



The Experience of Caregivers with First-Episode Psychosis Children at General Hospital of Dumai, Riau Province

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Abstract

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BACKGROUND: Caregivers with first-episode psychosis (FEP) children often encounter problems and challenges. The importance of caregiver role in managing FEP appropriately will influence the life quality of a person with psychosis.

AIM: The study aimed to explore the experience of caregivers who have children with FEP at General Hospital of Dumai.

METHODS: The study was a qualitative study with a phenomenology approach. In-depth interviews were conducted with eight primary caregivers aged 41–58 years with FEP children at General Hospital of Dumai. The interview transcript was analyzed using the Colaizzi method.

RESULTS: Based on the study, five essential themes emerged, for example, caring for FEP is harder than looking after a thousand buffaloes, mixed feelings, believing that the child experiences mystical things, the extended family is a supporter in caring for FEP, and praying and surrender to God.

CONCLUSION: The implications for nursing practice are implementing support group therapy and family psychoeducation programs to reduce the caregiver burden.

Introduction

First episode psychosis (FEP) is a major worldwide health problem with an estimated incidence of 34 cases per 100,000 people over a year [1]. According to Lutgens *et al.* [2], FEP is the first presentation of psychosis symptoms preceded by a prodromal phase consisting of non-specific symptoms, such as depression, anxiety, sleep disturbances, decreased energy, impaired role function, and subthreshold psychotic symptoms. It usually occurs in adolescents or early adulthood between 15 and 30 years [3].

Youths with FEP will have missed opportunities in education and work [4]. It does not only damage the financial independence of youths experiencing FEP, but they will also experience disturbances in community inclusion, such as the formation of social relationships and self-actualization [4]. In addition, the impacts of post-psychotic diagnoses include the risk of suicide, substance abuse, and lower quality of life [5], [6]. All of which results in people with FEP dealing with stressful events.

The family is the person who provides emotional and physical “first aid” in the event of FEP.

The family plays a vital role in seeking initial treatment, continuing care, and social support in the treatment planning, and recovery process for patients diagnosed with psychosis [7]. It is challenging for parents or caregivers to understand whether their children act like ordinary teenagers or their moods and behaviors are actually symptoms of psychosis. Teenagers or early adults can become moody and sometimes reluctant to talk openly about emotions or behavior [8].

A study by Gleeson *et al.* [9] showed that caregivers experienced depression, emotional stress, anxiety, and burden after caring for people post-diagnosed with FEP. Apart from dealing with stress during this critical period, caregivers also generally have insufficient information about caring for relatives with FEP because they have never had such experiences before. It leads to improper treatment of their sick family members and increased recurrent symptoms [10].

Based on a preliminary study conducted at General Hospital of Dumai, where the researchers accessed participants, the medical record department informed that 43 patients experienced FEP in the past 6 months with an age range between 15 and 30 years. The researchers also conducted a preliminary study

at Dinas Kesehatan Kota Dumai, recording that the mental disorder patients increased, with 219 patients in 2018 and 367 patients in 2019. It indicates an increase by 148 people. Based on the phenomena data, the researchers were interested to conduct a deeper study regarding the experience of caregivers with FEP-diagnosed children or family members.

Methods

The study design used was qualitative with a descriptive phenomenology approach. The inclusion criteria used to select participants in this study were primary caregivers with FEP children aged 15–30 years with a duration of antipsychotics usage <1 year. This study was conducted in September 2020 in the psychiatric ward and outpatient clinic psychiatric in General Hospital of Dumai. Data were collected through in-depth interviews by asking open-ended questions to explore caregivers' experiences with FEP children. Each interview lasted approximately 30–70 min. Interview procedures were carried out by considering the COVID-19 preventive health protocol.

Data analysis in this study used the Colaizzi method. In the first stage, the researchers conducted transcripts obtained from the recorded interviews. After creating the transcript, the researchers asked the participants to reread the transcript to confirm and clarify statements that did not describe their experience. Furthermore, the researcher repeatedly read the transcript results to find the essence and identify significant statements following the objectives to be achieved in this study. This significant statement was then formulated into a more general meaning and then into theme groups. Next, the researchers integrated all information related to the studied phenomenon to write a complete description based on the compiled themes. Researchers also performed bracketing to avoid mixed meanings with existing theories. In the final stage, the researchers validated the descriptions to ensure that the themes were following the participants' experiences.

The ethic approval of this study was provided by the Research Ethics Committee Universitas Padjajaran with the issuance of ethical clearance number 3041/UN6.L6/LT/2020. The participants in this study had signed informed consent, data confidentiality was guaranteed by the researcher.

Results

Participants involved in this study amounted to eight people, with five men and three women.

Participants were primary caregivers with children or family members experiencing FEP. Seven participants were parents, while one participant was a sibling. Children with psychosis were declared not in remission by the psychiatrist and still using antipsychotic drugs for less than a year.

Five essential themes emerged in this study, i.e., (1) caring for FEP is harder than looking after a thousand buffaloes, (2) mixed feelings, (3) believing that the child experiences mystical things, (4) the extended family is a supporter in caring for FEP, and (5) praying and surrender to God.

Caring for FEP is Harder than Looking after a Thousand Buffaloes

Based on the interview results, all participants illustrated the experience of having FEP children as an experience that poses high stress and burden. In this condition, four participants stated that they were overwhelmed and a sense of giving up when handling the child. One of them asserted that it is better to look after a thousand buffaloes than one human. The following is participant 2's statement:

"How can I take care of child at this age, it's better to look after a thousand buffaloes than one human. If we tell a thousand buffaloes to the left, they will all go left." (P2)

Participant 2 expressed that a thousand buffaloes are easier to handle because they are submissive and easy to direct. Caring for FEP children is a challenge. It is evidenced by the difficulty of caregivers when advising children, as expressed by participant 8 as follows:

"The challenge is if he violates my advice. For example, you have to come home at this time, and he doesn't come home. I could find him back then, but now I'm tired." (P8)

As a result of the child's rebellion, participant 6 expressed a sense of giving up when facing and caring for children. Overwhelming causes a sense of surrender to carry the burden as expressed by participant 7:

"Actually, sometimes we want to throw him away because we can't carry the burden any longer." (P7.4)

Mixed Feelings

Based on the study results, all participants experienced mixed feelings, such as sadness, stress, confusion, concern, and denial. All participants were

devastated to have FEP children, such as stated by participant 1 follows:

"That's my children. I gave birth to him. Of course I am sad (crying)." (P1.20)

Apart from experiencing sadness, the majority of participants said that they experienced depression. During the interview, one participant declared that mental distress was the first thing they felt. The following is an expression from participant 2:

"I have mental distress. What can I say? Mental is the first thing affected. I am speechless." (P2.1)

Based on the study results, most of the participants were also had confusion regarding the children's conditions, as stated by participant 6:

"My current feeling is what will happen to my child, what's wrong with my child, why does it get like this. Sometimes it's good, and sometimes it's not, sometimes it's good, sometimes. That's the only thing I think about." (P6.1)

Regarding the above statement that describes confusion over the children's conditions, participant 7 experienced confusion about caring for and nurturing the child. The following is participant 7's expression:

"Sometimes we are confused about how to take care of him to recover, even though we have tried to maintain his balance. For example, being offended. We're confused." (P7.3)

In addition to feeling confused about caring for and nurturing FEP children, four of eight participants also experienced concerns regarding the children's conditions. Participant 1 was worried and having thoughts about the child as follows:

"We don't know what to do. My head is heavy. If you think too much, you'll forget about eating. I think too much, and people say not to think too much because it will hurt. But I can't." (P1.12)

Based on the interview results, two participants asserted that children did not have mental disorders:

"He is not sick. He's fine with his mother. He's actually close to anyone and he has many friends." (P5.5)

Believing that the Child Experiences Mystic Things

Based on the interview transcript results, all participants brought their children to seek treatment in a village shaman. In this study, five of eight participants believed that their children experienced mystic things, such as possessed, as expressed by participant 3 as follows:

"I initially thought that he was possessed because he suddenly got angry." (P3.5)

The children's conditions perceived to appear suddenly caused participant 5 to think that their child was in a trance. The following is an expression from participant 5:

"He was acting like a possessed person. I thought he was possessed. The disease was sudden, like a trance." (P5.6)

A similar thing was experienced by participant 6 who believed that their child talked to mystical creatures:

"The shaman said that he talked to a mystical creature. I then grabbed some salt and threw it to him. He then went silent." (P6.7)

The Extended Family is a Supporter in Caring for FEP

The majority of participants stated that family members were involved in caring for FEP children. In fact, according to participant 7, the bond and cooperation between family members made them strong and able to survive:

"Alhamdulillah, we are not alone. There are nine siblings from my mother's family, which strengthens my younger siblings and me. Yes, we are strong because we are not alone. We take care of him together, not alone." (P7.10)

Meanwhile, for participant 1, family members' involvement was a success in bringing the child for treatment to a professional service. The following is the statement from participant 1:

"Because he was invited by his uncle yesterday, his father's younger brother, he was persuaded to be brought to the puskesmas. That's why the brother managed to bring him here for treatment. He doesn't listen to us, his brother, his father, and me." (P1.9)

Meanwhile, participant 6 revealed that the cohesiveness between family members was not only based on their perceptions but it also comes from other people's judgments, such as the following:

"As for the older siblings, all of us are well together. Yes, people say that we are united. Children and in-laws are helping each other." (P6.12)

Praying and Surrender to God

Based on the study results, seven of eight participants expressed their surrender to God. The following is participant 2's expression, stating that although it is difficult to hope that the child can return to normal, they believe that God is almighty:

"That's what I think. Total recovery is challenging. 100% normal condition is difficult, but Allah is almighty, so I believe in that." (P2.9)

Meanwhile, participant 1, who usually performs compulsory prayers, had been performing Sunnah prayer to get closer to God since the child experienced the FEP.

"According to my faith, we have Sunnah prayers beside the compulsory ones. We can only surrender." (P1.18)

As with other participants, participant 6 also continued to hope and surrender to God by carrying out prayers, inviting families to pray together, and watching lectures to gain peace of mind and have hopes for the child's healing:

"I pray. I also watch lectures, pray for my child. I ask my husband to pray together." (P6.13)

Discussion

Caring for FEP is harder than looking after a thousand buffaloes

Based on the data analysis results, the first theme of the study was "caring for FEP is harder than looking after a thousand buffaloes," and this theme was the new insight into the experience of caregivers with FEP children. Stating that caring for FEP is harder than looking after a thousand buffaloes reflects the burden and difficulties encountered by caregivers due to the challenges in taking care a child than a buffalo, a submissive animal. Although several studies stated that caregivers carry a higher burden, there has never been any study stating that the burden felt results from difficulties in managing or caring for children.

Precedent results from McCann *et al.* regarding caregivers with FEP children, it was stated that being a caregiver is a heavy, demanding, and unpredictable experience [11]. Overall, in their study, it was stated that caregivers could be overwhelmed by the burden they bear in caring for children. It resembles previous studies by Boydell *et al.* [12], [13] and Knock *et al.* [14], asserting that the most common issues related to caregiver difficulties were the emotional burden and daily demands and sacrifices involved in caring for a child. The results showed a higher level of family burden, the number of difficulties, and psychological stress experienced by caregivers.

A sense of giving up and overwhelming are common illustrations experienced by caregivers with FEP children. One of the study participants expressed: *How can I take care of such a big child, it's better to look after a thousand buffaloes than one human.* In contrast, another participant stated: *Actually, sometimes we*

want to throw him away because we can't carry the burden any longer. These findings are consistent with the study by Allard *et al.* [15], declaring that caregivers experienced difficulties and hopelessness in caring for family members with psychosis, and therefore, affected every aspect of their life.

Caregivers caring for patients with mental disorders, such as schizophrenia, require help in the treatment process because of the lack of information and support [16]. In this case, one of the treatment implications to reduce the burden on caregivers is to provide support group therapy or commonly known as support group therapy. Support group therapy is a type of psychological therapy carried out in groups, where members provide emotional support and information to others with the same problems [16].

Mixed Feelings

Based on the analysis, all participants in this study experienced mixed feelings and various negative emotions when having children with FEP. Changes in children's behavior to be abnormal made them feel miserable, depressed, confused, worried about the child's condition and future, and denied the child's conditions. It follows the study by Azman *et al.* [17], stated that caregivers experienced feelings of sadness, fear, confusion, stress, shame, self-blame, and depression. Research by Suryani shows that 30 respondents (37.5%) have negative perceptions of schizophrenia [18]. This shows that there is still a negative family perception of schizophrenia.

The most common impact on caregivers when caring for people with psychosis diagnosis is "emotional" feelings [19]. Other studies presented by Chadda [20] stated families that having teenagers with mental disorders were often unprepared and unsupported in carrying out their roles. Hence, they experienced mild-to-severe depression. The literature also demonstrated that caregivers did not get adequate information regarding the condition and treatment of patients with psychosis symptoms [21]. A study by McCann *et al.* [10] concerning caregivers who have family members with FEP indicated that caregivers reported a number of specific problems related to their roles, such as worrying about the child's behavior and the child's future; worry that symptoms will get worse; and worry about ineffective treatments for children.

One of the possible interventions to overcome this problem is family psychoeducation (FPE). According to Stuart [22], FPE is a form of mental treatment therapy in solving psychological problems related to family members' physical problems. Psychoeducation allows a nurse to provide effective and efficient services immediately to solve problems in each family [23].

Based on the study by Drapalski *et al.* [24], participation in intensive family services, such as FPE, was associated with a significant reduction in relapse rate or rehospitalization, increased social functions, greater hope and empowerment, reduced distress and family burdens, and better overall family functioning.

Believing that the Child Experiences Mystic Things

In this study, the longer duration of untreated psychosis is usually due to financial limitations, lack of awareness or knowledge regarding mental illness, and belief in myths or unseen things. The study by Rostina *et al.* [25], [26] examining the behavior of families of schizophrenics in Aceh revealed that the majority of caregivers sought first treatment from shamans. The in-depth interview results by Harun and Arman [27] on the families of patients with mental disorders demonstrated that most families perceived their children's illness as mystical due to black magic. According to Tasijawa *et al.* [28], mental disorders are chronic diseases that do not just happen. Mental disorders are not caused by supernatural things such as witchcraft and until now, there is no specific cause for mental disorders.

Another finding, based on the majority of Thai spiritual and cultural beliefs, expressed that the causes of schizophrenia were supernatural powers, black magic, and bad karma from past actions [29]. Following the study results by Igberase and Okogbenin in Nigeria, it was discovered that (72.0%) caregivers stated supernatural as the most trusted cause in the etiology of schizophrenia [30]. The most frequent supernatural subcategories were Satan's work (59.5%) and curses from enemies (45.5%). It is consistent with findings from other studies showing that most people in developing countries attributed mental illness to magical or spiritual causes [31].

Caregivers' and patients' beliefs (commonly referred to as causal beliefs) regarding the causes of mental disorders affect help-seeking behavior, adherence to medication, disease management, and clinical outcomes [32]. Causal beliefs are usually classified into three categories: biological (mental disorders are brain disorders caused in part by heredity), psychosocial (mental disorders caused by external factors such as economic conditions, stress, or level of educational attainment), and magical-religious (mental disorders originating from supernatural or spiritual power) [32]. Patients and caregivers with magical causal beliefs tend to replace or delay medical care. Similarly, studies on caregiver causal beliefs showed that the magical religious belief was strongly associated with the lack of psychiatric care for schizophrenic patients [33].

The Extended Family is a Supporter in Caring for FEP

The study results revealed that the majority of caregivers received various supports from close and extended families. The support provided by the family to caregivers was in the form of assistance or involvement, including the availability of time and energy in seeking treatment and care for patients. Besides, family members also provided emotional support in the form of closeness and openness. Information support was also created between family members to give advice, responses, and suggestions to help the recovery process for children with FEP.

A study by Shiraishi *et al.* [34] showed that caregivers were helped by having the closest people around them, i.e., relatives and relatives in childcare. This incident is closely related to Tamrin [35] findings, which revealed strong kinship bonds in everyday life in Malay culture even though they were not living together or already had their own family. In the study by Eggenberger and Nelms [36], family involvement made them robust while caring for family members who experience critical illness. Being a family unit gives strength to endure emotional upheaval and burdens during the critical illness caring experience.

In the case of factors affecting family care, previous studies also discovered that the family context, including family roles, cultural background, and relationships among family members, could influence sick family members [37]. In the context of Asian culture, it was found that family members and other relatives assisted in care because they considered it a family responsibility [38], [39]. However, the study results of this study contrast the studies by Sin and Norman and Eassom *et al.* [40] in Western countries, which showed that in terms of care, they only emphasized siblings' involvement. This theme is a new insight because no studies state that the extended family is a supporter in treating FEP.

Praying and Surrender to God

The majority of participants in this study expressed their feelings of surrender to God regarding children's illnesses. One of the sources of strength and hope for the participants in this study was their religion and beliefs. It is related to cultural factors where the Melayu Riau community highly respects religious values. Melayu Riau defines its Melayu as being Muslim, having a Melayu culture, and speaking Melayu.

A literature review by Smolak *et al.* [41], which included 43 studies, reported that religion provides a supportive role in almost every case. Methods of

religious management, including religious beliefs, religious practices, and participation in religious or spiritual communities, could help a person deal with illness, deal with stress, provide comfort, personal relief, resignation, acceptance, and hope [41]. One participant also stated that although it is difficult to think that a child can return to normal, they believed that God is almighty. Therefore, nothing is impossible. It is consistent with the findings of Lippi [21], which showed that when caregivers felt the “Creator” is in control of life, it reduced the level of difficulty and increased their hopes for future. Spirituality and religion can help caregivers accept and overcome their difficulties [42].

Worldwide, several studies evaluated the religious management of caregivers of schizophrenia patients. A study by Vallurupalli *et al.* [42] involving 83 caregivers of patients with severe mental illness demonstrated that increased religiosity was associated with less depression, improved self-esteem, and better self-care in caregivers. The study results support the treatment implications that religious-coping strategies are a form of treatment to be implemented in interventions because they are proven to reduce burdens, provide comfort, and improve life quality.

Conclusion

Comprehensively, this study’s results reveal that caregivers’ experience in caring for FEP is a heavy responsibility and burden. It poses caregivers to various emotional stresses such as sadness, mental stress, confusion, and worry. The burden experienced by caregivers will undoubtedly impact their welfare and life quality. The qualities possessed by caregivers can influence assessing, treating, and caring for individuals with psychosis. Although most caregivers in this study experienced various difficulties and felt a heavy burden, it was revealed from the results that extended families were supportive in caring for FEP. Some participants even stated that what made them strong so far was that of extended families’ ever existence. Moreover, in this study, caregivers’ greatest strength to survive was faith and belief in God.

Caregiver involvement in policymaking and sustainable care planning is critical to improving mental health services. Mental health professionals should involve families as active members in providing mental health care. Besides, designing and implementing programs such as post-discharge surveillance and home visits can create opportunities to involve families in the care process, while implementing support group therapy and FPE programs can significantly reduce the caregiver burden.

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