

Making it better

Experiences of Thai caregivers in managing psychotic symptoms of persons with schizophrenia

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Abstract

Purpose – The purpose of this paper is to describe experiences of caregivers in managing psychotic symptoms of persons with schizophrenia in various circumstances.

Design/methodology/approach – The data were obtained via a focus group and in-depth interviews among caregivers who cared for relatives with schizophrenia for more than five years. Thematic analysis was used for data analysis.

Findings – “Making it better” emerged as the main theme describing caregivers’ experiences in trying to manage psychotic symptoms. It comprises four sub-themes including cutting off the wind, protecting from harm, preventing relapses and pulling back to normality. The caregivers gradually learned and adjusted their strategies through trial and error. They tried to stop aggressive and violent behaviors soon after they had begun by giving cool water to their relatives to drink or shower, while expressing their own affect with gently talking. They also dealt with a hardship in protecting the patients, other people, their properties and their own selves from harm resulting from violent behavior. When the psychotic symptoms improved, the caregivers tried to prevent relapses by using various strategies to maintain medication adherence and by soothing their relatives’ mental state. They also tried to pull their relatives back to normal as much as they could by promoting their relatives’ memories and abilities to perform daily functions.

Originality/value – The findings increase knowledge in nursing regarding psychotic symptoms management. The findings can be applied to the development of a program to help caregivers to manage psychotic symptoms effectively in order to promote good clinical outcomes of patients and alleviate the caregivers’ burden.

Keywords Schizophrenia, Psychotic symptoms management, Thai caregivers’ experiences

Paper type Research paper

Introduction

Schizophrenia is a severe and chronic disease. In Thailand, a report from the Department of Mental Health revealed that the numbers of hospitalized schizophrenia patients increased from 42,7333 in 2013 to 44,556 and 46,837 in 2014 and 2015, respectively[1] which may reflect an increase in relapses of the disease. This may be the result of the policy of psychiatric hospitals to decrease the number of admissions and length of stay in the hospitals in order to enable patients to live in real-world circumstances. As a result,

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in Thailand, the majority of schizophrenia patients (98 percent) returned home with some psychotic symptoms[2]. Therefore, caregiving became the responsibility of family members.

Caregivers have to face difficulties in their caregiving role at home and yet have to promote continuous care, prevent relapse and improve the patients' functioning. Because the patients' psychotic symptoms remain, medication alone is not able to control all of the symptoms. Dealing with psychotic symptoms needs special skills. Moreover, most patients have poor compliance with medication, which adds more difficulties to the management and responsibility of the caregiver[3–6].

Many studies related to experiences of caring for persons with schizophrenia had mainly focused on the impacts of caring on the caregiver's life. The findings showed that caring for patients caused poor physical and mental health conditions of the caregivers[7–9] and affected other functions and the family situation[10, 11]. Caregivers were stressed by the fluctuation of their relatives' psychotic symptoms. They struggled to make the patients achieve normalcy by maintaining medication adherence, vigilantly managing the symptoms, preventing any relapse of the symptoms and managing the consequences of being sick resulting in poor judgment, stigma, loss and other difficulties. In some cases, parents gradually accepted the untreatable conditions which were a new normal for their children[6, 7].

The studies focused on the coping process[5, 12, 13] and developing caregiving skills[14, 15] explain that the coping behaviors of caregivers changed over time[14]. Caregiving skills were developed gradually and cumulatively via trial and error. The main tasks were parental caring, psychotic symptoms management and medication management[15]. Medication management was rated as the most difficult caregiving task[6, 16]. Caregivers used methods including checking, observation and warning patients about taking medications[14]. Moreover, they also used deceptive methods, forced patients to take medications and helped to alleviate the side effects of medications, which were a reason for not taking medications[6]. In psychotic symptoms management, caregivers made non-intrusive observations and used many methods, including direct observation, symptom inquiry and restraint when necessary to control the symptoms.

Although some studies shed light on psychotic symptoms management, little is known about the caregivers' strategies in managing psychotic symptoms in various circumstances. Therefore, we were interested to study this issue in greater detail.

This study presented Thai caregivers' experiences in managing psychotic symptoms of their relatives with schizophrenia. The purpose was to understand the meaning, situation, process, methods and results of psychotic symptoms management among caregivers in various circumstances.

Methods

This qualitative phenomenological study collected data by first using a focus group and also in-depth interviews, in order to enhance trustworthiness via the triangulation method. Participants included caregivers who had taken patients to the outpatient department of a hospital in Thailand. The study was approved by the ethics committee of Burapha University (IRB No. Sci 024/2560) and of the study site hospital (IRB No. BSH-IRB 012/2560).

Key informants

The participants were purposively selected for the focus group and the in-depth interviews using the same inclusion and exclusion criteria: being primary caregivers and living with patients; looking after patients who had been diagnosed with schizophrenia by a psychiatrist for at least five years; and being more than 18 years old and able to communicate in the Thai language. Caregivers who looked after other family members who were sick with other chronic diseases and caregivers who had a psychiatric illness themselves were excluded from the study.

Instruments

The interview guidelines contained open-ended questions to elicit the experiences in psychotic symptoms management in various circumstances. Sample questions included the following: "Could you please give me the meaning of psychotic symptoms management?" Or, "Could you describe your experience in managing your relative's psychotic symptoms?" The researchers then used specific questions for more detail about each issue. For example: "how did you deal with (each psychotic symptom the caregivers mentioned)?" Or, "As you use such methods, what were the results?"

Procedure

To select the participants, the researchers asked for their interest in participating and informed them of the objectives, methodology, benefits and risks, and their rights as a participant prior to obtaining consent to participate in this study. The focus group took about 60 min and the in-depth interviews took about 70 min. The data were collected from July to August 2017.

Data analysis

The data were analyzed in the Thai language using Colaizzi's method[17] by the following steps: read all protocols to acquire a feeling for them; review each protocol and extract significant statements; spell out the meaning of each significant statement and formulate meanings; organize the formulated meanings into clusters of themes; integrate results into an exhaustive description of the phenomenon under study; and the researchers used member-checking techniques to check the conclusion from the data with participants. 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 English instructor at a local university.

Results

Characteristics of the study participants

There were eight participants in the focus group, including three mothers, two daughters, one sister, one son and one father. Their ages ranged from 30 to 68 years with a mean of 50.9. The duration of their experience as caregivers was 9.75 years on average. All of them were Buddhist. Six of them finished elementary education and were married. Half were employees and seven of them earned an adequate income.

The patients' ages ranged from 18 to 56 years with a mean of 40.8. All of them were male and single. Six of them were unemployed and were educated to elementary level. The frequencies of hospitalization were between one and six times.

The number of caregivers taking part in the in-depth interviews was 13 and most of them were female, including 6 mothers, 1 father, 5 elder sisters and 1 younger sister. Their ages were between 39 and 75 years with 58.07 years being the average. The duration of being caregivers was between 5 and 30 years with a mean of 14.46. Ten of them were Buddhists and the rest were Muslim. Eight of them were educated to elementary level and were married. Six of them had unstable occupations with an inadequate income.

The patients' ages ranged from 25 to 60 years with a mean of 46. Nine of them were male, unemployed and single. Only one patient had never experienced a hospitalization, four patients had been hospitalized one to two times, five of them had been hospitalized three to six times and the rest had more than six hospitalizations.

The experiences of psychotic symptoms management for persons with schizophrenia. "Making it better" emerged as the main theme describing an overview of the caregivers' experiences in psychotic symptoms management for persons with schizophrenia. It also encompassed the meaning of psychotic symptoms management as perceived by all participants. Most caregivers perceived psychotic symptoms as aggressive and violent behaviors caused by brain problems. The aims of making it better were to improve the

situation, to prevent relapses or worsening of the symptoms which affected patients, other persons or belongings, and to give psychological support to prevent the exacerbation of aggressive behaviors, which could happen at any time. They also make an improvement in the patients' daily functions. This involved a process of trial and error learning over a long time period and in many different circumstances. It comprised four sub-themes: cutting off the wind, protecting from harm, preventing relapses and pulling back to normality.

Cutting off the wind. This is an approach in dealing with initial signs of aggression such as irritability or a bad mood which might lead the patients to uncontrollable aggression. They tried to calm down the patients by giving them cold water to drink or advising them to take a bath. It was effective when the symptoms were minimal, as one caregiver said: "When I saw perspiration or a harsh stare, I told him to take a bath to make him cool down and feel refreshed, which was helpful sometimes." In doing this, caregivers had to control their own mind even though they were full of stress, anger and frustration; as one caregiver stated in the focus group: "Use cold water to rub" (Thai proverb which means calming down anger). "When he is heated up we have to be water."

In addition, caregivers used carefully modulated speaking to make them cease their unwanted behaviors. They would adjust their speaking tone according to the level of psychotic symptoms, which needed observation and understanding. They learned that criticizing, or blaming, would trigger the psychotic symptoms. When patients were aggressive, caregivers would talk with a soft and tender tone, supportive content and careful explanation and reasoning. It could improve their condition but also depended on the severity of the symptoms at that time. One mother explained:

I politely talked to him "Stop! It was wrong. You should not harm him. The police would arrest you if you did so". He listened to me. "Who would I stay with? Did you know how much I love you?" It seemed to calm him down if his conditions were not severe.

Moreover, caregivers also used silence in cases of uncontrolled aggression. They explained that talking at that moment was useless because the patient would not listen but would become more aggressive.

Protecting from harm. This was a method used to deal with the patients' uncontrollable aggression or disorganization. Caregivers understood that the patients could not make good decisions, which might lead to injury. They used many strategies to protect the patients, others, their belongings and their own selves, including detaining, bringing back and letting go.

When the patients were chaotic and confused, the caregivers would first try to keep them at home to keep an eye on them. One caregiver said: "The first thing was to keep him at home. He goes away when he relapses. Retention to make him safe was the most difficult thing."

Besides, if the patients were uncontrollable, such as running away from home or engaging in aggressive behaviors and frightening others, caregivers had to detain the patients in their room for the safety of the patients, others or their belongings. It would be the last strategy before taking the patients to a hospital. As a caregiver explained:

No one wanted to detain him. I did not want to do so but if he came out, the others could not accept it. He was aggressive. It was a small community near a mosque. The children would come to study religion in the evening after school. The children would not come because they were afraid of him. He had a harsh stare.

Some caregivers further explained that if the symptoms were severe, the patients would break windows or doors to get out. Caregivers had to make their room more secure by making a cement wall to close a room.

If the patients ran away from home, caregivers tried to bring them back home by seeking help from others such as rescue teams. They also used direct phone calls and would know the location to find them if the patients brought their mobile phone with them. It was not

effective if the patients did not receive the calls or their mobile phone batteries were dead, as a caregiver said: "Tried to call him at 3 a.m. The phone had no money or a charged battery, so I could not contact him. Could not do anything except keep waiting."

Some caregivers prepared in advance, such as including contact lists of other relatives or putting coins in the wallet of the patient for them to call back via public telephones. However, these techniques were useless if the patients did not take their wallets with them.

When the patients had severe psychotic symptoms, caregivers would let things go for the safety of others and themselves even though their belongings were destroyed. Patients would finally calm down after acting out, as in the following example:

If he had severe symptoms, he would not stop. We had to let him do it. We knew that if he had severe symptoms, he would be chaotic and walk around. At the beginning, we tried to control him but the situation became worse, so we had to let go.

Preventing relapses. The strategies for preventing relapses consisted of continuing medications and psychological care.

Continuing medications

All caregivers were aware of the importance of drugs compliance. They later realized that the patient's psychotic symptoms could relapse after they discontinued their medications. They tried to ensure medications adherence using various methods according to the severity of the symptoms. When the symptoms were still severe, the caregivers would closely monitor the patients taking medication because they knew that patients could not take care of themselves. The caregivers would give the medications on schedule by putting medication in boxes or bags according to the time of taking them and for the convenience of the patients when caregivers were away. However, caregivers also reminded the patients to take medication.

When a patient's condition improved, the caregivers began to let the patient take medication by themselves, because they believed that the patients would be able to assume responsibility. In doing so, the caregivers reminded the patients to take their medication, or asked about taking medication, and emphasized the reasons for taking medication. As one caregiver said: "I would constantly warn him so that he would not forget. I told him that if he got sick again he would not recover."

Additionally, if the patients underwent relapses, the caregivers would strictly check the medication or count the number of the pills, as one caregiver said:

I had to check. I looked at the medication packages to count the number of doses left and observed when he took medication. I looked in the medication bags when he was sleeping to confirm he was taking medications.

However, the caregivers had to deal with patients' medication noncompliance for many reasons, such as believing that they were already well, not realizing the importance of continuing medication, avoiding the side effects of antipsychotics or not being aware of being sick. Caregivers faced difficulties in using various strategies to deal with this situation, including putting medication into liquids or putting it into food. However, this method did not always work if the patients noticed the changed taste of their food or drink. A caregiver said:

We developed various techniques. We put small pieces into jelly but he did not always eat it. We put it into what he liked to eat. Put it into curry but he did not eat all of it. Put it into rice which made the rice too wet so it was easy to notice. It was not working. If it was powder, it felt like gravel and he would never eat it at all.

Some caregivers used bartering techniques tempting the patient with what they liked such as giving them soft drinks or cigarettes if they complied with taking medications. If patients resisted, caregivers would threaten them with recounting the bad consequences of not

taking medications. They explained that they had to find reasons to threaten the patients as described below:

We told him that if he did not take medications he would have a headache and twisted mouth. If he wanted to stop taking his medication, he had to talk to the doctor. If he resisted, the doctors would send him to hospital. He was afraid, gave respect and asked us not to send him to the hospital.

Moreover, caregivers also tried to minimize the side effects of antipsychotic medications, which include constipation, drowsiness, muscle rigidity and tremors. Caregivers learned through experiences to observe, ask whether side effects had previously happened and attempted to minimize them. As a mother said: "I did not know it was a drug side effect until he told me. I bought laxatives if he was constipated. I had to look after everything."

Psychological care

This was a method to support patients psychologically such as preventing stress in order to prevent relapses. They made observations for learning, knowing and understanding the behaviors, thoughts, feelings, symptoms and needs of patients. Caregivers had to truly stay with their patients. Knowing and understanding helped caregivers to adjust their responses appropriately in different circumstances, as in this caregiver's elaboration: "I tried to observe him. I could ask him when he looked unwell, or when he was upset by someone talking. I had to monitor this otherwise the symptoms would return."

Most caregivers explained that patients were easily stressed and irritable especially when they were hungry. Therefore, they tried to avoid making them feel stress by not opposing, not complaining, not blaming, giving morale boosters and not letting them get hungry. When the patients performed inappropriate behaviors, the caregivers would let them act out if those behaviors were not harmful. A caregiver said: "Prevent whatever made him stressed or in a bad mood, for example, I would prevent whatever made him stressed. I would not oppose him if he did not cause any damage."

Pulling back to normality. The caregivers noticed that though psychotic symptoms were improved, the patient's daily functions had declined. They were slower, inert and poor in performing daily routines. Most of the caregivers tried to help their patients to care for themselves, minimize their burden to others and normalize the patients' functions as much as possible. They tried to improve memory and daily routine performance. In doing so, caregivers tried talking with patients or encouraged them to do various stimulating mental activities because they believed that something was wrong with the patients' brain. One caregiver said: "I thought that if he had activities to do, his brain would be improved."

Additionally, more than half of the caregivers tried to improve the patients' responsibility for daily living by warning them regularly. When caregivers were not at home, they phoned to remind their patients to do their daily activities. If telling them what to do was not enough, they had to teach their ill relatives how to perform these tasks themselves. For example, they had to help the patient to take a bath properly or to shave their mustache neatly. After telling them, they observed whether the patients did it or not. One caregiver said: "I had to listen when he took a bath to make sure that he really did it. (The patient's name), did you wash with soap or not? I sometimes had to teach him as if he was a child."

Discussion

This study has offered some understanding of caregivers' experiences in managing psychotic symptoms of their relatives with schizophrenia. The findings shared some common attributes with "struggling to restore normalcy" in a study among caregivers of persons with early schizophrenia[6]. The caregivers tried to use a variety of techniques to alleviate psychotic symptoms. They developed their strategies through trial and error,

learning in a long duration of caregiving experience. Each strategy depended on the severity of their relatives' psychotic symptoms.

Unlike the findings of a study focused on caregiving in the early phase of schizophrenia[6], the informants of this study felt stability in caring for their ill relatives. This is in line with many studies focused on long-term caregiving[7, 14, 18–20] which indicate that the experience taught the caregiver how to overcome troublesome situations[6, 7, 14–16, 18–20]. They began to be familiar with or aware of the chronic trajectory through the cycle of exacerbations and relapses[18, 20]. They tried their best in caregiving to make it better and to maintain balance in their lives while gradually developing caregiving skills and strategies for various circumstances through experiential learning[6, 7].

In managing psychotic symptoms, most caregivers were concerned with aggressive behaviors that they portrayed as themes, such as cutting off the wind and protecting from harm. It is consistent with previous studies which indicated that safety concerns were most commonly mentioned in association with symptoms of agitation, irritability or hostility[6, 7, 19, 21]. This suggests that persons with schizophrenia are more likely to engage in aggressive or violent behaviors than those without such conditions. Besides, prior studies regarding caregivers' perceptions of mental illness showed that caregivers described the person with mental illness as a violent person who needed to be controlled[22–26].

In protecting from harm, the caregivers focused on the safety of the patients, property, others and their own selves. They tried to make it better by using a complicit approach to calm down the patients and to prevent the escalation of aggression (cutting off the wind). This is consistent with previous studies[6, 7, 12, 19, 21, 26] which showed that caregivers had to be modest and humble when talking to the patients in order to handle agitated behaviors. They had to watch them carefully or follow them everywhere[6, 12]. This approach was effective if the patients were in an irritable or bad mood that needed early attention. The previous study also showed that early intervention in terms of environmental and behavioral approaches is important in calming aggressive patients[21].

However, the informants of the current study had no concerns about managing delusion or hallucination, which was noted as a cause of patients' acting out[22]. The social media information on the nature of mental illness nowadays, which places emphasis on aggressive and violent behavior, could create misunderstanding among people. Caregivers additionally had little knowledge regarding psychotic symptoms, especially the warning signs of relapses. They discussed their experience mainly in terms of managing aggressive behaviors. Therefore, the concerns about safety came along with the concerns about preventing relapses, focusing on aggressive or violent behaviors. They tried to prevent relapses by maintaining medication adherence while preventing stressors, which is in line with previous studies[6, 7]. The caregivers used various approaches to maintain medication adherence and to comfort the mind of their relatives with schizophrenia in order to control psychotic symptoms[6].

In addition, the caregivers tried to pull their relatives back to normality, which shed light on psychiatric rehabilitation. Unfortunately, they focused only on daily routines and memory, which relied on their perception that a brain problem is a cause of mental illness. The evidence suggests that the benefits of other approaches of psycho-social or psychiatric rehabilitation, such as improving their housing, providing adequate education and a meaningful work career, satisfying social and intimate relationships and participation in community life with full rights, should be related to caregivers. A prior study showed that medication alone did not solve all problems; psycho-social support and rehabilitation were also needed. An individual's recovery could benefit the whole community, particularly if they could return to work[27].

Conclusion

Our study contributes to psychiatric nursing practice in that it offers a new understanding how caregivers manage psychotic symptoms. It is evident that the caregivers experienced

difficulties in managing the patients' psychotic symptoms. Aggressive and violent behaviors are viewed as a major concern among caregivers. In addition, there is also some concern regarding the warning signs of psychotic symptoms and psychiatric rehabilitation. Thus, a program to develop and enhance caregivers' skills and competencies in managing psychotic symptoms should be developed in order to promote clinical outcomes of persons with schizophrenia and to decrease caregivers' burden.

Strengths and limitations

This study obtained data from both focus group and individual in-depth interviews to confirm reliability by the method of triangulation, which is trustworthy. However, there were two limitations. First, since the research project had a time frame limitation of only one year, we could not make a further deep exploration of caregivers' experiences, though we encountered some important points regarding managing delusion and hallucination. Second, although the study carefully recruited caregivers to increase the diversity of relationships between the caregivers and the patients, there were a limited number of male caregivers (two in the focus group and one in the in-depth interviews). As such, gender-specific caregiving experiences, in terms of the style of managing psychotic symptoms, need to be further explored. Recruiting a larger number of male caregivers would enhance the variety of experiences recorded.

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