Avicenna Journal of Neuro Psycho Physiology
doi: 10.32592/ajnpp.2025.12.1.10 2025 July;12(1): 10-16 https://ajnpp.umsha.ac.ir

Original Article

Lived Experience of Main Caregivers of Patients with Borderline Personality Disorder

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Received: 22 December 2024
Accepted: 16 June 2025
ePublished: 17 July 2025

Abstract

Background and Objective: Borderline personality disorder (BPD) is a disturbing disorder for the patient and his caregivers, especially the main caregiver. The present study aimed to investigate the lived experience of the main caregiver of patients with BPD.

Materials and Methods: The research method was qualitative. The statistical population consisted of all caregivers who referred patients to Sina Hospital in Hamedan (Iran) in 2023. Among them, eight caregivers were selected by random sampling, considering the researcher's theoretical saturation.

Results: The results of the interviews include five sub-themes: "Aggression," "Feeling of Helplessness," "Family Relations," "Social Relations," and "Quality of Relationship with the Patient," as well as two main themes: "Inability to Control Emotions and Feelings" and "Caregiver Relations." The results indicated that the main caregivers are always affected by patients in their emotional instability and relationships.

Conclusions: The main caregivers' ability to control their emotions is low, and the quality of their relationship is not satisfactory.

Keywords: Borderline personality disorder, Communication instability, Emotion control, Main caregiver

Background

Personality disorders are among the most significant social and medical issues. Psychiatrists, psychologists, mental health professionals, and sociologists have shown serious attention to personality disorders. One type of personality disorder in Cluster B is borderline personality disorder (BPD) [1]. The BPD is a chronic psychological disorder characterized by deficits in emotional regulation, instability in interpersonal relationships, and self-concept, accompanied by intense fear of loss, abandonment, or rejection in relationships with others [2]. The average prevalence of this disorder in the general population is 1.4%, approximately 10% in patients visiting outpatient clinics, and nearly 20% among hospitalized patients [3]. This disorder is one of the most common personality disorders that often starts in adolescence and early adulthood and appears in various fields. It occurs three times more frequently in women than in men [4]. There is significant variability in the phenomena studied under the term "emotional dysregulation" in BPD, including emotional sensitivity, intense and sensitive negative affect, lack of appropriate regulatory strategies, and excessive maladaptive regulatory strategies [5]. Since this disorder is related to insufficiency in emotional regulation and response, therefore, people with this disorder have many problems in many fields, including work and developing interpersonal relationships [6].

One of the most important pathological models of BPD is the biological-social model of Linehan [7], which states that BPD is the result of the interaction of biological factors related to emotional dysregulation and an invalid social environment. In other words, people suffering from BPD are vulnerable in terms of bio-cognition and have been brought up in environments that repeatedly invalidate a person's inner experiences and behaviors. Emotional trauma, along with growing up in an invalidating environment, causes a person to face deficiencies in ability, motivation and regulation of emotions and problems in his life [8].

One of the factors that affects the problems and experiences of people with BPD is their family and their main caregivers. In general, the mental burden of caring for chronically mentally ill patients, while reducing the quality of life of caregivers, can endanger their physical and mental health and ultimately lead to poor care, abandonment of treatment, or violent behavior with patients, and these problems can aggravate and become a disorder in patients [9]. Due to the non-institutionalization of treatment and care of chronic mental patients, Family caregivers of patients with mental disorders play the most important role in the care of psychiatric patients (PPs) and preventing their readmission [10]. Caregivers of BPD, while being able to manage and control patients' behaviors, play a vital role in maintaining and rehabilitating patients [11].

Patients and their families are constantly affected by the changes caused by this disorder and its treatment. These changes gradually decrease the level of performance and ability of family members, destroy the emotional system and communication structures of the family, affect the relationships between members, the occurrence of financial and economic problems, decrease the social interactions of the family, change roles, decrease life expectancy, and it may appear with symptoms such as anger, guilt and sadness [12]. As mentioned, one of the major issues in this group is excessive sensitivity in interpersonal relationships, characterized by a strong feeling of happiness and gratitude resulting from understanding the kindness of others, as well as sadness, grief, and intense anger resulting from perceived criticism or abuse [1]. Their feelings often change from admiration and love to anger and hatred. They are sensitive to others' views of themselves, especially those who are valuable in their eyes. This phenomenon is known as splitting, where, after idealizing the other person, the person considerably lowers their value and comes to hate them. This state is stable in family relationships, friendship, cooperation, or with a spouse [7]. The results of the Caluza et al' study [13] on family members' experiences of having a sibling with BPD showed that participants experienced multiple challenges including lack of understanding, lack of control, struggling to cope with their lives, difficulty in interpersonal relationships due to lack of constructive communication, and emotional suppression. Grenyer et al [14] reported that the caregivers of BPD patients experience more sadness than the mentally ill patients themselves.

Numerous quantitative studies have been conducted in the field of BPD patients; however, it is not possible to fully investigate the experiences of patients and their caregivers using quantitative methods. In other words, they have dealt with BPD and how to treat it, while their experiences and problems of living with the disease as a phenomenon should be dealt with. In order to understand the mental experiences of people, it is necessary to go beyond the existing methodological fences to reveal an area of existence that presents itself with complete certainty through experience, and the appropriate method to implement such a goal is qualitative research [15]. Therefore, by examining the experiences of patients and their caregivers from a phenomenological perspective, we can provide the necessary groundwork for a deeper understanding of the world of these individuals, and ultimately, the results can be used to develop strategies to support patients.

Objectives

The present study aimed to investigate the lived experience of the main caregiver of patients with BPD referring to psychiatrists in Hamedan city. Moreover, the researcher seeks to find the answer to the following question: How do the main caregivers of patients with BPD experience interpersonal problems, and what meaning do they attribute to their emotional experiences?

Materials and Methods

The present study is a qualitative study with a descriptive phenomenological approach that aims to understand the communication and emotional instability in parents of patients with BPD. The statistical population of the research is the main caregivers of patients with BPD who went to Sina Hospital in Hamedan City (Iran) in the period of the first to the sixth months (April to September 2023). The cases were purposefully selected using an available sampling method. The selection of samples was stopped after reaching saturation, that is, when increasing the number of samples did not add any further insight to the findings. Therefore, the number of subjects was eight of the main caregivers. The inclusion criteria for the study were direct caregiving relationship with the person with BPD, official diagnosis of borderline disorder of the person being cared for based on the diagnostic criteria for BPD based on the SCID diagnostic interview, at least 18 years of age, willingness to participate in the interview and sign a written consent form, and the ability to share experiences. Exclusion criteria included requesting to leave and unwillingness to participate in the study. In addition, data collection was conducted through semi-structured interviews. The content of this interview was first prepared in the form of open-ended questions based on the existing research background in the field of the research topic and the brainstorming of the researcher and supervisors, and then reviewed by several clinical psychologist evaluators in terms of content validity and how suitable they were for examining the research objectives, and revised and rewritten based on their opinions. The interviews were recorded with the participants' permission . Each interview session lasted 30 to 45 minutes, and if needed, with the consent of the caregivers, the interview could continue for up to two additional sessions. After each interview, all conversations were implemented and written down by the researcher. After analyzing each interview and shaping the organized concepts, the next interview was conducted. This method continued until all interviews were completed. The data analysis method involved reading the interviews multiple times after recording them to become familiar with the overall content. At the next stage, based on the Claise method, important sentences from each interview were extracted. It should be noted that the information discarded at this stage was kept in a separate file for future access if needed. Afterwards, a phrase was assigned to each sentence to explain the hidden meaning within the sentence, known as a semantic unit. In the third stage, the semantic units were compared with each other and placed in a larger category, called sub-themes, based on their similarities and differences. In the last stage, the sub-themes were compared and merged with each other, and finally, the main themes of the research were formed based on the research objectives.

To validate and strengthen the strength of the present qualitative research, four main criteria of Lincoln and Guba [16] were used, including verifiability, transferability, reliability, and believability. To ensure that the findings accurately reflect the participants' lived experiences, in-depth and semi-structured interviewing techniques were used with participants, codes and themes were reviewed with the help of two qualitative analysis experts to reach a consensus and strengthen the accuracy of the analysis. Some of the findings were shared with participants to ensure that the researcher's perceptions were consistent with their experiences. Although the aim of qualitative research is not to generalize statistically, by providing a rich description of the context, participants, and interview conditions, it is possible to compare and transfer the results to similar contexts. An attempt has been made to report the interview transcripts, contextual conditions, and sample characteristics in sufficient detail. To examine the sustainability of the findings, if the study were repeated under similar conditions, methods such as careful documentation of the data analysis process, recording of coding and theme extraction steps, and peer review would be employed. All stages of the research (from interviews to final analysis) are recorded and traceable. Finally, to ensure that the findings were the result of an unbiased analysis of the data and not the researcher's bias or assumptions, a second coder was used to increase the objectivity of the analyses.

Results

In this study, the participants included eight main caregivers of patients with borderline disorder aged from 38 to 62 years, five of whom were females. In addition, their level of education was usually a diploma. After analyzing the obtained data, 40 semantic units, 5 subthemes, and 2 main themes were extracted. Among the semantic units extracted, the most frequency is related to "hurry," "feeling of frustration," "feeling of hatred towards the patient," "rejected from the family," "desire for the death of the patient," "lack of peace in everyday life," "desire to die," "neighbors' disgust with the family," and "lack of patience."

Table 1. Themes obtained from interviews of the main caregivers of patients with BPD

Main themes	Sub-themes	Semantic units	Frequency
Inability to control emotions and feelings	Aggression	Aggression towards oneself	3
		Aggression towards the patient	2
		Impulsivity in expressing anger towards oneself and others	3
		Being subjected to aggression from the patient	3
	Feeling of Helplessness	Inability to manage life	3
		Feeling depressed	2
		Feeling failure in life	3
		Not enjoying life	2
		Lack of peace in daily life	4
		Desire to die	4
		Self-Blame	3

		Feeling Guilt	3
		Lack of patience	4
		High cost and effort of caregiving	3
Caregiver Relationships	Family Relations	Lack of satisfying relationships	3
		Distance from family and relatives	2
		Violence in the family	3
		Reluctance to attend family gatherings	3
		Loss of previous status in the eyes of relatives	3
		Being rejected by the family	4
		Reducing communication with relatives	3
		Neighbors' disgust towards the family	4
		Reduction of family interactions due to ethical issues	3
		Hiding the disease in the presence of others	2
		Disappointment from family and relatives	2
	Social Relations	Occupational depression	3
		Poor communication skills	3
		Stress in the crowd	2
		Feeling ashamed of the presence of the patient	2
		Feeling frustrated	4
		Restlessness	3
		Haste	3
	Quality of Relationship with the Patient	Feeling of hatred towards the patient	4
		Feeling angry towards the patient	3
		Wishing for the death of the patient	4
		Inability to control the patient	2
		Confusion in care	3
		Feeling guilty	2

As shown in Table 1, the two main themes, "inability to control emotions and feelings" and "caregiver relationships," were extracted.

1-Inability to control emotions and feelings

This theme includes two sub-themes, "aggression" and "feeling of helplessness." Aggression was a common behavior among main caregivers, which included aggression toward oneself, toward the patient, and toward others. Caregiver #4 said to himself, "I yell at myself, I cry loudly when I'm alone." Caregiver #7 mentioned aggression towards the patient and said, "Even when he calms down, I start fighting and yelling." In this regard, caregiver #2 stated: "I get angry when there is nothing I can do." Regarding the patient's aggression, caregiver #1 said: "He yells at me so much that I can't stand it anymore." Most caregivers felt helpless in caring for patients, which led to aggression and discomfort. Caregiver #8 stated: "I don't have control over my life anymore." Caregiver #7 said: "I want to die, but I can't bear this life for one more day." Caregiver #3 stated: "I don't get any peace or pleasure from this life". Caregiver #3 also said: "We spend a lot of money in this way. "

2- Caregiver relationships

This theme includes three sub-themes: "family relations," "social relations," and "quality of relationship with the patient." Caring family relationships refer to the quality of relationships within families and with others. Caregiver #4 said in this regard: "My family distanced themselves from me because of my wife's behavior." Caregiver #3 stated: "My father's behavior is such that I am embarrassed to communicate with my friends." Caregiver #7 also mentioned the relationship between the neighbors and said: "Because of my wife's pessimism, we don't have a relationship with any neighbors." Social relationships refer to the caregiver's participation in society. Caregiver #4 stated: "I have a good job position, but I have no desire to work." Caregiver #8 said about this: "I am ashamed to sit in the crowd." Caregiver #2 said: "When I have to say something, I am embarrassed by the reaction of people in the crowd." In relation to the patient, some caregivers expressed their inability. As an example, caregiver #1 said: "I hate it, I want to get out of this life as soon as possible". Caregiver #5 also said: "I don't know what to do anymore, I'm tired and confused." Caregiver #5 stated: "Because I am always so aggressive and restless, I have a guilty conscience that why I can't help him".

Discussion

The present study aimed to investigate the lived experience of the main caregiver of patients with BPD, qualitatively and with a phenomenological approach, on eight main caregivers of patients with BPD referred to Sina Hospital in Hamedan, Iran. The results of the analysis of interviews with the participants, five sub-themes "aggression," "feeling of helplessness," "family relations," "social relations," and "quality of relationship with the patient," as well as two main themes "inability to control emotions and emotions" and "caregiver relations."

According to the results of this research, most of the caregivers had inappropriate family relationships and were dissatisfied with the conditions created in the family. Some caregivers mentioned a decrease in family communication, rejection by the family, and unwillingness to be part of the family. In terms of social relations, caregivers faced problems such as frustration, feeling ashamed in the patient's presence, stress in crowded areas, and poor communication skills. Some caregivers did not have a good relationship with the patient, in such a way that some people felt guilty that their loved one was suffering from this disease. Others wished for the death of the patient and treated him with anger and hatred. These results are in line with the results of [11].

The results revealed that the description and negative experiences of the main caregiver of people with BPD are in the context of family and social relationships. Some family relationships were on the verge of rejection and collapse. These results are consistent with those of [17, 18]. Although providing support and care to loved ones who need it can be rewarding, it often places a significant burden on family members and caregivers. Additionally, over time, stress can erode family members' ability to cope effectively, compromising their psychological well-being and quality of life. One of the main features of personality disorders is a significant impairment in interpersonal functioning that may cause challenges in close relationships. In a qualitative study, Bateman & Fonagy [19] implemented interventions to reduce tension in the relationship between family members of patients with BPD (fighting, distancing, separation, etc.). They also analyzed the extent to which the participation of caregivers (family members or relatives) can improve the relationship with the patient.

McCarthy et al. [12] provided interventions through community studies, designed for patients and their family members. However, they also provided training for other professional groups (teachers, counsellors, social workers, and educators) who may be involved with these vulnerable populations. These trainings aim to improve the quality of relationships between members close to patients (caregivers). Caluza et al [13] investigated the proper functioning of families in people with BPD in family interactions. They concluded that the self-destructive behaviors of patients have a direct effect on the relationship of family members and caregivers with them; therefore, interventions are necessary to be able to examine these relationships.

It seems that the participants experience emotional feelings that are almost as close to those of the patient, due to their closer relationship with the patient. In this regard, they experience feelings such as fatigue, sadness, grief, depression, lack of peace and self-blame and all kinds of aggression. Caregivers reported a lack of understanding about their role and a need for support to address the challenges they faced. They also perceived a lack of sensitivity to their own needs and concerns and believed that they were seen as overly anxious. They also described the financial burden of not being able to work because of a caring role or paying for treatment. Caregivers of people with personality disorders experience burden, grief, and similar interpersonal challenges in their support role. These results align with those of [11, 13, 14, 20]. Living with a mental patient person causes the family members to be under severe stress, and affects all aspects of their lives. Since a family member develops a mental illness, it disrupts the vital balance of the family system in relationships, roles, and desires. Therefore, the integrity of the family system cannot be ignored in the occurrence of such disorders [21].

The results indicate that the main caregiver or caregivers do not have an excellent understanding of the experiences of a person with BPD and the complexity of caregiving, especially negative experiences. This result is inconsistent with the results of [22]; it was shown that the family and relatives of people with BPD see their experiences and understand them with their feelings due to their constant presence with the patient. The results also showed that some caregivers tend to continue caring for a person with BPD due to feeling pity and guilt. In addition, some caregivers have demonstrated that they are not fully aware of the patient's emotional state and the harm they may inflict on themselves, which can complicate the provision of effective support to patients. Bailey & Grenyer [23] reported that caregivers of people with BPD experience objective and subjective burden, sadness and poor empowerment, and may also report depression and anxiety.

The present study included some limitations. The caregivers had a rich experience with the BPD patient. Due to the lack of research in this area, the current study is one of the first to demonstrate this phenomenon in Iran. According to other qualitative studies, the generalizability of this study is limited. Additionally, this research may not encompass all experiences of caregivers residing in other cities. Therefore, it is recommended that research be conducted on the lived experiences of primary caregivers in various cities and cultures across Iran. In addition, it is recommended to examine family roles and the way of dividing tasks between family members when caring for the patient.

Conclusions

The results of this study indicated that the experiences of BPD caregivers faced a variety of unpredictable problems in caring for their patients. Due to care pressure, caregivers experience a low quality of life. Two key elements in relation to these caregivers should never be forgotten. First, every member of society should respect and pay attention to the vital role of caregivers of BPD patients, and this can reduce much stress these caregivers experience. Second, authorities and policymakers can address the problems of these caregivers by developing appropriate legislation that facilitates the solution to their issues. Therefore, the need for comprehensive support seems to be essential for caregivers of patients with BPD.

Compliance with Ethical Guidelines

The ethics ID of (IR.IAU.SHIRAZ.REC.1401.041) was received from the Research Ethics Committee of Islamic Azad University, Shiraz Branch, and the detailed working method of the device was fully explained to the participants. In addition, necessary explanations were provided regarding the absence of complications and no cost to the subjects.

Acknowledgments

The authors would like to express their gratitude to the participants and their families for their cooperation in this study.

Authors' contributions

All authors made equal contributions to this study.

Funding/Support

The research, authorship, and/or publication of this study were not financially supported.

Conflicts of Interest

The authors declared no conflict of interest.

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