to going out which made her stressful. If needed, she talked with people who she felt familiar with while joining the community activity.

Reference


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