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Identifying The Psychological Challenges of Mothers with a Chronically ill child: A Phenomenological Study

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Abstract

Introduction: Having a child with a chronic mental illness puts a lot of psychological pressure on family members, especially the mother who takes care of the child. Therefore, this study aimed to identify the psychological challenges of mothers of children with chronic diseases in Karaj.

Methods: This study employed a descriptive phenomenological approach using a purposive sampling method and was conducted in 2017. The data were collected through semi-structured interviews with the participants who were mothers of children with a chronic mental illness at the Rehabilitation, Treatment, and Care Center for Neurological and Psychiatric Patients in Mehrafarin, Karaj, of whom 17 were selected to take the interviews. The collected data were analyzed using Colaizzi's seven-step method for data analysis.

Results: The results of the study showed that the psychological challenges faced by mothers with chronically ill children can be divided into five main categories: Feeling uncomfortable at home, feeling of constant fear, mental fatigue caused by continuous maternal care, social stigma and restricted interactions, and insufficient financial and support resources.

Conclusion: Mothers who have to care for a child with a chronic mental illness are exposed to substantial burden of care and psychological pressure. Some of these psychological challenges are rooted in individual and family issues, and others are rooted in social conditions and seeking support for the patient. Therefore, it seems that the teaching of psychological interventions to mothers should be individually and socially oriented to reduce the psychological challenges and pressures tolerated by mothers with chronically ill children. Of course, concerning objective burden and seeking support, benefiting from insurance and other health services can reduce the problems faced by these mothers.

Keywords: Psychological Stressors, Mental Disorders, Mothers, Qualitative Research

Introduction

In the modern world, science has extended incredibly, and therefore the rapid and accurate transmission of information and the provision of public access to scientific discussions are regarded as the most basic components of development. In this arena, the sciences that deal with the health of individuals in society have special importance and position. Schizophrenia, for various reasons, is one of the

most important disorders, and it is necessary to pay attention to it from different dimensions. Schizophrenia is not a single disorder, but a set of psychiatric disorders (1). This disorder is characterized by a set of symptoms including severe impairment in perception, thinking, action, self-concept, and how to communicate with others (2). Today, it has been shown that schizophrenia, once thought to be the result of maternal behavior (schizophrenic mothers), is a disorder that is caused by defects in neurological development whose symptoms are manifested in interaction with other biological, psychological, and social factors (3).

One of the most important factors influencing a person's behavior is the family. The family environment is the first and most enduring factor that affects a person's personality development. The social status of the family, the way the members interact with each other, the economic situation, the thoughts and ideas, the customs, and desires of the parents, their personality, and parenting styles have a great influence on children's behavior (4). Among the many types of human relationships influencing the growth and development of children, the mother's personality is of great importance, and the mother's attitudes toward childbearing, the spouse, and other family members, social life, her role as a mother and more importantly her attitudes toward her child and understanding their special needs for motherly love and accepting and controlling the child play a vital role (5).

Some schizophrenic patients come from dysfunctional families, so it is important to recognize the impact of the pattern of family behavior on these patients as such behavior can significantly increase the emotional stress that a patient with schizophrenia has to deal with. Dysfunctional behavioral patterns such as interfering with or arguing with family members about a patient with a mental disorder are stressful, and the stress a family member is experiencing is a major cause of relapse. Because of the criticism and pity of others, the patient does not know what to do when he/she recovers. As a result, these negative attitudes and behaviors of family members cannot help the patients recover their health (6). Chronic mental disorders such as schizophrenia, bipolar disorder, and major depressive disorder are associated with severe physical health as well as premature death (7). Patients with such symptoms have poor mental health, which affects the quality of life of those around them (such as their caregivers and parents) (8).

Symptoms recur frequently and become resistant to treatment in people with mental disorders. These people are known as chronically ill patients (9). These patients have difficulty controlling their emotions and thoughts, as well as in their daily functioning or activities (10). Mental illness affects other patient’s abilities, such as self-care and decision-making ability, and the patient may also be exposed to abuse by others or even caregivers (11).

Accordingly, the presence of a patient with a chronic mental illness such as a patient with schizophrenia or bipolar disorder in the family is a source of stress (12). Mental illness always leads to many sufferings and restraints for affected individuals, which negatively affects all aspects of their life (13). Accordingly, people involved in this group of patients including nurses and families (parents) face many problems (14). These problems can be discussed in terms of three family, social, and cognitive dimensions, which will be addressed in the following section.

From a family perspective, it can be stated that family caregivers of mental patients are actually the backbone of the healthcare system and are often considered as patients themselves because their commitment and obligation to care for the sick and disabled person in the family may lead to psychological harm. This study aims to determine the extent of burnout and mental fatigue among family caregivers of mental patients (15). Families with patients suffering from a chronic mental illness are examined for two reasons: First, caring for this group of patients is associated with psychological challenges and tensions, as well the reduced quality of life. Second, the problems created by this group of patients for families are among the

most important issues affecting the mental state and recovery of chronic mental patients (16). Studies have shown that a person's suffering from a mental illness can also affect their family's economic and financial situation, personal habits, or job performance of other family members. Moreover, concerns about the future, being a scapegoat, and the use of unsuitable coping strategies are considered some psychological effects of the presence of a mentally ill patient in the family, facing it with numerous challenges (17).

From a social perspective, families having a patient with a chronic mental illness are also socially under pressure due to the behavioral problems of these patients (18), which in some cases is due to the need for services in society, which is ignored for this group of patients (19). It may be argued that the inability of these patients for social adaptation is one of the most significant issues associated with them, which also affects the family (20). In some cases, social issues related to families with a chronically ill person indirectly inflict the family. Studies have shown that fear at work, workplace problems, and the ability to do things are more serious in families with a mentally ill patient, and these issues, regardless of the social problems caused by the behavior of these patients and their social incompatibility and adaptation, indirectly involve them in other problems (21). Accordingly, studies have indicated that mental health, the need for care, low quality of life, and poor social functioning of these patients also make them face social challenges (22). In general, it can be argued that in the family of a person with a mental disorder, changes occur that cause other family members not to be able to achieve their maximum capacity in job, social, or recreational activities. Furthermore, the concern about social dignity is another problem faced by this group of families (23, 24).

From a cognitive perspective, sine a person with a mental illness, in addition to imposing high costs on the family and society, causes psychological pressure on family members and given that the degree of recovery of these persons depends largely on the family's ability to provide physical, emotional, and social support, and this, in turn, depends on the patients and their families' reactions to mental illness, a phenomenological study of people related to persons with a chronic mental illness especially their parents is essential (25).

These issues together show that families with a patient suffering from a chronic mental illness face challenges from family, social, and cognitive perspectives. However, previous studies have been conducted often based on quantitative rather than qualitative methods. Accordingly, the present study seeks to answer the question: What are the psychological challenges of mothers of children with a chronic mental illness?

Methods

This study is a qualitative research that was performed using a descriptive phenomenological method. The study aimed to explore the lived experiences of the participants and to understand the meaning and concept of the phenomena from their point of view. Individuals talk about their actions or experiences and feelings, and then the researcher interprets their explanations. This research method can provide researchers with information about the experiences and perspectives of the research population that covered mothers of children with a chronic mental illness in this study.

The research population included mothers of children with a chronic mental illness in the Rehabilitation, Treatment, and Care Center for Neurological and Psychiatric Patients in Karaj in 2017. The research sample consisted of 17 mothers of children with a chronic mental illness who were selected through purposive sampling as the participants in this study. The inclusion criteria were: (1) Having a middle school degree for the interview and the ability to understand and comprehend the contents of the interview, (2) Living with a child diagnosed with a chronic mental illness by a psychiatrist, and (3) Taking care of the child for more than five years. The exclusion criteria were: (1) Divorced or widowed mothers because they experience more psychological and social problems, (2) Mothers

who had more than one child with a mental disability or those who had a child with another physical or mental disability, and (3) Mothers who became very sentimental during the interview and could be psychologically harmed during the interview process. In phenomenological studies, sampling should continue until saturation of the data related to the concept of the phenomenon under study to the point that an increase in the sample size does not lead to a significant increase in the collected data (26-27). In this study, to avoid the researchers' bias and their interpretation of data saturation, sampling was continued until data saturation point. Besides, the collected data were reviewed by three experts and they approved the adequacy of the data.

The data were collected through in-depth, semi-structured, open-ended interviews that were designed and conducted based on qualitative research questions and focused on the psychological challenges of mothers of children with a chronic mental illness. Since the interviews were semi-structured, other questions were asked based on the responses provided by the participants if necessary, to further clarify the participants' statements. Besides, at the end of each interview session, the participants were asked if they had additional comments to add to their statements. Examples of the question asked include What is it like to live with a chronically ill child? How do you take care of your child?

The data collected through the interviews were analyzed using Colaizzi's seven-step method for data analysis to identify the psychological challenges faced by mothers of children with a chronic mental illness (28,29).

The reliability of the data was checked through the credibility criteria. Besides, the triangulation of the data was ensured by reviewing the literature on chronic diseases and psychological challenges of mothers and the participants' opinions, and their engagement in interpretation, revisiting the participants to clarify any possible ambiguity and inconsistency to ensure the validity of the collected data.

Upon the approval of the study by the Islamic Azad University of Tehran Research Sciences Branch and after completing administrative procedures that lasted for a week at the Karaj Welfare Department and Mehrafarin Center, the researcher obtained the permission to interview the participating mothers. The researcher made the necessary arrangements through phone calls with mothers of children with a chronic mental illness and made an appointment with them to attend the face-to-face interviews on even days at the counseling office of Mehrafarin Center in Karaj. Each interview lasted 60 minutes and all interviews took 17 hours (1020 minutes in total). The duration of each interview was 92 minutes and the minimum time was 30 minutes, with an average time of 61 minutes. The collected data were saturated with 17 interviews. The interviews were recorded with the permission of the interviewees, and the researcher tried to establish good communication with the mothers and they were assured that their information was for scientific research only and their information would not be disclosed. All interviews were conducted for a period of 2 months. In this study, a semi-constructed interview technique was used. For this purpose, a list of questions was prepared in advance and they were asked during the interview. The interviewer also recorded the participants' age, occupation, and type of mental illness affecting their children.

To comply with ethical considerations, written consent was obtained from the participants for conducting the interviews and recording them, and the voluntary participation and withdrawal from the study, and keeping confidential the participants' names, phone numbers, and addresses were assured. Moreover, after transcribing the interviews, the recorded audio files were deleted.

The data collected in this study were analyzed using Colaizzi's seven-step method for data analysis. (27). In the first step, the researcher read a description of the study protocols to each person participating in the study to gain a sense of the protocols. Next, the statements with significance to the research question and topic were extracted. In the third step, the meaning of each important statement was extracted as

asystematic description of the phenomenon under study. The third step was repeated for each explanation and the formulated rich meanings were organized as clusters of topics. These clusters were then reviewed based on the initial protocols to validate them. At this step, there might be some inconsistencies within or between the clusters, as some of the themes did not match others. Afterward, the themes in each category were summarized as a comprehensive explanation of the problem under study to form a clear structure accounting for the phenomenon in question. Finally, the validity of the findings was confirmed by asking each participant to review the findings and express their opinions about them.

Results

As can be seen in Table 1, a total of 17 mothers were interviewed in this study. The participating mother age ranged from 58-81 years and their children's age ranged from 29 to 50 years. Twelve children had paranoid schizophrenia, 3 of them had chronic disorganization, and 2 others had chronic catatonia.

Table 1. The participants' descriptive data

Row	Patient's age	Mother's age	Type of illness
1	42	64	Paranoid schizophrenia
2	51	81	Paranoid schizophrenia
3	48	74	Paranoid schizophrenia
4	39	62	Paranoid schizophrenia
5	50	78	Paranoid schizophrenia
6	42	66	Paranoid schizophrenia
7	38	63	Paranoid schizophrenia
8	33	64	Paranoid schizophrenia
9	41	72	Paranoid schizophrenia
10	45	75	Chronic disorganization
11	29	58	Paranoid schizophrenia
12	35	61	Chronic disorganization
13	40	70	Chronic catatonia
14	36	70	Paranoid schizophrenia
15	40	74	Paranoid schizophrenia
16	40	72	Chronic catatonia
17	38	78	Chronic disorganization

The findings of the study showed the challenges faced by families of children with physical-motor disability in the form of primary categories, main categories, and themes. The analysis of the data revealed 16 primary categories and 5 main categories as shown in Table 2

Table 2. Categories and themes identified in the study

Primary categories	Main categories	Theme
- Feeling uncomfortable at home - Feeling of being harassed - Withdrawal of siblings - Constant consideration in speaking	Feeling uncomfortable at home	The mother's psychological fatigue and restlessness
- Fear of the future and death of parents - Fear of worsening the patient's condition	Feeling of constant fear	
- Concern about the timely use of medications - Constant presence at home - Fear of the patient committing suicide	Psychological fatigue caused by constant patient care	
- Obvious fear and apprehension of the patient's conflict with neighbors - Limited social relationships - A pitiful look at the family - Judging parents' inability to discipline the child	Social stigma and very limited interactions	
- Inadequate government support -Unemployment and insufficient income -High costs of medications and hospitalization	Insufficient financial and support sources	

Feeling uncomfortable in life: The presence of a mentally ill person in the family leads to a feeling of unhappiness with the family life, which affects the adaptability and adjustment of family members. For example, one of the interviewees stated, "*Most of the days when he is not feeling well, he starts fighting impulsively and breaks or throws away all the household items, and he/she disrupts the family's peace*" (Participant 15).

Feeling of being harassed: The harassment of family members because of a mentally ill person is a painful experience. As a case in point, one participant said, "*I'm often embarrassed in the presence of others. she uses offensive words and this makes me feel uncomfortable, but what can I do? I can't do anything*" (Participant 2).

Withdrawal of siblings: The presence of a mental patient in a family causes the withdrawal and separation of the siblings. For example, one interviewee said, "*My sons and daughters don't come to our house because they can't stand his behavior. He/she insults them and their husbands/wives or their children. Even on days when he/she is in a good mood, they still prefer not to visit us*" (Participant 7).

Constant consideration in speaking: One of the psychological symptoms of caregivers, especially mothers of mentally ill children is a constant consideration in speaking. According to one of the participants, "*I have to watch for my behaviors and statements. Because when he does not feel well, he picks on me as he/she misunderstands the things I say and if I argue with him, he will start fighting with me*" (Participant 8).

Fear of the future and death of parents: Fear of the unknown future induces the worries and fears of the mother. For example, one participant said, "*I'm constantly worried about what would happen to this child in the future. Who will take care of her? If I die tomorrow, who will take care of her? He/she can't take care of herself. His siblings are not willing to do anything. I really can't sleep at night for fear of her future. I'm always thinking about it*" (Participant 12).

Fear of worsening the patient's condition: Persistent anxiety and fear of worsening the patient's condition are one of the problems for mothers caring for a mentally ill patient. For example, an interviewee said, "*It's been a while since she is taking her medications on time and there's been no problem and I feel relaxed. But sometimes she gets sick suddenly and even suspects me and makes a lot of trouble." That's why I'm always afraid of the time she is feeling sick. It's like the calm before the storm*" (Participant 9).

Concern about the timely use of medications: Timely use of drugs following the advice of a doctor and constant control is one of the concerns of mothers. For example, one of the interviewees stated, "*I am very happy as long as she listens to the doctor and takes her medication on time. But the doctor says I have to be constantly careful so that there is no problem and I have to pay attention to her so that she can take her drugs on time. Otherwise, she will feel bad and may harm herself or others*" (Participant 6).

Constant presence at home: One of the psychological challenges of mothers is to play a permanent role of a caregiver. According to one of the participants, "*I haven't been anywhere for a few years. I can't leave him alone at home, because he may be hurt himself or the house. No one is willing to come to the house to take care of him. I need to rest for a while. I always have to look after the house. Sometimes I get very tired. All I have to do is to stay indoors and not to go out*" (Participant 4).

Fear of the patient committing suicide: Fear of child suicide is one of the concerns of such mothers. One of the participants stated, "*He has attempted suicide twice especially when he is depressed, I'm always worried lest he hangs himself* for *eats something poisonous. He overdosed sleeping peels twice but I took him immediately to the hospital and saved his life. Well, sometimes he says I want to die so that everyone can get rid of me. I become heartbroken and feel sad*" (Participant 3).

Obvious fear and apprehension of conflict with neighbors: Problems with neighbors and the fear of locals to communicate with the patient are one of the main problems of these families. One of the participants stated, "*He often says something and is misinterpreted by others. When he wants to go out, I'm constantly worried and anxious about what would happen. Lest he*

starts fighting with people because some people don't know he does not intend anything malicious when he says something. Well, a lot of people avoid him and don't talk to him. I'm always afraid that he may go out end up in fighting with other people" (Participant 1).

Limited social relationships: Feelings of rejection, isolation, and loneliness lead to a decline in the social relationships of the families with a patient with a chronic mental illness. For example, an interviewee said, "*We rarely go to a party. We often don't go to a party unless we visit a close family member or relative. I'm always worried that lest she does something that offends other people. Many people have cut off ties with us or we don't want to communicate with them. We are alone most of the time*" (Participant 5).

Having a pitiful look at the family: Peoples' feeling of pity for a family with a chronically ill patient can exacerbate the distress and psychological problems of mothers. Accordingly, a participant said, "*I think even our close relatives do not understand or avoid us or show pity for us. They keep saying that they are very sorry for us and advise us to have patience. But their empathy makes us feel sad and they cannot help it*" (Participant 12).

Judging parents' inability to discipline the child: Such judgments are inevitable and the mothers of these patients are often exposed to them. For example, one of the interviewers stated, "*Many people, relatives, or strangers who see my son, are quick to say that he was not getting disciplined or that his mother was not competent enough to discipline him and this is the result. Many times these judgments bother you. I feel guilty that I may not have discipline him well*" (Participant 13).

Inadequate government support: Insufficient support and resources as one of the economic problems have long-term psychological consequences for mothers. According to one of the participants, "*Our economic situation is such that we hardly make a living. Now suppose that you have a mentally ill person. The government has to find a solution for us. For example, it can give us a pension or have medical centers to treat these patients for free, so that to reduce our problems*" (Participant 17).

The patient's unemployment and insufficient income: Unemployment and lack of financial independence contribute to the psychological problems of chronically ill patients and their families. For example, an interviewee said, "*Even though he used to work and earn a living, but he has no jot at the moment and whenever he applies for a job they say healthy normal people are unemployed and they cannot give him a job. I tried to find a job for him. But there is no place for him to work. He has no income. The government subsidy does not cover these high expenses, not even the money for his cigarettes*" (Participant 11).

High costs of medications and hospitalization: The inability to pay for medications and medical treatment was another concern of the participating mothers. According to one of the interviewees, "*These patients don't have special insurance and the costs are free. Some of the foreign high-quality medications are very expensive and we cannot afford them. Sometimes the drug is not available in the market so I become anxious and am constantly afraid that his condition will deteriorate because his doctor said that he should take his/her drug on time*" (Participant 10).

Discussion

The results of the present study suggested that mothers with a chronically ill child face many challenges such as feeling uncomfortable and mentally exhausted due to the constant care of their sick child. The results of this study in line with the studies conducted by Akbari et al. (24) and Cheraghi et al. (25). Akbari et al. (24) concluded that when families have a higher awareness of how to treat the patient and also the government is more supportive, the family will enjoy more peace. Cheraghi et al. (25) showed that mental patients need to follow up on medical and care services after discharge from the hospital, and this reduces the length of hospital stay, increases the well-being and comfort of patients, increases the effectiveness of medical treatment, and reduces the risk of recurrence.

The present study also indicated that the mothers have constant fears and anxieties about the patient's conflict with siblings and others. The patient's poor social relationships and skeptical thoughts upset the siblings and thus they prefer to leave the house under any pretext. Similarly, Koolaee and Etemadi, concluded that many siblings are not interested in socializing with their sick brother/sister and are constantly afraid that they or their child will develop the disease (27).

Our findings also indicated the mothers with a mentally ill child face psychological challenges such as social stigma, limited social interactions and unfair judgment of others. The most important obstacle to the success of people with mental disorders in society is stigmatization and discriminations associated with, which need to be combated by implementing public awareness-raising programs to educate and inform the public about the nature, severity, and impact of mental disorders to replace negative attitudes with more positive attitudes and behaviors. The participation of mothers in psychological training programs can have a positive effect on expressing positive feelings towards their children and reducing the psychological burden on mothers. Koolaee and Etemadi, for example, concluded that raising public awareness, education, and culture could reduce the social stigma surrounding mental illness (27).

Besides, government inadequate support and lack of financial resources were other psychological challenges faced by the mothers, which, if continued, could lead to psychological problems for the mothers. From an economic perspective, the most important challenge is the financial inability of families. This finding was consistent with the observations made by Nadem et al. who found that there was a significant relationship between appropriate economic status and reduced psychological symptoms in caregivers (30). However, this finding was not consistent with a study by Caqueo-Urízar et al. They did not report a significant relationship between economic status and caregiver problems (31).

One of the significant psychological challenges faced by mothers who care for a patient with a chronic illness is their constant feeling of fear. Zahid et al. suggested female caregivers tolerate a higher burden of care than male caregivers, and this can increase maternal anxiety. Moreover, factors such as religious attitudes, culture, social support for family and patient, emphasis, and follow-up of caregivers for the patient to take medication on time, as well as the recommendations of professional staff including psychiatrists, psychologists and physicians can affect maternal stress and worries (32).

The limitations of this study were the time-consuming and difficult nature of conducting the interviews, the lack of similar studies to compare the results, and the restriction of the research population to mothers of children with a chronic mental illness in Karaj in 2017. The findings of the study were also based on the participants' experiences and personal perceptions.

Based on the results of the study, it is suggested that education and raising the awareness of families can play an important role in the rate of patient acceptance by other family members and caregivers.

Conclusion

The results of the present study showed that the challenges faced by mothers of children with a chronic mental illness can be placed into five main categories including feeling uncomfortable at home, feeling constant fear, psychological fatigue caused by constant patient care, social stigma, and very limited interactions, and insufficient financial and support sources. The results revealed that the higher the awareness of families and society on how to rationally treat mentally ill patients, there would be less pressure on mothers due to social and psychological problems. It is therefore suggested that psychosocial rehabilitation measures as a process that allows patients to achieve the highest level of independent social functioning should receive more attention on the part of the relevant organizations. Besides, authorities in charge are recommended to plan for resolving psychological and social challenges faced by

mothers of children with chronic mental illnesses.

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Conflicts of Interest

The authors declare that there is no conflict of interest in this study.

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