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## LIVED EXPERIENCES OF FAMILY MEMBERS WHO HAVE A SIBLING WITH BORDERLINE PERSONALITY DISORDER

ΒY

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#### MINOR DISSERTATION

Submitted in partial fulfilment of the requirement for the degree of

#### **MAGISTER CURATIONIS**

In the

#### FACULTY OF HEALTH SCIENCES

DEPARTMENT ON NURSING SCIENCES

JOHAN<sup>At the</sup>SBURG

#### UNIVERSITY OF JOHANNESBURG

Supervisors:

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#### DEDICATION

I would like to dedicate my work to God almighty for giving me strength and life to be who I am today. To my friends and my family, for your love, support and prayers during the wearisome times. To my mother, for bringing me into this world.



#### ACKNOWLEDGEMENT

I wish to express my sincere appreciation and gratitude to all the people who played a crucial role in my life and career, both directly and indirectly.

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#### ABSTRACT

Mental illness does not only affect the individual with the illness but their whole family. Amongst mental illnesses, borderline personality disorder (BPD) has been found to be the most difficult and challenging to manage. People with BPD have unstable and very intense interpersonal relationships which are characterised by excessive idealisation and devaluing of a loved one as well as fear of real or imagined abandonment. Family members, like siblings, are the most affected because of these challenges.

The purpose of this study was to understand the lived experiences of family members who have a sibling with BPD, and to formulate specific recommendations to facilitate family members' mental health. The siblings with BPD can be very challenging to those close to them and have frequent emotional outbursts which can range from verbal abuse to physical attacks. At times, they act out in self-destructive activities as an act of revenge towards their loved ones.

A qualitative, exploratory, descriptive and contextual research design was utilised in this study. There were two phases to this research. In Phase One, the lived experiences of family members who have a sibling with BPD were explored and described. A purposive sampling of family members who have a sibling with BPD was utilised in this study as it provides information-rich cases. Data were collected using in-depth, semi-structured, phenomenological interviews until data saturation was achieved.

Lincoln and Guba's approach to ensure trustworthiness was adopted. Tesch's method of data analysis was employed to analyse the data. The researcher made use of the services of an independent coder who is an experienced psychiatric nurse practitioner, and a consensus discussion was held between the researcher and independent coder. The findings of the research were discussed in light of the literature relevant to this study as well as other similar studies to verify the findings.

Findings showed that the participants passionately divulged their very challenging journeys. It seemed that living with a family member who suffered from BPD cause

chaos and distraught in all spheres of life, especially before the family members were diagnosed. The diagnosis brought some relief, as they suddenly had a 'name' for what was happening; however, they still had a hard time coping with all the demands of the family member with BPD while at the same time trying to live their own lives.

In Phase Two, specific recommendations were formulated to promote the mental health of the family members who have a sibling with BPD. The role of the psychiatric nurse practitioner in mobilising resources to facilitate the mental health of family members who have a sibling with BPD was formulated. Recommendations were made for psychiatric nursing practice, psychiatric nursing education, and psychiatric nursing research.



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## CHAPTER 1 OVERVIEW OF THE STUDY AND RATIONALE

#### 1.1 BACKGROUND AND RATIONALE

Borderline Personality Disorder (BPD) is a serious mental health problem in South Africa and globally. The incidence of BPD has been variously estimated to be from about 0.7% to 2.0% of the general population (Veysey, 2014:20; American Psychiatric Association, 2013:53), and of those, 75.0% are females (Zeichner, 2013:2). Many authors believe that males are under-represented and under-diagnosed in mental health institutions and that they are likely to be found in substance use centres and the justice system, undiagnosed with BPD (Hengartner, Ajdacic-Gross, Rodgers, Muller & Rossler, 2013:477; Robitaille, Checknita, Vitaro, Tremblay, Paris & Hodgins, 2017:1).

In a recent study, Keltner and Steel (2015:36) indicated that various forms of childhood adversities, such as bullying, violence in schools, and emotional abuse have a higher association with personality disorders, particularly BPD, compared to sexual abuse. However, it is estimated that 70.0% of those diagnosed with BPD have a history of past sexual abuse, with 46.0% being victims of adult violence (Baumann, 2015:591). It is evident from previous studies that people with BPD are prone to feeling angry at members of their families, and they are thus alienated from them while family members may feel helpless and angry in terms of how their siblings with BPD relate to them.

The most prominent characteristics of people with BPD is that they have a pervasive disturbance of interpersonal relationships, self-image and affect, illustrated by marked efforts to avoid rejection. This can lead to identity disturbance, impulsivity and unstable and intense relationships (Baumann, 2015:591).

These individuals have also been noted to make frequent use of health services and are difficult to manage without team supervision and support. Little support – sometimes no support – is given by psychiatric nurses and other healthcare providers to family care givers and family members who have siblings with BPD. Family

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members are not trained and have no skills to manage their siblings with BPD even though at times they find themselves having to manage situations for which they are not ready. While international studies focus on programmes for relatives of people with BPD, like Family Connections, and the experiences of family caregivers of people diagnosed with BPD (Bailey & Grenyer, 2013:249), there are limited, if any, studies that are directed at the experiences of family members with siblings who have BPD, especially in South Africa. Research shows that BPD is the most stigmatised condition in mental health and that mental health professionals often have negative attitudes towards people with BPD. It reveals itslef in lowered empathy, reduced availability of services and also reduced quality of services (Sheehan, 2016). Thus, the family members are an underserved population.

The researcher hoped that this qualitative, exploratory, descriptive, phenomenological study would enhance insight into the lived experiences of family members with a sibling with BPD. She also aimed to develop specific recommendations for the promotion of mental health of the family members through the mobilisation and implementation of resources by the psychiatric nurse practitioner in the psychiatric institutions as well as in primary healthcare settings in South Africa.

## 1.2 PROBLEM STATEMENT NIVERSITY

Burns and Grove (2009:69) describe the research problem as an area of concern in which there is a gap or a situation in need of a solution, improvement or alteration, or in which there is a discrepancy between the way things are and the way they ought to be. Family members with BPD pose a significant challenge to their siblings. BPD can be thought of as a disorder which affects not only the person with the disorder but also those around them (Giffin, 2008:136).

Fitzpatrick, Wagner and Manson (2019:2) state that theorists in biosocial theory explain the effect of BPD in close relationships in adulthood when emotional intensity increases in individuals with BPD and those close to them. People close to BPD individuals may attempt to avoid the emotional intensity and rather engage in ineffective problem solving, emotional validation or emotional tolerance. Moreover, they may respond with judgement and fail to express their own emotional experiences,

resulting in behaviours involving demands, criticism, withdrawal or attacks on people with BPD. This creates a history of conflict in relationships and perpetuates vulnerability and negative emotions in relationships between people with BPD and those close to them.

There is extensive literature that examines the stress on family members who care for patients with BPD. There is, however, a gap in the description of the extent of the experiences of family members who have a sibling with BPD.

Programmes to intervene with families to modify familial interactions and/or to educate family members are almost non-existent (Hoffman, Fruzzetti & Buteau, 2005:217), and individuals are unable to understand and cope with their siblings with BPD. These individuals are thus an underserved population as there is no standardised information available to educate, support and help them understand the disorder, the chaos that often exists, or the impact of the illness on their ill relatives or themselves (Hoffman & et al. 2005:222). The research questions that arose from this problem statement are:

- What are the lived experiences of family members who have a sibling with BPD?
- What specific recommendations can be formulated to facilitate the mental health and promote optimal care of family members who have a sibling with BPD by the psychiatric nurse practitioners?

#### 1.3 **RESEARCH PURPOSE AND OBJECTIVES**

The purpose of this study was to understand the lived experiences of family members who have a sibling with BPD, and to formulate specific recommendations to facilitate family members' mental health.

The research objectives were:

• To explore and describe the lived experiences of family members who have a sibling with BPD.

 To describe specific recommendations for the facilitation of mental health and the promotion of optimal care of family members who have a sibling with BPD by psychiatric nurse practitioners.

#### 1.4 PARADIGMATIC PERSPECTIVE

According to the Theory for Health Promotion in Nursing (Department of Nursing, University of Johannesburg, 2017:4-8), the purpose of theory is the promotion of health in individuals, families, groups and the community. Paradigms are models or frameworks that help researchers to be organised in their thinking, observation and interpretation processes. Therefore, the paradigm frames the way in which the disciplines concerned are viewed and the direction that the research project takes. Neuman (2014:14) describes a paradigm as a whole system of thinking, while Babbie and Mouton (2011:646) describe a paradigm as "model or framework for observation and understanding which shapes what people see and how they understand it". The paradigmatic perspective for this study included meta-theoretical assumptions, theoretical assumptions and methodological assumptions.

#### 1.4.1 Meta-theoretical assumptions

The context of this study was psychiatric nursing. The researcher was guided by the Theory for Health Promotion in Nursing (Department of Nursing, University of Johannesburg, 2017:4) as the basis for the theoretical framework of the whole person, which embodies the dimensions of body, mind and spirit. This wholistic view led to the concepts that are discussed in the following paragraphs.

#### 1.4.1.1 Person

In this study, the 'person' refers to an individual who has a sibling with BPD. The individual embodies the dimensions of body, mind and spirit. A person functions in an integrated, interactive manner within their environment (Department of Nursing, University of Johannesburg, 2017:4).

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#### 1.4.1.2 Mind

The 'mind' refers to the capacity and quality of the psychological processes of thinking, association, analysis, judgment and understanding of which the individual is capable (Department of Nursing, University of Johannesburg, 2017:4) as a basis for the theoretical framework.

#### 1.4.1.3 Environment

The environment includes an internal and external environment. The external environment consists of a physical, social and spiritual dimension. The internal environment consists of the dimensions of body, mind and spirit (Department of Nursing, University of Johannesburg, 2017:5). In this study, the environment consists of the physical structure of the family, the family member and his or her interactions with the sibling who has BPD.

#### 1.4.1.4 Mental health

According to the World Health Organisation (WHO) (2016:5), 'mental health' is a state of being in which an individual person realises his or her potential and can cope with the normal stresses of life. They can work productively and fruitfully and are able to make a contribution to their own community.

#### 1.4.1.5 Psychiatric nursing

Psychiatric nursing is a speciality in the nursing profession in which a nurse directs efforts towards the promotion of mental health and the prevention of mental disturbances. It also includes early identification of and interventions in emotional problems, and follow-up care in order to minimise the long-term effects of mental disturbances (Uys & Middleton, 2014:833).

#### 1.4.2 Theoretical assumptions

The Theory for Health Promotion in Nursing (Department of Nursing, University of Johannesburg, 2017:4) was utilised as a framework for this study, and the study was conducted inductively. After analysing the results, it was contextualised in the literature. In this study, the researcher used the theory based on the Christian approach and aimed to promote the mental health of individuals, family, groups and the community. These assumptions are important beliefs that the researcher holds about the person, the environment and mental health and interactive patterns with regards to the study undertaken.

#### 1.5 DEFINITION OF CONCEPTS

The conceptual definition of terms used in this study will now be discussed.

#### 1.5.2 Lived experience

Phenomenological studies examine human experiences through the descriptions that are provided by the people involved by answering the questions posed to them (Creswell, 2014:80). In this phenomenological study, the lived experience refers to the description of meaning of a concept or phenomenon experienced by family members who have a sibling with BPD.

#### 1.5.2 Borderline Personality Disorder

Borderline Personality Disorder (BPD) is a pervasive pattern of instability in interpersonal relationships, self-image, affects, and marked impulsivity beginning in early adulthood and presenting in a variety of contexts (American Psychiatric Association: DSM-5, 2013:663-666; Sadock & Sadock, 2015:750). In this study, the researcher planned to explore and describe the lived experiences of family members who have a sibling with BPD.

#### 1.5.3 Sibling

A sibling is one of two or more individuals sharing one or both parents in common (Oxford Learners Dictionaries, n.d.). A male sibling is a brother, and a female sibling is a sister. In most societies throughout the world, siblings often grow up together, thereby facilitating the development of strong emotional bonds. In this study, a sibling is a sister, a brother, or an adopted brother or sister, of a family member who has BPD.

#### 1.5.4 Family

A family unit in a community represents a group which consists of close-knit, mutually independent and reciprocal memberships (Kreigh & Perko, 1988:87). In a family, individuals establish norms and roles and validate their thoughts, actions and feelings through continuous interaction with the primary group. In this study, a family member refers to an individual who has a sibling living with BPD, who is 18 years old and older.

#### 1.6 METHODOLOGICAL ASSUMPTIONS

Methodological assumptions reflect the researcher's view of the nature and structure of the science of a discipline (Department of Nursing Science, University of Johannesburg, 2017:9). Methodological assumptions give form to the research objective and context, which influence decisions about the research design. In this study, the researcher followed a qualitative approach and applied the strategies of trustworthiness to ensure rigour. The evaluation of rigour was based on the logic of emerging theory and the clarity with which it sheds light on the phenomenon being studied (Gray, Grove & Sutherland, 2017:65).

#### 1.7 RESEARCH DESIGN METHOD

In this section, the research design and method that was followed in this study are described.

#### 1.7.1 Research design

In this study, a qualitative, exploratory, descriptive, contextual design (Creswell, 2014:12) was applied to capture the essence of the lived experiences of family members who have a sibling with BPD. The research design is a plan that describes when, how and where data are to be collected and analysed (Parahoo, 2006:215). According to Burns and Grove (2009:219), a research design is a blueprint for conducting the study that maximises control over factors that could interfere with the trustworthiness of the findings. It guides the researcher in planning and implementing the study in a way that is most likely to achieve the intended goal.

#### 1.7.2 Research method

In this study, descriptive phenomenology (Reiners, 2012:119) was utilised as the researcher described the lived experiences of family members who have a sibling with BPD.

This research took place in two phases as described in the sections that follow.

# 1.7.2.1 Phase One: The lived experiences of family members who have a sibling with BPD are explored and described

In this section, the population and sample, method of data collection, data analysis and literature control are discussed.

#### a. Population and sample

A population in qualitative research is determined by selection criteria, which seek individuals with special knowledge or unique experiences of a particular phenomenon to increase the researcher's understanding of the topic (Burns & Grove, 2009:343). The researcher selects a portion of a population, referred to as a sample. The purposive sampling method was used in this study, which is also known as judgmental sampling since it entails making a judgment about the population to be studied (Parahoo, 2006:212; Burns & Grove, 2009:355). In this study, the participants are

family members who have a sibling with BPD admitted in a psychotherapy unit in a psychiatric institution.

Participants who were chosen met the following inclusion criteria:

- They were either male or female
- They were living with or had lived with a sibling who has BPD
- They were 18 years and older
- They had a sibling living with BPD
- They were preferably able to communicate in English, Zulu or Xhosa.

#### b. Data collection

In the qualitative research methodology, data collection and data analysis occur at the same time (Creswell, 2014:198). Researchers bracket or put aside their own preconceived opinions according to Husserl's descriptive phenomenological design (Reiners, 2012:119). In order to avoid bias in this study, the researcher entered the field with an open mind and implemented bracketing by ensuring that she treated the participants' experiences without any preconceived ideas or any unfairness (Burns & Grove, 2009:546).

#### **OHANNESBURG**

During data collection, the researcher utilised in-depth phenomenological interviews to explore and describe the phenomenon, and she used bracketing, observation and field notes to avoid bias in the research (Burns & Grove, 2009:545). Moreover, the findings were contextualised by the literature control.

#### c. In-depth phenomenological interviews

A qualitative research approach requires the collected data to be rich in description of the phenomenon under study. The researcher conducted interviews at a public institution on the days and times arranged and agreed to by the participants. According to Burns and Grove (2009:409), an interview is a method of data collection whereby an interviewer obtains responses from a participant in a face-to-face encounter, through a telephone call or by electronic means. The researcher built a good rapport with the participants by showing them honesty and respect (Wellman, Kruger & Mitchel, 2005:169). Participants were made to feel that the researcher was interested in them as individuals and that their uniqueness was respected. She allowed them to feel completely free during the interviews. In this study, the in-depth, phenomenological interviews were used in order to produce dense and quality information on the phenomenon under study. The interview sessions lasted 40-60 minutes and were audio-recorded and transcribed verbatim.

The researcher asked one main question to participants:

#### "How is it for you having a sibling with BPD?"

Follow-up questions, probing, and minimal verbal responses were used only to confirm or to look for underlying meaning in the statements given by the participants (De Vos, Fouche & Delport, 2011:298).

#### d. Observation and field notes

Field notes are handwritten notes by the researcher, compiled during the qualitative interview process. During this study, the researcher made use of different types of field notes, including observational notes, personal notes, methodological notes and theoretical notes (Polit & Beck, 2012:218). These notes were later processed and converted into write-ups so that they could be edited for accuracy and made readable for analysis (Wellman, et al. 2005:196).

#### e. Data analysis

To analyse qualitative data, the researcher sought meaning from all the raw data that were available. The purpose of data analysis is to make sense of all the data that would have been collected, by placing it in a format to be able to distinguish the content (Wellman, et al. 2005:214). The researcher used Tesch's open-coding method of descriptive data analysis (Creswell, 2014:198) to analyse and make sense of data that were collected.

Units of meaning were identified from the data, transcribed interviews and field notes, and were linked together to form themes with supporting categories. The raw data were provided to an independent coder for analysis, who was selected purposely because of their experience in qualitative research. The independent coder used the same protocol for data analysis, separately from the researcher. The researcher and the independent coder met for a consensus discussion on the results of the data analysis.

#### f. Literature control

After the completion of data analysis, a literature review was done to grasp the essential meaning of the identified themes and sub-themes. The purpose of the literature review was to compare existing knowledge to the findings of the current study. The literature control therefore provides a framework for establishing the importance of the study, as well as a benchmark to compare the results with other findings (Creswell, 2013:133). This assisted the researcher in formulating specific recommendations to promote the mental health of family members who have a sibling with BPD.

## JNIVERSITY

# 1.7.2.2 Phase Two: Recommendations to facilitate the mental health of family members who have a sibling with BPD

Recommendations were generated based on the results derived from Phase One and were contextualised within the literature.

#### 1.8 MEASURES TO ENSURE TRUSTWORTHINESS

Guba's model of trustworthiness (Lincoln & Guba, 1985:289) were adhered to during the study and is described next.

#### 1.8.1 Credibility

Credibility is the notion of internal validity, which means that the participants recognise the meaning that they themselves give to a situation or condition, and the 'truth' of the findings in their own social context (Lincoln & Guba, 1985:289). According to Houser (2012:425), credibility is focused on the results accurately representing the underlying meaning of data; it is improved by prolonged engagement in the data collection process and triangulation. In this study, the researcher made use of a reflective diary, peer evaluation, member checking and in-depth interviews to ensure the credibility of the study. The researcher conducted fieldwork to meet with participants and used different methods of data collection like field notes, phenomenological interviews and transcripts from audio-recorded interviews to confirm findings (Merriam, 2009:105).

#### 1.8.2 Transferability

Lincoln and Guba (1985:297) use the term 'transferability' instead of generalisation, which means that the findings in one context can be transferred to similar situations or participants. A dense description was provided of the demographics of the participants. At the end of the process, a rich description of the results with supporting direct quotations from the participants in the form of extracts from selected interviews was made available.

## JOHANNESBUR

#### 1.8.3 Dependability

Lincoln and Guba (1985:299) use the term 'dependability' instead of reliability, which means that the findings of the study should be consistent and accurate to establish the trustworthiness of the study. This requires an audit which follows the process and procedures used by the researcher in the study and determines whether these findings are acceptable; that is, dependable (Burns & Grove, 2009:393). Dependability therefore refers to the provision of evidence so that if the study was to be repeated with the same or similar participants in the same or similar context, the findings would be similar. A dense description of the research methodology was presented.

In qualitative research, consistency is defined in terms of dependability. The researcher conducted in-depth, phenomenological individual interviews, which she audio-recorded to ensure an audit trail. The researcher used Tesch's method of data analysis (Creswell, 2014:198), which was followed step-by-step. A dense description was given where the researcher explained the full method of data collection and analysis. The researcher ensured triangulation by using data from interviews and field notes.

#### 1.8.4 Confirmability

Lincoln and Guba (1985:300) support confirmability, meaning that an audit or decision trail is available where readers can trace data to their sources. When confirmability exists, readers can trace data to their original source. Burns and Grove (2009:546) state that the findings, conclusions and recommendations should be supported by the data, and there should be internal agreement between the researcher's interpretation and the actual evidence. This is accomplished by incorporating an audit procedure. An audit was done of the whole research process to ensure confirmability.

#### 1.9 ETHICAL CONSIDERATIONS

Permission to conduct the study was obtained from the psychiatric institution where the researcher conducted the study. Approval from the Ethics Committees of the University of Johannesburg and the University of the Witwatersrand were obtained (refer to Appendices 1 and 2). According to Dhai and McQuoid-Mason (2011:174), there are four ethical principles to be considered when conducting research, namely autonomy, non-maleficence, beneficence and justice. In this study, all these principles were adhered to throughout the research process.

#### 1.9.1 Autonomy

This principle involves respecting people's right to make decisions based on their personal values and beliefs, free from the controlling influence of others. It also takes into consideration the individual's self-determination and is the basis of informed consent. Informed consent is the most central of the ethical principles and is prominent

in the federal regulations governing social research. Informed consent has four elements to ensure it is genuine, namely disclosure, understanding, the capacity to give consent, and voluntarily providing consent to participate (Burns &Grove, 2009:201).

Dhai and McQuoid-Mason (2011:174) state that the researcher has a responsibility to ensure that participants in a study are not unduly influenced to participate. Participants were given all the relevant information regarding the study, including the purpose of the study, and the risk-benefit ratio. Moreover, their right to privacy, confidentiality and anonymity were adhered to. It is an individual's right to determine the time, extent and general circumstances under which personal information will be shared with or withheld from others (Burns & Grove, 2009:196). The participants agreed on the time and date when the interviews were to be held with the researcher. Participants were informed that the researcher would provide each participant with a number or code, or that they could devise their own codes to ensure that their identities are not recognised and kept anonymous. The list of real names was destroyed after data analysis was completed. The researcher only kept the matching code numbers in a safe place.

According to Burns and Grove (2009:189), a right to self-determination is based on the ethical principle of respect for a person. Individuals should be treated as autonomous agents who have the freedom to conduct their lives as they choose without external controls. In this study, the participants were fully informed that their right to choose whether or not to participate was voluntary. The purpose of the study and the benefits were explained thoroughly.

#### 1.9.2 Beneficence

The basic idea is that it is up to the research participants to weigh the risks and the benefits associated with participating in the research study before they decide whether or not to participate. In this study, the researcher ensured that participants understood the potential risks and benefits of participating in the study. They were informed about their right to choose whether to participate or not, in a manner free from coercion.

#### 1.9.3 Non-maleficence

In the principle of non-maleficence, it is stated that one should do no harm to others. The researcher ensured that during this study the participants were protected against any kind of harm and potential risk to their psychological well-being, mental health, personal values and/or dignity. Participants were not exposed to any kind of harm. The participants were not exposed to risks greater than or in addition to those to which they are exposed in everyday life. Burns and Grove (2009:200) state that when the risk is high, the researcher must make every effort to reduce it and to maximise the benefit. Debriefing sessions were offered to the participants should they have experienced feelings of discomfort that arose during the interviews.

#### 1.9.4 Justice

Participants were treated with fairness at all times during the process of this study by making sure that they were respected equally. The researcher selected the participants for reasons directly related to the research problem and not because they were readily available or could easily be manipulated (Dhai & McQuoid-Mason, 2011:175). All participants had the opportunity to ask questions relating to the study. They were informed about their right to withdraw from the study at any time if they so wished and they were informed of the findings of the study.

#### 1.10 DIVISION OF CHAPTERS

- Chapter 1: Overview of the Study and Rationale
- Chapter 2: Research Design and Method
- Chapter 3: Discussion of Results

Chapter 4: Discussions of Specific Recommendations, Limitations and Conclusions

#### 1.11 SUMMARY

In this chapter, the researcher aimed to provide an overview of the study. The background and rationale of the study were outlined, and the research question and purpose were identified. The researcher's paradigmatic perspective was clarified,

followed by the research design and method that were used in this study. The researcher concluded the chapter by explaining the ethical considerations that were adhered to throughout the study. In Chapter 2, the research design and method are described.



## CHAPTER 2 RESEARCH DESIGN AND METHOD

#### 2.1 INTRODUCTION

In this chapter, the researcher discussed the research design and method that were used for this study. Burns and Grove (2009:236) define a 'research design' as a blueprint for conducting a study. Therefore, the researcher presented the following concepts in this chapter: the research design used in the study, the setting where the study was conducted, the target population, the sampling method and inclusion criteria. The procedure that was used to collect data, data analysis, how the trustworthiness of the study was ensured, and ethical principles were also outlined (Polit & Beck, 2012:170).

#### 2.2 RESEARCH PURPOSE AND OBJECTIVES

The purpose of this study was to understand the lived experiences of family members who have a sibling with BPD, and to formulate specific recommendations to facilitate family members' mental health.

The research objectives were: HANNESBURG

- To explore and describe the lived experiences of family members who have a sibling with BPD.
- To describe specific recommendations for the facilitation of mental health and the promotion of optimal care of family members who have a sibling with BPD by psychiatric nurse practitioners.

#### 2.3 RESEARCH DESIGN AND METHOD

A qualitative, descriptive, exploratory and contextual design was applied in this study.

#### 2.3.1 Qualitative design

Qualitative designs aim to reveal participants' perceptions. Qualitative research produces social explanations for intellectual puzzles. Edmonds and Kennedy (2013:112) state that a qualitative method represents a form of data collection and analysis with the focus on understanding and emphasis on meaning. The researcher in this study explored the lived experiences of having a sibling with BPD as they were described by the family members. According to Creswell (2013:16), qualitative research is interpretative in the sense that the biases, values and judgments of the researcher should be explicitly stated in the study report. In this study, the researcher aimed to gain insight into the lived experiences of family members who have a sibling with BPD.

#### 2.3.2 Descriptive design

A descriptive research design is employed when there is no theory to work from, or when the researcher begins to explore a new area that has not been researched before. The interviewer seeks a "holistic description and explanation of phenomena" (Burns & Grove, 2009:54). According to Burns and Grove (2009:237), a descriptive study is a study that strives to discover answers to the questions 'who?', 'what?', 'when?', 'where?' and sometimes 'what?' Polit and Beck (2013:725) postulate that descriptive research typically has its primary objective, namely the accurate portrayal of people's characteristics or circumstances, and/or the frequency with which a certain phenomenon occurs. Therefore, in this study, the researcher attempted to explore and describe the lived experiences of family members who have a sibling with BPD.

#### 2.3.3 Exploratory design

Burns and Grove (2009:313) and De Vos, et al. (2011:95) define exploratory research as research that is conducted to gain new insight, discover new ideas or increase knowledge of a phenomenon. This is done from a point of not knowing to provide new data regarding the phenomenon in context. In this study, the researcher aimed to gain insight about the lived experiences of family members who have a sibling with BPD.

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#### 2.3.4 Contextual design

Contextual inquiry is a data collection technique used to capture detailed information about the phenomenon. The aim of the contextual design is to produce extensive descriptions of phenomena in the specific context in which they occur (Babbie & Mouton, 2011:272). Burns and Grove (2009:8) warns that researchers should not forget the context, what produced the context, or what produced the sections of data they are indexing. In this study, it was therefore important to remain within the unique understanding and perceptions of family members who have a sibling with BPD.

#### 2.3.5 Research methods

This study was conducted in two phases. These are described next.

# 2.3.5.1 Phase One: The lived experiences of family members who have a sibling with BPD are explored and described

In this phase, the fieldwork was conducted by the researcher. The purpose was to gain insight into the lived experiences of family members who have a sibling with BPD. A phenomenological research approach was followed to understand the participants' meanings. This approach is most useful when the purpose of the study is to understand experiences as described by those having the experiences with regards to the specific phenomena as well as how they interpret these experiences or what the experiences hold for them. In this process, the researcher brackets or sets aside her own experiences in order to understand those of the participants in the study (Creswell 2009:13).

#### a. Target population and sampling

The researcher selected a portion of the population, referred to as the sample. A nonprobability, purposive sampling method was used in this study, which is also known as judgmental sampling since it entails the researcher making a judgment about the population to be studied (Burns & Grove, 2009:355). In this study, the participants were family members who have a sibling with BPD.

#### b. Criteria for inclusion

The researcher works in a psychiatric institution, with over 400 in-patients but fewer than a handful of these patients are diagnosed with BPD. After consultation with the Hospital Ethics Committee, the researcher was advised to apply and conduct the research in another hospital which has a specific psychotherapy unit that works with people who are diagnosed with personality disorders. She introduced the study to the patients who admitted in that unit with a diagnosis of BPD, and obtained their written permission allowing her to interview their family members and giving her their contact details. She allowed them to ask questions about the study and gave them time to read the information letter that she provided for them. She spoke to the participants a few times over the phone before she met with them for the interviews.

Participants met the following inclusion criteria:

- They were either a male or female
- They were living or had lived with a sibling who has BPD
- They were 18 years and older
- They had a sibling living with BPD
- They were preferably able to communicate in English, Zulu and Xhosa

#### c. Data collection

Data were collected in this study using in-depth, phenomenological interviews, field notes, observational notes, personal notes, methodological notes and theoretical notes, as discussed next.

#### d. In-depth phenomenological interviews

A qualitative research approach requires that the data collected must offer a rich description of the phenomenon under study. According to Brink, van der Walt and van Rensburg (2012:157), an interview is a method of data collection whereby an interviewer obtains responses from a participant in a face-to-face encounter, through

a telephone call or by electronic means. In this study, in-depth phenomenological interviews were employed in order to produce dense and quality information. The researcher met with participants in an office at a psychiatric institution. The researcher built a good rapport with the participants through honesty and showing them respect (Wellman, et al. 2005:199). Participants were made to feel that the researcher was interested in them as individuals and that their uniqueness was respected. They were allowed to feel completely free.

In most qualitative research studies, data are the participants' thoughts, ideas and perceptions. In this study, the researcher asked one main question of participants. Follow-up questions, probing, and minimal verbal responses were used only to confirm or to look for underlying meaning in the statements given by the participants (De Vos, et al. 2011:66). The main question was:

#### "How is it for you having a sibling with BPD?"

The researcher used in-depth interviews which were informal and less threatening for the participants and allowed them to talk freely. The interview sessions lasted 40-60 minutes and were audio-recorded and transcribed by the researcher. An excerpt of an interview is presented in Appendix 7. Data saturation was achieved after seven participants were interviewed.

#### e. Field notes

Field notes are handwritten notes by the researcher, compiled during the qualitative interview process (Wellman, et al. 2005:211). During this study, the researcher made use of different types of field notes. These notes were later processed and converted into write-ups so that they could be edited for accuracy and made readable for analysis. Botma, Greeff, Mulaudzi and Wright (2010:17) describe field notes as a written account of the things that the researcher hears, sees, feels, experiences and thinks about in the course of the interviews. The notes are much broader, more analytical and more interpretive than a listing of occurrences.

#### f. Observational notes

The researcher took note of what she observed during the interviews. These notes were used during data analysis and were analysed in relation to the interviews to determine their categories. Reflective notes were also used to capture the essence of the content of the interviews.

#### g. Personal notes

Personal notes are comments that were made by the researcher about her own feelings during the research process (Polit & Beck, 2013:218). They are notes about the researcher's observations, her own reactions and reflections.

# h. Methodological notes

These notes were kept by the researcher for her exclusive use to remind her of things that she needed to look out for during interviews. In these notes, she also wrote her own feelings and emotions to later establish if they affected her observations (Wellman, et al. 2005:196).

# i. Theoretical notes OF \_\_\_\_\_\_\_\_ OF \_\_\_\_\_\_\_ JOHANNESBURG

Theoretical notes were used by the researcher to document her thoughts and own interpretations of what was really meant by what was said or shown, and what was actually going on (Polit & Beck, 2012:218).

#### j. Data analysis

To analyse qualitative data, the researcher sought meaning from all the raw data that were available. The purpose of data analysis was to make sense of all the data that were collected, by placing it in a format that distinguishes the content (Wellman, et al. 2005:212). The researcher used Tesch's open-coding method of descriptive data analysis (Creswell, 2014:198) to analyse and make sense of the collected data.

The following steps were followed:

- Get a sense of the whole. Read all the transcriptions carefully. Perhaps jot down some ideas as they come to mind.
- Pick one document (one interview) the most interesting one, the shortest, the one at the top of the pile. Go through it asking yourself "what is it about?" Do not think about the substance of the information, but the underlying meaning. Write thoughts in the margin.
- When you have the topics, cluster similar topics together. Organise these topics into columns that might be arranged as major topics, unique topics and leftovers.
- Now take this list and go back to your data. Abbreviate the topics as codes and write the codes next to appropriate segments of the text. Try this preliminary organising scheme to see if new categories or codes emerge.
- Find the most descriptive wording for your topics and turn them into categories. Look for ways of reducing your total list of categories by grouping topics that relate to each other. Perhaps draw lines between your categories to show interrelationships.
- Make a final decision on the abbreviation for each category and alphabetise these codes.
- Assemble the data material belonging to each category in one place and perform a preliminary analysis.
- If necessary, recode your existing data.

Literature control therefore provides a framework for establishing the importance of the study as well as a benchmark to compare the results with other findings (Creswell, 2013:133).

#### k. Literature control

The results of the research were discussed in light of the relevant literature and information obtained from similar studies. This was done by reading existing literature on the experiences of family members who have a sibling with BPD.

# 2.3.5.2 Phase Two: Recommendations to facilitate the mental health of family members who have a sibling with BPD

In this phase, specific recommendations were derived from the findings of Phase One.

#### 2.4 MEASURES TO UNSURE TRUSTWORTHINESS

Polit and Beck (2013:295) describe 'trustworthiness' as a term that is applied to the evaluation of qualitative data using specific criteria. Guba's model of trustworthiness (Lincoln & Guba,1985:289) suggests the following four criteria should be adhered to during the study to develop the trustworthiness of a qualitative inquiry: credibility, transferability, dependability, and confirmability.

# 2.4.1 Credibility UNIVERSITY

Credibility refers to the confidence in the truth of the study findings (Polit & Beck, 2013:296). The criteria used in this study to ensure credibility was triangulation, member checking, persistent observation, prolonged engagement, peer examination and reflexivity.

#### 2.4.1.1 Triangulation

According to Burns and Grove (2009:231), triangulation comes from various points or angles towards a 'measured position', where the true position is found. In this study, different methods of data collection were used such as individual, in-depth, phenomenological interviews with all chosen participants, observations and field notes. These findings were compared to existing literature.

#### 2.4.1.2 Member checking

The researcher met with the participants individually at the end of data collection and analysis, before communicating the findings to share a summary of what transpired during the data analysis. This was done to confirm and validate what the participants shared during the data collection phase. At this stage, the participants were given a chance to add or retract information that might have been omitted or misinterpreted.

#### 2.4.1.3 Prolonged engagement

The researcher spent time with participants to build rapport and trust before commencing the interviews. The researcher allowed the participants to verbalise their experiences of having a sibling who has BPD. Face-to-face, in-depth phenomenological interviews were conducted for 45-60 minutes with each participant. After the interviews, the researcher immersed herself in the recordings by repeatedly listening to them, as soon as she was able. She also spent time transcribing the interviews verbatim and conducting the data analysis.

#### 2.4.1.4 Persistent observation

According to Lincoln and Guba (1985:304), persistent observation provides depth to an inquiry as it involves identifying those characteristics and elements in the situations that are most relevant to the problem being pursued and focusing on them in detail.

#### 2.4.1.5 Peer examination

The researcher was guided by her supervisors throughout the research process. In addition, the services of an independent coder with experience in qualitative research were employed to discuss the analysis of the results.

#### 2.4.1.6 Reflexivity

During the research process, the researcher explored any personal experiences and feelings that might have influenced the study. She could integrate this understanding

into her findings of the study. The researcher achieved this through continuous observation by means of field notes and constantly pursuing interpretations in different ways, in conjunction with a process of constant and tentative analysis. This process requires a conscious awareness of self (Burns & Grove, 2009:545).

#### 2.4.2 Transferability

A purposive sample was used to select the participants for this study. Seven family members who have a sibling with BPD were chosen. A dense description of the participants' demographics and a rich description of findings, supported by direct quotations, is given in Chapter 3.

#### 2.4.3 Dependability

A dense description of the research methodology used in this study was provided. This included step-wise replication of the research method, code-recode of data analysis, and a dependability audit (Babbie & Mouton, 2011:278).

#### 2.4.3.1 Step-wise replication

The researcher described the steps taken and supported them with reference to literature. These steps were explained in Chapter 1.

#### 2.4.3.2 Code-recoding of data

All raw material, such as audio-recorded interviews and comments from the independent coder, are kept in a safe place under lock and key as proof of the research. This raw material will remain under lock and key for two years after the publication of the study, and will then be destroyed.

#### 2.4.3.3 Dependability audit

This study was submitted and evaluated by research supervisors in addition to the independent coder who assisted with data analysis. This contributed to the dependability audit of the study.

#### 2.4.4 Confirmability

Confirmability refers to the degree to which findings are a function solely of the participants and conditions of the research and not of other biases, motivations and perspectives; it is the worth of the findings (Babbie & Mouton, 2011:646). The findings should produce the same results if the study was to be repeated by other researchers using the same participants in a similar context. In qualitative research, this neutrality is defined in terms of confirmability.

#### 2.5 ETHICAL CONSIDERATIONS

The ethical standards for nurse researchers serve as a framework for nurses conducting and participating in research. Ethical standards were applied throughout this study as guided by the 2015 Ethical Standards for Nursing Research by DENOSA (Brink, et al. 2012:36). According to Dhai and McQuoid-Mason (2011:174), there are four principles to be considered when conducting research, namely autonomy, non-maleficence, beneficence and justice. In this study, these principles were adhered to throughout the research process and were fully described in Chapter 1.

#### 2.6 SUMMARY

In Chapter 2, the researcher introduced and described the research design and method in detail. The researcher chose a qualitative, exploratory, descriptive and contextual approach in order to obtain in-depth information from the participants. The researcher also addressed measures and strategies to ensure trustworthiness. In Chapter 3, the results from the in-depth phenomenological interviews are discussed.

### CHAPTER 3 DISCUSSION OF THE RESULTS

#### 3.1 INTRODUCTION

In Chapters 1 and 2, the focus was mainly on the research methods and the research design that was used in this study. In this chapter, the lived experiences of family members who have a sibling with BPD are explored and described.

#### 3.2 DEMOGRAPHIC DESCRIPTION OF PARTICIPANTS

The participants for this study were family members who have a sibling with BPD. Purposive sampling was used for the selection of participants as discussed in Chapter 2.

The interviewed participants lived or have lived with siblings who have BPD. Some had moved out of family homes to live on their own as a result of the stressful relationships in the family and how it affected their mental health. Participants grew up with their sibling who has BPD, up to their early adult phase.

Seven participants were interviewed out of nine potential participants after patients gave consent for their siblings to participate in the study (see Table 3.1). One family member was excluded as she was admitted to hospital after attempting suicide before the interview date was confirmed. Her sibling reported that she was diagnosed with BPD as well. The second participant refused to participate in the study. She reported that she did not want to be reminded of the difficult times she had gone through while growing up with a sibling who has BPD. She was 45 years old with two daughters aged 20 years and 18 years, respectively. Data saturation was achieved after the seven participants were interviewed. All participants reported that they preferred to be interviewed in English. The participants' demographics are presented in Table 3.1.

Participants number (P)	Age	Gender	Relationship	Race	Living with the sibling
1	22	Male	Brother	White	Not currently
2	25	Female	Sister	White	Not currently
3	24	Female	Sister	White	Not currently
4	33	Male	Brother	African	Not currently
5	22	Female	Sister	African	Yes
6	37	Male	Brother	African	Yes
7	49	Male	Brother	African	Yes

 Table 3.1:
 Participants' demographics

#### 3.3 DESCRIPTION OF THE ENVIRONMENT

The interviews were conducted in an office in a psychiatric institution in Gauteng on the day and time as agreed with the participants when they felt comfortable. The researcher put a note on the outside of the door stating: "Do not disturb" to reduce interruptions during the interviews.

#### 3.4 OBSERVATION DURING THE INTERVIEWS

All participants who were interviewed participated freely. They all gave informed consent to partake in the interviews and for the interviews to be audio-recorded. The third participant appeared emotional during the interview, and the researcher spent another 20 minutes with her after the interviews to allow for debriefing. The second participant appeared reserved during the interview, but when the interview was finished, she appeared to open up further about her experiences of having a sibling with BPD. During interviews, the researcher made use of different types of field notes, namely observational notes, personal notes, methodological notes and theoretical notes, as stated in Polit and Beck (2013:218).

#### 3.5 DISCUSSION OF THE RESULTS

The results that were obtained during the data collection phase are discussed in this chapter (See Table 3.2).

#### 3.5.1 The central storyline

The participants divulged their challenging journeys. It seemed that living with a sibling who suffers from BPD caused chaos and distress in all spheres of life, especially before they were diagnosed. They explained the stress of not knowing what was wrong with their loved one after noticing changes in their siblings. The diagnosis brought some relief, as they could finally give a 'name' to what was happening; however, they still had a hard time coping with all the demands of their sibling with BPD, while at the same time trying to live their own lives.

The relationship with the sibling who has BPD was described as stressful because of the instability of their emotions, angry outbursts, and impulsive behaviours like rage and violence. Some participants reported that they needed to distance themselves from their siblings with BPD in order to protect themselves.

Other participants took on the responsibilities of caring for their siblings. The burden of illness on the family left some family members with negative emotions of anger, fear, resentment and blame towards the sibling with BPD. The illness affected the family and the relationships in the family. The participants seemed frustrated that the siblings with BPD were apparently unaware of the impact their behaviour had on the people around them. They expressed a great need for constructive two-way communication between themselves and their sibling with BPD.

#### 3.5.2 Discussion of themes and categories of experiences

An overview of the themes and categories that emerged from the data analysis of the in-depth interviews is presented in Table 3.2.

THEMES	CATEGORIES
	1.1 Family members experienced a range of
	emotions while trying to make sense of
	what was going on with their sibling before
	and after the diagnosis was made. They
	faced intense affective responses which
Theme 1: Family members	included sadness, fear, anger and joy
experienced having a sibling	1.2 Family members experienced that they
with BPD as emotionally	sacrificed their own lives to manage their
challenging in their quest to	sibling's lives
get answers and gain control	1.3 Family members experienced that having a
of the situation at hand, while	sibling with BPD was challenging when
struggling to live their own	trying to look for answers for their
lives	behaviour; they used different strategies to
	regain control, but all their attempts failed
	1.4 Family members had a great need to share
	their stories and to build constructive
	communication channels between family
UP	members
JOHA	2.1 Family members experienced that the
0011/	relationship between their parents and the
Theme 2: Family members	sibling with BPD was strained
experienced that interpersonal	2.2 Family members experienced that the
relationships suffered due to	relationships with the sibling who has BPD
lack of constructive	were conflicting
communication and lack of	2.3 Family members experienced that the
education on the disorder	healthcare professionals did not
	communicate with or educate the families
	regarding the diagnosis and the
	management thereof
Theme 3: Family members	3.1 Family members applied different coping
used different mechanisms to	mechanisms to manage the situation they

#### Table 3.2:Themes and categories

THEMES	CATEGORIES
cope with the situation on	faced even though they did not have the
their own	tools or resources to help them

A discussion of the themes and categories follows.

### 3.5.2.1 Theme 1: Family members experienced having a sibling with BPD as emotionally challenging in their quest to get answers and gain control of the situation at hand, while struggling to live 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. Participants experienced that having a sibling with BPD was emotionally draining and they felt frustrated, lost, powerless and angry due to the highs and lows of not knowing what to expect from their siblings.

BPD is a disorder that affects not only the person with the disorder but also those around them. Family roles and relationships become strained. Giffin (2008:133) states that people appear less tolerant of their sibling's self-harming behaviour and are readier to express their expectations that the sibling should take more responsibility for their lives and behaviours.

### a. Family members experienced a range of emotions while trying to make sense of what was going on with their sibling before and after the diagnosis was made

Participants reported that they felt exhausted due to all the demands they faced, and they experienced sadness, fear, anger, resentment and joy.

#### a.i Family members experienced sadness

Participants shared that they felt severe helplessness when failing to assist their sibling and/or to protect their parents, and they just ran out of options and answers.

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

Participants felt hurt and disrespected because of their sibling's words and actions.

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

They were sad because they loved their sibling but sometimes also hated them. This created a sense of ambivalence.

"It's difficult to feel certain things... You half feel guilty because she is such a nice person... How can I think or feel like this?" (P2, 25yrs old, sister)

Participants also described different emotions, including grief:

"It is not an easy thing because your family member used to be a normal person and with the illness she changes, she is our sister what can we do…" (P6, 37yrs old, brother)

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"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)

"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)

*"I have made peace with it because she keeps on influencing my life in a bad way"* (P3, 24yrs old, sister)

Betts, Pearce, McKechnie, McCutcheon, Cotton, Jovev, et al. (2018:5) state that families and friends of an individual with BPD experience high levels of psychological symptoms, including anxiety and depression, objective and subjective burdens and grief. Moreover, according to Kay, Poggenpoel, Myburgh and Downing (2018:89),

family members experience negative feelings, which include despair, sadness and regret, humiliation, guilt and shame towards their relatives diagnosed with BPD.

#### a.ii Family members experienced fear

Participants reported that they were afraid they could get killed by their sibling or that someone else could be hurt or killed during their sibling's outbursts of rage.

"What if she met somebody on the street? She could harm them" (P6, 37yrs old, brother)

The unpredictable behaviours displayed by siblings with BPD affected everyone in the family. A participant explained:

"When she gets aggressive she would hit anyone. She actually at some stage picked up my granny and threw her against the cupboard" (P3, 24yrs old, sister)

Participants were cautious in their interactions with their sibling, as they did not want to trigger their illness.

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"You're so careful in whatever you say or do to him because what if what if it triggers him and that thing start all over again" (P7, 49yrs old, brother)

"In most cases you have to be considerate at what you are saying. When dealing with a person with this disorder, it is light things that can trigger them into having an off day" (P4, 33yrs old, brother)

Gunderson (2011:8) indicates that family members are understandably tormented by the threat and/or carrying out of aggressive acts. Their reactions vary from wanting to protect the patient, to anger at the perceived attention-demanding aspects of the behaviour. He cautions that family members should not assume the primary burden to ensure the patient's safety. Instead, he advises that family members should contact professionals for help if there is a perceived threat of harm, or the patient has already engaged in self-harm.

#### a.iii Family members experienced anger

Participants were frustrated because of their sibling's poor co-operation. Others blamed their parents for not taking more control over their sibling with BPD. Some participants felt resentment because they observed that their affected siblings always got their way and did not realise the impact it had on others' lives.

"You try and sort things out ...go all out. And next the person does not show any signs of appreciation, and says it was you." (P7, 49yrs old, brother)

Participants were also angry because their sibling did not think about how their behaviour affected those around them when they attempted to commit suicide.

"I was angry with her for trying to kill herself, leaving us behind..." (P5, 22yrs old, sister)

Some participants wanted to act in a vengeful manner so that their sibling could get an idea of how their behaviour and actions affected their family members.

"I actually feel like on purpose, choose a dress that she would not look good in just to a... (**hesitant**). show her a little bit of ... But that is not me, I will never do that. That is not how I was raised but that is how I feel" (P3, 24yrs old, sister)

Another participant shared:

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

Family members may feel helpless and angry in terms of how their siblings with BPD relate to them (Keltner & Steel, 2015:359). Fossati and Somma (2018:2) postulate that family members often experience an emotional and financial burden, and may blame themselves for their relative's illness or for not being able to do more to help. These emotions can lead to emotional pain, including anxiety, guilt, anger, frustration, despair, and hopelessness. The literature describes these negative experiences in the

context of family conflict, rejection and relationship breakdown (Giffin, 2008:136; Ekdahl, Idvall, Samuelsson & Perseius, 2011:70; Bailey & Grenyer, 2014:10).

Bailey and Grenyer (2014:12) found that BPD carers are more prone to post-traumatic stress than other types of mental health carers. Therefore, this highlights the need for further clinical interventions and support for family members or carers of people with BPD. Hoffman et al. (2005:224) state that when siblings have knowledge about the diagnosis, they appear to get along better with their sibling with BPD, compared to when they were ignorant about the illness.

#### a.iv Family members experienced joy

Some participants were relieved after the final diagnosis, or when a 'name' was given to all the chaos.

"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" (P1, 22yrs old, brother)

Participants were grateful when things went well, and when their siblings cooperated and took their medicine.

"The Doctors then treated her and she got better and that is when we noticed that she was ill and was not herself" (P6, 37yrs old, brother)

The families of a patient with BPD who has been experiencing distressing symptoms without a name might feel a sense of relief once the constellation of symptoms has been named (Lequesne & Hersh, 2004:174). Families want to be an integral part of treatment and community rehabilitation teams as they are deeply concerned about the recovery of their loved one (Batemen & Fonagy, 2019:76). However, research has shown that few patients are asked by mental health providers for their permission to share health information with family members. Greater knowledge of BPD would benefit those who have the disorder as well as their relatives and work colleagues who

could offer help early on, once symptoms have been spotted and a diagnosis has been made (Furnham, Lee & Kolzeev, 2015:322).

# b. Family members experienced that they sacrificed their own lives to manage their sibling's lives

People with BPD engage in suicidal and self-injurious behaviour. Family members at times experienced being confused, powerless and trapped as they felt they were no longer in control of their own lives as they wanted to help their siblings but did not know how. Due to the emotional roller-coaster displayed by the sibling with BPD, some family members took the behaviour of their loved ones personally. They found it difficult to differentiate that the angry outbursts or rage and their sibling were not the same person. In an attempt to protect themselves, they eventually decided to move out of the family home.

"I felt that maybe she should just get through with it and actually die, then we don't have to sit and deal with this because we're constantly worried and can't live our own lives" (P3, 24yrs old, sister)

They took on the roles of caretaker and protector towards their siblings and monitored their sibling to ensure they were safe.

"Sometimes I had to wake up at night because she was not able to sleep, and it was becoming my duty to help her, talk to her, moving out of home worked to my advantage because it was draining for me" (P4, 33yrs old, brother)

*"It was like we were in a nightmare, we couldn't sleep at night and during the day we had to watch her."* (P6, 37yrs old, brother)

They had to put aside their own baggage and feelings to focus on their sibling's moods and behaviour.

"At times when she was having bad days I took it upon myself to be there for her directly and leave my own baggage" (P4, 33yrs old, brother) *"It affected me emotionally and caused a lot of problems between my parents."* (P5, 22yrs old, sister)

"I always had to put my decisions and my feelings aside because hers are more important..." (P3, 24yrs old, sister)

"You're like always tired because you can't get your own time" (P2, 25yrs old, sister)

Participants constantly had to adjust their own lives to be available for and attend to their sibling, which influenced other spheres of the family's life, like academic performance.

"There's nothing much we can do about it other than persevering at times, with that particular person until things are ok." (P7, 49yrs old, brother)

"I even dropped at school as it affected me emotionally" (P5, 22yrs old, sister)

Some family members take on an enormous amount of responsibility and end up being the caretakers for their sibling with BPD. They make life decisions based on the fact that they have a relative with BPD (Kreger & Mason, 2008:31).

c. Family members experienced that having a sibling with BPD was challenging when trying to look for answers for their behaviour; they used different strategies to regain control, but all their attempts failed

There was confusion about the way in which the sibling behaved, and family members attempted to find a solution to deal with the behaviour, but without success. Participants tried to approach their siblings with BPD in different ways; sometimes aggressively. Family members explained:

"I actually hit her back for the first time in my entire life. I hit her so bad..." (P3, 24yrs old, sister)

"We wanted to make sure that everyone was safe that is why we tried to lock her in until we took her to hospital in order to get assistance" (P6, 37yrs old, brother)

Sometimes, the approach was gentle:

"I will go and engage with her, try to talk to her so that she doesn't think too much" (P5, 22yrs old, sister)

"It's quite stressful, because you don't know what to do. I mean, we are not talking about a child here. He is a grown up person, you can't force him to do things. You can only advice on certain things" (P7, 49yrs old, brother)

They sometimes took their sibling to sangomas and traditional healers for treatment:

"We thought she is bewitched we even consulted the traditional healers on the sides to find out what is wrong with her but they couldn't find anything." (P6, 37yrs old, brother)

"As part of culture as black people we decided then to take him to the Sangomas just to find out what was causing him to behave like that. But nothing came out and there was still no difference in his behaviour" (P7, 49yrs old, brother)

Family members looked for reasons for these behaviours but found it hard to get answers.

"I did my own research on the personality disorder and then it says that they do take things personally" (P2, 25yrs old, sister)

"We discovered that she had an illness after we took her to the doctor" (P6, 37yrs old, brother)

"He was behaving like umuntu onamademoni (a possessed person) ... "We will talk about it trying to get solutions but nothing seemed to be working" (P7, 49yrs old, brother)

Choi (2018:163) postulates that 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 who are potentially contributing to the problem may be addressed and challenged effectively.

# d. Family members had a great need to share their stories and to build constructive communication channels between family members

Participants expressed the need to learn the basics of constructive communication, behaviour management, and problem-solving strategies to help them deal with their sibling's illness and to avoid accelerating or triggering the illness. Therefore, they needed to understand that their own anger, guilt, anxiety, and frustration were normal responses. These emotional responses could be controlled with effective tools, but participants had no platform to share their thoughts and feelings, or to learn appropriate skills.

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"I can't always say what I want in front of my parents. They don't know what I feel" (P3, 24yrs old, sister)

"It was very painful. It was actually traumatic to me. I felt that even our parent's still needed guidance or assistance coming out and to deal with this but only when we feel that she is better" (P6, 37yrs old, brother)

According to Weight and Kendal (2013:37), improving communication skills and a positive attitude is critical in caring for people diagnosed with BPD. Moreover, effective communication helps build therapeutic relationships, leading to better outcomes for patients and their families.

# 3.5.2.2 Theme 2: Family members experienced that interpersonal relationships suffered due to lack of constructive communication and lack of education on the disorder

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 any number of behaviours that are considered disruptive, such as causing self-harming injuries, violent behaviour, impulsivity, or suicide. These behavioural tendencies put the patient at significant risk to themselves and others if left unmanaged.

### a. Family members experienced that the relationship between the parents and the family members were strained

Participants appeared to need attention and encouragement from their parents in how they responded to their sibling with BPD. Lack of support from parents had an impact on their reaction to their sibling's illness. When they felt unsupported, they were more likely to respond negatively and develop resentment towards their sibling, while if they felt supported, they would likely contribute positively to the care and support of their sibling with BPD.

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"I don't think my parents are helping because they are saying its fine to ask for everything yet you are not working for it and it just fall in your lap, so enabling her" (P3, 24yrs old, sister)

"It's not really her doing... but my parent's... she gets a different treatment to us to a point. There's 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) Bailey and Grenyer (2015:22) state that the family environment was found to have an important implication for the clinical outcome of patients with a mental illness. Giffin (2008:133) agrees that where parents focused their energy on actively caring for the sibling with BPD, their relationships with other adult siblings became more distant.

# b. Family members experienced that the relationships with the sibling who had BPD were conflicting

Participants were aware of their sibling's lack of awareness of the impact of their behaviour on their family. 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 always wants to be around people and can't be by herself" (P2, 25yrs old, sister)

"I didn't understand what she was going through" (P5, 22yrs old, sister)

"You cannot talk to her even if you wanted to because then it is going to make the situation worse" (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)

BPD patients appear to have hair-trigger responses to what they perceive as 'invalidation' of any kind. This is problematic for those who interact with them, because at times innocuous words or actions, whether real or imagined, may be interpreted as secretly harbouring malicious abandonment (Zeichner 2013:3). Patients with BPD have unstable and conflicted relationships as they tend to view others as all good or all bad, which is labelled as 'splitting'. These patients can easily become dependent on others, but they can also have dramatic shifts in their feelings towards others

(Kulacaoglu & Kose, 2018:1). These dramatic shifts can be difficult for family members to understand, and the challenges are of such magnitude that they often deplete the family members' capacity to cope effectively, compromising their health and life agenda. Families cannot do it alone (Hoffman, et al. 2005:68).

# c. Family members experienced that the healthcare professionals did not communicate with or educate the families regarding the diagnosis and the management thereof

Participants reported having difficulties understanding what was going on as they were not educated (including the parents) about the illness that their sibling had; this caused great confusion amongst the family members. When their siblings were diagnosed, the family members were rarely – sometimes not at all – included in the treatment plan. Sometimes family members who have siblings with BPD act as caregivers and case managers during a crisis. They may struggle with knowing how to respond effectively to the problematic behaviours that are displayed by their siblings who have BPD, like angry outburst, self-harming and fear of abandonment. Little, if any, support is offered to family members who have siblings with BPD in regards to education, and most family members have little knowledge of the treatment programmes that their siblings receive when admitted in hospital. They still do not know how to manage or support their siblings after discharge. This left the family members searching for information themselves. They resorted to using the internet to obtain information about the disorder just to clarify it for themselves.

"It was difficult before the diagnosis..." (P3, 24yrs old, sister)

"Eixh (sighing) you know automatically if she is in a bad space everyone in the house is affected because she is the youngest everyone becomes down, automatically it affects everyone." (P4, 33yrs old, brother)

"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) "Our family is not solid and not close in a way that we can help each other. Hence, we have never spoken about her illness as a family thus it's up to an individual to support my sister or to visit her in hospital, I have three siblings but where we stay there are my aunts and also their children" (P5, 22yrs old, sister)

Uys and Middleton (2014:54) state that currently, patients and their families are still provided with very little information, often not even the diagnosis and sometimes vague terms like 'breakdown' are used. Also, in a focus group that was run by Dunne and Rogers (2013:644), family members reported that 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. This suggests that everyone would benefit from understanding the experiences of family members of people diagnosed with BPD. It will allow them to receive better education and training on how to manage their interactions with their siblings more effectively. Family members experienced that meetings with health professionals and the treatment team was for the benefit of the clinicians, and often just fact-finding or information giving session (Giffin, 2008:136). The family members' experiences or the impact of having a sibling with BPD were not considered.

In addition to challenges experienced by the family members, Fossatti and Somma (2018:3) highlight that there is a consensus that relatives of BPD subjects should have the opportunity to receive state-of-the-art, evidence-based information on BPD and its available treatments in order to destigmatise a BPD diagnosis as well as the role of the family in BPD development. Therefore, adequate family interventions in BPD treatment programmes should be accessible and not expensive.

In light of the above, family intervention programmes are likely to give answers to the different problems that family members who have siblings with BPD may have. Lawn and McMahon (2015:234) state that family carers of people diagnosed with BPD experience significant exclusion and discrimination when attempting to interact with mental health services. Therefore, education for all health professionals is indicated, especially those who are likely come into contact with BPD carers in order to improve their skills and attitudes in working with people diagnosed with BPD, and also their skills and attitudes in working with family members with siblings who have BPD.

# 3.5.2.3 Theme 3: Family members used different mechanisms to cope with the situation on their own

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. They reported that they were frustrated, lost, powerless and angry due to the highs and lows of not knowing what to expect from their siblings. They tried coping with the situations that they faced using different strategies. Some of the coping strategies used were defence mechanisms such as suppression, avoidance, rationalising, blaming and projection. Family members often experience subjective burdens, or emotional consequences because of their relative's illness. It can be incredibly difficult to watch a relative with BPD endure so much psychological pain (Porr, 2010:220).

a. Family members applied different coping mechanisms to manage the situation they faced even though they did not have the tools or resources to help them

#### a.i Suppression

Participants explained that they put off dealing with their own thoughts or feelings, and put it all aside.

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"She used to be a normal person and with the illness she changes, she is our sister what can we do. 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)

*"Even at home if they say something bad about her, I would put them in place and reprimand them."* (P5, 22yrs old, sister)

#### a.ii Avoidance

Family members rejected and avoided contact with the affected sibling, and some cut off the relationship and/or stopped talking about that person.

"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)

#### a.iii Rationalising

Participants justified the sibling's acts and moods by convincing themselves that they are 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 didn't realize that she was using dagga" (P6, 37yrs old, brother)

"Imagine if she had hurt her boyfriend or he died. It would have been my sister's fault. They (the family) forget that she is struggling to deal with things" (P5, 22yrs old, sister)

Attitudes, stormy and volatile interpersonal relationships towards others can shift from idealisation to anger and dislike as a result of black-and-white-thinking as people with BPD are sensitive to rejection; they react with anger and distress even to minimal separation (Kanwar & Sokhey, 2015:978).

#### a.iv Blaming

Some participants blamed their parents for not controlling and disciplining the sibling with BPD:

"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)

"Our parents are enabling her to be the way she is now because they are giving her what she wants because if they don't then it always end up in a fight, so they would rather have peace then the moaning and her being aggressive" (P3, 24yrs old, sister)

"We are asking ourselves why is it that our father can change his plans for her, but he cannot change them much for me and my brother. My anger is directed more towards my father" (P2, 25yrs old, sister)

"When someone in your family is not well and you feel like you are failing them yourself ... Your conscience is going to work on you telling you things like I could have been there for her" (P4, 33yrs old, brother)

At times, the participants thought that their parents blamed them for not helping their sibling with BPD.

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"Our mother feels that we are not doing enough to help our brothers, but it is not the case" (P7, 49yrs old, brother)

#### a.v Projection

The family members found it hard to understand the cause of their sibling's behaviour change. 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 think also 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)

Family members of siblings with BPD are likely to be involved in stormy, roller-coaster relationships, and as a result, they may feel overwhelmed by the extreme, unpredictable feelings and situations, even when they do not suffer from any mental disorder themselves (Fossati & Somma, 2018:1). 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 (Miller & Skerven, 2017:81).

Kay, et al. (2018:81) states that ineffective coping skills were often related to lack of knowledge by family members, and this prevents family members from making appropriate choices in assisting their relatives diagnosed with BPD. Families struggle in their own daily lives and in dealing with their relative with BPD. These experiences signal the need for the members of mental health communities to become more knowledgeable about BPD and its treatments, the availability of support groups for family members, and ways to communicate this information to those who need it (Buteau, Dawkins & Hoffman, 2008:212).

#### 3.6 CONCLUSION

From the findings discussed in this chapter, it was evident that the participants experienced a range of emotions in their quest to gain answers and control of the situation at hand, while also battling to live their own lives. Their interpersonal relationships suffered due to a lack of constructive communication and a lack of education on the disorder. They applied different strategies to cope with their situations. Therefore, it was clear that there is a need for family members to learn tools to help cope with having a sibling who has BPD. In Chapter 4, specific

recommendations to facilitate the mental health of family members who have a sibling with BPD are generated.



#### CHAPTER 4

### DISCUSSION OF SPECIFIC RECOMMENDATIONS, LIMITATIONS AND CONCLUSSION

#### 4.1 INTRODUCTION

The experiences of family members who had a sibling with BPD were explored and discussed in Chapter 3. In Chapter 4, the researcher presents specific recommendations to facilitate the mental health of family members who have a sibling with BPD.

These specific recommendations for the facilitation of the mental health of family members who have a sibling with BPD were formulated for the psychiatric nurse practitioners based on the Theory for Health Promotion in Nursing (Department of Nursing Science, University of Johannesburg, 2017:4)

#### 4.2 SPECIFIC RECOMMENDATIONS

Family members need to be provided with skills that will facilitate healthy family functioning. The main recommended skills that need to be provided include:

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- Education about mental illness signs, symptoms and management.
- Promotion of effective interpersonal relationships in the family through constructive communication.
- Facilitation of enhanced coping.

These skills would increase the potential for family members to be successful in overcoming and addressing family problems, as well as facilitate healing for them and their siblings with BPD. Table 4.1 presents the themes and specific recommendations.

Т	hemes and Categories as per results in Chapter 3	Specific recommendations and recommendations	
Theme 1: Family members experienced having a sibling with BPD as emotionally challenging in their quest to get answers and gain control of the situation at hand, while struggling to live their own lives		SPECIFIC RECOMMENDATION 1: Provision of education about mental illness signs, symptoms and management	
1.1	Family members experienced a range of emotions while trying to make sense of what was going on with their sibling before and after the diagnosis was made. They faced intense affective responses which included sadness, fear, anger and joy	1.1 Facilitation of healthy coping mechanisms	
1.2	Family members experienced that they sacrificed their own lives to manage their Bl sibling's lives	1.2 Facilitation of personal growth and development in support groups	
1.3	Family members experienced that having a sibling with BPD was challenging when trying to look for answers for their behaviour; they used different strategies to regain control, but all their attempts failed	<ul><li>1.3 Facilitation of education for family members about BPD</li></ul>	
	eme 2: Family members experienced that erpersonal relationships suffered due to	SPECIFIC RECOMMENDATION 2: Promoting effective	

Table 4.1:	Themes and specific recommendations
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Т	hemes and Categories as per results in Chapter 3	Specific recommendations and recommendations	
lack of constructive communication and lack		intrapersonal relationships	
of e	education on the disorder	in the family through	
		constructive communication	
2.1	Family members had a great need to share their stories and to build constructive communication channels between family members	2.1 Facilitation of family therapy	
2.2	Family members experienced that the relationship between their parents and the sibling with BPD was strained	2.2 Facilitation of couple's therapy for parents	
2.3	Family members experienced that the relationships with the sibling who has BPD were conflicting	2.3 Facilitation of conflict resolution skills	
2.4	Family members experienced that the healthcare professionals did not communicate with or educate the families regarding the diagnosis and the management thereof	2.4 Facilitation of mental health education regarding diagnosis, management, treatment plan and crisis management	
Theme 3: Family members used different mechanisms to cope with the situation on their own		SPECIFIC RECOMMENDATION 3: Facilitation of enhanced effective coping strategies for families who have a sibling with BPD	

Themes and Categories as per results in Chapter 3	Specific recommendations and recommendations
3.1 Family members applied different coping	3.1 Facilitation of training on
mechanisms to manage the situation they	coping skills using
faced even though they did not have the	Dialectical Behavioural
tools or resources to help them	Therapy (DBT)

# 4.2.1 Specific recommendation 1: Provision of education about mental illness signs, symptoms and management

Family members should receive education about BPD and understand the diagnosis, prognosis, and the expected course of the illness, yet they are often misinformed. Left to seek information on their own, family members often find out-of-date resources, mainly through the internet and in books that simply describe BPD without any guidance on how to locate treatment or updated statistics on remission (Buteau, et al. 2008:207).

#### 4.2.1.1 Facilitation of healthy coping mechanisms

Smith (2008:60) states that it is most effective for a member of the clinical team to reach out and offer information and education as a way of supporting the family. They should enquire about the family's perspective on the presenting problem as this can help to establish that they have valuable information to share and their views and concerns matter. A continued alliance should be built as the treatment proceeds.

Families need to share their grief and their hopes with others, and they need support so that they themselves can become support systems for people they love (Gunderson & Hoffman, 2005:218).

#### **4.2.1.2** Facilitation of personal growth and development in support groups

The psychiatric nurse practitioner should implement and facilitate support groups for family members who have siblings with BPD to encourage communication at their level of understanding. The family members will benefit from these groups by learning different effective coping skills, constructive communication, listening skills, and learn from others who are facing similar situations. Moreover, they will be able to share information in an environment that is free from criticism and has a non-judgemental atmosphere.

Smith (2008:60) reveals that active listening without defensiveness can be difficult and frustrating, and thus it is critical that the supportive setting of the group is also a place for family members to vent their negative feelings and grieve their lost dreams without censure.

Paradoxically though, families are expected to provide care to their mentally ill family members, but it seems that they are faced with many challenges themselves. These include a lack of understanding and skills related to mental illness, and they often become frustrated, stranded, overburdened and exhausted by caring for their relatives (Monyaluoe, Mokoena-Mvandaba, du Plessis & Koen, 2014:2)

Gunderson (2011:8) states that family members can play an important role in diminishing the likelihood of recurring self-destructive threats by simply being present and listening to their loved one, without criticism, rejection or disapproval.

#### 4.2.1.3 Facilitation of education for family members about BPD

The psychiatric nurse practitioner has the role of providing psycho-education to individuals, families and community members about mental illness. Participants in this study reported that their siblings with BPD or their parents are the ones who usually tell family members about the diagnosis. The information they get is usually not enough to help them in dealing with their sibling's behaviour or to contribute positively to the management and support of their sibling. Therefore, some participants took it

upon themselves to find information by reading books or searching the internet for answers about BPD.

In order to close this knowledge gap, the psychiatric nurse practitioner should conduct psycho-educational groups with family members and provide them with tools that they can use in order to assist their siblings at home and still be able to live their own lives. Lawn and McMahon (2015:241) postulate that the nature of BPD treatment often occurs in the context of crises and emergency department contacts; they suggest that more effective therapies in the community are needed in order to reduce carers' predominant exposure to crisis points.

Psycho-education is an important part of BPD treatment as it includes informing patients and families about the disorder, signs and the symptoms of the disorder, and also possible causes and treatment options (Kulacaoglu & Kose, 2018:11).

Hoffman, et al. (2005:68) state that it is essential to develop and disseminate accessible programmes that help family members reduce their stress, distress, and burden (while increasing education and effectiveness), both as a means to help disordered family members recover (and to prevent relapse) and as an end in itself for family members.

According to Fitzpatrick, et al. (2019:1), theory and research suggest that incorporating significant others into BPD treatments may present a novel and unique opportunity to maximise treatment outcomes.

Persons with BPD have a limited capacity to cope with strong emotions and stressors, and often struggle to engage in healthy interpersonal relationships. These factors lead to impulsive and destructive behaviours largely outside of the person's control (Aguirre & Galen, 2014:404).

Family intervention can increase positive alliances between the treating team and family members of clients with BPD (Choi, 2018:156). Accessing helpful information can be challenging without the guidance of professionals, and obsolete information can be quite discouraging or difficult to understand (Porr, 2010:221).

Bateman and Fonagy (2019:76) state that patients' attitudes towards family members are more positive if professionals encourage family involvement in treatment and family members' satisfaction is directly related to receiving information from providers.

Gunderson (2011:11) states that family members are usually grateful to be educated about BPD, the likely prognosis, reasonable expectations from the treatment, and how they can contribute. These interventions can improve communication, decrease alienation, and relieve family burdens. Greater knowledge of BPD would benefit those who have the disorder as well as their relatives and work colleagues who could offer support once symptoms are spotted and a solid diagnosis is made.

# 4.2.2 Specific recommendation 2: Promoting effective interpersonal relationships in the family through constructive communication

Effective interpersonal relationships in the family can be promoted by family therapy, couples' therapy for parents, conflict resolution skills and personal growth and development. In some BPD models, family members can be understood as implicitly implicated as part of a causal pathway leading to the disorder, and this inevitably increases family distress (Batemen & Fonagy, 2019:71).

### 4.2.2.1 Facilitation of family therapy

Family therapy is a process that allows families to learn how to maintain healthy family relationships, communicate effectively with family members, and work cooperatively to solve family problems. The participants in this study made it clear that having a sibling who has BPD affects everyone in the family and it is therefore important for the psychiatric nurse practitioner to facilitate family therapy; not only with parents and those with BPD, but to also include their siblings in the therapy as they are also affected. The aim of therapy will be for the family members to gain better understanding of healthy boundaries and family dynamics. It will also enhance communication within the family where all family members will be able to talk in a free and safe environment. The psychiatric nurse practitioner will also assist families in developing problem-solving skills.

Lord (2007:213) reports that in her experience it is very difficult to keep everyone in the same room at one time, and someone will run out of the room during a session 95% of the time; usually not the person with the diagnosis. Choi (2018:160) states that family therapists view clients and their family members as inseparable, formulating complex relational issues between family members is problematic, and working with family systems to restore healthy functional relationships is critical to the recovery process when developing a treatment or management plan.

Therefore, it is of utmost importance that the psychiatric nurse practitioner facilitating family therapy is experienced in working with people who have BPD and has a good relationship with them. Family therapy can educate families about the illness and work out problems associated with the care of the family members as a unit.

Family members can improve their own well-being by learning how to set limits, validate their own experiences, and prioritise their own health (Penney, 2008:230, Miller & Skerven, 2017:81). Choi (2018:158) reports that on discharge, the client returns to the same environment, psychosocial circumstance, family relationships, and dynamics, which may be contributing to and maintaining their problem.

#### 4.2.2.2 Facilitation of couples' therapy for parents

Families are different and different families and couples deal with problems differently. Having a child with BPD can cause a strain on the parents, especially since the individual with BPD exhibit splitting behaviour. Parents can differ in how they handle certain situations. Some situations can turn messy if they are not addressed early and appropriately, resulting in conflicts amongst couples. The psychiatric nurse practitioner can help the couples to identify the root of their problems and help them determine how to solve these challenges.

Aguirre and Galen (2014:406) postulate that family treatment should focus less on meaning-making and searching for the 'causes' of the patient's dysfunction, and more on the here and now interactions and the transactional nature of his or her difficulties. Therefore, the psychiatric nurse practitioner needs to keep in mind that the parents

have also been influenced and behaviourally shaped by their child; it is very much a two-way street.

#### 4.2.2.3 Facilitation of conflict resolution skills

Conflicts within families are inevitable and are not necessarily all negative, but problems arise from ineffective conflict resolution. The psychiatric nurse practitioner should teach families conflict management strategies where family members can ensure there are clear boundaries and expectations for the relationship, and family members and siblings with BPD know what is expected of them. The psychiatric nurse practitioner will assist family members in finding ways to collaborate and agree on what is acceptable and unacceptable behaviour; for instance, violence of any kind is not acceptable.

Families will be encouraged to have hope about the person with BPD's capacity to change and recover, and support them through setbacks. Stobie and Tromski-Klingshirn (2009:414) state that due to the nature of clients living with BPD, the families experience a lot of chaos, thus needing timely crisis intervention. Family therapy approaches aim to change the relational dynamics in the family and related systems. Identifying common problems in family systems and addressing the issues amongst family members needs to be a constructive process (Choi 2018:156).

There can be no doubt that an emotionally volatile home environment is likely to worsen the course of the disorder and will compromise treatment outcomes (Batemen & Fonagy, 2019:71). Research has shown that few patients are asked by mental health providers for their permission to share health information with family members.

## 4.2.3 Specific recommendation 3: Facilitation of enhanced effective coping strategies for families who have a sibling with BPD

The facilitation of effective coping strategies should take place through support groups using DBT.

According to Betts, et al. (2018:5, 13), carers and or families want information about BPD, but few psycho-educational interventions have been developed and, to the authors' knowledge, been subjected to formal empirical evaluation. 'Dialectical Behavioural Therapy - Family Skills Training' 'Family Connections' and 'Staying Connected when Emotions Run High', and the evaluations of these programmes, indicate that psycho-educational programmes consistently reduce carer burden and grief, and increase perceived capacity to cope. However, their effects on psychological distress have been mixed.

Participants in the study identified a lack of knowledge about what was going on with their family member or what it meant for their sibling to be diagnosed with BPD. They also raised concerns about how they can balance their own lives and cope with the emotional challenges of having a sibling with BPD.

Research has shown that BPD is difficult for everyone involved, and if the family has skills to manage the situations they face with a sibling with BPD, their lives will be less overwhelming and less stressful. As they adapt to the mental illness in their midst, family members develop skills for coping with the mental illness and its impact on their own lives. Along the way, they may develop coping strategies and abilities, often paying a high personal price that can affect their mental health and well-being. Dowdell and Cavanaugh (2009:35) suggest that the families of individuals suffering from BPD should be offered support groups to encourage communication at their level of understanding.

Lockhart, Davis and Miller (2017:31) state that when families participate in therapy, they learn about goal setting and boundary setting, along with coping strategies for their own responses to the individual with BPD. By participating in support groups, family members have a chance to receive understanding, support and encouragement from others (Miller & Skerven, 2017:81). According to Aguirre and Galen (2014:404), decreasing the behaviours within the family that erode family functioning, such as contextually inappropriate emotional displays, invalidation, and emotional avoidance, is an overarching goal of family therapy.

# 4.2.3.1 Facilitation of training on coping strategies using Dialectical Behavioural Therapy (DBT)

The psychiatric nurse practitioner should facilitate DBT to help family members cope with their own stressors and learn effective ways to communicate and interact with their relatives with BPD. The participants in this study reported that they felt left out and were not involved in the treatment programmes that were provided for their siblings who had BPD. That appeared to be unhelpful in the long run as the family impacted on the mental health of the person with BPD and vice versa.

According to Miller and Skerven (2017:79), DBT was developed as a comprehensive treatment for persons with BPD, but there are programmes designed specifically to treat family members to help them cope with their own stressors. They also learn more effective ways to communicate and interact with their relatives with mental illness. Batemen and Fonagy (2019:76) state that families want to be an integral part of treatment and community rehabilitation teams, as they are concerned about the recovery of their loved one.

#### 4.3 **RECOMMENDATIONS**

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The following recommendations are directed at nursing practice, nursing education and nursing research in order to promote the mental health of the family members who have siblings with BPD. Psychiatric nurse practitioners need to mobilise resources to facilitate the mental health of family members who have siblings with BPD and provide them with knowledge and communication skills to facilitate effective interpersonal relationships and enable them to cope with the challenges of having a sibling with BPD while they maintain their own lives. The family members should be equipped with skills and tools that they can apply to effectively interact with their siblings and cope with the challenges of having a sibling with BPD while they maintain their own lives.

#### 4.3.1 Recommendations for psychiatric nursing practice

In this study, it was evident that the provision of support for family members who have a sibling with BPD is not readily available. These family members are an underserved population even though having a sibling with BPD affected them and their mental health. Therefore, it is necessary for family members to be included in the nursing process when providing nursing care to siblings who have BPD in order to promote their mental health as well as the mental health of the individual with BPD.

### 4.3.2 Recommendations for psychiatric nursing education

The psychiatric nurse practitioner should mobilise resources and implement workshops to train nurses on how to manage patients with BPD and support families. All psychiatric nurse practitioners should be actively involved in supervising and training student nurses when they are allocated to wards for their clinical practice.

The course curriculum should include teaching skills to families so they can modify their attitudes and behaviour towards patients who have BPD (Hoffman, et al. 2005:69).

### 4.3.3 Recommendations for psychiatric nursing research

The researcher recommends that more studies be conducted in this area, focusing more on the provision of collaborative care for people with BPD and their families. Further research could also be conducted on the effectiveness of support groups for family members who have siblings with BPD.

### 4.4 LIMITATIONS

The researcher had difficulty finding participants for this study. In the public hospital where the researcher works, there are over 400 in-patients but fewer than a handful of these patients are diagnosed with BPD. After consultation with the Hospital Ethics Committee, the researcher was advised to apply and conduct the research in another hospital which has a specific ward that admits people with BPD. This hospital had a specific psychotherapy unit that works with people who are diagnosed with personality disorders.

### 4.5 CONCLUSION

A qualitative, descriptive, exploratory and contextual design was used to describe and explore the lived experiences of family members who have a sibling with BPD in this study. In-depth phenomenological interviews and field notes were used to collect data and were used in data analysis. The researcher recommended that the psychiatric nurse practitioners needed to mobilise support services to help the family members who have a sibling with BPD. These support structures would be obtained by implementing and facilitating psycho-education, support groups and family therapy that include the family members who have siblings with BPD. Crisis intervention plans for sibling who have BPD should be developed and clearly dictate what kind of support they will need from their family members during times of crisis. The family members should also be provided with contact details of resources that they can use for themselves after a crisis for debriefing.

UNIVERSITY \_\_\_\_\_\_OF\_\_\_\_\_ JOHANNESBURG

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# APPENDIX 1: ETHICAL CLEARANCE FROM UNIVERSITY OF WITWATERSRAND



R14/49 Ms W Caluza, et al

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) CLEARANCE CERTIFICATE NO. M181130				
NAME:	Ms W Caluza, et al			
(Principal Investigator) DEPARTMENT:	Department of Nursing University of Johannesburg			
PROJECT TITLE:	The lived experiences of siblings of family members with borderline personality disorder			
DATE CONSIDERED:	30/11/2018			
DECISION:	Approved unconditionally			
CONDITIONS:				
SUPERVISOR:	Professor M Poggenpoel			
APPROVED BY:	6Bt enny			
DATE OF APPROVAL:	Dr CB Penny, Chairperson, HREC (Medical) 31/01/2019			
This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.				
DECLARATION OF INVESTIGATORS				
To be completed in duplicate and ONE COPY returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg				

Building, Parktown, University of the Witwatersrand, Jonannesburg. I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. <u>I agree to submit a yearly progress report</u>. When a funder requires annual re-certification, the application date will be one year after the date of the meeting when the study was initially reviewed. In this case, the study was initially reviewed in <u>November</u> and will therefore reports and re-certification will be due early in the month of <u>November</u> each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

# APPENDIX 2: ETHICAL CLEARANCE LETTERS FROM UNIVERSITY OF JOHANNESBURG AND HIGHER DEGREE COMMITTEE



### FACULTY OF HEALTH SCIENCES

### **HIGHER DEGREES COMMITTEE**

HDC-01-44- 2016

30 August 2016

TO WHOM IT MAY CONCERN:

STUDENT.º CALUZA, W STUDENT NUMBER: 201037857	
TITLE OF RESEARCH PROJECT:	The Lived Experience of Families that have a Sibling with Borderline Personality Disorder
DEPARTMENT OR PROGRAMME:	NURSING
SUPERVISOR: Prof M Poggenpoel	CO-SUPERVISOR: Prof CPH Myburgh
	CO-SUPERVISOR: Mrs M Ntshingila

The Faculty Higher Degrees Committee has scrutinised your research proposal and concluded that it complies with the approved research standards of the Faculty of Health Sciences; University of Johannesburg.

The HDC would like to extend their best wishes to you with your postgraduate studies

Yours sincerely,

Prof B Shaw

Chair: Faculty of Health Sciences HDC Tel: 011 559 6891 Email: brandons@uj.ac.za



# FACULTY OF HEALTH SCIENCES

### RESEARCH ETHICS COMMITTEE NHREC Registration no: REC-241112-035

REC-01-135-2016

15 September 2016

TO WHOM IT MAY CONCERN:

STUDENT: STUDENT NUM	CALUZ/ BER: 2008102		
TITLE OF RESEARCH PROJECT:		The Lived Experience Borderline Personality	of Siblings of Family Members with Disorder
DEPARTMENT O	R PROGRAMME:	NURSING	
SUPERVISOR:	Prof M Poggenpoel	CO-SUPERVISOR:	Prof CPH Myburgh
		CO-SUPERVISOR:	Mrs M Ntshingila

The Faculty Academic Ethics Committee has scrutinised your research proposal and confirm that it complies with the approved ethical standards of the Faculty of Health Sciences; University of Johannesburg.

The REC would like to extend their best wishes to you with your postgraduate studies.

Yours sincerely,

Marie Poggerpor

Prof M Poggenpoel Chair : Faculty of Health Sciences REC Tel: 011 559 6689 Email: <u>mariep@ui.ac.za</u>

# APPENDIX 3: LETTER TO THE CHIEF EXECUTIVE OFFICER OF THE HOSPITAL

## DEPARTMENT OF NURSING REQUEST TO CONDUCT RESEARCH

February 2018

Nursing Service Manager Tara- The H Moross Centre Hospital 50 Saxon Road Sandton 2169

Dear Sir/Madam

I Wendy Caluza, hereby request to conduct a research study on "The lived experiences of family members who have a sibling with Borderline Personality Disorder (BPD)" at Tara Hospital. In order to comply with the requirements for M.Cur in Psychiatric Nursing Science at the University of Johannesburg. This study will be done under the supervision and guidance of Professor M Poggenpoel, Professor CPH Myburgh and Mrs N Ntshingila.

Once permission has been granted arrangement will be made to introduce the researcher to the patients in the ward. The researcher will introduce the study to the patients and allow them to ask questions relating to the study. She will leave information leaflets about the study as well as her contact details for the patients so that they can read it at their own time. The patients that are interested in having their siblings to take part can then inform the researcher and give signed informed consent and provide the researcher with the contact details of their siblings. The researcher will contact siblings and introduce the study to them and invite them to take part in the study. The researcher will meet with the participants at Tara hospital.

The main purpose of this research study are:

The purpose of this study was to understand the lived experiences of family members who have a sibling with BPD, and to formulate specific recommendations to facilitate family members' mental health.

- 1. To explore and describe the lived experiences of siblings of family members with BPD
- 2. To formulate recommendations to facilitate siblings mental health.

For these objectives to be achieved, a qualitative design study which is exploratory, contextual and descriptive in nature will be used. The number of participants in this study is not specific but will depend on data saturation as evidenced in repeating information.

Interviews will be conducted with individual participants at their homes. The interviews will last for 40-60 minutes. The participants will be requested permission to audiotape the interview. The data will be kept under lock and key in the researcher's office. Only the researcher and supervisors will have access to the data. The data will be will be destroyed two years after publication of the research.

Participation is voluntary and they may withdraw from the research if they wish to do so without any penalty. The results of the research will be made available to your institution as well as to the participants on request.

I will be delighted to answer any further questions about this research study. If you have any question regarding this study feel free to contact me at 079 287 1224.

Regards,

Wendy Caluza, RN, B Cur ed Admin,

Alternatively you may contact the Chairperson of the Faculty of Health Sciences Research Ethics Committee at the University of Johannesburg who is also my supervisor:

MARIE POGGENPOEL RN; PhD, fANSA PROFESSOR; DEPARTMENTOF HEALTH SCIENCES Tel: 011 559-6686 Email: mariep@uj.ac.za

You may also contact my co-supervisors:

C P H MYBURGH BSc Hons, M.Comm, D.Ed, DHE PROFESSOR: DEPARTMENT OF EDUCATION PSYCHOLOGY Email: <u>chrism@uj.ac.za</u>

MRS MPUMI NTSHINGILA RN, M Cur LECTURER: DEPARTMENTOF HEALTH SCIENCES Email: mpumin@ uj.ac.za

# APPENDIX 4: REQUEST TO INTERVIEW FAMILY MEMBERS FROM PEOPLE DIAGNOSED WITH BPD AND CONCENT FORM



#### DEPARTMENT OF NURSING

### RESEARCH CONSENT FORM FOR MY SIBLING TO PARTICIPATE IN THE RESEARCH STUDY NAMELY:

The Lived experiences of family members who have a sibling with Borderline Personality Disorder

Please initial each box below:

I confirm that I have read and understand the information letter dated April 2018 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation of my sibling is voluntary and that they are free to withdraw from this study at any time without giving any reason and without any consequences to them.

I agree to allow my sibling to take part in the above study.

Name of Patient	Signature of the Patient	Date	
Name of the Witness	Signature of the Witness	Date	
Name of Researcher	Signature of Researcher	Date	

# APPENDIX 5: INFORMATION LETTER FOR THE PARTICIPANTS AND CONCENT FORMS

### DEPARTMENT OF NURSING RESEARCH STUDY INFORMATION LETTER

**APRIL 2019** 

#### Good Day

My name is Wendy Caluza I WOULD LIKE TO INVITE YOU TO PARTICIPATE in a research study on: The lived experiences of family members who have a sibling with Borderline Personality Disorder.

Before you decide on whether to participate, I would like to explain to you why the research is being done and what it will involve for you. I will go through the information letter with you and answer any questions you have. This should take about 10 to 20 minutes. The study is part of a research project being completed as a requirement for a Master's Degree in Psychiatric Nursing through the University of Johannesburg.

**THE PURPOSE OF THIS STUDY** is to gain insight into the lived experiences of family members who have a sibling with Borderline Personality Disorder (BPD) and to describe recommendations that can be utilised by psychiatric nurses to facilitate the mental health of siblings.

Below, I have compiled a set of questions and answers that I believe will assist you in understanding the relevant details of participation in this research study. Please read through these. If you have any further questions I will be happy to answer them for you.

**DO I HAVE TO TAKE PART?** No, you don't have to. It is up to you to decide to participate in the study or not. I will describe the study and go through this information sheet. If you agree to take part, I will then ask you to sign consent forms which are attached to this letter.

WHAT EXACTLY WILL I BE EXPECTED TO DO IF I AGREE TO PARTICIPATE? I will meet with you at the time and place that is convenient to you. I will ask you one main question namely: "What is it like for you to have a sibling with BPD?" I might need to ask you follow up

questions only to get clarity where there is a need to ensure that I understand exactly what you are saying. The interview will take 40-60 minutes of your time. With your permission I will tape the interviews. These tapes will be kept under lock and key in a cupboard in my office. Only the supervisors myself and the independent coder will have access to the tapes. The tapes will be destroyed two years after publication of the research.

#### WHAT WILL HAPPEN IF I WANT TO WITHDRAW FROM THE STUDY? If you decide to

participate, you are free to withdraw your consent at any time without giving a reason and without any consequences. If you wish to withdraw your consent, you must inform me as soon as possible.

**IF I CHOOSE TO PARTICIPATE, WILL THERE BE ANY EXPENSES FOR ME, OR PAYMENT DUE TO ME**: Your participation is voluntary; no compensation will be given for your participation.

**RISKS INVOLVED IN PARTICIPATION**: No permanent risks are foreseen in this study. Some of the questions asked during the study interview might make you feel uncomfortable, debriefing or counselling will be provided to you if you need support you can make an appointment with Dr Maria Kay at 082 9245187

#### **Participant Initials:**

**BENEFITS INVOLVED IN PARTICIPATION: There are no direct benefits for you to participate in this research.** There are no direct benefits for you to participate in this research.

WILL MY PARTICIPATION IN THIS STUDY BE KEPT CONFIDENTIAL? Yes. No names will be used on the data sheets. All data and back-ups thereof will be kept in password protected folders locked away. Only I or my research supervisors will be authorised to use and/or disclose your anonymised information in connection with this research study. Any other person wishing to work with your anonymised information as part of the research process (e.g. an independent data coder) will be required to sign a confidentiality agreement before being allowed to do so.

OR

WILL MY TAKING PART IN THIS STUDY BE ANONYMOUS? Yes. Anonymous means that your personal details will not be recorded anywhere by me. As a result, it will not be possible for me or anyone else to identify your responses once these have been submitted.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY? The results will be written into a research report that will be assessed. In some cases, results may also be published in a scientific journal. In either case, you will not be identifiable in any documents, reports or publications. You will be given access to the study results if you would like to see them, by contacting me.

WHO IS ORGANISING AND FUNDING THE STUDY? The study is being organised by me, under the guidance of my research supervisor at the Faculty of Health Science s in the University of Johannesburg. Funding for this study will be obtained from the bursary funds granted by the hospital where I am employed and from the supervisor's grant from the University of Johannesburg.

WHO HAS REVIEWED AND APPROVED THIS STUDY? Before this study was allowed to start, it was reviewed in order to protect your interests. This review was done first by the Department of Nursing, and then secondly by the Faculty of Health Sciences Research Ethics Committee at the University of Johannesburg. In both cases, the study was approved.

WHAT IF THERE IS A PROBLEM? If you have any concerns or complaints about this research study, its procedures or risks and benefits, you should ask me. You should contact me if you feel you have any concerns about being a part of this study. My contact details are:

Contact number is 079 287 1224, and communication can be done between 16h00 and 20h00 Thank you Researcher WENDY CALUZA RN MCUR (Psychiatric Nursing Science) Student Email: wendy\_caluza@yahoo.co.uk

If you feel that any questions or complaints regarding your participation in this study have not been dealt with adequately, you may contact the Chairperson of the Faculty of Health Sciences Research Ethics Committee at the University of Johannesburg who is also my supervisor:

MARIE POGGENPOEL RN; Phd PROFESSOR; DEPARTMENTOF HEALTH SCIENCES Tel: 011 559-6686 Email: <u>mariep@uj.ac.za</u> Participant Initials: You may also contact my research co-supervisors:

C P H MYBURGH Bed, BSc Hons, M. Com, D.Ed. PROFESSOR: DEPARTMENT OF EDUCATION PSYCHOLOGY

Email: chrism@uj.ac.za

MRS MPUMI NTSHINGILA RN, M Cur Psychiatric Nursing LECTURER: DEPARTMENTOF HEALTH SCIENCES Email: mpumin@ uj.ac.za

**FURTHER INFORMATION AND CONTACT DETAILS**: Should you wish to have more specific information about this research project information, have any questions, concerns or complaints about this research study, its procedures, risks and benefits, you should communicate with me using any of the contact details given above.



**Participant Initials:** 



### DEPARTMENT OF NURSING RESEARCH CONSENT FORM OR INTERVIEWS TO BE AUDIO-TAPED

### THE STUDY OF LIVED EXPERIENCES OF FAMILY MEMBERS THAT HAVE A SIBLING WITH BORDELINE PERSONALITY DISORDER

Please initial each box below:

I hereby give consent for my interview, conducted as part of the above study, to be						
audio-taped.						
I understand	that my personal details and iden	tifying data will be changed in	order to			
protect my identity. Th	ne audio tapes used for recording n	ny interview will be destroyed	two			
years after publication	of the research.					
	JOHANNESB					
I have read this consent form and have been given the opportunity to ask questions.						
Name of Participant	Signature of Participant	Date				
Name of Researcher	Signature of Researcher	Date				



### DEPARTMENT OF NUERSING RESEARCH CONSENT FORM

### The Lived Experience of family members who have a sibling with Borderline Personality Disorder

Please initial each box below:

I confirm that I have read and understand the information letter dated April 2018 For the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.



I understand that my participation is voluntary and that I am free to withdraw from this study at any time without giving any reason and without any consequences to me.

# JOHANNESBURG



I agree to take part in the above study.

Name of Participant Signature of Participant

Date

Name of Researcher Signature of Researcher

her

Date

### DEPARTMENT OF NURSING **RESEARCH CONSENT FORM OR INTERVIEWS TO BE AUDIO-TAPED**

### THE LIVED EXPERIENCES OF FAMILY MEMBERS WHO HAVEA SIBLING WITH BORDELINE PERSONALITY DISORDER

Please initial each box below:

I hereby give consent for my interview, conducted as part of the above study, to be audio-taped.

I understand that my personal details and identifying data will be changed in order to protect my identity. The audio tapes used for recording my interview will be destroyed two years after publication of the research.

I have read this consent form and have been given the opportunity to ask questions.

Name of Participant.

Signature of Participant

Date

Name of Researcher Signature of Researcher

Date

### **APPENDIX 6: CODING CERTIFICATE**

#### Independent Coder Certificate

Dr Douline Minnaar minnaarh@gmail.com 0827966700 28-June-2019

I hereby state that I have done the independent data analysis and coding for student Wendy Caluza's study:

The lived experience of siblings of family members with borderline personality disorder



### **APPENDIX 7: EXTRACT FROM A SELECTED INTERVIEW**

#### Extract from a selected interview

Researcher: "Good morning"

Interviewee: "Good morning"

Researcher: "my name is Wendy Caluza, I'm a Master's student at the University of Johannesburg"

Interviewee: "yes"

Researcher: "...as I have already explained to you the purpose of my study , and informed you that you that whatever we discuss here will be kept in confidence and no one will know about it except my supervisors at the University . Your name will not be mentioned at all times in order to protect your identity. you have agreed to be interviewed and for the interview to be audio taped as well"

Interviewee: "yes, thanks."

- Researcher: "How is it for you having a sibling who has Borderline Personality Disorder?"
- Interviewee: "It was not fun at all. When I was still living with my parents and with my sister. My sister was sometimes very aggressive, and we would have fallout about anything. If it was not going her way, we would have a fights and it was really not pleasant. It's not always unpleasant, but most of the time when she was not 100 percent and she was upset then it was not fun at all

I actually had to move out because of that. We are not married yet and I wanted to get married first then move in out .It was my father actually who suggested it, and at the time it was actually so rough, we were so scared she was going to do something to me. I would actually sleep with my door closed.

She has only been recently diagnosed with BPD, so we never actually knew but it makes sense now".

Researcher: "You are saying in the beginning you did not know what was wrong with your sister?"

Interviewee: "Yes, 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".

Researcher: "Can you tell me more about those times when things got bad?"

Interviewee: "Yes of course there were lots of times but there is one that I keep referring back to. We were walking in mall , me , my sister , my mum and my boyfriend who is now my fiancé, we have been together for 8 years now, so he has also been going through it. We actually went there for him to buy, my mum and my sister came along. And then she got so angry because she wanted to go to another shop to buy something for her room but my mum said " No we are first going to buy the beds " and she got very aggressive suddenly. She then pushed me, I nearly fell in front of everyone. My fiancé then had had enough and he said ". If you need to hit someone hit me but you are not going to hit your sister again" she always had words to say and she said: " I'm not scared of you" to him now (my fiancé) .He would never hit her but if needs be she must admit to him so that she doesn't hit me.

After that I actually hit her back for the first time in my entire life. I hit her so bad that she actually she pushed me and I nearly fell .We just went back to the car , when we got to the car she sat next to my mum she then hit my mum and that's when I hit her back. I was bleeding from my arm.

It was so bad she screamed so bad that everyone was standing around the car to see what we were doing".

Researcher: "Were there other occasions where she used would hit you before that?"

Interviewee: "She wasn't, it was not something that she would do often. When she gets aggressive then she would hit anyone. She actually at some stage picked up my granny and threw her against the cupboard. That is how bad she was really. Sometimes when she gets aggressive she would not just hit she would do anything, she becomes this different person that I really do not want to see or meet or to have anything to do with. My relationship with my sister is not great at all even now I don't think we will ever, ever have a relationship because she is very manipulative. Even today there is like times when she comes to sleep here in my place , she would that eat anything we own, she would just make everything always about her. I am getting married in December. I had to ask to be my bridesmaid because she is my sister but every time something big happens in my life she would always make it miserable. The first time I got the car, she never congratulated me, it was not even a brand new car just a second hand car. She was 16 years, I was 18 years and she was like "when am I getting a car?". And I was like you are 16 you will get it when you are 18. *(Sounding irritated)* 

I am still scared even today of what she is going to do and like yesterday we were going to look for the bridesmaid dresses and it was just her and my mum . I asked her to put the dress on so that we can see how it looks. She was unhappy because of the cup because she has gotten very fat. We never say it to her but she had put on a lot of weight. I mean she was skinnier than I am and you know how she looks now.

I think her not doing anything at home even now makes it even worse because we always thought that nothing is going to..(*hesitant*) If you have nothing to do you would also become mad, and that is what she does, she does at home, she sits all day long. She phones my mum and dad to hear what they are doing.

She is very manipulative till to this day so I don't think she is better, and I think it is her decision that she will not be better because she will not be enjoying all the attention that she is getting".

Researcher:" Can you tell me more about that?"

Interviewee: "She will always ask my dad if somebody to goes to buy something or whatever for the next day for work, she would always say "oh but I need a magazine, or I need sweetie" every time I go anywhere she needs to get something and she always gets it. I don't think they are helping her because they now are saying its fine to ask for everything and you are not working for it and it just fall in your lap, so enabling her".

- Researcher: "When you say you don't think they are helping her, who are you referring to?"
- Interviewee: "My parents they are basically just enabling her to be like that by not allowing her. My father never accepted her but now he is. They are enabling her to be the way she is now because they are giving her what she wants because if they don't then it always end up in a fight, so they would rather have peace then the moaning and her being aggressive , but she is now much better . She is not aggressive anymore but she is still very manipulative and that won't change at all because it's been like that forever".

Researcher: "How do you feel about all that?"

Interviewee: "I hate her for that..(Sounding angry and clenching a fist on the table) I know it's bad word to use but I do because she made it, she influenced my life. I didn't have (*paused and looking around the room*) we didn't want to live like this now because we could have been able to save so much money if I still lived with my parents.

> So now that you live on your own its nice to eat what you want, it's nice but it's not the way I planned my life, so she basically ruined my life and she ruined my relationship with my parents. No it's not ruined but it's not as if we have a great relationship

Whenever I'm with my mum she is always there, so I can't have a relationship with just my mum. It's always my sister involved".

Researcher: "And when this happens, how do you feel?"

Interviewee: "I feel angry with her. I just want her to leave, leave my party, leave my house, leave everything and don't come back. I'm sad, I'm, I'm enraged at her still today *(jaws clenched, face turning red*) but I will never say it to her , in her face but I do feel like that".

# APPENDIX 8: LETTER OF CONFIRMATION FROM THE LANGUAGE EDITOR



Leatitia Romero Professional Copy-Editor, Translator and Proofreader (BA HONS)

> Cell: 083 236 4536 leatitiaromero@gmail.com www.betweenthelinesediting.co.za

13 October 2019

To whom it may concern:

I hereby confirm that I have edited the dissertation entitled: "LIVED EXPERIENCES OF FAMILY MEMBERS WHO HAVE A SIBLING WITH BORDELINE PERSONALITY DISORDER". Any amendments introduced by the author hereafter are not covered by this confirmation. The author ultimately decided whether to accept or decline any recommendations made by the editor, and it remains the author's responsibility at all times to confirm the accuracy and originality of the completed work.

Leatitia Romero (Electronically sent – no signature) OHANNESBURG

Affiliations

PEG: Professional Editors Group (ROM001) EASA: English Academy of South Africa SATI: South African Translators' Institute (1003002) SfEP: Society for Editors and Proofreaders (15687) REASA: Research Ethics Committee Association of Southern Africa (104)