The Lived Experiences of Family Members of a Sibling with Borderline Personality Disorder in South Africa: A Qualitative Study

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Abstract

Background: Family members of people living with borderline personality disorder (BPD) experience a considerable objective and subjective burden. This article aims to report on a study that explored family members' lived experiences of having a sibling with BPD in South Africa.

Method: This qualitative study used in-depth phenomenological individual interviews, supported by participant observations and field notes for data collection. Data were analysed using Tesch's thematic coding.

Results: Seven participants were interviewed, and three themes emerged from the collected data. The study revealed that participants experienced multiple challenges in understanding, gaining control, and struggling to cope with their own lives. Participants also experienced the impact of a lack of communication and education. Lastly, the study revealed that the participants used individual coping mechanisms to cope with having a sibling with BPD.

Conclusions: This research illuminated the challenges experienced by family members of a sibling with BPD. These findings provide a basis for recommendations for mental health nurses to promote the mental health of affected family members.

Background

Borderline personality disorder (BPD) is a serious mental health challenge worldwide. Globally, the incidence of BPD has been estimated to be about 1–3% of the general population,[1] but little data is available on the number of patients with BPD in South Africa. The most prominent characteristics of people with BPD are pervasive disturbances of interpersonal relationships, self-image and affect. These characteristics are illustrated by marked efforts to avoid rejection, which can lead to identity disturbance, impulsivity, and unstable and intense relationships.[2] Individuals with BPD make frequent use of health services and are difficult to manage without team supervision and support.

Family members of people living with BPD experience a considerable objective and subjective burden.[3] Fossati and Somma[4] agree that BPD places a heavy burden on people suffering from the disorder and those living with them. Moreover, Nouvini[5] confirms BPD often leads to tumultuous interpersonal relationships, where those suffering from the disorder feel invalidated and misunderstood by loved ones who believe them to be manipulative and immoral. People with BPD are prone to feeling angry and alienated from members of their families, while family members may feel helpless and angry at the way their siblings with BPD relate to them.[6] Therefore, living with a person with BPD may cause widespread disruptions in family members' routines.[7] It has also been determined that family members of relatives diagnosed with BPD have ineffective coping strategies related to a lack of communication skills and knowledge, and at times they find themselves having to manage situations for which they are not prepared.[8]

Family caregivers of people diagnosed with BPD's experiences have been studied by Hoffman, Fruzzetti and Buteau,[9] Buteau, Dawkins and Hoffman,[10] Lawn and McMahon,[11] and Kay et al.[8] Various challenges, such as negative feelings towards their relatives, social humiliation, financial strain, marital discord, caregiver and financial burden, grief, and isolation, were some of the similarities in these studies.[8, 9, 10, 11] Barr et al.[12] also examined family members' or carers' experiences supporting someone with a personality disorder. The authors[12] reported that carers described the importance of early assessment and intervention for personality disorders. In support, Greer and Cohen's[13] research focused on the partners of individuals with BPD, who experienced emotional challenges, dual roles as both a romantic partner and parental/therapeutic figure, and a lack of control.

Individuals with BPD pose a challenge to their siblings, as BPD affects not only the person with the disorder but also those around them.[7] This notion is supported by Kovacs, et al.,[14] who claim the mental health problems of one family member influence the whole family system, including sibling relationships. Furthermore, siblings may not identify themselves as carers and therefore feel unable to access health services themselves, even though they play a significant part in providing support for their brother or sister.[15]

The Oxford Learners' Dictionaries[16] defines a 'sibling' as one of two or more individuals sharing one or both parents in common. In most societies throughout the world, siblings often grow up together, thereby facilitating the development of strong emotional bonds. In this article, a sibling refers to a sister, a brother, or an adopted brother or sister of a family member who has BPD.

There seems to be a gap in the literature, as previous studies have not clarified siblings' caring relationships and experiences in the South African context. The aim of this article is thus to report on a study that explored family members' lived experiences of a sibling with BPD in South Africa. Insight into these lived experiences could provide recommendations for mental health nurses to promote the mental health of family members affected by this phenomenon.

Methods

Participants

A qualitative, exploratory, descriptive, and contextual design was applied[17] to capture the essence of family members' lived experiences of a siblings with BPD. Purposive sampling to used to select information-rich participants who met the criteria of having a sibling with BPD. The participants had to have lived with their siblings for most of their lives. They were 18 years and older, either male or female, and were willing to participate in the study. Participants were recruited from a psychotherapy unit that admits people diagnosed with personality disorders. The setting of this psychotherapy unit was a mental health hospital in Johannesburg, South Africa. The researcher introduced the study to the patients admitted in that psychotherapy unit with a diagnosis of BPD, and obtained their written permission allowing interviews with their family members and providing their contact details.

Potential participants were informed of the purpose of the study and invited to participate telephonically. In line with the ethical requirements of universities, ethical clearance was obtained with the following reference numbers: HDC-01-44-2016, REC-01-135-2016 and M181130. Written informed consent was obtained from all participants before the interviews commenced. Nine potential participants were approached, but only the seven who agreed to participate were interviewed. There were three female and four male participants aged between 22 and 49. Table 1 outlines the participants' demographic characteristics.

Table 1
PARTICIPANTS' DEMOGRAPHIC CHARACTERISTICS

Participant	Age	Relationship	Race	Living with the sibling
1	22	Brother	White	Not currently
2	25	Sister	White	Not currently
3	24	Sister	White	Not currently
4	33	Brother	African	Not currently
5	22	Sister	African	Yes
6	37	Brother	African	Yes
7	49	Brother	African	Yes

Procedure

Data were collected using in-depth phenomenological individual interviews, supported by observations of participants, and field notes kept by the researcher. The main question posed to the participants was: "How is it for you to have a sibling with BPD?" The researcher conducted interviews on a day and time suitable for the participants in 2019. The interview venue was an office at the mental health hospital, free from interruptions. Appropriate follow-up questions were asked during the interviews as required, using communication skills such as probing, reflecting, clarifying, and summarising. The interviews ranged from 37.9 minutes to 55 minutes, were audio-recorded and transcribed verbatim. Any information that was personally identifying was removed from the transcripts.

Data analysis

Data were analysed to understand participants' lived experiences using Tesch's thematic coding[17] method. The researcher also adhered to Husserl's descriptive phenomenological approach,[18] which meant she bracketed or put aside her own preconceived opinions. For data analysis, all transcripts were read carefully while making notes as they came to the researcher's mind. Similar ideas were clustered and then organised as major topics, unique topics, and leftovers. The data (transcribed interviews, field notes and observations) were coded, units of meaning were identified and linked together to form themes with supporting categories. Direct quotations from the participants were included to support the identified

themes. An independent coder, experienced in qualitative data analysis, also analysed the data, and consensus was reached between the researcher and independent coder after discussion. Themes were then presented to participants for validation to ensure that accurate meaning was captured.

Results

Three themes emerged from the data analysis. These are discussed in the sections that follow.

Theme 1: Multiple challenges in understanding, gaining control, and struggling to cope with their own lives

Participants reported that having a sibling with BPD put a strain on families as it affected not only the person with the illness but also those around them. Their reported experience was that their sibling with BPD was emotionally draining. Participants felt sad, frustrated, lost, powerless and angry due to the highs and lows of not knowing what to expect from their siblings. The participants expressed how their families were affected:

"It was affecting everybody in the family, my grandparents ... It was taking a large toll on all of us." (P1, 22yrs old, brother)

"It affected everybody as everyone felt disrespected" (P6, 37yrs old, brother)

"*Seeing your sister like that is not fun, it's not nice and it affects you because half the time you ask yourself why, why?"* (P4, 33yrs old, brother)

Participants were cautious in their interactions with their siblings, as they did not want to trigger their illness. They also reported their frustration at their sibling's poor cooperation. Others blamed their parents for not taking more urgent control over their sibling with BPD. Some participants felt resentful because they observed their siblings with BPD always got their way and did not realise their impact on others' lives. Participants were angry because their siblings with BPD did not think about how their behaviour affected those around them when they attempted suicide. The following direct quotation supported this view:

"I was angry with her for trying to kill herself, leaving us behind … I felt disappointed and was also sad that I was going to lose my sister over something that I don't even know." (P5, 22yrs old, sister)

Some participants wanted to act in a vengeful manner so that their sibling with BPD could get an idea of how their behaviour and actions affected others:

"I actually feel like it's on purpose, to choose a dress that she would not look good in just to … show her a little bit of … But that is not me" (P3, 24yrs old, sister)

"*My graduation is coming … but I have decided not to invite her"* (P2, 25yrs old, sister)

Some participants experienced joy and were relieved after their sibling's final diagnosis, when a 'name' was given to all the chaos. These experiences of joy were reported as:

"Now that I understand living with her is easier because I have an idea of what the condition is about." (P5, 22yrs old, sister)

"I read more about it and it did make sense now." (P1, 22yrs old, brother)

Theme 2: Impact of a lack of communication and education

Participants loved their siblings but wished for two-way communication channels where both parties could be heard and validated. Patients with BPD often present with a number of behaviours that are considered disruptive, such as causing self-harm, expressing violent behaviour, impulsivity, or suicidal ideation. These behavioural tendencies put the patient at significant risk to themselves and others if left unmanaged.

Participants appeared to need attention and encouragement from their parents in how they responded to their sibling with BPD. A lack of support from parents had an impact on participants' reactions to their sibling's illness. When they felt unsupported, they were more likely to respond negatively and develop resentment towards their sibling. However, if participants felt supported, they tended to contribute positively to their sibling's care. Parents' lack of support is expressed in the following direct quotations:

"*It's not really her doing … but my parent's … she gets a different treatment to us to a point. There is a fine line between treating her differently for her condition and favouring her"* (P2, 25yrs old, sister)

"I feel very bad because she is the fragile one ... I can say umatebe (she is like an egg). So even if our parent's fight I try to pull myself together so that I can comfort her and my younger sister and be there for them" (P5, 22yrs old, sister)

Family members experienced that their relationships with the individual who had BPD were conflicting. Participants were aware of their sibling's lack of awareness of the impact of their behaviour on their family. Still, they yearned for calm discussion and respectful communication:

"If it was not going her way, we would have fights and it was really not pleasant at all" (P3, 24yrs old, sister)

"*She makes it obvious around the house: 'Please keep your distance' and puts that face that says, 'stay there.' We therefore need to have a strategy around how we approach her*." (P4, 33yrs old, brother)

According to the participants, healthcare professionals did not communicate with or educate families regarding individuals' BPD diagnosis and the management thereof. Participants reported having difficulties understanding what was going on as they (and their parents) were not informed about their

sibling's illness; this caused great confusion amongst the family members. Sometimes, family members act as caregivers for the individual with BPD and are case managers during a crisis, yet they are rarely – if at all – included in the treatment plan when their siblings are diagnosed. Therefore, they may struggle knowing how to respond effectively to these individuals' problematic behaviours, like angry outbursts, self-harming acts, and expressions of a fear of abandonment.

Little support and education are offered to family members, and most have limited knowledge of the BPD treatment programmes that their siblings receive when admitted to the hospital. Participants reported they still do not know how to manage or support their siblings after being discharged. The family members were left to search for information themselves and resorted to using the internet to obtain information about the disorder. The following direct quotations are illustrative of this finding:

"*We had to find out on the internet what borderline personality disorder after the doctors told us her diagnosis. I still think it would help us as a family if they explained this illness in more details"* (P7, 49yrs old, brother)

psychiatrists and everyone had their own ideas they said it is Bipolar and all the medicines they gave her never did anything for her, it actually made it worse and I think that is why she became so aggressive I don't know" (P2, 25yrs old, sister)

"We didn't know what was wrong until we took her to hospital to see a doctor. That is when they told us about the disorder that she has and how we should go about dealing with her" (P6, 37yrs old, brother)

Theme 3: Individual coping mechanisms

Participants reported that having a sibling with BPD put a strain on families and they tried coping with the situation using different strategies. Some coping strategies included defence mechanisms such as suppression, avoidance, rationalising, blaming and projection. Family members often experienced subjective burdens or emotional consequences because of their sibling's illness. Participants used suppression to cope and explained they postponed dealing with their own thoughts or feelings, and put it all aside. Participants' use of suppression as a coping mechanism was explained as follows:

"We just have to bear with her and assist her as much as we can" (P6, 37yrs old, brother)

"I'm enraged at her still today (jaws clenched, face turning red) but I will never say it to her but I do feel like that" (P3, 24yrs old, sister)

One participant used avoidance. Family members rejected and avoided contact with the affected individual, and some cut off the relationship and/or stopped talking about that person. A participant said: "*I don't want her in my life and it's not a nice thing to say because she is my sister*" (P3, 24yrs old, sister), reflecting her use of avoidance as a coping mechanism.

Some participants also used rationalising as a coping mechanism. Participants justified their sibling's acts and moods by reminding themselves they were vulnerable or ill:

"*He was diagnosed with HIV, which I later then thought that could have been the reason why he was behaving the way he was*" (P7, 49yrs old, brother)

"*We didn't know what was wrong, but we felt that the illness began when she was at school because there she had all the freedom … we did not realise that she was using dagga*" (P6, 37yrs old, brother)

A few participants blamed their parents for not controlling and disciplining the sibling with BPD. The use of blame is illustrated in these comments:

"Now that you live on your own it's nice but it's not the way I planned my life, so she basically ruined my life" (P3, 24yrs old, sister)

"She didn't think about us or her family who need her. She didn't even think about her children" (P5, 22yrs old, sister)

Participants also used projection as a coping mechanism. They found it hard to understand the cause of their sibling's behaviour changes. Some family members experienced mixed emotions of loving yet hating their siblings due to how they relate to them:

"I mean, this is my sister. I'm not supposed to want her dead" (P3, 24yrs old, sister)

"At home … (hesitating) I also think things that triggers her illness is that she is not happy with the environment that we are living in but there is nothing that we can do because we live in a tavern. Our parents don't have money to buy a house, so they rented a place somewhere and left us at home. I think that is one thing that triggers her. She also mentioned our parents' issue, our parents fight a lot that also affects her. My family is not a conducive family" (P5, 22yrs old, sister)

Discussion

This study explored individuals' experiences of having a sibling with BPD. Multiple challenges were experienced by the participants, including a lack of understanding, gaining control and struggling to cope with their own lives. Families and friends of an individual with BPD experience high levels of psychological symptoms, including anxiety and depression, objective and subjective burdens, and grief.[19] Moreover, family members experience negative feelings, despair, sadness and regret, humiliation, guilt, and shame towards their relatives diagnosed with BPD.[8] Family roles and relationships become strained due to the emotional challenges of having a sibling with BPD. Giffin[7] agrees and states that people appear less tolerant of their sibling's self-harming behaviour and are quick to express their expectations that they should take responsibility for their lives and behaviours. Uys and Middleton[20] further concur with the findings of this study that patients and their families still receive very little information about mental illness. Often, they are not even told what the diagnosis is and sometimes vague terms like 'breakdown' are used. Also, in a focus group run by Dunne and Rogers,[21] family members reported they

had to research the diagnosis for themselves using books and websites. They expressed a wish to be informed about how to effectively manage situations that arose with their loved ones.

The findings of the study on which this article is based indicated that families struggle in their own daily lives and in dealing with their relatives with BPD. These experiences signal the need for mental health communities to become more knowledgeable about BPD and its treatments, the establishment of support groups for family members, and ways to communicate this information to those who need it, as proposed by Buteau et al.[10] This suggests mental health nurses would benefit from understanding individuals' experiences of having a sibling diagnosed with BPD. The mental health nurses could then develop material to educate and train families on how to manage their interactions with their siblings living with BPD more effectively.

A lack of communication and education was empasised by participants in this study. Interpersonal relationships suffer due to a lack of constructive communication and education on the disorder, resulting in family members understandably being tormented by the threat or perpetration of aggressive acts, as noted by Gunderson.[22] Participants' reactions varied from wanting to protect their sibling, to anger at the perceived attention-demanding aspects of their behaviour. Mental health nurses should therefore assist family members by providing support and referral information for mental health education.[22] Gunderson[22] further states family members should not assume the primary burden to ensure patients' safety. Instead, family members should contact professionals for help if there is a perceived threat of harm, or the patient has already engaged in self-harming behaviour. According to Choi,[23] when families contribute to a collaborative treatment plan and are empowered to participate in the therapy or treatment process, all participants in the family system potentially contributing to the problem may be assisted and effectively challenged.

Bailey and Grenyer[24] emphasise that the family environment has an important implication for the clinical outcome of patients with a mental illness. It has also been found that where parents focused their energy on actively caring for a child with BPD, their relationships with their other children became more distant.[7] Therefore, it is important when mental health nurses engage with families of people with BPD to emphasise the dynamics within the family and remain aware of how it impacts the whole family.

As stated, according to Uys and Middleton,[20] patients and their families receive very little information on the affected individual's diagnosis and treatment plan. This view is supported by Giffin,[7] who claim family members experienced meetings with health professionals and the treatment team were for the benefit of the clinicians, and often just fact-finding sessions for health professionals. In light of the challenges family members experience, Fossati and Somma[4] highlight that relatives of individuals with BPD should have the opportunity to receive state-of-the-art, evidence-based information on BPD and its available treatments to destigmatise the diagnosis and support the family's role in BPD development. Therefore, adequate family interventions in BPD treatment programmes should be accessible and inexpensive.

Moreover, family members of siblings with BPD are likely to be involved in stormy, roller-coaster relationships, and as a result, may feel overwhelmed by the extreme, unpredictable feelings and situations, even when they do not suffer from any mental

disorder themselves.[4] As illustrated in this study, family members may blame themselves for their relative's illness or for not being able to do more to help. This can result in emotional consequences, including anxiety, guilt, anger, frustration, despair, and hopelessness.[25] Ultimately, ineffective coping skills are attributed to a lack of knowledge among family members, preventing them from making appropriate choices in assisting their relatives diagnosed with BPD.[8] Similar findings were reported in this study, and the inadequate coping mechanisms mentioned by the participants were related to their lack of knowledge of the disorder.

Based on this discussion, family intervention programmes are likely to create awareness of the different problems family members who have siblings with BPD encounter. Lawn and McMahon[11] determined that family carers of people diagnosed with BPD experience significant exclusion and discrimination when interacting with mental health services. Therefore, education for all health professionals is indicated, especially those who are likely to encounter BPD carers, to improve their skills and attitudes in working with people diagnosed with BPD.

Limitations And Future Research

Although data saturation occurred in the analysis of qualitative interviews, the study's small sample size may be a limitation, as other views may not have been represented. Further research focusing on the provision of collaborative care for people with BPD and their families could be conducted.

Conclusion

BPD affects the person diagnosed with it and everyone around them. Individuals face significant challenges when their sibling is diagnosed with BPD. They often have difficulty coping with their sibling's demands while trying to live their own lives. They also experience a range of emotions in their quest to get control over the situation at hand while battling to live their own lives. Often, interpersonal relationships suffer due to a lack of knowledge and education about the disorder. Family members yearn for constructive communication and support to help them balance their lives and cope with the demands of having a sibling with BPD. Recommendations are proposed for mental health nurses who spend time with patients and families of patients with BPD:

- Mental health nurses could play an advocating role in the multidisciplinary team caring for the individual with BPD. This advocacy role would ensure healthcare professionals communicate and provide education to families about the diagnosis and management of BPD.
- Mental health nurses could establish support groups for families and patients with BPD.

- The mental health nurses could establish family intervention programmes, such as family therapy, which would focus on conflict resolution. Couples' therapy for the parents of individuals with BPD could be conducted to ensure they are able to manage the challenges brought into the family when one child has BPD.

These recommendations provide a basis for mental health nurses to promote family members' mental health.

Declarations

Ethics approval and consent to prior to the start of the study

This study received ethics approval from the University of Johannesburg Research Ethics Committee (REC-01-135-2016) and the University of the Witwatersrand (M181130). All participants were informed of the aims and risks of the study and provided informed consent to participate.

Consent for publication

Not applicable.

Availability of data and materials

Data from the current study will not be made available, as participants did not consent for their transcripts to be publicly released. Extracts of participant responses have been made available within the manuscript.

Competing interests

The authors have no competing interests to declare.

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Authors' contributions

NN –Supervision, Writing, Review & Editing

WC – participant recruitment, data collection, data analysis, and writing- original draft.

MP – Supervision

CPHM – Supervision

All authors read and approved the final version of the manuscript.

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