Experiences of Family Caregivers of Patients with Borderline Personality Disorder of Social Stigma

Abstract

Background: Social stigma is the most common and challenging burden of care on the family of people with Borderline Personality Disorder (BPD) In Iran, despite the cultural and social influences, this issue has been less studied. Therefore, present study was conducted to determine the lived experiences of caregivers of patients with BPD of social stigma. **Materials and Methods:** This qualitative study was performed at Ibn Sina hospital in Mashhad, Iran from 2017 to 2019. Participants were selected by purposive and snowball sampling method. Data were collected through semi-structured interviews. Data saturation was achieved after 16 interviews. Finally, the data were analyzed by the method proposed by Diekelmann (1989). **Results:** In data analysis, one main theme and two sub-themes emerged. The main themes include Black shadow. Two sub-themes consisted of society dagger and secrecy. The sub-theme of society dagger included the two common meanings (inner turmoil in response to the stigma of others and weakening of family status among relatives and acquaintances). The sub-theme of secrecy comprised of the three common meanings (concealment of disease, hide hospitalization, and seclusion). **Conclusions:** An understanding of the experience of family stigma can lead to the development of supportive strategies to manage this problem among caregivers of patients with BPD. Nurses can support caregivers by offering them opportunities to discuss how stigma is disrupting their caregiving roles. They can also support the caregivers in negotiating the experienced social and emotional distress and when necessary, refer them to the other members of healthcare teams.

Keywords: *Borderline personality disorder, caregivers, Iran, qualitative research, social stigma*

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Introduction

Personality disorder is characterized by pervasive maladaptation and inflexibility in behavior, cognition, emotional state, and impulse control that significantly deviates from one's cultural expectations and often results in mental distress, social, and occupational dysfunction.[1] Among the personality disorders, Borderline Personality Disorder (BPD) has the highest prevalence.[2] Diagnostic and Statistical Manual of Mental Disorders (DSM-5) estimates that the prevalence of this disorder in the United State are about 1.6% and can increase to 5.9%. The prevalence rate of this disorder in primary health care centers is about 6%, in those who refer to outpatient mental health clinics about 13% and in patients admitted to mental hospitals about 23%.[3] Suicide and self-harm are indicators of this disorder. 70–75% of these patients have a history of at least one self-injury. These range from minor scratches, knocking the head on the wall, burning with cigarettes, up to high doses of drugs, and self-laceration with a knife.[4]

Today, after the failure of the de-institutionalization movement, family has always taken the major role in responsibilities of patient care.[5] Families are the most important social support for these patients in society. However, caring of these patients puts a great deal of stress on family and leading to decrease of physical and mental health of caregivers and eventually lead to decrease in quality of care for these patients.[6] Psychosocial challenges are enhanced by the stigma attached to mental illness, which is a problem affecting not only the patient but also the family.[7]

Stigma was first defined by Goffman as a highly disgusting feature that makes

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patients with mental disorder from an ordinary person to a minor person and became different from every individual that had ever in society.[8] In this regard, the results of the study conducted by Yin *et al.* (2014) showed that the discrimination and ridicule of the family of patients with schizophrenia is common.[9] Also, the results of the qualitative study conducted by Taghva (2017) indicated that stigma is experienced by the family of patients with psychiatric disorders.[10]

Family stigma includes perceptions of blame and shame. Public attitudes blame family members for being incompetent in patient's care that is ultimately leads to poor quality care and recurrence of the disease. When family experienced shame after being blamed, in which, avoids social interactions and hides the mentally ill person from the society.[11] On the other hand, patients' behavior may also lead to more family discrediting and lead to disconnect family with neighbors and friends and ultimately isolation of the family, as some studies showed that these emotional consequences occurred.[12,13] Other study also showed that stigma leads to the destruction of social identity and social isolation of the family of mentally ill person.[14] Social stigma prevents the family from received support of neighbors, acquaintances, and medical staff.[15] In addition, social stigma can lead to isolation and poor quality of life in family caregivers.[16] Social stigma is also associated with psychological and social pressures.[17] Caregivers of BPD patients showed a high level of mental and physical distress compared to the normal population.[18] In this regard, one study showed that caregivers of patients with BPD experienced more sadness than other mentally ill patients.[19]

In general, caregivers have many problems in relation to social stigma, nurses can identify and prioritize these problems and needs in relation to social stigma and they can use the nursing process to support and reduce problems and help to improve the quality of life in caregivers. Supporting caregivers are the duty of all members of the health care system but nurses are in a special position and in fact are the important support system of family members in the hospital.[20] On the other hand, a deeper understanding of unknown aspects of social stigma can facilitate the planning of a comprehensive health care plan. A full understanding of the caregivers' experiences of social stigma is not possible without a qualitative research. In the present study, the researchers used interpretive phenomenological research because they try to gain a better understanding of the caregivers' experience of social stigma. Phenomenology can obtain the lived experiences of humans from the world of their everyday lives and interpretive phenomenology give meanings to a person's perception of a particular phenomenon and are influenced by all internal and external factors.[21] On the other hand, sharing the experiences of social stigma can help modifying stigmatizing attitudes in society, which reduces negative stereotypes and discriminations against family caregivers and thus improves patients care.

Therefore, considering the negative consequences of social stigma on family of BPD patients and their importance roles in the care, follow-up, and treatment of patients and limited studies on stigma in Iran, the present study aimed to determine the explaining the lived experiences of family caregivers of patients with BPD of social stigma.

Materials and Methods

This study is a part of an extensive PhD dissertation in nursing education conducted with a hermeneutic phenomenological approach at Ibn Sina hospital in Mashhad from 2017 to 2019. In hermeneutic phenomenological research, in addition to describing human experience, it is possible to gain a deeper understanding and interpretation of experiences. Of course, in this interpretation, researcher's perceptions also play a significant role.[22]

Inclusion criteria included willingness to participate and interview, no history of psychiatric disorders and substance abuse, and having the ability to provide experiences. In qualitative research, sampling is purposeful and data collectionof continues until the researcher feels that the information is saturated. Ultimate goal of sampling is based on obtaining higher information cases for the study.[23] In present study, participants were selected through purposive and snowball sampling.

Primary participants were selected from caregivers who experienced cares of patient of BPD and if they had perceived social stigma during patient care. Some participants were selected by snowball method and introduced by previous participants. Sampling continued until the data were saturated (either the obtained data were repeated or the new data confirmed the previous ones). After interviewing 10 participants, the data were saturated and six more interviews were conducted to confirm the themes and sub-themes and finally, no new data was obtained. Interview duration varied between 40 and 80 min and conducted in a quiet place with the choice of participants. The location and time of the interviews were determined according to the desire of participants in their workplace, home, and the researcher's office. The interview guide included questions, such as "What does it mean to you when others stigmatize you?" "Please describe your experiences of stigma" and "Please describe the effect of stigma on your life." Then the probing questions were used to lead the answers to the research goals, such as "Please explain more! or what do you mean?

In this study, data were analyzed based on the interpretative method of Diekelmann, Allen, and Tanner (1989).[24] This method is a process seven stages based on Heidegger's phenomena and its steps are as follows: 1-Read all the interviews and texts to gain a general understanding, 2-Write commentary summaries for each interview,

3-Group analysis of selected versions of Interview texts and identification and extraction themes, 4-Come back and see again interviews to explain, clarify, and classify disagreements and contradictions in interpretations and write a comprehensive analysis of each text (interview), 5-Compare and contrast texts (interviews) with the purpose of identifying, defining, and describing meaning common, 6-Identifying and extracting fundamental patterns that communicates the themes and so on to connect to each other, 7- Providing a draft copy of the themes, with selected excerpts from the interview text interpretive and individual team members using the method and the content of the work is familiar, the direction of extraction and applying their answers and comments in writing Final version of plan report.

The four criteria of Guba and Lincoln's including credibility, dependability, conformability, and transferability were used for consideration of rigor.[25] For credibility; the researcher had long and close contact with the participants. For member check, some parts of the interviews along with their extracted codes and groups were observed by the participants to evaluate data analysis and its accuracy. Moreover, the research team members coded some of the interviews separately and evaluated their similarities, and in cases of conflicts, they reached consensus after consulting sessions. For transferability, all the procedures must completely be explained. Therefore, we tried to present the participants quotes as they were said. In addition, the demographic characteristics of the participants and studied field are demonstrated in detail, so that the reader could decide about using the results. Confirmability was evaluated through controlling the data by outside observes familiar with qualitative studies, meaning that some parts of the interviews with their common meanings and extracted sub-themes and theme were evaluated and approved by two observers familiar with qualitative studies. Dependability of the stages of the study was carefully recorded and reported. In this study, in order to eliminate the bias in one's personal view and inference in diagnosing information saturation, sampling was continued until the data was saturated and the data collected from the participants were given to three professors familiar with the phenomenological method and sampling was continued to confirm the adequacy of the information collected by all three persons.

Ethical considerations

This study was approved by the ethics committee of Mashhad University of Medical Sciences (IR.MUMS. RESEARCH.REC.1396.407). For each interview, the researcher explained the field and aim of the study and, if the participant was satisfied and they signed the consent form. The researcher committed to stop recording the interview if the participants did not wish to continue the interview. In addition, participants were assured that they were free to resign from the study. Providing feedback to the authorities and participants was conducted in compliance with the confidentiality of the names of the participants.

Results

In total, 10 participants (16 interviews) were participated in present study. The caregivers' age range was 25–55 years [Table 1]. The experiences of this caregiver were reflected within the main theme (Black shadow of stigma) and two sub-themes (society dagger and secrecy) [Table 2].

Black shadow of stigma

The main theme of "Black Shadow of stigma" reflects the negative beliefs of the community about clients with psychiatric disorders. Many people often readily accept this idea and prejudice about psychiatric disorders and treat everyone with mentally illness in this bad name group according to common stereotypes. This leads to inappropriate and discriminatory behavioral reactions to them, which has devastating effects on their clients and caregivers. This theme has two sub-themes: "society dagger" and "secrecy" as described below.

Society dagger

Sub-theme "society dagger" indicates the lack of awareness and understanding of the critical condition of caregivers of BPD patients by their neighbors and acquaintances. This sub-theme consists of two common meanings: "Inner turmoil in response to the stigma of others" and "Weakening of family status among relatives and acquaintances."

Inner turmoil in response to the stigma of others

This common meaning reflects participants' bitter reactions to others behaviors toward their patients. In addition, caregivers suffered from lack of community awareness of BPD. A male participant with 8 years of care experience of BPD patient said: "*My Relatives and acquaintances in any place saying that, this person is crazy. When I heard these words, I was overwhelmed. They humiliated me .In that situation, my face was flashed, and my blood pressure was going up. I was getting angry. I was frantic but did not say anything .I did not want to stay in that place*" (Participant 1).

Neighbors also harassed caregivers with their words, and they were very upset. A female participant with 4 years of care experience of BPD patient commented: "*the neighbors were saying to their children that he is crazy, don't go near him. He is dangerous, caught in god's curse; devil is in his body. My son was coming to tell me these issues. I was heartbroken. I said: I wish god bring this calamity on your loved ones*" (Participant 6).

Hospital staff who called patients and caregivers with inappropriate labels made caregivers sad, because they did not expect the staff to mistreat them. A female participant with 10 years of care experience of BPD

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Table 1: Demographic characteristics of the study participants
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Participant's No	Education	Gender	Interview of Time (Minutes)	Duration Of care (Year)
1	Primary school	Male	80	8
2	Primary school	Female	70	5
3	Diploma	Female	100	3
4	Bachelor of Science	Male	90	12
5	Master of Science	Female	70	10
6	Primary school	Female	60	4
7	Diploma	Male	85	6
8	Bachelor of Science	Male	75	9
9	Master of Science	Female	60	7
10	Diploma	Female	85	11

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Table 2: Meaning units, Common meanings, Sub-themes, Themes
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Meaning units	Common meanings	Sub - themes	Themes
- Resentment in response to the stigma of hospital staff	Inner turmoil in response to the stigma of others	Society dagger	Black shadow of stigma
- Feeling heartbroken in response to the stigma of neighbors			
- A sense of helplessness in responding to the stigma of close friends			
- No previous place in the family	Weakening of family status among relatives and acquaintances		
- Family rejection			
-Decreased communication with relatives due to problems with patient symptoms			
- Neighbors' disgust with the family			
- Loss of relationship with family due to patient's moral problems			
- Knowing others about a spouse's illness is a barrier to communication	Concealment of disease	Secrecy	
- Changing the behavior of others with awareness of the child's illness			
- Not telling the disease to others for not understanding			
- Maintain relationships with others by concealing child illness			
- Keeping the family secret because of the bad judgment of others			
-Hiding being hospitalized is a way of preventing the stampede from eating friends	Hide hospitalization		
- Different view of others with the awareness of child hospitalization			
- Forced to conceal hospitalization from close relatives			
Lack of family presence due to low mood-	Seclusion		
Home Imprisonment for Defamation-			
-Willingness to isolate because of the neurotic stresses of caring			
Being alone is better than being in the crowd-			

patient, while complaining about hospital staff behavior, said: "*At the time of my son's visiting hours, the staff told him to shut up crazy, we will restraint you, and I was very upset. It was painful for me. I came home and cried a lot. If ordinary people say these words, I say to myself, they have no information about this disorder, but these behaviors are not expected from hospital staff*" (Participant 5).

Weakening of family status among relatives and acquaintances

One of the problems that caregivers were expressing was rejection by relatives and loss of family status among them. In this regard, a female participant with 5 years of

care experience of BPD patient said: "*The acquaintances are no longer the same as before. I was already versatile in my relatives and I would solve their problems. Everyone had everything that couldn't do, he came to me but now, No one comes around me, even close relatives*" (Participant 2).

Other relatives did not invite them to parties and ceremonies, so they were isolated families who did not interact with relatives. A female participant with 7 years of care experience of BPD patient, while very upset with his family, said: "*No one invites us to a party, even my sister, or my brother. They reject us one by one, we are now isolated, we are alone*" (Participant 9).

Secrecy

The sub-theme of "secrecy" in the participants' experiences indicated that some caregivers were hiding the disease to get rid of others judgments looks. Therefore, as a protective strategy, they attempted to hide their patients from others. They were concerned that if they introduced their child or spouse as a psychiatric disorder person to others, they would always be judged and treated differently. They were trying to control the world around them by concealing their sick person. This sub-theme has three common meanings of "Concealment of disease," "Hide hospitalization," and "Seclusion."

Concealment of disease

This common meanings implies that caregivers resort to concealing their child and spouse's illness to prevent others from changing their behavior, not understanding, maintaining a relationship with others, maintaining family secrets because of the judgments of others. They even tried to keep the patient unaware of the medication and introduced the drugs as a booster. A female participant with 3 years of care experience of BPD patient said: "*I didn't like others to know that my husband is sick, if I told them, they thought about my husband in some other way, it would definitely change their behavior*" (Participant 3).

Hide hospitalization

All caregivers said it was a painful experience to receive stigma after receiving information from others about the patient's admission to a psychiatric hospital. In particular, they emphasized that the hospitalization of the patient was not in accordance with their wishes, but after discharge, they would receive frequent stigma of others. When a person hospitalized, he or she is generally described as "crazy." For these reasons, caregivers referred to hiding their patients in the hospital for prevent provoking the curiosity of others for fear of being disabled and mentally ill and for misinforming others.

In this regard, a male participant with 12 years of care experience of BPD patient said: "*My husband, who was hospitalized, when he was discharged and doing everything, others called him chain insane. Get lost. You have to be admitted to a mental hospital. For these reasons, I did not tell anyone*" (Participant 4).

Seclusion

Participants stated that they avoided the community because of their negative views about clients with psychiatric disorders and to avoid being labeled as patients. They had chosen avoidance as a strategy of coping with the stigma of others that led to their forced isolation because they had to step down to avoid stigma. A male participant with 6 years of care experience of BPD patient said: "*I always thought that if I got out of the house, my neighbors would ask me about my daughter and her illness. Therefore, I would not go anywhere and stay at home. We were caught in the fence that caused our illness*"(Participant 7).

Discussion

The purpose of this study was to explore how social stigma was manifested in families living with BPD patients. Analysis of the data identified "Black shadow of stigma" as the main theme that contain two sub-theme: "society dagger" and "secrecy." This finding was based on the actual reported experiences of caregivers rather than answers to questions about hypothetical situations.

The main theme of experiences of caregivers in the present study was "Black shadow of stigma." It can show that psychiatric illness have negative effects on the patient's family. In general, the presence of a person with psychiatric disorders leads to a crisis in the family. Living with a mentally ill person causes the family members to be under severe stress, and affects all aspects of their lives. For this reason, patients 'families are reluctant to express the disease of family member to others because the label of the disease affects the way others views them and respond to patients' families and, in turn, influences the attitude of the family toward itself. On the other hand, families believed that, because of the stigma of the disease, they were treated differently. They felt that they were being judged negatively and simply ignored. Studies in the past have indicated that patients' families share experiences of stigma.[26] On the other hand, the feeling of shame about having a sick relative and the fear of being blamed has been suggested as a consequence of various studies.[27]

Major problem in caregivers is the socio-cultural wrong beliefs about BPD patient in the community. The label of mental illness is often associated with a lack of knowledge about the nature of mental illness, and is exacerbated by other people's beliefs and misconceptions about patients with psychiatric disorders.[21] The caregivers in the present study were worried about the negative beliefs in the society and felt shame and hopelessness because of stigmatizing the patient and family, thus keeping the disease as a secret. Consistent with this finding, the study showed that 47% of patients' family members believed that community attitudes toward psychiatric disorders were negative and there is a view in society that psychiatric disorders should be kept secret.[28]

Family caregivers in this study reported that attempted to conceal or hide diagnosis or condition of family ill member from others to avoid shame and/or abandonment associated with BPD. All participants experienced judgment and rejection and because they did not receive stigma, were not judged, and were not rejected, they avoided telling to others about the disease of patient medication, and hospitalization. Consistent with this finding, the study also reported that 36% of caregivers of patient with schizophrenia kept the disease secret.[9] In a qualitative study in Iran, about half

of families with a mentally ill person reported stigma experiences as hiding family member illness from others and its negative impact on work and education.[10] In a study, most family caregivers hid their family member's illness and lacked the support of friends.[29] In other study, families of patients with psychiatric disorders had limited social relationships with friends and relatives because of stigma.[30]

In the present study, caregivers also concealed their hospitalization of patients to prevent ridicule and harassment by others. Consistent with this finding, one study showed that hospitalization in a psychiatric hospital was kept secret in 50% of the patients' families.[31] Family caregivers described seclusion as a strategy that they used as a means of avoiding of stigma. In this regard, one study showed that the stigma of a patient with mental disorder caused isolation of family members.[13]

Exclusion from the total relatives and isolation of the family and on the other hand, hiding the disease of the family member from others, causes loss of social support in the families, whereas conscious social support (health care system) or unconscious (friends and relatives) is a problem-based positive coping mechanism that results in less stigma experienced in the family and has a positive role in helping caregivers overcome negative information in the community.[32]

The findings of this study have shown that stigma is worryingly increasing in the families of psychiatric patients. Given that most families referred to the ignorance of people in the community about stigma, it seems that giving more information and familiarity with mental illness can modulate the effects of stigma, as the findings suggest. As noted, awareness and familiarity with psychiatric illness is associated with a lower tendency to isolate patients' families.[33] The results of this study can be helpful to healthcare professionals in designing educational interventions related to decrees social stigma in caregivers and health care staff with knowledge of the experiences of social stigmatized caregivers can deal with them appropriately, which in itself plays an important role in the prevention, care, treatment, and rehabilitation of the client.

All of these results have revealed the necessity of paying attention to the knowledge and attitude of caregivers about social stigma more than ever. Nursing education should be training nurse about issue of stigma with psychiatric disorders for patients and caregivers and in Iran, the number of studies that focus on social stigma is very rare, so by conducting such research, it is possible to obtain significant sources of knowledge that can be designed and planned based on the experiences of clients. The main limitation of this study was related to the difficult to interview some caregivers because of the lack of enough time. The problem of access to the full text of some articles was another limitation of this research.

Conclusion

An understanding of the experience of family stigma can lead to the development of supportive strategies to manage this problem among caregivers of patients with BPD. Nurses can support caregivers by offering them opportunities to discuss how stigma is disrupting their caregiving roles. They can also support the caregivers in negotiating the experienced social and emotional distress and when necessary refer them to other members of healthcare teams such as a psychiatrist. More research on BPD caregiving is needed to find out how to provide caregivers with appropriate help about this important issue.

Conflicts of interest

Nothing to declare.

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