AN UNSETTLED LIFE: CARERS EXPERIENCE OF LIVING WITH A PERSON HAVING BORDERLINE PERSONALITY DISORDER

By

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ABSTRACT

Background: The responsibilities of providing care to a person with borderline personality disorder (BPD) and the pressures of maintaining a family may have a negative impact on the caregivers. This may lead caregivers to experience stress and burnout. Despite this, healthcare professionals tend to focus more on the person affected with the disorder (patient) and neglect the caregivers needs for support.

Objective: The aim of the current study was to explore the meaning that informal carers attribute to the experience of caring for their relative with BPD. The objectives of the study were to explore the impact of caring for a relative with BPD and identify the coping strategies used by the informal carers.

Design: A qualitative approach following the principles of Interpretative Phenomenological Analysis (IPA).

Setting: The study was conducted in the caregivers' homes (n=2), or within a public hospital (n=3) depending on the participants' preferences.

Participants: Five spouses, consisting of two females and three males and who were caring for a person having BPD.

Methodology: Purposeful sampling was used to recruit participants. Semi-structured interviews were audio-recorded and transcribed verbatim. Data analysis were done using IPA.

Results: Three superordinate themes emerged namely: 'An Unsettled Existence', 'Searching for Meaning and Peace' and 'Supportive Relationships'.

Conclusion: Participants described how caring for their spouse with BPD impacts on their life leading to an unsettled existence. The burden on the caregiver is high and affected their overall quality of life. The caregivers are affected psychologically, emotionally, socially, physically and their relationships are impacted by the stress associated with caring for their spouse with BPD. Furthermore, the caregivers described learning how to search for meaning and peace through self-preserving strategies. Furthermore, results showed that caregivers need support from health professionals. In addition, caregivers verbalised that they need to be more involved in their relatives' care plans and need more knowledge about BPD.

Key words: 'Borderline Personality Disorder', 'Relatives', 'Caregivers', and 'Lived Experiences'.

DEDICATION

To

My son Lucas and my daughter Layla

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LIST OF ABBREVIATIONS

BP	Borderline Personality
BPD	Borderline Personality Disorder
CINAHL	Cumulative index to Nursing and Allied Health Literature
CPDS	Community Personality Disorder Services
CSM	Common Sense Model
DBT	Dialectic Behaviour Therapy
FC	Family Connections
FREC	Faculty Research Ethics Committee
GPs	General Practitioners
HCP	Health Care Professionals
ICD-10	International Classification of Diseases - 10
IPA	Interpretative Phenomenological Analysis
KAI	Knowledge Assessment Interview
MCH	Mount Carmel Hospital
MHA	Mental Health Association
MS-BPD	Making Sense of Borderline Personality Disorder
NGOs	Non-Governmental Organisations
OTAU	Optimised Treatment As Usual
PD	Personality Disorder
PEO	People, Exposure and Outcome
PRISMA	Preferred Reporting Items for Systematic Review and Meta-Analysis
RCT	Randomised Controlled Trial

SCL-90	Symptom Check List -90
SO	Significant Others
UoM	University of Malta
UREC	University Research Ethics Committee
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

1.1 Background to the study

Personality disorders (PD) are developmental conditions which appear in late childhood or adolescence and continue in adulthood. According to the World Health Organisation (WHO) in the International Classification of Diseases (ICD)-10 (2003), BPD presents with symptoms of disturbed or uncertain self-image, unstable relationships which lead to emotional crisis, efforts to avoid abandonment, chronic feelings of emptiness and threats or acts of self-harm. In addition, the person diagnosed with BPD has a tendency to have traits of impulsivity. Gunderson (2011), posited that although it is straight forward to follow the criteria to recognize BPD, the diagnosis is often underused. The main possible reason for under diagnosis of BPD might be that because of the emotional volatility, recurrent crises and self-injurious behaviour that characterize people with BPD, BPD is perceived to be signs of wilful and manipulative episodes rather than an illness (Gunderson, 2011). Leichsenring et al. (2011), state that the cause of BPD may be linked to both genetic factors and adverse life events.

The annual report released for Mount Carmel Hospital (MCH) shows that there was an increase in patient admissions of persons diagnosed with BPD. In fact, in 2017 there were 10 males and 12 females, in 2018 there were 20 males and 23 females and in 2019 there were 42 males and 26 females. Leichsenring et al. (2011), state that the rate of BPD admission to a psychiatric setting is approximately 20%, however the rate is even higher in high secure settings. BPD is estimated to affect 1-3% of the general population.

In view of the characteristics of the disorder, BPD influences not only the person with the disorder but also the family members. In fact, Fossati and Somma (2018) posited that people

in intimate relationships with a person suffering from BPD, are overwhelmed with the extreme and unpredictable situations that they face. They experience emotional and psychological burden which is perceived as overwhelming even though they, themselves do not suffer from any mental disorder. Furthermore, these informal carers have a tendency to blame themselves for their relative's illness or for not being able to help them. In turn, this leads to emotional torment, anxiety, guilt, frustration, anger, despair and hopelessness.

Taking into consideration the background of BPD and its impact on informal carers, evidence suggests that family interventions (such as family connections programme) may be effective for caregivers to deal with the burdens of caring for their relative with BPD (Fossati & Somma, 2018).

Hence, the current study is intended to raise the level of awareness of health professionals on the burden that BPD place on the relatives living with a BPD person. Moreover, to the knowledge of the present researcher this is the first local study to explore the perceptions of carers of persons with BPD and hence, the information generated may assist in the formulation of interventions that target the needs and concerns generated. Furthermore, this study is intended to contribute to the dearth in international research about the lived experiences of informal carers of BPD individuals.

The next section presents an overview of the local scenario of the mental health system and informal carers of people with BPD.

1.2 The Local Scenario

The Mental Health Strategy for 2020-2030 was launched by the Office of the Deputy Prime Minister (2018), where it highlighted that families and caregivers of people with mental illness need to be supported. However, these services needs to be developed in Malta. The Mental Health Strategy 2020-2030 (2018), anticipated that such services for informal carers will be setup in collaboration with associations that represent carers of persons with mental illnesses. Moreover, the document upholds that a priority will be given to develop care pathways so that one ensures that information is easily accessible for families. Care pathways will ensure that family members and carers are aware of their rights and responsibilities and puts them in touch with the services that can provide them with knowledge, training and support. However, the document highlighted that the ways of improving the interface and involvement of informal caregivers needs to be explored. It was also acknowledged that the carers are under severe strain, and thus respite services are considered as an important source of support for carers. Hence, respite services are envisaged to be developed and be part of the mental health services.

In Malta, support for relatives of people with mental illness is provided by the Malta Mental Health Association (MHA), St Jeanne Antide Foundation and Richmond Foundation.

The MHA is a non-governmental association which is run by family members of people with mental illness and offers support, empowerment and promote the interest of the relatives and family caregivers of people with mental illness. The MHA is involved in educating the general public on mental illness and works to combat stigma. The MHA has a role to advocate for mental health and social care improvements. The aim of the association is to educate family members to cope with a family member having a mental illness. Psycho-educational talks are organised, where professionals in the mental health field provide knowledge about mental illness to the relatives of the mentally ill.

The St Jeanne Antide Foundation provides support to vulnerable individuals and their families. "Lwien" is the service which enables family care givers of people with a mental illness to

access support that enables them to continue caring for their relative without impairing their own health and wellbeing. The service is based on enabling the people to increase their ability to solve problems, build better relationships in the community, access their rights and obtain the resources that they need.

The Richmond Foundation is a non-governmental organisation (NGO) run by professionals that support people with mental health problems and their families. In addition to the therapeutic care and assisted living for people with a mental illness, they offer support services for caregivers. Caregivers have the opportunity to be involved in support groups, educational programmes and counselling services which help them to cope during difficult and/or challenging situations.

The named organisations offer support for informal carers of people with different mental illnesses. There are no support groups specifically designed for families of individuals with BPD. This scenario should be interpreted in a context where according to Hoffman et al. (2007) the treatment of people with BPD must involve both the affected person and the family members.

In addition to the NGOs, the Mental Health Services in Malta supports persons with chronic and severe mental illnesses and their families in the community through outreach mental health

services and community-based clinics. There are five community mental health clinics and three outreach teams that support people with mental illness and their families.

In Malta and internationally, it is acknowledged that mental illnesses are very common and pose a burden for the affected people, their families and society. Governments play an important role in adopting legislative and economic measures that foster mental health and well-being. Furthermore, the mental health system itself also needs to be resilient to adopt and cope with change (Mental Health Strategy 2020-2030, 2018). The Mental Health Strategy 2020-2030 (2018), declares that the planning and delivery of mental health care will involve different stakeholders, including the patients with mental illness and their families. Family members will be considered as important partners in the care process. Thus, local research studies which represent the informal carers' needs and concerns can be used to contribute to the local mental health reform. According to Billington (2006), 'insider' accounts are a valuable source of information in evaluating the efficacy of existing care and to initiate change. Furthermore, nurses are in an optimal position to be change agents in the mental health system as nurses are pivotal in working with people having mental illnesses and their families.

1.3 The Present Study

The literature review, highlights that research to date on the experiences of informal carers providing support to their relative with BPD, mostly target the views of a range of carers by status collectively together. Hence, the 'carer' samples in seven studies used were composed of spouses, partners, parents, extended family members and siblings. Another study (Griffin, 2008) used in the literature review, was targeted for family members of persons with BPD, but only parents were nominated to participate in this study. In addition, one quantitative study (Bouchard et al., 2009), focused on comparing 35 couples with the women who suffered from BPD with a nonclinical control sample of 35 couples.

Therefore, this study contributed to the literature by conducting a qualitative approach to explore the lived experience of spouses living with their relative with BPD. The qualitative approach chosen to guide this study was IPA. This approach was chosen as IPA allows an in-depth examination of the participants' experiences (Smith et al., 2009). Data was collected

using semi-structured interviews. Semi-structured interviews placed the participants and their accounts at the heart of the research. This is believed to be an appropriate approach towards data collection which provides rich accounts of the informal carers' lived experiences and hence, to better understand the caregivers' interests and concerns (Smith et al., 2009).

Therefore, the aim of this study is to explore the meaning that informal carers (spouses) attribute to the experience of caring for their relative with BPD. The objectives of the study are:

1. To explore the impact of caring for a spouse/partner of a person with BPD.
2. To identify the coping strategies used by the informal carers of individuals with BPD.
3. To explore the support strategies of the spouse/partner of a person with BPD.

1.4 Significance of the Study

The decision to conduct a qualitative study emerged as this design enables the researcher to extract in-depth information and explore the following research question set for this study:

'What are the lived experiences of informal carers of persons with BPD?'

My interest in this research area is linked to my own experience as in-charge of an acute ward. This experience provided me with the opportunity to observe the admissions and readmissions of individuals with BPD and the intense emotional impact on the carers. During this period, I noticed that spouses and partners would often verbalise their concerns about the behaviour and impulsivity of their spouse with BPD, in addition to their helplessness regarding how to best support their ill relative and cope themselves.

Furthermore, as evidenced in the extant literature and from my own personal experience, it is a challenge for health professionals to nurse individuals with BPD and thus my interest grew in understanding the experience of the caregivers who share their life with these persons. Moreover, it became apparent that family members may not be encouraged to verbalise their needs and concerns, as care tended to be more focused on the in-patient.

In an effort to increase my understanding on the experiences of carers, I conducted a literature search. However, after reading the articles extracted, I noticed that the few articles available discussed the experiences of carers of persons with BPD coactively together. They failed to

differentiate between the experience of spouses/partners from that of the other family members (e.g., parents, children) caring for their relative with BPD. Thus, there was a lacuna in qualitative research focusing on partners/spouses of BPD individuals. Consequently, through this study I hope to contribute to this lacuna in international and local literature by addressing this research gap.

Hence, I hope that this study will highlight the needs of the spouses living with a relative with BPD so this may be utilised to help the health care providers to understand these needs, so they can support more the caregivers and include them more in care planning. In addition, no study was conducted locally that explores this phenomenon and hence, through this study I hope to provide a voice for these informal carers.

It is through an understanding and exploration of participant beliefs that health professionals may provide person-centred care, achieving outcomes such as a good care experience and a feeling of well-being in these carers.

The next section describes the structure of this dissertation.

1.5 The Dissertation Structure

In order to facilitate the readers' understanding of this research project, a brief description of the layout will be outlined. Chapter one provides an introduction and rational for the choice of the topic. Chapter two provides a critical discussion of the retrieved literature. Chapter three provides the details in relation to the research method used in this dissertation. Chapter four outlines the data analysis and my interpretations. Chapter five presents a critical analysis of the findings of this study and the existent research, in the light of the Common Sense Model (Leventhal et al., 1980) and the Person-centred Practice Framework (McCormack & McCance, 2017). Chapter six brings this dissertation to its conclusion and provides recommendations for clinical practice and for future research.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter describes the theoretical framework and search strategy applied to identify research targeting the experience of informal carers of persons with BPD. In addition, this chapter provides a critique of the extant literature and highlights gaps identified in the literature. A comprehensive search was conducted using various electronic databases.

The aim of this literature review is to present a critical appraisal of the literature that explores the lived experiences of informal carers caring for their relative with BPD. The researcher identified that there is a lacuna in the experience of carers namely, the partners, husbands and wives. This is addressed in the present research study.

Extraction of relevant literature in relation to the aim of this study was influenced by the inclusion and exclusion criteria set and which are presented in more detail in the following section.

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2.2 Inclusion and Exclusion Criteria

The question addressed in this chapter is: What are the lived experiences of informal carers of persons with BPD?

The Population, Exposure and Outcome (PEO) method by Khan et al. (2003), was used to develop the criteria that determined the studies that were extracted for this review. Table 2.1 describes the inclusion and exclusion criteria.

Table 2.1 – Inclusion and Exclusion criteria for the present literature review

PEO		Inclusion Criteria	Exclusion Criteria
Population		Adults aged 18 years and above. Partners, Wives and Husbands.	Participants aged less than 18 years since the focus of the researcher was on adults.
Exposure		Participants who lived with and were caring for their relative with BPD.	Participants who did not live with the person having BPD and those caring for their relative with an additional mental health condition to BPD.
Outcome		Quality of life Coping	Experiences other than coping or Quality of life.

Following the inclusion and exclusion criteria, the researcher proceeded to develop search strategies from the electronic databases. The next section describes the search strategy in more detail.

2.3 The Search Strategy

Multiple electronic databases were used to maximise the number of relevant studies and to prevent introducing search bias to the literature search (Randolph, 2009). A thorough literature search was conducted in the University of Malta (UoM) electronic databases: Academic Search complete (EBSCO), the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline (ProQuest), PsycINFO (EBSCO) and Web of Science. The search was limited to research written in the English language only. This might have led to language bias because non-English articles could have been missed (The Cochrane Collaboration, 2011). Reference

lists of the full text articles identified were examined in order to obtain additional relevant literature. Wherever possible the primary sources of information were utilised as these provide direct evidence related to the research question. Secondary sources were only considered when the original sources could not be obtained. The search timeframe covered the years 1996 to 2018, as it was observed that research related to the topic was available for this period of time. The search was carried out between January 2019 - June 2020. The search terms used are illustrated in Table 2.2.

Table 2.2 – The search terms used in the search strategy

PEO	Population	Exposure	Outcome
Search terms	Relatives, Partner, Family, Informal Carers, Caregivers.	Borderline Personality Disorder, Borderline Personality Disorder Individuals, Borderline Personality Disorder Relative, Mental Health condition.	Lived Experiences, Coping, Impact on the quality of life.

Using the search terms: "Borderline Personality Disorder", "relatives", "caregivers" and "lived experiences" yielded 1,070 hits. To focus on the specific research question, the terms were combined using "of" and "and". The search provided an array of research dating back to 1998. The next section describes the screening process undertaken which identified the relevant studies.

2.4 Identification and Screening of Studies

The PRISMA guidelines (Moher et al., 2009) were followed to identify papers for eligibility to use in this review. Figure 2.1 presents the flow diagram describing the screening process based on Moher et al. (2009). At this stage, 1,070 articles were screened for eligibility based on the titles. Articles which had an unclear title, had their abstracts reviewed. After removing the papers which were not relevant to the topic of interest, 70 relevant papers remained. The full texts were read as it was difficult to determine the eligibility of these papers by reading their titles and abstracts. The reasons for excluding irrelevant papers were 1) papers were not written in English; 2) full text was not available and 3) they did not include relatives of individuals with BPD. The relevant papers were exported into a bibliographic software (Refworks) and duplicate papers were removed.

At this stage a total of 9 studies were included in this review for critical appraisal. The studies were conducted in France (1), United Kingdom (1), Australia (2), America (1), Sweden (1), Germany (1) South Africa (1) and another study used a sample from the internet and the different geographic locations were not indicated in the study. The literature search yielded 8 papers that conducted their research on families as the caregivers of individuals with BPD. An additional paper was used which directly studied couples with one of the partners having BPD. I then thoroughly re-read these papers in order to conduct a critique of these studies.

The following section presents a critique of the literature in relation to the emotional and psychological impact and the interpersonal relationships of the informal caregivers of BPD relatives.

Figure 2.1- Flow diagram describing the screening process based on Moher et al. (2009).

Papers identified through database searching (n = 1070)

No. of additional papers found outside of database search to be screened for inclusion (n = 0)

No. of records screened for potential relevance based on titles and abstracts (n = 1070)

Papers excluded after reading titles and abstracts (n = 985).

Reasons for exclusion

● participants not diagnosed with BPD.

● Participants were patients or HCP.

● Participants aged < 18 years

● Did not report on lived experiences carers.

No. of papers exported into Refworks (n = 85)

No. of duplicate papers removed (n = 15)

No. of articles excluded after reading the full texts (n = 63)

Reasons for exclusion

● Studies focused on therapeutic programmes.

● Participants were not families/ couples on individual with BPD.

● Did not report on the outcomes of interest.

● Participants < 18 years.

Full text articles assessed for eligibility (n = 70)

No. of articles included after scanning reference list (n=2)

Studies included for critical appraisal = 9 papers

2.5 A Critique of studies on the informal carers of persons with Borderline Personality Disorder

2.5.1 Quality of life studies

BPD is a complex and challenging mental health condition both for the person and the carers supporting them (Lawn & McMahon, 2015). Furthermore, caring for a relative with BPD is described to be an emotionally draining role (Dunne & Rogers, 2013). Giffin (2008), posited that BPD is not only emotionally painful for the affected person but also for those in a relationship with them. BPD is considered as a chronic mental illness, for which psychotherapeutic treatment is a challenge for mental health professionals.

Bailey and Grenyer (2014), conducted a study using online or a printed version of the survey on the impact of caring for a person with BPD. The survey used a mixed methodology (using validated tools and one open question which was analysed qualitatively). A strength of such a research designs includes the provision of an in-depth understanding of the data collected (Creswell, 2014). 287 carers of persons with BPD completed the survey. Initially a total of 474 carers consented, however 187 were excluded, out of which, 59 carers did not have a relative with BPD, 108 did not complete any of the questions and 20 did not meet the inclusion criteria. The participants age ranged between 16 to 75 years. The majority of carers were female (n=194, 67.6%) and 93 (32.4%) were males. 106 (36.9%) participants were spouses/partners, while 90 (31.4%) were mothers, 16 (5.6%) were fathers, 39 (13.6%) were children, 14 (4.9%) were siblings and 22 (7.7%) were significant others. The carers recruited for the study all provided care for a family member with BPD and were all seeking support and education from different mental health forums. For this research a convenience comparison group was drawn for each measure from published literature. The measures included in this study were the Burden Assessment Scale (Reinhard et al., 1994), the Grief Scale (Struening et al., 1995), the Mental Health Inventory-5 (Cuijpers et al., 2009) and the Difficulties in Emotion Regulation Scale (Gratz & Roemer, 2004). Furthermore, Leximancer was used to analyse one qualitative question that was in the survey (the question was, as a carer, what is your experience of caring for your relative [what impact has it had on you, your life and relationships]?). 228 participants provided a response to the qualitative question.

Burden and grief in carers of BPD relatives was significantly higher than that reported by the carers of other serious mental illnesses (e.g., schizophrenia and affective disorders in

the comparison group from published literature). This was evident by one partner who stated, *"I had to learn to tiptoe around issues and give up things I liked whether I wanted or not…"* (Bailey & Grenyer, 2014, p. 803).

Furthermore, another partner stated, *"The biggest impact has been the grief of losing the person … my life has basically been "on hold" hoping she will get better and become independent and now gradually realising this probably won't happen and starting to accept that I may have to care for a long time for someone with what I am starting to accept as a disability."* (Bailey & Grenyer, 2014, p.803).

The qualitative data also highlighted that caring for a person with BPD had a huge impact on interpersonal relationships. One participant stated, *"it has become a huge emotional weight and pressure on the family … All other family members are experiencing stress and anxiety due to (the person with BPD) behaviour … Husbands had to pass up job … Less social life, not having people over as it causes anxiety for relative and behaviour is erratic".* Thus, living with a person having a BPD has an impact on the carer's family, work and social relationships (Bailey & Grenyer, 2014, p. 804).

Moreover, carers also reported an impaired wellbeing, that included experiencing mental health problems and difficulties with their own emotional regulation. These symptoms of impaired wellbeing were similar to that expressed by participants who were diagnosed with anxiety, mood disorder and post-traumatic stress disorder in the convenience comparison group for which data was extracted from the published literature.

This research study highlighted that the three predominant sectors of impact in caring for a family member with BPD are burden (and grief), impaired wellbeing and interpersonal struggle (Bailey & Grenyer, 2014). It was recommended that further research is conducted to explore the interpersonal experience of caregiving. This would in turn help professionals and researchers to understand the relational dynamics that may contribute to the experience of burden and mental health problems in carers of individuals with BPD. Although this study helped to increase understanding in the experience of carers with a family member with BPD, it was limited in providing a control sample to allow direct comparison with other mental illnesses. Furthermore, the sample was recruited over the internet and thus it was only accessible to internet users from multiple countries. In addition, the samples responses were not analysed by geographical locations to determine whether this aspect may have an influence on findings obtained.

Another study conducted by Griffin (2008) used a qualitative design and explored the experience of parents of a relative receiving treatment for BPD. This focus on parents only as representative of carers provided for the homogeneity of the study. The study had a small sample size of four parents, compromising of three mothers and one father. Data were collected using unstructured, in depth interviews. A strength of this method of data collection is that it enables the participants to describe their major problems according to their own priorities (Griffin, 2008), which ensures the rigour of the study (Polit & Beck, 2006). However, a potential bias and limitation of this study was that participants were aware that the interviewer worked for an agency that offered treatment for people with BPD.

The findings demonstrated that the informal carers were suffering from chronic and traumatic stress, from repeated witnessing of self-harm and near death incidents of their child with BPD. This study suggested that when an out of the ordinary shocking experience is witnessed, this triggers traumatic stress. In addition, the participants described their emotional impact and exhaustion through physical health concerns and lack of sleep. One of the participants talked about physical symptoms such as nausea and angina which she perceived as symptoms associated with the stress of caring for their relative with BPD. In addition, the participants verbalised their concerns between giving support to their relative or stepping back. However, stepping back created fears of the consequences (Griffin, 2008).

Results also showed that couple's relationships were strained when the mother actively cared for the daughter with BPD. In addition, family relationships were additionally strained when the daughters had children themselves. This is in view that mothers prioritise their care for the daughter and her children over other siblings and the marital relationship. The parents, siblings and partners verbalised their fears that the children might find their mother self-harming.

This study focused only on parents of siblings with BPD. Thus, further research with other family members can provide information on the perspectives of other members of the family who support persons with BPD.

Another study (Ekdahl et al., 2011) that has contributed to research on carers described the experiences of significant others' (SO) living with an individual having BPD and their experience with health care. The researchers believed that if health professionals understood the carer's experiences and life situations, this could be an important step to improve care for persons with BPD and their carers. 30 carers from a Swedish association of persons with BPD were invited to participate in the study. This study had a purposeful sample of 19 SO, of whom

17 were parents, 1 was a spouse and 1 was a grown-up child. 14 participants were women and 5 were men. 11 out of the 19 participants consented to participate in the additional group interviews, of which 9 were female and 2 were male. The majority of participants were parents (n=10) and 1 was an adult child. The age range of the participants varied between 43 and 75 years. The data was first collected using questionnaires in free-text format which were returned back to the author by mail. The questions enquired on their experiences: a) that relate to the ill relative's health condition; b) about the impact on the family and c) on their encounters with health care. This was then followed by group interviews. A narrative approach was used during the interviews to provide an opportunity to participants to share their stories. The interview guide questions focused in-depth on the carers experience of: a) living close to a person with BPD; and b) encounters with health care and psychiatric care.

The main part of the sample were parents and hence one may question whether the bulk of the findings may have been influenced by this fact. However, the trustworthiness of this study was enhanced as the researchers used different data sources namely, free hand questionnaires and interviews to study the topic (Sandelowski, 1995).

Four main themes were elicited from the study, namely tiptoeing in life, powerlessness, guilt and lifelong grief, feelings of being left out and abandoned and loss of trust (Ekdahl et al., 2011). The participants described their life as being constantly worried for their relatives' impulsive acts of deliberate self-harm or attempted suicides. Furthermore, interrelationship issues emerged, where the parents verbalised their concerns for the neglected siblings, and relationship strain between the couples. Therefore, all the family members tiptoe around the life of the person with BPD because of the constant fear that something will happen. This might be related to the emotional instability, lack of impulse control, suicidality and self-harm behaviour that are associated with BPD and which the carers feared to trigger themselves. According to Ekdahl et al. (2011) the 'tiptoeing' behaviour is a behaviour that is specific to persons with BPD. However, a local study by Camilleri (2015) has also identified this behaviour in informal carers of persons with chronic depression. In fact, the participants (Camilleri, 2015) expressed their emotional fears arising from the unpredictability of their relative's behaviour in particular relatives with a history of aggression and attempted suicides. Furthermore, informal carers caring for relatives with chronic depression also described that the experience of caring changed their life completely. Such similar results in the studies of both caregivers of BPD and depression might arise because both conditions are severe mental

illnesses and thus their caregivers are faced with possibly considerable challenges of caring for a relative with a severe mental illness (Crowe & Lyness, 2014).

The participants in this study pointed out that they had no time to focus on their own wellbeing. They also experienced shame and lack of understanding from the people around them due to the stigma associated with mental illnesses. In addition, feelings of frustration were expressed due to their ill relative's lack of recovery from BPD, despite all the efforts from the carers and the health professionals. The carers described their guilt feelings as parents of BPD children. Guilt was further emphasised with the preconceptions that the parents contributed to the BPD of their child. This belief was further consolidated through contact with health professionals, who made the parents feel useless.

Although the study by Ekdahl et al. (2011) focused on carers of BPD individuals and the results were consistent with other studies, this research recruited participants from a Swedish association of SO of persons with BPD and therefore, the findings may not be representative of the general population of SO of individuals with BPD (Ekdahl et al., 2011).

In another study, Dunne and Rogers (2013) used focus groups to explore the informal carer's role of caring for their relative with BPD in the community. Two focus groups were organised by the Community Personality Disorder Services (CPDS) in East England for carers of service users with BPD. 8 carers participated in the first focus group, 5 out of the 8 participants participated in the second focus group. The participants were 5 males and 3 females of which 4 were partners, 3 were parents and 1 was a sibling. The first focus group aimed to explore the experience of the caring role. the second focus group aimed to explore the carers' experience with mental health and community services. The super-ordinate theme "the service user and carer relationship" emerged, which highlighted the carers effort to understand their relatives. A central sub-theme that was identified, was the stress and the pain that the carers experienced in caring for their ill relative, as they felt unable to understand their relative's feelings. A common feature that emerged was "walking away" when the carers were faced with an over-whelming and painful situation. One of the participants expressed *"after her breakdown I walked away I just had, I was too shocked and too damaged"* (Dunne & Rogers, 2013, p. 646).

 Participants also expressed that caring for their relative was life changing. The carers pointed out that caring became their full-time role and thus this had an impact on their lifestyle. The caregiving role even impacted on the carer's work and on their leisure time. Furthermore, it

was also elicited that being a partner had a different impact on the carer as there was an element of choice in the role. On the other hand, being a parent felt more stressful as the carer had a greater burden on them in comparison to other parents. One parent expressed "*I'm doing a lot more than a mum would probably do for another nineteen-year old ...*" (Dunne & Rogers, p. 646). Hence, the treatment and support of BPD individuals must take into consideration the ill relative and their relationships with the family and the health care team. Due to the qualitative methodology, the emphasis of the study was on the phenomenological experiences of the carers which offered rich contextual data. On the other hand, the limited number of carers who participated in the focus group may be the result of the carers being unable to find the time to attend because of their responsibilities as caregivers. Furthermore, to increase inter-rater reliability of the data, the analysts cross-checked each other's themes. It was acknowledged that in view that there is a lacuna in research with this specific group of carers, further research would not only increase awareness but also encourage action among traditionally neglectful mental health services (Dunne & Rogers, 2013).

The influence of caring on relationships was also evident in the research by Kay et al. (2018), who conducted a qualitative study using a purposive sample of family members of patients with BPD. Purposive sampling enabled the researcher to be well informed about the research phenomenon under examination (Creswell & Poth, 2018). Eight in-depth phenomenological interviews were conducted and field notes were taken. A strength of this study was the use of triangulation of data using interviews, observations and field notes to increase trustworthiness of the study. The sample consisted of three mothers, two husbands, one uncle, one father and one daughter aged between 24 and 74 years. The sample was reasonably homogenous which allowed the researcher to examine in detail the psychological variabilities within the sample however it still varied in relation to the diverse carers included. The study also provided a rich description of the demographics that allowed for transferability which refer to the applicability of the findings in other contexts (Kay et al., 2018). The purpose of this study was to explore and describe the experience of family members having a relative with BPD. Results showed that chaos and family disorganisation were experienced by the relatives as a result of dysregulation in the home environment. Furthermore, emotional dysregulation in the family member suffering from BPD created difficulty in their relatives to manage their own emotions. Moreover, relatives verbalised that they were not aware of their family member's unpredictable behaviours and in turn this had a negative effect on the relationship between the individual

having BPD and the relative. Thus, these behaviours create confusion and destroy family relationships. This was also evident in having the relatives expressing feelings of despair, guilt, humiliation, sadness, regret, being judged by the extended family and experiencing financial challenges and marital conflicts. Family members felt humiliated by the impulsive behaviour of their relatives diagnosed with BPD and judged by the extended family as being viewed to unable to handle their relative's behaviour. This study demonstrated that all the family members were affected by caring for a relative with BPD.

Although the study provided a detailed description of the interviews, the data collated related to a diverse range of carers. The present study targets this limitation by focusing on a homogenous sample consisting specifically of spouses of persons having BPD. Furthermore, the study by Kay et al. (2018) was conducted in a mental health hospital and thus the result may not be representative of the experiences of caregivers of a relative with BPD in the community.

Bauer et al. (2012) in their qualitative study aimed to assess the burden on caregivers of patients with BPD. Furthermore, using a bottom-up approach, quantitative analyses was used to study the impact of socio-demographics and illness-related variables with the aim of deducing effective and ineffective interventions for working with caregivers of BPD people. Over a period of 6 months, 89 admissions were asked to give permission to their closest relative for an interview, out of which 51 agreed to participate. Out of the 51, 1 gave an incorrect address, 15 refused to participate and 3 could not arrange an appointment for the interview. Thus, 32 caregivers were interviewed. However, 1 interview had to be abandoned due to language barrier and another interview was discarded because he was a priest and not a close relative. The sample consisted of 16 females (53.3%) and 14 males (23.3%). The ages varied from 30 years to over 50 years of age. The care givers relationship were: spouse (n=7), partner (n=3), parent (n=10), child (n=2), sibling (n=2), friend (n=5) and aunt (n=1). In addition, regarding the marital status 24 caregivers were married or cohabitating and 6 were single, divorced or widowed. Moreover, 15 of the caregivers were living together with the patient and the other 15 were not living with the patient. Semi-structured interviews were conducted and commenced with an introductory question namely: "which types of burden arose for you from your relative's illness?" The transcripts were analysed using a summarizing qualitative content analysis. Global statements were quantified by taking into consideration only one statement per global statement.

Most of the participants revealed worries about the burden on other members of the family, burden related to poor cooperation from clinical centres, financial burden, dissatisfaction with the treatment and rehabilitation and worrying about the patient's future. Moreover, the interviews were characterised by high caregiver involvement particularly high emotional pressure. In fact, 96.6% of the participants named one or more emotional burdens, 50% named three or more and several participants named up to eight emotional burdens. Therefore, this showed that caregivers had varied emotional burdens. The emotional burdens named were worries about the patient's future (n=16, 53.3%); fear of self-harm and suicide (n=15, 50.0%); caregiver's helplessness and fear of being subjected to excessive demands (n=14, 46.7%); constant worry about the patient (n=1, 36.7%)); feelings of guilt (n=9, 30.0%); being alone in caring for and being responsible for the patient (n= 8, 26.7%); sadness resulting from the extent of patient suffering (n=6, 20.0%); caregiver's refusal to accept the illness (n=4, 13.3%); resignation and emotional blunting due to the fluctuations of the illness (n=4, 13.3%); worries about the heredity of mental illness (n=4, 13.3%); caregiver's grief and feelings of loss due to the necessary revision of life plans (n=3, 10.0%).

In addition to the emotional burden, the participants felt that the symptoms and the progress of the person's condition (18.6%) and the caregiver's quality of life associated with the illness (15.4%) were both additional burdens. Furthermore, analysis showed that 47% of the participants named dealing with the patient's mood and personality changes and dealing with the patient's self-harming behaviour and attempted suicides (47%) as the most difficult aspects to deal with. These were followed by the patient's lack of trust, irresponsibility, and aggressive behaviour (33%). Furthermore, 33% highlighted as a burden, the lack of understanding about this psychiatric disorder in the community and 40% of the caregivers experienced stigmatisation and prejudice.

Classification and regression tree (CART) analysis of the overall level of burden of this study (was based on the data from 30 caregivers, with a mean of 13.2 burdens per carer) revealed that the overall burden was more extensive if the carer was the spouse or partner of the individual with BPD (M=18.9) rather than other relative e.g., parent, child or sibling (M=11.5). This finding may further corroborate the need for phenomenological studies similar to the present one, that explore the experiences of homogenous samples of informal carers. The most common complaints in marital relationships were the uncertainty in the interactions with the individual, emotional isolation and doubts in the relationship, problems in the sexual relationship with their sick partner, fears about the patient who might end the relationship and

cheating on the caregiver (Bauer et al., 2012). Moreover, these results might be more understandable in view that the caregivers who live with the individual with BPD share the daily activities with the patient and thus experience specific burdens such as, the caregivers often bring up the joint children alone and may have to act as an intermediary between the children and the ill individual. This might add to the burden felt when compared between the partner/spouse caregiver and other caregivers (Bauer et al., 2012). The present study contributed to the literature by providing in-depth accounts of the experiences of a relatively homogenous sample of spouses living with persons with BPD.

An important limitation of the study was the large number of patients who refused to give permission for their relative to participate in the interview. In addition, it was also noted that these patients might be the ones with the most disturbing pathology, who in turn might inflict more burden on their caregivers (Bauer et al., 2012).

As found in previous studies, this study confirms that caring for a relative with BPD has adverse emotional and psychological consequences for the caregiver. Thus, more initiatives should be targeted to collaborate and alleviate the burdens on the caregivers especially the groups recommended by Bauer et al., (2012), being a spouse/partner to the patient with BPD and relatives of patients with irregular discharges from hospital. Moreover, on the basis of the results of this study the researcher also recommended to include the caregivers in the care plans, to provide psychoeducation programmes, consultations with the caregivers and self-help groups.

The above results are complimentary to the results obtained in the quantitative study by Bouchard et al., (2009). The aim of the researchers was to examine and compare the psychosocial functioning of 35 couples of whom the women were diagnosed with BPD to a nonclinical control sample. However, the researchers did not indicate the use of any computation analysis to determine the sample. The participants completed self-report measures of couple functioning using Experience in Close Relationships Questionnaire (Brennan et al., 1998), Communication Pattern Questionnaire (Christensen, 1987), Psychiatric Symptom Inventory (Ilfeld, 1978) and Dyadic Adjustment Scale (Spanier, 1976). The sample of clinical couples was composed of 35 heterosexual couples, out of which 8 were married, 21 were cohabitating and 6 were dating couples. The caregivers were on average 38 years old. The mean duration of the relationship was 5 years and 11 months (ranging from 2 months to 38 years). Most of the couples have been living together for a mean duration of 4 years and 11

months and had a mean number of 1.28 children (range 0-5). 22.9% of the partners completed a collage education or more. On the other hand, the 35 controls were cohabitating or married. 35 couples were selected from representative sample of 316 couples. To select the control group, the couples in which the women met traits for BPD were excluded. The control couples were matching with the clinical couple in terms of age, education and income. The caregivers were of average 37.3 years of age. The couples were in the relationship for a mean duration of 16.5 years and had a mean number of 1.71 children.

68.7% of the couples in which the female suffered from BPD revealed frequent breakups and returning back together, and nearly 30% of these couples dissolved their relationship over a period of 18 months. Furthermore, the clinical couples demonstrated lower levels of marital satisfaction and higher attachment insecurities. These results showed that BPD traits tend to disrupt the quality of relationships (Bouchard et al., 2009). The researchers suggest that behaviours of perceived abandonment, fears of dependency, bursts of rage and avoidance behaviours may be leading factors to low quality relationships. Furthermore, the researchers posited that the results confirmed the hypothesis that relationship satisfaction is lower in couples with BPD partner. Men with a partner having BPD reported lower couple satisfaction compared to men from the control group. Low relationship satisfaction was confirmed as the couples having the female partner/spouse with BPD evidenced less mutual communication and more general avoidance of communication than the control couples.

The results also revealed that men in the clinical group evidenced higher avoidance of intimacy and higher rejection anxiety when compared to nonclinical men. An important finding in this study was, that couples with having the female with BPD differed from the control couple in a number of psychosocial variables, namely insecure attachment, communication patterns, psychological distress and relationship dissatisfaction. Another important finding in this research was that nearly half of the men who were involved in a relationship with a woman having BPD met the criteria of a PD themselves. Thus, this might indicate that the partner choice in individuals with BPD is not random. However, results cannot be generalised due to the small sample size and thus, replication of the study with a larger sample was recommended. The strength of this study included providing a detailed account of participant demographic characteristics, the use of a case-control group and the utilisation of a standard diagnostic interview. This study recommended the need for more research on BPD in couples. Furthermore, future research was recommended to study the relation of men personality characteristics and women with BPD. An important contribution of the present study to the

extant literature which the quantitative research by Bouchard et al., (2009) was unable to provide, is the in-depth detail of the impact of caring for a BPD spouse has on family relationships and the strategies caregivers use to find meaning and peace during this experience.

Research studies also present their results about the caregiver's experience with health professionals and the support that they received from health professionals and support groups. This are discussed in detail in the following section.

2.5.2 Reaching out for Support

The available research showed that informal caregivers need to be better informed about their relative's condition and to be more involved in decisions being taken. In fact, informal carers verbalised that they were invisible in the process of care. Furthermore, research also showed that the caregivers need to feel better supported and understood by health professionals. Support groups were reported to be a helpful source of support for caregivers (Buteau et al., 2008).

The study by Dunne and Rogers (2013), [methodology and demographics data described earlier in this literature review] focused only on the carers as they were the ones who are mostly neglected. The carers' needs as a super-ordinate theme emerged from the analysis of data from the focus groups. The participants commented about the limited information that they received about the diagnosis. In fact, one participant commented that the information about BPD was obtained from books and from the internet. Some of the participants also reported that they were aware of parts of the care plan, however other participants had never been consulted about the care plan. In addition, most of the participants reported that there was lack of understanding from the staff. This was particularly related to the caring for the service users, where the informal carers felt that there were stigmatising comments from the staff. In turn, it was felt that this created more stigma toward the patients and carers of BPD individuals. Furthermore, carers perceived that the staff were not aware of the stressful role of being a carer of a BPD relative. This therefore, highlighted the carers needs to receive more communication from the mental health professionals.

One of the themes that emerged during the second focus group was the issue of support. There was a consensus among the carers that they were not aware of the support available. Furthermore, one participant mentioned the need to have a health professional to turn to for advice. The carers also expressed their need for respite to help them alleviate the stress experienced in the caring role. Another sub-theme identified from the focus group was the lack of support groups that are specific for BPD. However, one of the carers who was involved in a carers' support group expressed the benefits of the support groups. One participant claimed that being involved in a support group helped the relationship between herself and her daughter with BPD in dealing with the difficult situations arising.

Although this study had a small sample size (n=8 in the first focus group and n=5 in the second focus group), the data was rich and helped to increase awareness of the experiences of carers of individuals with mental illnesses with a particular focus on BPD.

The above focus groups outcomes are consistent with the findings presented by Griffin (2008), where the participants reached out for information from health professionals and read about the condition as a means to search for understanding and making sense of the experience. Participants pointed out that health professionals were not involved enough with the families and does not understand the family perspectives. The families felt that they were left to struggle and solve their concerns alone. Results also showed that the participants felt left out as they were not involved in treatment plans and discharge plans. Participants claimed that to the family treatment appeared to be ad hoc. Furthermore, the participants also verbalised that the meetings with health professionals were only for the benefit of the health professionals. The participants emphasised that they needed more knowledge, understanding and support from the meetings. It was also pointed out that meetings with the focus on the family were uncommon. Parents expressed that during their meetings with health professionals they needed to be provided with knowledge, understanding and support. On the other hand, they described the meetings to be only for the benefit of the clinicians and were described as information provision from the parents to the health professionals. This in turn created frustration for the carers.

Carers' need for knowledge was also evident in the study by Buteau et al. (2008) who used semi-structured interviews with 12 families with the aim to learn from the family members about their knowledge about BPD, the treatment, coping and hope in caring for their relative with BPD. The family members included 2 males and 10 females, where the sample consisted

of 10 parents (including 1 legal guardian), 1 spouse and 1 sibling. Hence, the data collected was from carers having diverse relations to the person with BPD. This may not permit a sufficient in-depth exploration of the diverse needs and concerns of these diverse groups. Another limitation of the study was the lack of information regarding the demographic details of the participants. The interview questions focused a) their difficulties in accessing evidence-based knowledge about BPD, b) a stigmatizing health care system, c) prolonged hopelessness, d) limited social networks, and e) the financial burdens. Results showed that the participants were eager not only for information about the diagnosis but they wanted a sense of hope by receiving information about the treatment of BPD. Moreover, hopelessness was also felt by the families who themselves searched for trained professionals and programmes that were specific for the treatment of BPD. This scenario left the family members with no option but to search for information themselves. Furthermore, participants expressed their frustration with moving around the mental health system searching for effective treatment. While navigating the mental health services, the participants also pointed out the issue of miscommunication between the family members and the health care system. This was especially evident in inconsistency and lack of sharing of information between entities in health care, causing more frustration in caregivers.

In this study, a sense of hopelessness was strongly emphasised. This was reflected in the concerns verbalised about treatments that failed to improve the symptoms, few or no support systems, and the emotional and financial depletion experienced by the carers. The participants expressed that they felt most hopeful when their relative was started on a new treatment. One participant claimed that the families wanted to know that there was hope for their sick relative. The failed treatment attempts, lack of support, emotional and financial burdens left the carers hopeless that their own life and that of their sick relative would ever improve. One of the participants described this hopelessness as a feeling of drowning and with no ship or a life saver in sight. Results also showed that in a crisis the family members had no one to support them. Others felt that support groups with families in similar situations were helpful source of support. These results highlight that there is a need for more trained health professionals to support and give accurate information about BPD. Furthermore, from these experiences the researchers recommended to involve support groups for the affected families to provide them with hope and communicate the information they need.

Another study by Ekdahl et al. (2011) demonstrated that during hospitalisation, carers received little or no information from health professionals about the progress of their relative.

This left the carers with feelings of uncertainty and insecurity when their relative was in hospital causing lack of trust in health professionals, where one of the participants explained that as a carer she was not involved in care planning and felt uncertain with the health professional's decisions. The participants argued that the nursing staff might not be equipped with adequate information about the patients and about the BPD, and this might be a reason for having a bad experience with the health care team. Thus, this may result in the relatives losing trust in the health care system.

Furthermore, in the study conducted by Lawn and McMahon (2015) in Australia, a mixed methodology was used. However, only the quantitative part of the study was published. The qualitative part of the survey is currently being researched by the researchers. The aim of the study was to explore the experience of the carers and their intention to seek help for their ill relative and for themselves. Online surveys were used to collect data from the participants (n=121). The carers in this study were composed of mainly females (75.5%), and 24.5% were male. This might indicate that there are a greater number of females in caring roles or that females may be more willing to respond to online surveys. The ages of the participants were from 18 years to over 65 years, but mostly were between age of 50 and 64 (42.9%). In addition, there were (2.5%) between 18-24years, (21.8%) 25-39 years, (26.1%) 40-49 years and (6.7%) 65+ years. The marital status of the participants was: 61.7% were spouses/partners, 25.5% were separated/divorced and 12.8% were single. The carer's relationship to the ill relative were either as: parent/guardian (29%), spouse/partner, sibling, son/daughter (47%) and others (foster parent, aunt, daughter-in-law, or mother-in-law, concerned community member) (24%). The carers in this research were carers for a female person with BPD symptoms. The 121 family carers of BPD individuals showed that they experienced challenges when seeking support from health care services. In addition, the support services for carers in the community were perceived to be inadequate. In fact, more than half of the respondents (62.3%) required support but were unable to access it. Furthermore, most of the respondents (60.5%) reported that they were not taken seriously by health providers and 56.6% reported that there was no support available for carers. 37.3% of carers also expressed about the financial costs required for the carers to access support services. These issues prevented the carers from being supported. Moreover, this lack of support was highlighted as causing anxiety in the participants. Conversely, where support was available, education about BPD was rated by 37.7% of the participants as the most helpful, this was followed by support from mental health professionals (27.8%), counselling services for the carer (23.4%), carer support group (19.7%) and support

from the carer's general practitioner (GPs) (17.3%). In fact, results showed that the GPs (70.8%) were perceived to be an important source of support for carers. However, the researchers suggest that the GPs and nurses working with them would benefit from being knowledgeable on how to respond, support and to refer BPD carers to the community support services.

More than 60% of the respondents did not receive any information about BPD. In addition, results showed that almost half of the respondents wanted to be involved in decisions regarding treatment and care issues but this was refused by the health providers. The results demonstrate that carers of individuals diagnosed with BPD require more individual support or diagnosis-specific support groups. This was also recommended by Griffin (2008), who stated that the treatment for BPD individuals needs to take into account the BPD individual and their significant family relationships, the relationships between the family members and should also include the treatment providers. Furthermore, Lawn and McMahon (2015), suggested that there is a need for effective therapeutic programs in the community to help in reducing the carers' exposure to crisis associated with BPD traumatic experiences.

This study (Lawn & McMahon, 2015), failed to specify whether the carers lived with their relative with BPD. Living with their relative might pose specific burdens on the carers such as more hours of contact with the ill relative with all that entails. In addition, being an online survey may pose a limitation in that the survey was only available to individuals who had access to a computer. Furthermore, the higher rate of female participants might indicate that online surveys might be less appealing for males or that more females take up the role of the main carer. However, despite these limitations, this study provided an insight about the needs of carers searching for support.

Education, health professional's support and therapeutic programmes for family members caring for people with BPD were identified as enhancing the coping strategies of the informal carers. However, a general limitation of literature targeting the support needs of carers is that studies interpreted these needs of all carers by status collectively together. The present study contributes to the extant literature by exploring the support needs specifically of spouses.

The next section discusses the literature on coping in more detail.

2.5.3 Searching for Meaning

The above critique discussed the challenges faced by informal carers. The families of people with mental illness need support and information about caring for someone with BPD to be able to assist their ill relative. According to Lucksted et al. (2012), family psychoeducation provides information and support to the family members to be able to cope with the challenges posed on the family system.

Kay et al. (2018), in their study found that the family members experienced a challenge in adapting to life with their relative with BPD and coping. In fact, the carers felt that they had ineffective coping skills because they lacked the ability to control the difficult situations in their family life. This made the carers feel disempowered to cope with the family and their ill relative. This reflects a lack of knowledge and information giving from the health care services to the carers on effective coping skills when caring for their relative with BPD. Furthermore, ineffective coping skills were also related to the lack of communication skills and knowledge by the family members of the ill relative. This comes from lack of awareness of BPD which resulted in the health care teams failing to meet the needs of the carers. Furthermore, the lack of knowledge in carers prevented the family members from making the appropriate choices to assist their relatives with BPD. Carers in this study expressed their need to receive professional and community support and were motivated to develop new skills to be able to care for their relative and to support themselves. Although this study was conducted in an in-patient setting, it sheds light on the need to support and empower the carers. This can be achieved by improving the family member's knowledge and skills which will in turn empower the carers to manage their own mental health and their relative with BPD (Kay et al., 2018). Crowe and Lyness (2014), posited that families with a member having a mental illness needs to develop their coping skills. The researchers suggest that passive acceptance coping and reframing coping are two coping skills that health professionals can teach the informal carers during psychoeducation sessions. The researchers claimed that passive acceptance is the ability of families to accept a problematic situation and reduce their emotional reaction to the situation. The researcher added, that this skill helps informal carers to feel more satisfied and to communicate more effectively. Furthermore, the skill of reframing coping helps the family members involved in caring for a relative with a mental illness to redefine a stressful event and make it more manageable. Thus, reframing a stressful situation in a positive light (Crowe &

Lyness, 2014). Hence, clinicians must consider supporting the informal caregiver in caring for their ill relative through developing coping strategies.

Moreover, Hoffman et al. (2007), acknowledged that because of the severity of the symptoms, BPD does not only affect the person with BPD but it affects the all family members and other individuals in the social environment of the person with BPD. However, the researchers posited that there are few interventions which address the needs of the affected family members. In this quantitative study, the researchers conducted a study using Family Connections (FC) program where the participants (family members) were referred for a 12-week program. 55 family members participated in this study, where 56% were mothers, 21% were fathers, 9% were spouses, 2% were partners, 5% were children and 7% were siblings. 55.4% of the participants lived with their relative with BPD. The age group ranged from 27 to 75 years of age. There was a 7% dropout from the group (dropout was defined as missing more than three sessions). The participants were assessed at entry to the program, at completion and 3 months after completion of the FC program. The family members were assessed using a) the Beck Depression Inventory (Beck et al., 1961), b) the Burden Assessment Scale (Reinhard et al., 1994), c) the Beck Hopelessness Scale (Beck et al., 1974), d) the Brief Symptom Checklist (Derogatis & Melsaratos, 1982), e) the Camberwell Family Interview (Vaughn & Leff, 1976), which measures the expressed emotion scales of emotional over involvement, hostility, warmth, positive remarks, and criticality. The family members' knowledge about BPD was assessed using the Knowledge Assessment Interview (KAI). Examples of the questions from the KAI includes a) what is the nature of your relative's problem?; b) what have you been told?; c) to what extent do you think it is accurate?; d) can you name his/her symptoms?; e) is s/he on medication?; f) do you think that your BPD relative needs medication?. A 5 point Likert scale was used based on the breadth and depth of information provided by each participant. 1 was equal to "no or low knowledge about the specifics of BPD" and 5 was equal to "high level of knowledge about BPD".

Results showed that from pre-program to post-program, the participants levels of burden, grief and depression decreased and mastery increased. However, at three months after completion of the program, mastery decreased. At this time-point, grief also decreased while depression, and burden in participants showed no changes. An important finding in this study was that the improvements reported by the participants who followed this program were either maintained or extended during the follow-up period (at 3 months after completion). Following these results, the researchers recommended that future research is required to determine whether the

length of the program is the optimal, to conduct randomised controlled trials (RCT) to understand the potential long-term change in the participants well-being and to determine the impact of the family members participating in the program on the relative with BPD. Longer duration of studies was suggested to study these recommendations (Hoffman et al., 2007). The researchers posited that FC is a successful program for relatives of BPD people because it focuses on the family members to learn to manage their own emotions (allowing them to pay more attention, act more and react less); learn to self-manage and so be less invalidating; learn to be mindful of the BPD relative (be able to listen, understand and accept the relative's experience); and learn to provide a validating response to the BPD relative's experience. In FC, validation is the key factor of the program together with emotional self-management and relationship mindfulness. Although more research was recommended on FC program, this study showed that it offers hope in improving the carer's grief, burden, depression and improve mastery in caring for their family member with BPD (Hoffman et al., 2007). The results of this study are considered to be robust as this was a replication of another FC study by Hoffman et al. (2005), where the initial results were supported.

In the study by Buteau et al. (2008), the participants verbalised that they tried to cope by striving to do something for their ill relative. However, they were not aware how to help them. The researchers (Buteau et al., 2008) noticed that the interviews were dominated with feelings of hopelessness. On the other hand, the participants coped with their hopelessness by searching for possible treatment for their sick relative. Furthermore, the participants also found that another useful coping mechanism was the family support program. Participants commented that family support programs helped them cope because they met people with the same issues and support them. They felt better knowing that they were not alone dealing with difficult situations. Moreover, family members expressed that they were tired of coping with the pains and difficulties of their relative with BPD, but rather they wanted to live their life and be joyful. The finding showed that the families struggle to cope in their own daily lives. Thus, from these results it was evident that the families need to be provided with hope through more knowledge about BPD and its treatment and providing family support groups for the family members to enable them to cope with caring for their relative with BPD.

The next section provides a brief conclusion of the outcomes from the critical discussion of the literature review.

2.6 Conclusion

This literature review discussed the lived experiences of carers of persons with BPD. This was tackled from the point of view of the caregivers' perceived impact, support and coping mechanisms. The literature search retrieved a total of 9 studies, of which the majority of study participants were family members with a high percentage being parents followed by partners and spouses. Only one study (Bouchard et al., 2009), focused directly on couples where the female partners had BPD. However, this study is quantitative in nature. Thus, the critique of literature in this chapter highlighted that there is a gap in evidence, where the partners and spouses are the least represented in studies on BPD. Hence, it was decided to focus on providing an in-depth account of the lived experiences of spouses caring for individuals with BPD in the present research study.

The critical discussion also demonstrated that most of the studies revealed the impact that caring for a family member with BPD has especially on one's well-being and on interpersonal relationships.   Research showed that caring for a relative with BPD has an impact on the relative's emotional and psychological well-being (Bauer et al., 2012). Moreover, the studies also demonstrate a greater need for knowledge, improved communication between health professionals and carers and support for the relatives. The absence of these factors might be causing hopelessness in the caregivers (Buteau et al., 2008). Thus, the need for support groups and therapeutic programs that include the whole family dealing with the family relationships was recommended (Griffin, 2008). In turn, improved knowledge and support for the carers were found to improve the carer's coping mechanisms (Buteau et al., 2008).

The methodology of the study is presented in the following chapter.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter presents a detailed account of the planning stages of this study and how it was conducted. The research methodology chosen was based on the best way to address the research question, based on the lived experiences of the participants. Therefore, IPA as described by Smith et al. (2009) was chosen to address the research question and this is outlined in this chapter. Moreover, the aims and objectives of the study, the operational definitions, the philosophical framework, research design, sampling technique, demographics, data collection, pilot work, data analysis, ethical considerations, quality assessment and reflexivity are also outlined and discussed.

3.2 Aim and Objectives of the study

The research question congruent to this study was: *What are the lived experiences of informal carers of persons with BPD*? The aim of this study was to explore the meaning that informal carers attribute to the experience of caring for their relative with BPD. In order to obtain this, the following objectives were identified:

- To explore the impact of caring for the spouse/partner of a person with BPD.
- To identify the coping strategies used by the informal carers of individuals with BPD.
- To explore the support strategies of the spouse/partner of a person with BPD.

3.3 Operational Definitions

The term 'experience' in this study attributes to the events, situations and emotions that relatives living with their spouse with BPD encountered and are still going through while living with their spouse.

The term 'borderline personality disorder' refers to individuals who present with symptoms of disturbed or uncertain self-image, unstable relationships contributing to emotional crisis,

efforts to avoid abandonment, chronic feelings of emptiness and threats or self-harm. In addition, the person diagnosed with BPD has a tendency to have traits of impulsivity (World Health Organisation in the International Classification of Diseases (ICD)-10, 2003).

The Mental Health Association Malta (MHA) refers to a non-profit organisation which offers support and empowerment to family caregivers of persons affected with mental health problems.

The terms 'Carer' and 'Caregiver' refers to the spouse/partner of a person having BPD. For the nature of this study, such carers must be living in the same household as the person having BPD.

The next section discusses the research designs that are used to conduct research.

3.4 Research Designs

Qualitative, quantitative and mixed methodology research methods are used to conduct nursing research. Nonetheless, the method chosen is dependent on the research question. In quantitative research, the phenomenon being tested can be empirically measured, thus following the positivist framework. Qualitative research emphasis on the meanings, understandings and actions of human behaviour (Topping, 2010). Mixed methods research incorporates elements of both qualitative and quantitative approaches to provide a more complete understanding of a research problem (Creswell, 2014). The research question of this study requires the interpretation of experiences and meanings of relatives in a particular situation (caring for their spouse with BPD), the qualitative method is considered as compatible with the aim and objectives of this study.

3.4.1 Research Paradigm

Research paradigms are known as the set of beliefs that direct action. Paradigms represent the world view (Guba & Lincoln, 1994). Paradigms are stances taken by the researcher to guide the study (Creswell & Poth, 2018) and are characterised by three questions, namely ontology (what is the researcher's point of view of reality?), epistemology (how does

the researcher recognize the reality?) and methodology (how the researcher goes about exploring and finding out?) (Guba & Lincoln, 1994). Another stance is axiology which refers to the value-stance retained by the researcher and ethics (Creswell & Poth, 2018; Mingers, 2003). Furthermore, axiology also invokes the researcher's values and opinion in the process of knowledge generation (Kafle, 2011). Thus, the current researcher presents the values and biases of the study and presents her own personal background and reflections about the study (Creswell & Poth, 2018). These stances create a holistic view of how knowledge is viewed and the way we see ourselves in relation to the knowledge and the methodology we use to discover this knowledge.

The next section discusses the paradigms within the interpretative frameworks.

3.4.2. Interpretative Frameworks

Paradigms are applied within the interpretative frameworks that are used by the researchers who conduct a qualitative study. Thus, ontology, epistemology, axiology and methodology are important stances in interpretative frameworks used in qualitative research (Denzin & Lincoln, 2011). Social constructivism is also described as interpretivism. It is a worldview, where individuals seek understanding of the world in which they live (Denzin & Lincoln, 2011). In social constructivism, individuals develop subjective meaning of their experiences. In social constructivism the goal of the researcher is to rely on the participant's views of the situation. These views and meanings are multiple, so the researcher looks for the complexities of the participants' views and meanings. These subjective meanings are often formed through interactions with others in the individual's life. In constructivism the researcher inductively develops patterns of meaning. Furthermore, the researcher makes an interpretation of the findings and an interpretation is shaped by the researcher's own background and experience (Creswell & Poth, 2018). Therefore, in interpretivism, the researcher understands the experience from those who live it, by connecting with the participants being studied and eventually being able to attain their views of reality (Appleton & King, 2002).

The constructivist paradigm is manifested in phenomenological studies (Creswell & Poth, 2018). The scope of this study is to explore the lived experience of carers of individuals with BPD. In addition, the present researcher works in a psychiatric setting and therefore has contact

with such carers and thus she could not conduct this qualitative study in an absolutely objective manner.

The next section presents the different qualitative research designs and focuses on the IPA as an approach to study the meaning that informal carers give to caring for their relative with BPD.

3.5 Qualitative Research Designs

Qualitative research refers to the methods of collecting and analysing data that are different from quantitative methods because of the lack of quantification and statistical analysis. Qualitative research starts with assumptions and uses interpretative or theoretical frameworks that enlighten the study of the research problem addressing the meaning that individuals or groups of people give to a social or human problem. Creswell and Poth (2018), posited that the purpose statement or the aim of the study is the most important because this conveys what the researcher hopes to accomplish in the study. The aim of the study is established following the identification of a problem which the researcher wants to discover. This problem leads the researcher to certain research questions, the data collection, the data analysis and interpretation related to the questions which eventually will lead to understand the research problem (Creswell & Poth, 2018).

Qualitative research consists of a number of approaches. Grounded theory, ethnography, phenomenology and IPA are some of the approaches in qualitative research. Grounded theory is an inductive approach that generates or discovers a theory. Grounded theory was developed by Glaser and Strauss in 1967. The grounded theory researcher develops theory from individuals who share the same process, actions or interaction. Whilst in ethnography, the researcher is immersed within the community being studied for an extended period of time and illustrates and interprets the shared patterns of values, behaviours beliefs and language. Ethnography has its beginning in anthropology in the early 20th-Century (Creswell & Poth, 2018).

Although these approaches amongst other approaches can be utilised, it was decided to use IPA as it is the best research approach to understand the meaning that informal carers give to caring for their relative with BPD. IPA was selected over other phenomenological approaches

because IPA goes beyond describing the participant's words to describe a phenomenon as it focuses on the experience and the meaning that the participants give to the phenomenon studied (Langdridge, 2007). IPA allows the researcher to interpret the meanings disclosed by the participants who strive to make sense of the experience themselves. This process is called the double hermeneutic circle (Smith et al., 2009). Hence, the application of IPA in this study enabled me to explore the informal carers experiences of living with a person having BPD and what this particular experience means to them.

The following section provides a detailed account about the philosophical underpinnings of IPA.

3.6 Philosophical Underpinnings of IPA research

IPA acknowledges that to comprehend an experience, participants needs to provide a marked description of their own experience. Following this, the researcher interprets the participant's account of the experience (Smith et al., 2009). Therefore, IPA allows the researcher to give in-depth descriptions of the experiences of the participants. By adopting an IPA approach, the caregivers in my study were given a voice to share their lived experience. This could not be possible if the researcher used a quantitative method.

Moreover, due to my role as a staff member working in a mental health setting, eliminating my thoughts and preconceptions related to carers experiences of living with a person with BPD would be difficult. In fact, being hermeneutic, IPA recognises that researchers have their own preconceptions, assumptions and personal experiences that can be used to interpret findings during the data analytic phase (Smith et al., 2009). Hence, IPA allowed the current researcher to be an active participant in the interpretation process. Using IPA, the researcher was inductive and grounded in the data.

The following sections present the three key areas of philosophy: phenomenology, hermeneutics and idiography of IPA (Smith et al., 2009).

3.6.1 Phenomenology

Phenomenology is a philosophical approach to study human experience. Phenomenologists postulate that human beings could be understood from their subjective experience. Furthermore, phenomenologists continue that the individual's perspective is required for a comprehensive understanding of human behaviour. Therefore, phenomenologist emphasis on the value of describing and interpreting human experience (Todres and Holloway, 2010). Furthermore, an outstanding significance of phenomenological philosophy is that it provides notions on how to evaluate and comprehend lived experiences.

Husserl, the founder of phenomenology posited that phenomenology involves the meticulous examination of human experience. Husserl was interested in finding the way in which individuals come to precisely know their own experience of a phenomenon. Thus, individuals allow themselves to identify the crucial qualities of that experience. Husserl posited that than these *essential* features transcend the particular circumstances and highlight a given experience for others. Husserl argue that we should focus on each particular 'thing' in its own right. This is the experiential content of consciousness. Furthermore, Husserl suggests the need to take a *phenomenological attitude*, which requires reflexivity to step out of our *natural attitude* as so being able to examine the ordinary experience. This implies that to be phenomenological, we need to notice the taken-for-granted of an experience. Therefore, a phenomenological enquiry focuses on what is experienced in the consciousness of the individual. Husserl argues that to focus on our perception of that world, we need to 'bracket' the taken-for-granted world. Husserl's method suggests a process of 'reductions' which intend to move the inquirer away from the distractions, one's own assumptions and preconception and concentrates on the essence of the person's experience of the phenomenon. Therefore, Husserl aims to establish the 'essence', the core of the subjective experience. Furthermore, in an attempt to accomplish the content of the conscious experience, Husserl wanted to look at the thing that underlies and makes possible the consciousness of anything. This was called '*transcendental reduction*'. These aspects of Husserl's work have been influential in phenomenology including IPA. It was particularly central for IPA researchers to focus on the process of reflection (Smith et al., 2009).

3.6.2 Hermeneutics

Smith et al. (2009), define hermeneutics as the theory of interpretation. IPA is associated to hermeneutics because it recognizes that the individual's experience is only attainable through a process of interpretation from both the participant and the researcher (Smith, 2011). Furthermore, Smith (2011), posited that experience cannot be elicited outright from the participant but it necessitates a process of engagement and interpretation. This process involves engaging in a double hermeneutic, where the researcher tries to make sense of what the participant is trying to make sense of their experience.

The theory of hermeneutics in IPA is underpinned from three theorists, Scheiermacher, Heidegger and Gadamer. This research was based on Heideggerian phenomenology as it is focused on the examination of something which may be hidden (Smith et al., 2009). The meaning given to a lived experience is fundamental for Heidegger. Heidegger contributed to IPA research where human beings are perceived of as 'thrown into' a world of objects, relationships and language, that is the Dasein - 'there-being'. Dasein requires reflexivity. In addition, our being in the world is always perspectival, temporary and in-relation to something. Therefore, it is the 'person-in-context'. The concept of inter-subjectivity points out to the shared and relational nature of one's engagement in the world. This in turn makes the interpretation of people's meaning-making central to a phenomenological enquiry.

Therefore, hermeneutics is the theory of interpretation. The lived time and engagement with the world of Dasein is accessible through interpretation. In addition, Heidegger posited that phenomenology is interested in examining something that is latent as it emerges into the light and is also interested in examining how the experience is manifested as it appears at the surface. This is because the latter is integrally connected with the deeper latent form. Heidegger also talks about *Logos* which is the discourse, the reason and the judgement. That is the way that things appear or are covered up are to be studied. Therefore, the proper way to seek meaning is by interpretation of text. This is the way Heidegger links phenomenology with hermeneutics. Another important contribution to IPA is the concept of fore-conception, where the researcher brings the pre-conception, previous experiences and assumptions to the encounter and interprets the new stimulus in the light of their own experiences. Therefore, as Heidegger claims the researcher cannot separate his thoughts from the reality during interpretation and thus allows room for subjective interpretation (Lopez & Willis, 2004). In fact, the current

researcher in this research project reflected on the preconceptions about the participant's experiences rather than bracketing.

3.6.3 Idiography

Idiography is another major influence to IPA. Idiography is immersed with the particular. Since IPA is committed to the particular detail, so the depth of the analysis of each case is important. IPA is idiographic as it grants for detailed examination of every case until saturation is achieved. When a degree of saturation was achieved, the researcher then moved to another case. It was only when a degree of saturation was accomplished that a cross-case analysis was conducted. This permitted similarities and differences across the transcripts to emerge (Shinebourne & Smith, 2010).

In addition, IPA is committed to making sense and understanding how an experience, relationship or event has been understood from the unique perspective of particular people in the particular circumstances. It also locates the participants' experiences within a specific context and provides detailed knowledge on the world of the individuals participating in the study. The Dasein's experience is hypothesized to be in-relation-to the phenomenon and not a characteristic of the individual. However, an individual can provide a personally unique perspective on their relationship to the phenomena being studied (Smith et al., 2009).

The following section describes the type of sampling and inclusion criteria of the study.

3.7 Sampling Technique and Inclusion Criteria

Participants are selected to grant the researcher access to a particular perspective on the phenomena being studied (Smith et al., 2009). It is recommended to select a homogeneous sample of individuals who have the actual experience of the phenomena under study. Clearly et al. (2014), argue that selecting a purposeful sample of participants who are living the experience being studied will equip the researcher with credible experiences.

Five relatives were recruited as specified in the inclusion and exclusion criteria described in Table 3.1. The participants had to be over the age of 18 years and taking care of their spouse or partner with BPD.

Table 3.1 Inclusion and Exclusion Criteria of Participants

Inclusion Criteria	Exclusion Criteria
Spouse / partner caring for a person with BPD.	Informal carers who were not spouses or partners e.g., parents, children.
Carer was taking care of a relative in the community setting.	Carers where the person with BPD is admitted to hospital and not living in the community. Is a relative of a person who was patient cared for in Female Ward 1. (This is in view that the researcher worked for more than 6 years in Female Ward 1, a ward in the Maltese psychiatric hospital).
Over the age of 18 years.	Under the age of 18 years.

3.8 Recruitment Process

The sample for the study was selected purposively, where the participants were contacted via an intermediary. The recruitment of potential participants involved contacting individuals who care for their spouse or partner with BPD.

Before commencing the research, I explained the research project to the intermediaries (Appendix A). Two intermediaries (a psychologist and a psychiatric nurse) were involved in recruiting the participants for this study. However, there were no potential participants for two months. Consequently, more intermediaries (a consultant psychiatrist and a psychiatric nurse from a community clinic) assisted in the recruitment process. The intermediaries contacted the potential participants according to the inclusion criteria. The intermediary explained the study process to the interested participants and gave them an information letter (Appendix B). The

potential participants were informed that participation is voluntary and that they can withdraw from the study at any point in time without giving a rationale. This allowed the potential participants to take a decision without feeling coerced. Since they were contacted by the intermediary, the researcher was not aware of any persons approached but declined to participate. Those persons who were willing to participate left their contact details with the intermediary and were then contacted by the researcher. Once contact was made by the researcher, an interview was scheduled and a consent form was signed at the encounter. Participants were informed that the information provided was confidential and their personal identity would not be shared at any stage.

The subsequent section provides details of participants selected on the basis of the inclusion criteria cited in section 3.7.

3.9 Demographic Data of the Participants

Data collection commenced in July 2019 and continued until September 2019. The participants in this study represent a reasonably homogenous sample. The participants are all spouses caring for their relative with BPD. There were three males and two female carers recruited to the study. The ages of the participants ranged between 35 to 64 years, with a mean average age of 49.2 years.

Table 3.2 presents the demographic characteristics of the participants and their relationship to the person with BPD. The duration of the caregiving experience for the participants was between 2 years and 30 years. The researcher opted to use a range to demonstrate the duration of caring, so that the participant's identity is protected. In addition, the names used are pseudonyms that have been used to protect the identity and confidentiality of the participants and the patients.

Table 3.2 Demographic data

Pseudonym	Kinship	Age/Years
Brian	Husband	50
Mark	Husband	64
Maria	Wife	57
Katie	Wife	35
Gary	Husband	40

The subsequent section provides information about the tool used to collect the data. In addition, information about the research setting and pilot interview are also presented.

3.10 Data Collection

The study was idiographic and had a small sample size. This is recommended in IPA because of the time consuming nature of the analytic process. Furthermore, a small sample size provides data which is rich and intensive (Clearly et al., 2014). Moreover, Smith et al. (2009) also recommend that the novice researcher who is looking for quality instead of quantity uses a small sample size.

Semi-structured interviews were used to collect the data as it is described as an excellent data collection method in IPA (Smith & Obsborn, 2003) that enables the researcher to comply with the participant's interest and produce richer data (Landridge, 2007). Semi-structured interviews enabled the participants to articulate a detailed encounter about their experiences. In addition, the researcher opted for semi-structured interviews with a guide, as this was valuable to carry out the interviews effectively given the time constraints (Langdridge, 2007). Furthermore, semi-structured interviews provide guidance to the interview so that the research question is answered effectively (Smith & Obsborn, 2003).

3.10.1 Interview Schedule

IPA recommends the use of an interview guide so that the researcher sets a loose agenda of the interview which can be used to anticipate potential sensitive issues. However, having an interview schedule does not guarantee the quality of the content of the interview. In IPA research, the researcher must immerse deeply with the participants, listen attentively and probe during the interview to understand more about the lifeworld. Otherwise, the data will be too thin to be analysed (Smith et al., 2009). Furthermore, Smith et al. (2009) recommends that constructing an interview schedule is a way to guide the novice researcher to think qualitatively.

Preparation of the interview guide allows the opportunity to consider what the interview will cover and to deal with any problems that may arise, in terms of wordings or sensitive questions. In fact, an interview guide was developed (Appendix C), which consisted of 13 open-ended questions. The questions were designed following a literature search and were formulated explicitly for the purpose of this study. The interview focused on asking the participants to describe and reflect on aspects of their experience in caring for their spouse or partner with BPD. The interview started with a general question to help the participants feel comfortable during the interview (Can you tell me about yourself?). The following questions then inquired more deeply into different aspects such as knowledge about the spouse's diagnosis, the effects of caring on the quality of life, the participant's feelings and emotions of living with their affected spouse, their coping strategies, and the support they needed during this experience. Prompts were used to encourage the participants to talk more about a subject (e.g. can you tell me more about your thoughts? And what were your reactions to this experience?). The interview guide and the prompts were practiced before the actual interviews (Smith & Osborne, 2003).

The researcher prepared both a Maltese and an English version of the interview guide since the participants were both Maltese and English speaking. This also ensured that participants could express themselves with ease. Two participants were English speaking (Brian and Katie) while three participants (Mark, Maria and Gary) and one participant (Ben) of the pilot interview were Maltese speaking.

Three interviews were conducted in the Maltese language, as the participants felt more comfortable to use their mother-tongue to express themselves and two interviews were

conducted in the English language, as the participants were English speaking. All the interviews were audio-recorded to ensure that the information could be recalled after and transcribed. This also allowed me to focus more on the interview and thus, minimizing the risk of missing out important aspects of the participant's experience. The interviews were transcribed verbatim in their spoken language. Any excerpt taken from the Maltese transcripts were then translated into the English language by a professional translator. Another professional translated the English versions back to Maltese language for comparison purpose. This process is called back translation and is used to ensure that translations are accurate (Sousa & Rojjanasrirat, 2011). The WHO guidelines on back translation posited that in this process the focus should be on the conceptual and cultural equivalence (WHO, 2020).

The interviews were conducted in a setting selected by the participants. In fact, two interviews were done at the participants' home and three interviews plus the pilot interview were done in an office within the hospital grounds. Selection of the time for the interview was also decided by the participants. These measures ensured that the participants felt more at ease to talk about their experiences.

The following section provides further details about the pilot study and the actual interviews.

3.11 Pilot Work

Pilot work is used in qualitative inquiry to prepare for a study. Furthermore, face-to-face interviews are acknowledged for qualitative inquiry to seek insight of those who are living the phenomenon being studied (Smith et al., 2009). I conducted a pilot interview before starting the study with one male partner who had his girlfriend with BPD. The pilot study lasted for three quarter of an hour. The pilot study was useful and assisted the researcher to practice asking the interview questions and to focus on what the participant had to say. Thus, the interviewer was aware of avoiding leading questions during the interview. The questions were not changed after the pilot interview. The transcript was later reviewed with the supervisor. It was decided that I needed to make better use of prompts during the interview as the data obtained was 'too thin' and this would create difficulties in the data analysis stage.

The findings of the pilot study were not included in the final analysis of the actual study as the interview data collated was not in-depth enough to allow proper analysis.

3.12 Data Analysis

The essence of IPA is in its analytic focus, where the focus is on the participants' efforts to make sense of their experiences (Smith et al., 2009). Giorgi (2000), criticized phenomenological research for providing a set of stages. Nevertheless, Smith et al. (2009), argued that providing a structure in IPA will enable the first-time researchers using IPA to find their way through the process of analysis. Furthermore, it is argued that the steps provide food for thought for the experienced analysts. The steps encourage the analyst to engage in reflection with the participants' accounts. Therefore, the analysis is the product of both the participant and the analyst. In IPA research, the focus is on the lived experience of the participant and the meaning which the participant gives to the lived experience. However, the end result of the research project is an account of how the researcher makes sense of the participant's account, where the participants themselves are trying to make sense of their own experience, and thus it is a double hermeneutic. Therefore, the analysis is subjective. However, the results are available for the reader and are presented in a dialogical, systematic and rigorous manner. Furthermore, as IPA is idiographic, the analysis focuses on the first case in detail before moving to the next case. The steps involved in the analysis are now described.

Step 1: Reading and re-reading

The first step involves the researcher immersing in the original data. Listening to the audio-recording and reading and re-reading is a process where the researcher ensures that the participant becomes the focus of analysis. Therefore, since 'bracketing' is difficult to achieve, it is recommended that the researcher records the powerful recollections of the interview and observations about the transcript in a notepad. This allows the researcher to remain with the data. Furthermore, repeated readings allows the researcher to acquire an understanding of the narratives and how parts of the interview can bind (Smith et al., 2009).

Step 2: Initial noting

The second step considers the semantic content and language used. At this step, the analyst keeps an open mind and records anything of interest in the transcript. In addition to acquainting oneself with the transcript, the analyst identifies distinct ways by which the participant speaks about, understands and perceives a phenomenon. The aim of the analyst is to have detailed remarks on the data. Through these notes the analyst looks for any phenomenological focus of

the participant's explicit meaning. The participants will be describing the things which matter to them and the meaning of those things to the participant. Alongside with this, interpretative notes help the analyst to understand how and why the participant has these concerns. The initial noting results in exploring for details in the transcripts. This is achieved by focusing on the descriptive comments that describe the content of what the participant has said, for example,

"Il-kwalita' tal-hajja tieghi ma kienetx   *"My quality of life was not good, I was*

tajba, kont dejjem stressjat, dejjem   *always stressed, always on edge."*

on edge." (Mark, p. 4, line 76)

This excerpt shows that the participant was feeling stressed and anxious and had an unsatisfactory quality of life as a result of the experience.

In addition, the linguistic remarks focus on exploring the specific use of language by the participant, for example,

"....ghajjejt u ma niflahx nissaportjaha izjed ...   *"... I'm tired and I can't support her*
Ghajjejt, dik il-kelma ezatt. Ghajjejt mentalment."   *anymore I'm tired, that's the exact word.*
                                                               I'm mentally tired."

(Gary, p. 2, line 40)

The repetition of the word 'tired' used by Gary was to emphasise his statement.

Examining more the transcript and focusing on a conceptual level helps the researcher to make more sense of the meaning of the participant, for example:

"My wife was not suicidal … If someone is suicidal by that time would have time to go on the roof and jump. That's what our friend did. No one knew and she killed herself after work. No one knew. It could be anyone." (Brian, p. 4, line 84)

Here the participant could be referring more to a conceptual meaning, that he is actually worried about suicide. This excerpt might indicate that the participant was worried that his wife commits suicide without informing anyone. However, he was trying to feel more in control of the situation and thus referred to the case of a friend.

Therefore, the researcher should explore the language used by the participant, thinking about the context of their concerns, and pointing out more abstract concepts which aid the analyst to make sense of the patterns of meaning in the participant's account (Smith et al., 2009). According to Clarke (2009), this step of the analysis helps the analyst to develop a sense of intimacy which otherwise would not be achieved.

Step 3: Developing emergent themes

This step consists of focusing on the exploratory comment to identify emergent themes. Thus,

organising the data to reduce volume. This process involves producing statements from the original transcript of the interview into sub-themes. Patterns between the sub-themes were identified by grouping relating statements together. In addition to the participant's words and thoughts, the themes encompass also the analyst's interpretation. Therefore, the emergent themes reflect a process of description and interpretation in chronological order.

Step 4: Searching for connections across emergent themes

This involves grouping emergent themes together and developing super-ordinate themes. The analyst examines the transcripts for commonalities and differences and identified the super-ordinate themes which emerged as strong participant's concerns. Furthermore, when looking for connections between the emergent themes, the analyst identifies contextual or narrative elements within the transcript. These present a better understanding about the participant.

Step 5: Moving to the next case

This step suggests to move to the next participant's transcript and repeating the same steps. The analyst is aware of the importance to treat each participant's account on its own. Therefore, the analyst had to bracket her ideas that emerged from previous accounts. Thus, keeping with IPA, being idiographic. Smith et al. (2009), acknowledges the difficulty of bracketing the ideas that may have emerged from previous accounts. This shows the emergent nature of the approach, where preceding ideas become superseded by strengthened and developing new themes (Pringle et al., 2011). The rigour of systematically following the steps as outlined and allows new themes to emerge with each account (Smith et al., 2009). While Giorgi (2000), argues against having a rigorous set of steps, Smith et al. (2009) advocates to have a clear and systematic process to follow instead of a rigid and prescriptive process.

Step 6: Looking for patterns across cases

As all transcripts were analysed, the super-ordinate themes and sub-themes of each interview were identified and were reviewed to produce a table of super-ordinate and sub-themes of all the participant's interviews, as illustrated in Chapter 4, table 4.1.

During the analysis of the data, the researcher was inductive by allowing the patterns and themes to emerge from the data gathered. Furthermore, at the analysis step, the super-ordinate themes and sub-themes were audited by the supervisor, the coding system used was also discussed with the supervisor to ensure that the super-ordinate and sub-themes truly reflect the findings from the transcripts.

The next section deals with the ethical issues that pertained to my study.

3.13 Ethical Issues

Appropriate permissions to conduct the study were obtained from Chief Executive Officer, Data Protection Officer, Chairman of Psychiatry, and Senior Nursing Manager (Appendix D). Approval for the study was granted from the University of Malta Research Ethics Committee (UREC) and is presented in Appendix E. Data collection started after the UREC approval. In this way, it was ensured that the rights of the participants in accordance with the research ethics guidelines were ensured. Smith et al. (2009) emphasise that ethical research practice must be monitored throughout the research process especially during data collection and analysis. The following section describes the recruitment process of the potential participants.

3.13.1 Recruitment

It is the obligation of the qualitative researcher to protect the participants' privacy, protect participants from harm, respect the right of self-determination and full disclosure (Parahoo, 2006). Since I spent over six years working as a Charge Nurse in an acute female ward in MCH, it was decided to recruit the participants from the community and whose relative was not currently a patient at hospital. This was done to avoid what Rebar et al. (2011) describe as the risk for coercion. Conducting my study in a different setting from that in which I worked, reduced any form of coercion that the participants may feel. In addition, to further prevent participants from feeling coerced to participate, the intermediaries were involved in recruiting

the participants for this study. Furthermore, the intermediaries did not give me any details of potential participants that refused to take part in this study.

The following section describes the process of obtaining an informed consent from the participants.

3.13.2 Informed Consent

The potential participants were given an information letter. The information letter provided the description of the study and what was expected from the participants. Furthermore, an explanation of the participant's rights if they choose to participate was also provided. Furthermore, details of a psychologist were provided in case any participant experienced distress as a cause of engaging in the study. The details included in the information letter and consent form respected self-determination as it allowed the participant to make an informed and knowledgeable decision to participate in the study or not. The participants were reassured that their participation was voluntary and that they were free to withdraw from the study at any time. This would not have any negative effect on them or their relatives. Prior to asking the participants to sign the consent form (Appendix B), it was ensured that the participants were given sufficient time to decide whether to participate in the study or not. Smith et al. (2009), stated that in IPA, informed consent is gained not only for data collection but must ensure that the participants are aware of what is expected during the interview and must also be informed about the data analysis, particularly informed about the inclusion of verbatim extracts.

The following section presents the steps taken by the researcher to ensure anonymity and confidentiality.

3.13.3 Pseudonymity and Confidentiality

Smith et al. (2009) stated that in qualitative research anonymity is paramount. Furthermore, Macnee and McCabe (2008), state that to safe guard anonymity, the participant's identity should be protected and the data should not be connected to the participants. For data protection purpose, the recordings and transcripts were coded and the participants' identities were

protected using pseudonyms. Only the researcher had access to the data, though, the research supervisor and the examiners may have access to the data for verification purposes. The present study guaranteed pseudonymity as personal data and the corresponding pseudonym were stored separately from the transcripts.

In fact, the audio-recordings and transcripts were saved on the researcher's personal computer that is password protected and in an encrypted format. Material in hard copy was stored in a locked cupboard during the research period and will be destroyed on completion of the study.

The following section describes the measures taken during the research to minimize harm to the participants.

3.13.4 Minimizing Harm

An important ethical practice in conducting a study is avoidance of harm (Smith et al., 2009). The researcher was aware that talking about delicate issues might cause 'harm' for the participants. Therefore, if any of the participants verbalised any psychological distress as a result of participating in the interview, a psychologist would have been provided at no cost on the participant (Appendix F). All the details for the professional help was provided to the participant on the information letter. According to Macnee and Cabe (2008), this protects the participants from any psychological harm. Participants could also choose not to answer any question and to withdraw from the study at any point throughout the study. In addition, should they decide to withdraw from the study the data collected would be destroyed.

The following section presents a discussion of rigour.

3.14 Quality and Trustworthiness

Smith et al. (2009) recommends that qualitative research is evaluated according to its own criteria. Furthermore, Smith et al. (2009) recommend using Yardley's (2000) criteria to assess quality and trustworthiness when using IPA. Yardley (2000) recommends the following four aspects to ensure quality and trustworthiness.

3.14.1 Sensitivity to Context

Yardley (2000), defines sensitivity to context as the way that the researcher is sensitive towards the theoretical aspects, the relevant literature, sociocultural setting, the participants' perspectives and the ethical considerations during the study. This was ensured during this study and was shown in the methodology, being idiographic. In addition, the sample recruited was from a specific context and with a particular lived experience. Furthermore, during analysis of the data which produced verbatim extracts both in English and Maltese, the transcripts and the recordings were kept in a locked storage and the researcher's computer was password protected. All data will be destroyed at the end of the study. Moreover, to abide with data protection, recordings and transcripts were coded and to preserve the identity of the participants, pseudonyms were used.

3.14.2 Commitment and Rigour

Commitment and rigour refers to the thoroughness that is expected in a research study (Yardley, 2000). Throughout this study, commitment was assured by outlining and describing the whole research process and by providing a rationale for the decisions taken. This includes the researcher's decision regarding the choice of participants, connecting with the participants with respect and sensitivity and a thorough data analysis (Shinebourne, 2011). Yardley (2000), defines rigour as the completeness of the data collection and the analysis. This also includes the choice of the sample. This was evident in the effort to select a relatively homogenous sample, conducting in-depth interviews to be able to collect rich data, and a systematic analysis of the data which is idiographic and interpretative (Smith et al., 2009).

3.14.3 Transparency and Coherence

Shinebourne (2011), states that in IPA, transparency is the clarity in all the stages of the research process. This was evident in this write-up by describing the research process which includes the method of selecting the participants, the preparation of the interview guide and the

interview itself, the steps used throughout the data analysis and the use of tables (Smith et al., 2009).

Coherence refers to the making sense of what the researcher is trying to make sense of what the participant is making sense of the experience (Smith et al., 2009). During the conduction of this study, this was achieved by reading several drafts of this project until satisfactory clarity was obtained.

3.14.4 Impact and Quality

The validity of a study is justified if the study contributed interesting results to the reader and that satisfies the purpose of the study (Smith et al., 2009). This study aimed to address the gap that exists in the particular sample studied about the phenomenon explored (spouses living with their relative with BPD).

Being a novel researcher, required the guidance of the research supervisor to conduct this study. The research supervisor ensured that I adhered to the principles of trustworthiness and quality.

The next section presents the reflexivity process before, during and after the collection of data.

3.15 Reflexivity

Reflexivity enriches trustworthiness, accountability and transparency of qualitative research (Finley, 2002). Moreover, reflexivity is a process to attend systematically to the context of knowledge especially attending to the influence of the researcher at every step of the research process (Cohen & Crabtree, 2006). In addition, reflexivity aids the researcher in becoming aware of her own prejudices and preconceptions that she may have which unintentionally may be introduced in the study. Therefore, during the study, a reflexive journal was kept where any preconceived ideas were documented. A record was kept of the logistics, decisions and the rationales during the study. In addition, my reflections and interests in relation to the study were also documented.

3.15.1 Summary from the Reflexive diary.

 Before data collection

I have been a charge nurse in an acute female ward in MCH for over six years. I had a number of opportunities to talk to the patient's relatives. My perception was that the relatives looked physically tired and psychologically burdened. In addition, I was inquisitive regarding how they managed to cope with their relative having BPD. I felt helpless since the hospital does not have any support groups, help line or informative session for relatives of clients with BPD. My preconceptions about the relatives were that they did not know what to do with their ill relative. Another preconception that I had was that caregivers saw the health care services as the only hope to help them when their relative having BPD is in crisis or is out of control of the situation. I also felt that at times the hospital was being used as respite. Furthermore, after observing the repeated admissions that people with BPD have in the acute wards, I was expecting the relatives to be aware of their spouse' diagnosis and knowledgeable about BPD and the treatment plan. Furthermore, I was expecting that the relatives are going to speak about their burnout and about the challenges they face with the spouse with BPD. Moreover, my experience in an acute ward exposed me to admissions and readmissions of people with BPD, mostly following attempted suicides or suicide threats. Thus, this shaped my preconceptions that suicide and its impact on the relative is going to be a challenge discussed by the participants. On the other hand, I was not expecting to notice a lot of support from the relatives towards their ill spouse because of their psychological burnout.

My only interviewing opportunities were with other students during the Bachelor of Science in Community Nursing. Therefore, I assumed that formally interviewing participants will not be an easy task for me. My perception was that I was going to feel anxious during the interviews as there was a difference between informally talking and educating the relatives to formally conducting interviews for this research project. Therefore, I had to coach myself to listen attentively to all the details, keep silent and focused and to probe at the right time.

During the data collection

During the interviews I was affirming and acknowledging the participants' emotions as they recalled their stories in great detail. I was impressed by the depth and range of emotions expressed such as anxiety, guilt, frustration, and deep sadness expressed by most of the participants, while talking about their difficult experiences. In fact, I was expecting that fears about suicide threats would be elicited from the interviews. However, I was not expecting to see participants showing their emotions (e.g. crying) while describing and revealing an experience of their spouse's suicide threat. This enhanced my understanding of the impact that living with a person with BPD has on the carer.

During the interviews I made an effort to differentiate between my professional role as a charge nurse talking to clients in one-to-one sessions and my role as a researcher, talking to the participants for research purposes. The hardest was that gathering information for research, I was not in a position to discuss the issues raised from a psychiatric nursing point of view. Thus, I was aware of the dual roles that I had to keep separate and distinct throughout the interviews.

As a professional I practice reflexivity that enables me to learn and improve from my practice. Writing the reflective journal helped me to write down my thoughts after each interview and thus clearing my mind before going to the next interview. Although the reflective journal helped me in interpreting the findings, discussing my analysis with my supervisor was an asset. This was necessary as since I am a novice researcher and the guidance from my supervisor motivated me to express and write my interpretations better by examining deeper the transcripts and understanding the meanings and concepts that the participants were expressing.

During the interviews I noticed that the participants were at ease describing their experiences and verbalised that they found the interview useful for them to share and vent out their experiences with a professional. This was a satisfactory statement for me as before the interviews I was concerned that the participants would view the interviews as a waste of time.

The informal carers indicated that caring for their relative with BPD was a complex issue. However, they were willing to disclose their experiences, their emotions and how this experience touched them. The interviews were charged with emotions and the impact of caring for a relative with BPD dominated during the interviews. I transcribed every interview prior to doing the next interview, thus I felt more committed to the participant's experiences. During

the transcription process it felt that I was living the experience with them and this helped me to understand them better.

After the data collection

I wanted to make sure that the participants perceived me as a researcher and not as a charge nurse and thus I interviewed relatives who I never met in the caring profession. They saw the interview as a chance to express themselves and verbalise their experiences. I realised that these interviews changed me in a way that now I am more aware of the pains and fears that they experience. Hence, the informal carers showed their fears about their ill relative's suicide threats. Moreover, the informal carers expressed their fears to share their experiences with others, because they do not want to be judged. In addition, they also verbalised how painful it felt to be helpless with uncontrollable situations relating to their ill relative. Furthermore, the experiences of the participants were an asset to reflect on my empathic skills and I feel that I can now be more empathic with the relatives of patients with mental illnesses. I was particularly touched with the impact of suicidal thought and suicidal threats and the nature of impulsivity of BPD on the relatives as these were the most worrying. I was also touched by the relatives need for support and their need for more information. These were factors which I can personally commit myself to do something about them in my nursing profession such as introducing family meetings in addition to the usual ward rounds with the patient.

3.16 Conclusion

In this chapter I discussed IPA, which was the most relevant methodology to address the research question. The philosophical underpinnings and the rationale for this option were also presented. In addition, sample recruitment, the interviews and data analysis were also described. Care was taken to adhere to all the ethical issues. Strategies were followed to ensure rigour and the lived experiences of the participants would be authentic. Finally, my reflexivity was presented to enable me to be better aware of my preconceptions and prejudices that could impact on the research process.

The following chapter presents the findings that emerged from the transcripts of the interviews.

CHAPTER 4: DATA ANALYSIS

4.1 Introduction

This chapter presents the interpretation of data collated from the informal carers (i.e., partners/spouses) of persons with BPD. Data analysis was carried out following the procedure described by Smith et al. (2009), that produced three superordinate themes and a number of emergent themes on the carers experiences. Hence, this chapter presents the themes and super-ordinate themes extracted that represent the participants' voice, together with my interpretation.

To ensure that the participants' voice was represented in this study, I have included a number of short excerpts taken from the transcripts as recommended by Smith et al. (2009). By providing excerpts I am attempting to assist the readers to better understand the participants' experience. The participants' excerpts are presented in this account using pseudonyms to ensure that the participants' identity is protected. The following pseudonyms are used throughout the chapter: *Brian, Mark, Maria, Katie* and *Gary*. Table 3.2 in Chapter 3 provides the details about these participants. The participants' age ranged between 35 to 65 years. All the participants were married for more than 2 years. Brian, Katie and Gary are currently employed and are the breadwinners of the family. Maria was employed before she was married and is currently living on social services benefits. Mario previously was a business man but is now a pensioner. Brian, Gary and Maria, have children living at home. Only Maria's son has his own income, while Gary and Brian have kids who are under the age of 18 years. Mark's children are married and have their own families. Katie does not have any children. Direct excerpts from interviews that were conducted in Maltese are presented both in the original Maltese version and in the English translation. The excerpts used from the interviews with Brian and Katie are presented only in English, as both participants are English speaking. The voices of Gary, Maria and Mark are presented in both Maltese and English as the participants are Maltese speaking. Excerpts are presented in italics and enclosed within quotation marks and labelled with the pseudonym. Ellipsis ("…") are used when parts of the excerpts are omitted for editorial reasons.

Prior to presenting the themes that emerged from the participants' experiences, the researcher felt that it was important to make reference to a number of linguistic components that were used by the participants during the interviews. In fact, Smith et al. (2009), suggest that researchers should take note of the language used by the participants, as this contributes to

a better understanding of their lived experiences. The following section describes the linguistic components identified from the participants' transcripts

4.2 Linguistic Components

During the analysis process, it was noticed that the participants often used repetition of words in the same sentence. In fact, Nevalainen et al. (2008), stated that repetitions in statements are used when the individual wants to make an emphasis.

For example, in the following excerpt, it is possible that Gary used repetition to emphasise the emotional impact of caring for this wife with BPD. This repetition relays a strong message that the participant is psychologically burdened and destroyed.

"Imfarrak, imfarrak. Spiccajt nibki,   *"Shattered, shattered. Ended up crying,*
waslitni to the limit."   *took me up to the limits."*
(Gary, p. 3, line 68)

Another participant used repetition to emphasise how hard it felt to live with his wife with BP symptoms:

"Kienet qiebsa hafna biex tghix maghha.   *" It was very difficult to live with her.*
Qiebsa hafna ..."   *Very difficult ..."*
(Mark, p.7, line 153)

Metaphors are another linguistic component noted in the participants' transcripts. The metaphors used by the participants facilitated the understanding of the lived experience of the participants. The researcher noticed that most metaphors were used by the participants to further explain their fears, anxieties, anger and helplessness.

These metaphors facilitated the listing of the super-ordinate themes namely: 1. An Unsettled Existence, 2. Searching for Meaning and Peace and 3. Supportive Relationships. The super-ordinate themes were elicited from the excerpts. The first super-ordinate theme, "An unsettled existence", provides a description of "living on edge", social impact and inter-relationships, "existing but not living" and "physically worn out". The participants gave their experiences

about the impact of suicide threats which was noticed to be the main factor causing fear. The experience of fear was also expressed in the following metaphor, where the participant feared that she could not handle the possibility of her husband's death following suicide. The participant lived in constant fear of such an eventuality. At the same time the participant compared herself to a sound board where she was reacting to the feelings of her husband. The participant's reactions were not only fear of the situation but also anger towards her husband's behaviour.

"I felt like a sound board, a reaction to his feelings. I was terrified that I will find my husband dead. I was angry at him because he knows what it feels, because he lost his mum with suicide. This made me worthless, made me feel used [as the participant felt that her husband would pass her through the same painful experience that he had when his mother committed suicide]. *I was mad and angry for him. I was terrified for his life, terrified that I can't handle this situation."*
(Katie, p. 4, line 118)

Another common metaphor used by these carers to describe their ill relative's behaviour related to animals. The term 'animal' was used in the context of a severely aggressive behaviour or a savage and fearless human being. It was also associated with an inability to reason out things. This is exemplified in the following excerpt:

"Mansa mieghi. Alla hares	*"Tame with me, God forbid*
ikollok xi tghid maghha …	*having a clash with her …*
ghax ma tibza minn hadd."	*She is not afraid of anyone"*
(Mark, p. 4, line 73)	

Furthermore, it was observed that the participants perceived that their relative with BPD was 'robbed' of their human nature and were actually taken over by supernatural forces. This is demonstrated in the excerpt "*He was acting as if possessed by a demon*" (Katie, p. 7, line 242).

Thus, the excerpts of both carers (Katie and Mark) demonstrated that the person with BPD was perceived as having taken on an additional supernatural and/or animalistic nature.

During the analysis, the researcher noticed that the participants also used metaphors related to water when discussing their caregiving experience. A Maltese metaphor related to the sea / water was used to express the psychological deterioration felt by a caregiver as a cause of supporting their ill relative. This metaphor demonstrates hopelessness of the carers which is associated with a person who is drowning.

"...inhossni mmur il-bahar u   *"... I feel that I am destroyed and*

[bil-hsieb] nibki" (Maria, p.8, line 181)   *[with the thought] I cry"*

Furthermore, during the analytic phase, the researcher noticed that during the interviews the participants verbalised the ways they strived to cope on an individual level during this experience. Thus, the second super-ordinate theme, 'Searching for meaning and Peace', demonstrated the way that the participants searched for meaning and peace as an individual. Spirituality was one of the themes that emerged as a way of searching for meaning. One of the excerpts showed that the participant perceived caring for this wife with BPD as a bonus for judgement day when he faces God after death. This was elicited from the excerpt:

"... irridu naghmlu l-kontijiet m'Alla..."   *"... we have to do our "accounts" with*

(Gary, p.6, line 126)   *God.."*

Participants expressed coping with this experience either by avoiding their partner or by accepting the situation. Furthermore, faith or the loss of it was also mentioned by the participants. In addition, resilience was a strong feature that came out in seeing a positive side to this experience that helped the participants to cope.

The final Super-ordinate theme 'Supportive Relationships', was elicited mainly from the participants who expressed the need for more interpersonal support, especially at the time of crisis. The need for support to deal with the experience was evident with the use of the following metaphor, where the participant showed that BPD destroys people and families from every social class. This metaphor reflects the crisis of families with a member having BPD and thus shows that these individuals need support to help them cope with this experience.

"It can destroy a lot of people. It can wreck a lot of managers. It can cause a lot of harm."
(Brian, p. 2, line 46)

The superordinate themes are presented in detail with the accompanying excerpts in the following section. Table 4.1 lists the themes and super-ordinate themes elicited from the experience of carers who lived with their spouse having BPD.

Table 4.1 The experience of caregivers living with their spouse with BPD:

Themes and super-ordinate themes extracted

	Super-ordinate Themes	Emergent Themes
"… she has changed so much … her presence worries me and confuses me …" (Gary, p. 5, line 115) "I felt emotionally very upset, … life cannot settle." (Mary, p. 4, line 79)	An Unsettled Existence	• Living on Edge • Social Impact and Inter-Relationships • Existing but not Living • Physically worn out
"I did not have a choice, life had to keep going. Now I have become used the situation." (Mark, p. 2, line 24)	Searching for Meaning and Peace	• Acceptance • Spirituality • Dedicating Time for One Self
"Wish I had more people that we knew that care for us … I really wished to have a support system to share the burden…" (Katie, p. 7, line 225)	Supportive Relationships	• Family and Friends • Support Groups and Non-Governmental Organisations (NGOs) • Health Professionals

The following section presents the first superordinate theme with accompanying excerpts.

4.3 An Unsettled Existence

The findings collated indicate that caring for a person with BPD has a substantial impact on the carer, with one describing the experience as "the end of the world". Most of the carers focused more on their relatives' health and neglected their own physical, psychological and social well-being. In addition, carers described this experience which has impacted negatively on their emotional well-being. The financial aspect was also brought up by some of the participants in relation to visits of their ill relative to see a psychiatrist or the impact on work and financial income.

4.3.1 Living on Edge

Participants described living in a state of constant worry. Some of the participants expressed being constantly on edge, stressed or anxious. Worries were described to arise from seeing their ill relative taking the recommended treatment and yet no improvement in symptoms were observed. In fact, Gary talked about the anxiety he experienced as a result of the BPD.

"Medicine doesn't seem to work.
Pruvat hafna medicini u l-problema
kienet hemm u ghadha hemm.
L-affarijiet tohodhom bi
kbar hafna. Dawn jinkwetawni
ghax bihom qed izzid l-anzjeta tieghi.
Ghandha hafna instabilita u lili
zzidli hafna anzjeta."
(Gary, p.1, line 20)

"Medicine doesn't seem to work.
She tried a lot of medicines but the
problem was there and is still there.
She amplifies things. These worry me
because she is very unstable and is
making my anxiety increase. She is very
unstable and for me she increases my
Anxiety."

Furthermore, the participants constantly worried about their relatives' reactions that developed into arguments between the couple. Such behaviour was worrying for the participants and caused a lot of stress in the carers. Two participants (Mark and Gary) voiced their concerns about the argumentative behaviour of their wife. This is exemplified in the following excerpt:

"Trid toqghod constatntly attent

"You have to be constantly attentive to

x'qed tghid, x'qed taghmel il-
hin kollu. Inhossni stressjat hafna.
Stressjat li l-anqas noqoghdu fl-
istess kamra. Ma nissaportijiex..
taqbad fuq kollox…
stressjat, dejjem on edge maghha…"
(Mark, p. 2, line 30 & 77)

what you are saying, what you are doing,
attentive all the time. I feel very stressed.
Stressed, to the extent that we do not even
stay in the same room. I can't stand her…
she picks up an argument on anything.
stressed, always on edge with her…"

Four carers (Gary, Mark, Maria and Katie), voiced their apprehension due to their spouse's unpredictable behaviours. Thus, behavioural aspects such as the inappropriate way of interacting with other people and the argumentative nature of the person with BPD made the carer feel insecure and unsafe with their spouse. These carers struggled with a gnawing fear and anxiety due to the impulsive reactions of their spouses and felt upset that a peaceful life was not an available option for them. Throughout all this, the carer was helpless as they perceived having no control over the situation.

"Inhossni stressjat, anzjuz u mdejjaq ghax
  dejjem nahseb li se jigri xi haga, jew li se
taghmel xi haga lil xi hadd, tghid xi haga
lil xi hadd, l-attitudni taghha, jew kif se tagixxi."
(Gary, p. 2, line 35)

"I feel stressed, anxious and miserable
Because I am always worried that
something is going to happen, or that she
will do something to someone, she will
say something to someone, her
attitude, or the way she will react."

"Dik il-haga li in any second din
jitlaghla kienet tinkwetani u tistressjani.
Ma tkunx qed tistenniha, impulsive,
taqla storja u storbju ghal kull xejn…
Hafna stress ma nafx meta se tisplodi."
(Mark, p. 4, line 86)

"That thing that in any second she loses
her temper used to worry and stress me.
You would not be expecting it, she's
impulsive, and makes up some story and
creates chaos over some insignificant#
event. Loads of stress, you never know
when she is going to explode."

This impulsivity rocked the basic foundations and stability of the family's functioning. Maria explained that her spouse left work and constantly insisted that he wanted to move into another residence.

"Qeghda ghaddeja minn fazi hazina.
Ghax minhiex stabli. Dejjem irid jitlaq
mid-dar… Kien telaq anke mix-xoghol...
Issa jrid immorru go dar ohra… Issa jekk
jivvinta xi haga ohra x'se naghmel jien?
Hemm din l-incertezza."
(Maria, p. 5, line 114)

"I'm passing from a bad phase. Because
I am not stable. He (person with BPD)
constantly wants to leave the
home… He even left work… Now he
wants us to move to another house…
Now if he invents something else, what
am I going to do? There is this uncertainty."

The above excerpts reflect the burden that the behaviour of a person with BPD has on the carers. The participants voiced their concerns about living with uncertainty, constantly on edge, stress, anxiety and lack of trust in the ill spouse. Thus, the behaviour of the BPD person has an impact on the psychological wellbeing of the carer.

Furthermore, suicide was also cited by the participants as a greatly preoccupying factor. Four participants, Katie, Maria, Mark and Gary, highlighted their fears when their relative mentioned or attempted suicide. The fears of suicide reflected worries not only to lose the person but also worries of the carers being helpless and having no control over their spouses' thoughts and actions. Moreover, the fear of finding a spouse dead raised recurring doubts in the carers as to whether and what more could they do to prevent such an eventuality.

This fear was emphasised by Katie, who described the worries of suicide as very scary. This was verbalised repeatedly while crying during the interview, thus indicating the intense psychological impact of suicide threats on the carer.

"I was constantly worried… I was scared to lose my husband. To lose the love of my life. I was scared he would die and there is nothing I could do to help him… It is a desperate feeling. It is a horrible feeling." (Katie, p. 1, line 33)

However, another participant Maria expressed the fear of losing the person but also the thought that the loss would be caused by the ill relative who would themselves 'self-destruct'. Moreover, the influence of religion on a person's perception can be further appreciated as Maria was a deeply religious person who interpreted suicide as a sin because one is destroying their life.

"Suicide jinkwetani mmens… suicide jinkwetani l-aktar ghax ikun spicca lilu nnifsu. Ninkwieta ghax qatt ma jien certa hux kalm jew qed jeghwden."
(Maria, p. 6, line 133)

"Suicide worries me a lot… suicide worries me most because he will destroy himself. I worry because I can never be certain if he is calm or if he is ruminating."

Due to the intense psychological pressure, in addition to the fear of a possible suicide attempt, some carers perceived a hospital admission as offering a safe solution to their problems and insecurities.

"Lili ftit affarijiet ibezzawni. L-aktar li nkwetajt hu meta qaltli li trid toqtol ruha b'idejha. B'hekk hallejtha tidhol l-sptar ghax bzajt li taghmilha."
(Mark, p. 2, line 42)

"There are few things which frighten me. I was the most worried when she told me that she wants to kill herself. For that reason I let her be admitted to hospital, because I was afraid that she will do it."

These excerpts convey the fear of death, the fear of losing a partner. The carer's lack of control over their spouse's thoughts and impulsivity, brings with it more insecurity and constantly feeling on edge as verbalised by the participants themselves. One might also point out that since the participants showed that they are highly worried about suicide, then this shows that they are constantly living with these fears in their life. The carers of people with BPD are

living with the fear that one day they will receive the bad news or witness the death of their spouse.

Brian's words however seem to be somewhat contradictory. On one hand, Brian strived to repress any thoughts about his spouse committing suicide, yet on the other hand he seemed to downplay the significance of such an event by stating suicide is a very common phenomenon and that his wife loved the family (hence would not commit suicide). People may choose to downplay something as this helps them to decrease their state of anxiety.

"There are no suicide threats …She loves her family and her daughter. She threatened only once in the hospital … The police took her to Mount Carmel because there was a threat to do suicide… There are a lot of suicides going on… I keep it at the back of my mind…" (Brian, p. 3, line 50)

In fact, Brian continue to explain that his wife in actual fact could not have been suicidal as she would have managed with her attempt. To prove his point and feel more in control over the situation, Brian backs his argument with a case that he heard about as exemplified in the following excerpt:

"*My wife was not suicidal. If someone is suicidal, by the waiting time at casualty department, one would have the time to go on the roof and jump. That's what our friend did. No one knew and she killed herself after work. No one knew. It could be anyone. This worries me."* (Brian, p. 4, line 84)

In this excerpt one can notice the repetition of the phrase "*no one knew*", therefore, this is what worries Brian, that someone who is suicidal would not reveal it to anyone and would then proceed with the action. Therefore, if his wife should actually one day in the future decide to commit suicide then as a carer he can exert little control.

The impact of living with a person with BPD on the carer's self-worth was especially evident in the interview with Katie. This participant explained that she felt worthless both in the relationship with her husband and with others. She expressed herself as being ashamed that she allowed herself to become 'invalid' in this life experience. The carer might be feeling invalid as the behaviour of a person with BPD becomes uncontrollable. The carer's priorities

become only focused on the needs of their spouse with BPD. Therefore, she did not attend to her own needs and she was neglecting herself because her husband required more attention than herself. This was perceived by the carer as describing herself as disappearing. The decisions she took to prioritize her husband's needs over herself, made her neglect herself and so she perceived this as becoming "invalid". This also indicates that a caregiver of a relative with BPD gets carried away caring while losing oneself during this journey. The excerpts showed that Katie also conveyed a sense of self-blame to be in this situation.

"I was there for him but I myself was disappearing... I felt I was not good enough. This affected my self-worth as a partner. I felt ashamed of myself ... Ashamed of how I allowed myself to become invalid in the situation." (Katie, p. 2, line 38)

 Moreover, Mark describes episodes where his wife asked him to leave the house and he felt that he had no other choice. These excerpts demonstrate how the carers lose their own identity in order to avoid conflicts with their spouse.

"Gieli anke bil-lejl kienet tkecini l-barra...
Imbaghad iccempel biex nigi lura. U kont
nerga mmur. Ghamilt zmien twil hekk ...
Ma kelliex choice... La ghamilt commitment
ghamiltu ghal ghomri kollu..."
(Mark, p. 8, line 173)

"Sometimes even at night she would kick
me out of the house... Then she phones me
to go back. And I used to go back again.
I spent a long time living like this.
I had no choice... since I made
a commitment, I made it for life..."

During the interviews the participants also talked about the impact of caring for their spouses with BPD on their social and inter-relationships.

4.3.2 Social Impact and Inter-Relationships

Most of the participants explained that they did not have a social life. Brian expressed how he had to adapt to changes in life as his wife took certain treatment and so they could not go out

for a drink together. Conversely, Gary claimed that he needed time for himself, away from the situation at home to help him to cope. It was interesting to note that Gary used socialising with colleagues not only as a means to cope with the difficult life experiences but also as a strategy of support for himself when his wife passes away.

".... Jien ghandi l-hin ghalija.   *"... I have time for myself.*
In the worst case scenario, jekk   *In the worst case scenario, if*
il-mara tigi nieqsa, ghandi l-hbieb   *my wife dies, I have my friends*
jissaportjawni ..."   *to support me ..."*
(Gary, p. 3, line 53)

Most of the participants pointed out that the behaviour of their relative had an impact on their social life. Maria claimed that she never had any social life because she herself had a mental illness and during her recovery, her husband exhibited BPD. Furthermore, Katie claimed that she did not have a social life because of her husband's unpredictable behaviour. Therefore, the carers become isolated and their caring role is a full time duty. This reduces their opportunities to socialise with their family and friends. In addition, another participant, Katie, also verbalised her that she had to change her role from a wife to a baby sitter of her husband. This might also be a factor that causes anger and frustration as the demands of caring for a person with a mental illness will not meet the perceived role of being a husband and a wife.

"I didn't know what I am expecting when I go home. I cannot predict his behaviour. This disrupted my work and my social life. I did not have a social life as I did not have time for my friends... I couldn't plan to have people in my house because I didn't know what kind of human I am going to find in the house... I had to say no to friends, trying to find excuses not to meet my friends and family and stay there like a baby sitter watching over my husband. I couldn't predict the behaviour of my husband." (Katie, p. 1, line 19)

On the other hand, Mark stated that his wife's behaviour affected not only his social life but also their relationship.

"Il-hajja social ma nafx fejnha... Kont   *"I do not know where the social*
niltaqa ma siehbi regolari imma mhux   *life is... I used to meet my friend*

mal- mara… Kont niskartaha lil mara.	*Regularly, but not with my wife.*
Ma konnhiex immoru nieklu jien u hi.	*I used to avoid my wife. We would not go*
Nohorgu mal-hbieb halli tghedha	*to eat me and her[alone together]. We*
maghhom … Mal-hbieb ma kienetx tkun	*go out with friends so she remains*
aggressiva"	*mentally occupied. ..With friends she would*
(Mark, p. 5, line 113)	*not be aggressive."*

The negative impact of caring on the relationship between the couple was highlighted by Gary, who constantly emphasised that his wife's presence agitated him because of her changed behaviour. For him, a BPD presents as a wedge between two persons. affecting their relationship and preventing any intimacy.

Gary also verbalised that the changes in his wife's behaviour affected all the family. He described this as creating chaos in the family, where for example he abandoned their daughter as he could not concentrate in helping her with her school work. This feeling of neglecting family members weighed down on the carers conscience.

"Ahjar meta ma nkunx maghha …	*"It's better when I'm not with*
tant inbidlet li mhux numbraha imma	*her… she has changed so much*
il-prezenza taghha tinkwetani u tgerfixni.	*that, I don't resent her but her*
Meta tara dawn l-azzjonijiet mill-persuna	*presence worries and confuses*
li tajt hajti ghaliha u nahdem ghaliha.	*me. When you see certain actions*
Gaghlitni nibred mir-relazjoni taghna…	*from the person that I gave my*
hemm xi haga bejnietna li ma tistax	*life for and that I work for.*
tghaqqdna. Qisu qeghdin vicin imma m'ahniex	*She made me lose interest in*
flimkien. Definetly habba changes li	*our relationship… there is*
gab il-mard fiha … il- bond tal- familja	*something between us that cannot*
m'ghadux hemm, il-familja kienet prijorita'	*allow any intimacy.*
ghalija. Din affetwatni hazin lili…"	*It's like we are close to one*
Gary, p.5, 115)	*another but not together.*
	Definitely because of the changes
	her illness brought on her… the
	family bond is no longer there, the

family was my priority. This affected me badly …"

"Ma nistax niffoka… It- tifla traskurajtha fil-homework, studju… Chaos shih. Qatt ma naf fejn jien. "
(Gary, p. 3, line 65)

"I cannot focus … I neglected our daughter in her homework, studies … Total chaos. I do not know where I stand."

In addition to the social impact on the carers, the emotional aspect was very evident. The carer's emotions are presented in the following section, existing but not living.

4.3.3 Existing but not Living

The verbatim of the carers in this study was heavily loaded with emotions associated with their caring experience. The participants expressed a gamut of emotions including hope, frustration, guilt, helplessness, emotionally destroyed, relief, anger and isolation.

One participant, Maria felt particularly guilty that her husband was suffering from a mental illness. She believed that her own struggles with severe obsessive compulsive disorder (OCD) triggered the BPD in her spouse. However, although she felt guilty about her husband's illness, she felt satisfied that she was now caring for him and thus reciprocating for the care that she received.

"Jien meta marad hassejtni li t-tort ta' dan hu kollu tieghi. Kieku ma ghejjiex mieghi, ma kienx jimrad. Li ha hsieb lili marida zgur li kkontribwixxa ghal mard tieghu … Jien ghandi feeling li hafna mil-persentagg li hu marid huwa ghax kien il-carer tieghi"
(Mary, p. 2, line 29)

"When he got sick I felt that I was to blame for all this. If he hadn't got exhausted with me he wouldn't be sick. The fact that he took care of me when I was sick, contributed to his sickness … I have a feeling that a great percentage of his sickness is due to having been my carer".

"Il-fatt li ha hsiebi huwa obligu li niehu hsiebu. U sodisfatta li kelli c-cans li niehu hsiebu. Fl-ahhar qed nghinu."

(Mary, p. 6, line 148)

"the fact that he took care of me, I am obliged to take care of him. And I am satisfied that I had the opportunity to take care of him. Finally, I am helping him."

Another participant, Katie expressed guilt feelings due to her anger when faced with a helpless situation. In addition to guilt, the interview with Katie was charged with emotions namely, anger, frustration, loss of control and helplessness. This scenario reflected the overwhelming emotional burden experienced by carers of persons with BPD. In addition, this excerpt demonstrates that carers are torn between the responsibility of deciding whether to care and support their relative or stepping back and letting their relative with BPD take responsibility for their own behaviour. This evoked a range of negative emotions in the carers.

"… I felt guilty for being angry at him because I understand the desperation he was feeling … I wanted to be strong enough to know that it was not my responsibility but it was his choice (to opt for attempting suicide). *I knew there was nothing I could do to help this person. I was very angry at him because he knows what it feels, he lost his mum with suicide. I was so angry at him… I just felt out of control. Nothing was in my control at all."* (Katie, p.4, line 132)

On the other hand, Brian expressed his anger and frustration in relation to the treatment approach. Brian expressed that he perceived better outcomes from a therapeutic relationship rather than the use of oral treatment.

"… she never had the right treatment. To be honest in Malta it is like take these tablets and come back in a couple of weeks. When she sees another doctor it gives us a boost that she's going to handle it (her moods). *It's hard to explain but I think she never had the right treatment. This pisses me off. Here [in Malta] there is more reliance on treatment …"* (Brian, p. 1, line 15)

"Mental health people need people to talk to… people to talk to at the second of crisis. People who know how to talk to you…" (Brian, p. 4, line 82)

In addition to coupling anger with a feeling of helplessness, two participants described helplessness as emotionally destruction. Mark explained that he felt emotionally destroyed when he saw his wife admitted to MCH but he could not do otherwise as did not know how to handle this situation. He expressed how he struggled at seeing his wife walking around with a toilet paper roll in her hands, whilst admitted at the psychiatric hospital. This statement resonates with emotions such as the grief of a caregiver at the depersonification of the woman in front of him. It also provides a powerful contrast of a woman who had everything that she desired but within a hospital environment just carried an item relating to a basic physical necessity in her hands. This excerpt also reflects the stigma that mental illness and hospitalisation has in Malta. However, Mark then experienced a sense of relief when his wife was discharged from hospital.

"Meta dahlet l-isptar kont emotionally destroyed. Ma kontx naf kif se nihendilja s-sitwazzjoni ... u meta kont naraha filli kellha d-dinja f'idejha w issa bir-romblu tat-toilet paper f'idejha, ma tantx hadtha sewwa ... Wara li harget mill-isptar hassejt relief. Kienet inbidlet kompletament."
(Mark, p. 3, line 48)

"When she was admitted to hospital I was emotionally destroyed. I didn't know how to handle the situation ... and when I saw her with the toilet paper roll in her hands, when she had the world at her feet I didn't take it that well...after she was discharged from hospital I felt relieved. She was completely changed."

To emphasis on the emotional burden, Maria associated the physical symptoms with the emotions that she was experiencing when her husband was admitted to hospital. The description of the physical symptoms helps the participants to express their emotional pains.

"Hassejtni emotionally very upset, ghejja kbira f'rasi, nhewden bil-lejl. X'hin inqum l-ewwel haga li niftakar hi li hu qieghed hemm [l-isptar]. Qisha l-hajja ma tistax tigi f'postha." (Mary, p. 4, line 79)

"I felt emotionally very upset, mentally exhausted, ruminating during the night. When I wake up, the first thing that comes to mind is that he is there there [psychiatric hospital]. Life just cannot settle."

4.3.4 Physically Worn Out

Some of the participants noticed that the burden of caring for their relative affected them physically. However, the interviews showed that the participants interpreted these effects differently. One of the participants, Katie talked about the physical changes that she noticed. She also included high blood pressure and shaking associated with anxiety and panic attacks along with this experience. In addition, Katie also talked about how she abandoned her physical self because she did not have energy for herself. She also pointed out that this experience changed her perception about her body image. From the excerpts one can notice that the carers showed physical symptoms of anxiety and burnout. Therefore, caring for a person with BPD is a stressful experience for the carers.

"I put aside my body. My energy and my brain just focused on him ... My hair is now grey, my skin breaks up a lot, anxiety, panic, high blood pressure. I've noticed these changes. And definitely my confidence in my body and myself are changed. Physically looking at myself, I am not the same person ... I look at my body and it was disgusting ... there was no self-love. I think this was because I felt worthless because of the situation. I had a lot of weight loss, I didn't shave, I didn't care if I didn't wash my hair for 3 weeks, I didn't care that I don't shower for 4 days. I didn't have energy."
(Katie, p. 5, line 160)

Gary, also posited that this experience affected him physically and stated that the situation was so stressful, that he felt tired and claimed that he loss an interest for those activities that previously gave him pleasure.

"... ghajjejt u ma niflahx izjed. Hija esperjenza stressful. Dan l-ahhar ftit gimghat l-anqas aptit inqum, qtajt il-gym, inhossha difficli mmur nigri. Jigifieri wasalt fil-limit li nwaqqaf dawn l-affarijiet."
(Gary, p. 4, line 95)

"... I am tired and cannot take more. It's a stressful experience. These last few weeks I did not even feel like waking up, I stopped going to the gym, I find it difficult to go for a run. Basically I have reached my limits since I have stopped these things"

On the other hand, Mark during the interview mentioned the physical changes that he noticed and pointed out that although stress from this experience might have contributed, he does not

put the blame on his wife. Actually he claims that he is a strong person and can handle problems. Therefore, this shows that the participants have their unique perceptions of the care experience.

"Jien tawni zewg heart attacks.
Pero ma nistax nghid li tawni
minhabba l-mara ghax jien nixrob,
inpejjep u niekol … Jista jkun li l-heart
attack tani qabel habba l-istress taghha.
Pero jien niflah ghal-problemi."
(Mark, p. 5, line 108)

"I've had two heart attacks. But I
cannot say that these happened because
of my wife because I drink alcohol,
smoke and eat … It could be that the
Heart attack happened before because I
Was stressed with her. But I am strong
and can handle problems."

The findings presented under this superordinate theme demonstrated that caring for a relative with BPD influenced the carers' quality of life. The excerpts were used to validate the carer's feeling and thus the superordinate theme "An unsettled Existence".   The following section outlines the individual strategies used by the participants to search for meaning and peace to help them cope in their life.

4.4 Searching for Meaning and Peace

The second super-ordinate theme presents how the participants in this study searched for internal peace and meaning to cope with the difficulties and challenges that they faced. This superordinate theme focuses on the carer and explores how the person strives to cope and find meaning in their circumstances. The participants developed different coping strategies which included acceptance or avoidance to manage their situations. In addition, spirituality, satisfaction in caring and one's own perception of resilience were all factors which enabled the carers to cope. The notion of the participants looking for peace was noted to be common during the interviews.

4.4.1 Acceptance

It was noticed that those participants who accepted the situation, are also the ones that perceived themselves as resilient. Brian posited:

"My life is like this. We have been together for 26 years. Half my life has been with her now … I always had a strong personality. I can handle a lot of things … I am strong in my head and that helps me to cope … I've adjusted to the changes… I got used to her ups and downs … it has never been flat waters but I personally get on with things. This is the life … I say tomorrow is another day." (Brian, p.4, line 91)

This demonstrates that Brian is hopeful and verbalises positive thinking about life.

Mark also claimed that he is a resilient person and uses this perception about himself to keep moving ahead in his life. Mark also verbalised that marriage is a commitment and this encouraged him to accept the situation as it was. He expressed his values of commitment and thus this explains the reason for acceptance.

"It comes naturally li niehu hsieb il-mara. Ma kellix choice, trid tibqa ghaddej fil-hajja. Issa drajtha s-sitwazzjoni. Ghalija saret xi haga li qeghda hemm u daqshekk. .. Jien la ghamilt commitment ghamiltu ghal ghomri kollu. Dan lili jzommni. Jien hekk tghallimt… Jien ghalija l-mard mentali huwa mard bhal fiziku. Allura sempliciment accetajtha… Jien lili xejn ma jkissirni. Mentally xejn ma jaffetwani ghax jien rasi iebsa…"
(Mark, p. 2, line 24)

"It comes naturally that I take care of my wife. I did not have a choice, life had to keep going. Now I have become used to the situation. It's there and nothing more… Since I did a commitment, I did it for life. This maintains me. That is what I was taught… For me mental health problems are like the physical problems. Hence, I simply accepted her … Speaking for myself nothing   will destroy   me   because   I   am stubborn…"

The following sub-theme described how spirituality helps the participants find meaning in their situation.

4.4.2 Spirituality

Two participants Gary and Mary claimed that faith in God helped them to cope. Furthermore, Mary not only used faith as a search for meaning and peace, but she also posited that this experience enhanced her faith in God. She also pointed out that through her faith this suffering made her experience less of a burden. The participants felt that the suffering was offered to God and this would help them reap benefits in heaven. This was also pointed out by Gary who stated that he thinks that life is only temporary and so everything will pass. This perception helped him to bear life's pain.

"Din l-esperjenza ssudatni. Jien nghid Alla hares m'hemmx Alla ghax kieku din it-tbatija hija fil-vojt. U hekk it-tbatija thossha inqas. Meta t-tbatija taghmilha ghal Alla, B'xi mod taghddi… Jin jikkunslani l-premju li qieghed fil-Genna."
(Mary, p. 7, line 157)

"This experience has made me stronger. God forbid that there is no God, otherwise this suffering is useless. And in this manner the burden is perceived lighter. When the suffering is offered to God, in some manner it will pass…I feel consoled knowing that the gift is in heaven."

"… irridu naghmlu l-kontijiet m'Alla. X'ghamilna tajjeb u x'ghamilna hazin. Il-hajja hija temporanja. Kollox irid jghaddi. Meta nahseb hekk il-wegghat ma nhosshomx…"
(Gary, p. 6, line 126)

"…we have to do "accounts" with God. The good we have done and the bad. Life is temporary. Everything has to pass. When I think in this way I do not feel the pains …"

However, not all participants found meaning through their spiritual beliefs. Katie thought only once of spirituality, when she tried to negotiate with a higher power. In fact, Katie claimed that this experience made her lose faith and while narrating her account, she was sobbing whilst describing that she only prayed once when she was feeling desperate.

"I didn't believe in Faith. I didn't understand how it was possible to allow someone to be in this situation. I felt let down by God or any higher power. I became an atheist, nothing was going to change, there was nothing I could do. There was actually one day when I sat down and prayed, if you are there and listening please help this man because I can't do anything. That was out of complete desperation. I lost any kind of faith… There was no sense of spirituality… I lost my beliefs, I couldn't meditate, self-reflect and understand my emotions…"
(Katie, p. 6, line 189)

4.4.3 Dedicating Time for Oneself

Finding time for oneself was perceived as enabling the carers to find a moment of peace and also personal happiness. One participant claimed that he finds his peace of mind by practicing his hobby, while another participant, Gary copes by going out with friends. Mark in his interview posited that he needed time for himself to find peace during this situation.

"Jien il-paci insibu fija nnifsi fi kwiet assolut fejn ma narax nies… Noqghod inhabbel rasi fuq xi haga mekkanika. Hemm nintilef."
(Mark, p.7, line 142)

"I experience internal peace when in perfect silence, where I don't come in contact with other people. I like to solve mechanical problems. I get carried away focusing on mechanical problems."

On the other hand, Gary also posited that work, alcohol, friends and going out to bars helped him to cope during difficult times. In addition, Gary stated that this strategy of coping also gives him energy to cope with his wife. Thus, distraction from the everyday life and communicating with people that can understand and empathise with a person were coping strategies used so the carers could continue to support their sick spouse.

The subsequent superordinate theme outlines how participants manage the caregiving situations through supportive relationships.

4.5 Supportive Relationships

Obtaining support from health professionals, family members and support groups was a notable aspect which emerged throughout the interviews. In addition, the need for more knowledge about the relative's care and condition was also evident.

4.5.1 Family and Friends

During the interviews it was noted that support from family and friends was highlighted by all the participants. Mark relied on his friends for support to guide him when to look for professional assistance and how to cope in difficult times with a wife suffering from BPD.

"Sapport m'ghand habiba biss sibt. L-isptar ma sibtx sapport, ma kelmuni xejn … Li ma sibtx lil habiba taghna ma kelli lil hadd."
(Mark, p. 8, line 183)

"I found support only from my friend. I did not find support from hospital, they never spoke to me … If I did not find this friend, I would have had no one."

In addition, both Maria and Brian relied on the other family members for support and other logistic assistance that they require (e.g. family members to take them for appointments). Furthermore, Gary considered contact with his friends and support from his work colleagues to be crucial for him to cope with his wife having BPD.

However, one participant, Katie did not reach out for support from family and friends, she spoke about her need to have family or friends to support her during this difficult experience. Katie claimed that she felt isolated and would have wished the support of her husband's family to help her cope with the situation. At the same time, she was also afraid to ask for family support to prevent her husband from being judged negatively because of his behaviour. This scenario demonstrates that some carers refrained from reaching out for support because of stigma. Therefore, in such cases they are hesitant to reach out for support as they fear not being understood by the other family members.

"I haven't been reaching for support. Not even to my mother. I think I was afraid to hear what I did not want to hear. I didn't want her to define him by his behaviour. I protected him."
(Katie, p. 6, line 184)

4.5.2 Support Groups and Non-Governmental Organisations (NGOs)

One participant (Brian) during the interview raised the need for support groups with sessions from people who passed through the same experiences. Therefore, caregivers were interested to know how other families in similar situations coped in similar experiences. Furthermore, people might feel some consolation knowing that they are not alone in a difficult situation, this would help them to cope. The participant also verbalised the need to have support when the family is in crisis. The need for support was also evident in Brian's facial expressions and tone of voice. Hence, carers need to communicate, carers need health professionals to empathise with them and support them in a crisis. This is also reflected in Brian's excerpt that the carers are not prepared for crisis and how to deal with difficult situations.

"the best people are the ones that have gone through it ... For me the best people to give advice are the people who passed through the same experience. Being a relative to advice a spouse or a mother, or a patient who has been through it and managed to control it. No one knows about what you go through and the hard times you experience, unless it's the partner who's with her through this ... We need the support at the second of crisis. We need people who knows how to talk to you there in casualty department..." (Brian, p.4, line 74).

Another participant Mark, pointed out the need for support from NGOs. This also reflects that the carers want to be armed with knowledge on how to manage a person with BPD. Carers strongly show that they need to know that people and health professionals are available, so they know where to turn for advice and assistance. Caregivers wanted to receive support and knowledge to help them cope. In fact, one participant, Maria verbalised that she learnt a lot about mental illness from attending the support group of the MHA. The following excerpt shows that the families are not aware of the local NGOs for mental health patients and relatives. This might reflect a need to promote further the services available and to give more information to the families caring for a person with mental illness.

"Fil-mard mentali ma hemm xejn sapport. Irid ikun hemm xi haga bhal hospice. Tkun tixtieq min jghidlek x'se tistenna, min xiex se tghaddi. M'hemmx informazzjoni,

"In mental illnesses there isn't support. There should be something like "hospice". One would like to know what you are expecting, what you will go through. There is no information,

m'hemmx sapport. Kont infittex ghal informazzjoni jien minn fuq l-internet. Pero kont dizappuntat li ma sibtx sapport mill-isptar."
(Mark, p.9, line 187)

there is no support. I used to look for information myself on the internet. However, I was disappointed that I did not find support from the hospital."

The next section presents the participant's excerpts in relation to support from the health professionals.

4.5.3 Health Professionals

This section outlines the need felt by some participants for more support from health professionals during their relative's hospitalisation. Furthermore, two of the participants (Mary and Katie) expressed a positive attitude as they felt that they received support from the health professionals. In fact, they were thankful and felt that they benefitted from the support they received from health professionals. On the other hand, three of the caregivers (Gary, Brian and Mark) in this study spoke about their need for support from health professionals.

Gary expressed his need to receive support from the health care professionals. The excerpt shows that the carers are often invisible in this process as their needs and concerns are not discussed. The carers feel isolated in relation to support from professionals. Hence, health professionals are more concerned about the patient and fail to include their carers, who are the ones that spend most of the time caring for the sick person.

"Jien xtaqt l-istess sapport li kellha l-mara. Hi akwestat is-sapport u jien le. Hi ghandha team warajha u jien m' ghandi lil hadd."
(Gary, p. 6, line 139)

"Wished I had the same support that my wife had. She managed to receive support but I didn't. She has a team behind her but I do not have anyone."

Furthermore, Mark not only claimed that there was no communication with health professionals, but he highlighted that he was only 'talked at', and in relation to his responsability once she was discharged from hospital.

"Lili l-isptar ma kelmuni xejn.
Hlief biex nohrogha, u
qabel tlaqna qaluli li jien
responsabli ghaliha."
(Mark, p. 8, line 184)

"In hospital they didn't tell me
anything. Except to take her out,
and before we left they told me
that I am responsible for her."

In addition, the participants also expressed their need to know more about their relative's mental illness. Two of the participants, Brian and Mark claimed that they were not given any information about the diagnosis and care. They only searched for the information themselves from the internet. Another participant Gary, was aware of the BPD as a diagnosis, however he claimed that he does not know anything about it. In fact, Gary perceived BPD to be something more than depression.

"Issemmiet borderline, pero ma nafx
xhini ezatt. Pero naf li hija aktar minn
depression. Nikkonferma dan ghaliex
il-medicina ma tahdimx."
(Gary, p. 1, line 18)

"Borderline was mentioned, but I don't
know what it is exactly. But I know that
it is more than depression. I confirm this
because the medicines don't work."

Furthermore, another participant, Katie was aware of mental illness symptoms from her own knowledge and past experience.

"I don't know what his mental illness is. I only know that it stems from the traumas in his childhood and genetic predisposition to mental illness. I understand him and his mental health problems because I suffered from depression in my 20s. I used to see a therapist. This helps me to take care of my husband because I have been in a similar place before I got better."
(Katie, p. 3, line 81)

Furthermore, Maria was not aware of her husband's diagnosis however she felt well supported and informed about mental illnesses in general because she herself was a sufferer of OCDs and had regular contact with health professionals.

Thus, the participant's voices demonstrate a need for more knowledge about the diagnosis and care of their relative. Having the relatives looking for the information themselves and going to doctors and other health professionals shows that knowledge gives the carers a sense of hope

which in turn helps them to cope. However, looking for the information themselves might pose unnecessary anxiety on the caregivers as they might not be able to understand and interpret the information well.

Conversely, Maria and Katie expressed their gratitude for the support that they received from the health professionals. Maria also mentioned the support groups and perceived the talks from experienced caregivers as beneficial. Maria, in her excerpt showed the importance of the multidisciplinary team and the inclusion of all the family members in care. In BPD, all the family members are affected and thus all the members need to receive support.

"Ghandna ghajnuna kbira.
Ghandna l-psikjatra, is-psychologist –
li tkellem lili wahdi, lir-ragel, lit-tifel
u couple therapy. Ma kontx nobsor li
hawn din l-ghajnuna kollha…
Sibt ghajnuna kemm mil-
Profesjonisti, psikjatra, psychologist, nurses."
(Mary, p.8, line 192)

"We have a lot of support. We have
the psychiatrist, the psychologist – who
talks to me alone, to my husband, my
son and does couple therapy too. I
was never aware that there is all this
help…I found help from professionals,
the psychiatrist, psychologist, nurses."

One of the participants Katie, has been a resident in Malta for a short period of time and was not aware of the local mental health services. However, she verbalised her satisfaction with the support she received from the health professionals. The excerpt reflects that caregivers need to feel accepted and listened to in their difficult times. Moreover, the therapeutic relationship between the health professionals and the carers has the ability to shape the person's health care experience.

"I wish I knew about Mount Carmel before [hospital]… I wish I had more people that we know that care for us in the vicinity… I really wished to have a support system to share the burden of his mental illness, to help me understand … I knew that I needed a therapist but I couldn't leave him alone. I was overwhelmed with fear and anxiety. It would have been nice to have family and friends to support both of us… I can't explain the difference that being in Mount Carmel made. The place, the nurses – that care without judging." (Katie, p. 7, line 225)

Hence, a therapeutic relationship with the caregiver where the individual's values are respected and supported helps the relatives to have a positive experience in care. Moreover, the

participants' voices clearly showed a greater need to be involved more in the care of their relative and to be equipped with information about the condition, care and availability of services.

4.6 Conclusion

This chapter presented three super-ordinate themes which emerged from the analysis of data collection from the participants. The first super-ordinate theme, "An Unsettled Existence" described living on edge, social and inter-relationships, existing but not living and physically worn out. "Searching for Meaning and Peace", described the coping strategies used by the participants during this life experience. The final super-ordinate theme "Supportive Relationships", incorporated aspects of support that the participants obtained or needed more to keep going in their life. Hence, this chapter provided an insight into the lived experiences of the spouses living with their relative with BPD.

The dialogue between the findings, the literature and theory will be presented in the next chapter.

CHAPTER 5: DISCUSSION

5.1 Introduction

The discussion chapter provides a dialogue between the existent literature, the results of the study and my interpretation, in the light of the Common Sense Model (CSM) (Leventhal et al., 1980) and the Person-centred Practice Framework (McCormack & McCance, 2017).

The findings of the present study which will be discussed focuses on the lived experiences of spouses caring for their relative with BPD. All the 5 participants (two females and three males) in this study were married and living with their spouse having BPD. This enabled the researcher to explore the perceptions of carers who are living and sharing this experience with their spouse having BPD. The findings originating from the study and their implications will be discussed in light of existing literature. My own personal interpretations also as the researcher are also taken into account through an interpretation of the findings and existing literature as recommended by Smith et al. (2009).

As highlighted in the literature review, the lived experience of spouses caring for their relative with BPD, has rarely been explored and consequently a gap in literature exists. Most of the extant literature had participants who were mixed family members, ranging from parents, siblings, extended family members (such as aunts and uncles), partners and spouses. Thus, extant research did not focus on a homogenous sample of partners or spouses living with people with BPD. Furthermore, the decision to take spouses specifically living with a person having BPD related to the fact that living together with a person presents a specific burden (Bauer et al., 2012). This is even greater when the couple have children and the carer has to bring up their children alone or has to act as an intermediary between the children and the sick spouse/partner. Hence, this research provides insight on the impact of caring for a spouse with BPD, as well as providing information regarding the meaning that carers attach to this experience. The data generated contributes to extant literature especially in relation to its focus specifically on spouses, considering that only one study (Bouchard et al., 2009) had a sample of couples with the women suffering from BPD, one study (Griffin, 2008), had a sample of parents only and seven studies (Bailey et al., 2014; Bauer et al., 2012; Buteau et al., 2008; Dunne & Rogers, 2013; Ekdahl et al., 2011; Kay et al., 2018; Lawn & McMahon, 2015) had a sample of mixed family members including partners and spouses.

Furthermore, the qualitative approach undertaken in this study provides in-depth accounts of the experiences of the informal carers which also contributes to broaden the health care professionals' understanding of the family members living with persons having BPD.

Table 5.1 presents a comparison of the findings from the existing literature presented in Chapter 2 with the findings extracted in the present research study. To ease comparability, the similar findings found from existent literature are aligned opposite to the corresponding findings obtained from the present research.

Table 5.1 The experience of informal carers of relatives with BPD: comparison of findings in the general literature and present study

Findings extracted from available literature	Findings from the present study
	The following aspects emerged under the super-ordinate theme 'An Unsettled Existence'
	Living on Edge
Parents in the study experienced chronic stress associated with ongoing worrying, and repeated self-harming behaviour of their daughters (Griffin, 2008). SO caring for their relative with BPD defined their life as life tip toeing, because of the constant worrying that something bad will happen to their relative (Ekdahl et al., 2011).	The participants were found to be psychologically impacted by constant worrying about their spouse. This was expressed as feeling constantly on edge, stressed or anxious. Such feelings arose because of their spouses' argumentative behaviour, fear of the suicidal threats, impulsive behaviours and aggressive reactions of their spouses. These all led the carers to lose trust in their spouse and feel insecure in the relationship with their spouse with BPD.
Frustration was elicited in seeing their relative with BPD not recovering despite all the efforts (Ekdahl et al., 2011).	The participants showed constant worrying about their spouse who shows no improvement in symptoms even though the relative takes the prescribed treatment.
Participants expressed their emotional weight, the pressure on the family, anxiety and stress of all the family members resulting from the behaviour of the relative with BPD (Bailey & Grenyer, 2014).	The participants expressed their concerns and unsafe feelings in relation to their spouse's unpredictable behaviour.

Findings extracted from available literature	Findings from the present study
	The participant's loss of control over the spouse's impulsivity and suicidal thoughts was noted in the interviews. The participants conveyed their fears of death and of losing their loved one. One participant verbalised that his fears were associated with the risk that a person who plans to commit suicide will not alarm anyone. Suicide threats and the fear that this brings with it, was the main concern that was highlighted by the participants.
Parents felt traumatised and one was diagnosed with posttraumatic stress disorder as a result of witnessing her daughter self-harming and suicidal behaviour. This suggests that parents are at acute risk of traumatic stress the first time they witness their daughters seriously injure themselves (Griffin, 2008). The parents showed that they adjusted their life to keep their sick child as healthy as possible. This resulted that their own well-being depends on their child's well-being (Griffin, 2008).	
	Impact on Relationships
Most of the couples (70%) with a BPD partner reported patterns of episodic relationship instability, with incidents of relationship termination followed by reuniting together (Bouchard et al., 2009).	One participant talked about his unstable relationship with his wife, who even kicks him out of their house and then calls him back to return home.
The overall burden was more extensive if the carers was a spouse/partner to the patient. In view that the couples live together, and share their life with the patient, the carers experience specific burdens, such as doubts about the relationship, emotional isolation, fear of ending the relationship, cheating on the caregiver and problems in the sexual relationship (Bauer et al., 2012).	One participant expressed that BPD is like a wedge between the couple which prevents them from being close to each other. Participants talked about their emotional isolation as a result of their spouse's impulsive behaviours and emotional instability that results from BPD.
Caregivers pointed out a feeling of uncertainty in their interactions with the patient (30%) (Bauer et al., 2012).	Participants named the interaction with his wife as "constantly on edge" because of her unexpected reactions.

Findings extracted from available literature	Findings from the present study
	Suicidality left the participants feeling insecure in the relationship with their spouse.
A relative with BPD in a family causes chaos and family disorganisation. Thus, the relative with BPD displays dysregulation in the family members' home environment (Kay et al., 2018).	One participant verbalised that the family life was affected, he described chaos in the family, where even the daughter was abandoned to do her work alone as he could not concentrate on anything.
Participants described that the other siblings in the family were often neglected. This created guilt that they were not there for the whole family (Ekdahl et al., 2011).	
Caring for a relative with BPD created strain and disagreements about the level of support given to the affected person. The level of strain was greater when the BPD person had children themselves. The other family members felt left out. Thus, BPD traits disrupt the quality of family relationships and cause attachment insecurities, which result in low marital satisfaction (Bouchard et al., 2009; Griffin, 2008).	
Carers reported that their relationship with the sick relative was painful and stressful. 'Walking away' was a prominent aspect when faced with overwhelming pain (Dunne & Rogers, 2013).	Two participants reported that going out with their friends was necessary for them to cope with the stress at home (caring for a BPD spouse).
Family members experienced negative feelings of despair, sadness, guilt, regret, shame, humiliation, felt worthless and described themselves as walking on eggshells with their relative with BPD (Kay et al., 2018)	Carers' feelings of worthlessness in the relationship with a spouse who has BPD was evident. Furthermore, carer's feelings of invalidity in a relationship was also expressed by the participants.
Parents struggle with guilt feelings and question themselves whether they could have done something earlier to stop this sickness. Guilt feeling were reinforced with the preconceived ideas about parents causing BPD (Ekdahl et al., 2011).	Self-blame and guilt feelings of the participants to allow oneself to be in this situation.
	Participants lose their identity to avoid conflict with their spouse with BPD.

Findings extracted from available literature	Findings from the present study
Research shows a high burden associated with caring for a relative with BPD. This was also evident in excerpts verbalising the change in role, from that of a partner to a father-like figure, doing things which one never imagined to be doing for another adult (Bailey & Grenyer, 2014).	One female participant particularly pointed out her change in role. She was not only a wife but she was a baby sitter, a nurse, a carer, a therapist, a doctor and a parent. The carer was taking care of everything in the family.
Unpredictable behaviours of the relative with BPD led to confusion and destruction of relationships between the BPD relative and family members (Kay et al., 2018).	One participant pointed out how the behaviour of his wife confuses him. This change in behaviour negatively affected the relationship with his wife. BPD is like a wedge between two persons which prevents them to be close to each other.
Couples with the women with BPD showed general avoidance of communication, which contributed to low relationship satisfaction (Bouchard et al., 2009).	The family bond was lost because of the changes that resulted from the wife with BPD. The behaviour of a spouse with BPD resulted in caregivers avoiding being with their BPD spouse because of the stress and anxiety that their behaviour creates.
	Social Impact
Participants verbalised that social life had to decrease because having people around caused anxiety and erratic behaviour in their relative with BPD (Bailey & Grenyer, 2014).	Participants pointed out that unpredictable behaviour of their spouse with BPD inhibits them from having a social life. One of the participants claimed that they had to make some lifestyle changes and adapt to life. He expressed that before they liked going for a drink together, but since his wife started on oral treatment, they stopped going to bars together.
The theme that being a carer was life changing emerged. Being a carer changed their lifestyle. Full-time caring meant limited time available for one self, for work and for leisure (Dunne & Rogers, 2013).	Another carer ensured that he had the time alone with his friends only to cope due to the difficult situations at home.
Carers found it difficult to maintain social relationships with friends and extended families. Friends and extended family members expressed frustration from hearing about the carer's problems frequently (Buteau et al., 2008).	Some of the carers felt isolated caring for their ill spouse. One of the participants did not want to share her burden with her family and friends as she was concerned that her spouse would be misjudged because of the symptoms of BPD.

Findings extracted from available literature	Findings from the present study
	Existing but Not Living
Being a parent reflected self-blame for their daughter's BPD. Parents try to understand their situation and reflect painfully on their own lives and parenting (Griffin, 2008).	
	Guilt was very evident in one participant who verbalised that her husband who now has BPD was her main carer when she was suffering from a mental illness. As opposed to feeling guilty, the participant expressed satisfaction by reciprocating the care that she received before.
	Guilt was also expressed towards oneself for being angry at their spouse's behaviour.
The parents felt torn between wanting to care and support their daughters or to step back. The latter however created intense fear of the consequences (Griffin, 2008).	Anger, frustration, and guilt were all emotions elicited from the participant who was confused between respecting her spouse's choices in relation to his suicidal behaviours and accepting that she is not responsible for his choices.
	Anger and frustration was expressed towards the treatment approach. This reflects the carers' perception about the treatment. Thus, showing that the family members want more psychoeducation rather than the use of oral treatment.
The grief of losing the person that might have been if the same person was not ill, has a great impact on the carer and creates hopelessness (Bailey & Grenyer, 2014).	Participants expressed that they felt emotionally destroyed seeing their spouse being an in-patient. Grieving also emerged seeing the spouse changing with the BPD.
	The carers talked about their spouses being admitted to hospital which was described as a traumatic experience.
Emotional burden in carers was multifarious, mostly (53.3%) named worried for the patient's future, followed by 50% who named their fear of self-harm and suicide in the patients (Bauer et al., 2012).	Fear was a strong emotion which came out both verbally and non-verbally by the participants when talking about suicide threats and the resultant needs for admission to a psychiatric hospital.

Findings extracted from available literature	Findings from the present study
	Physically Worn Out
	Participants talked about different physical changes that they noticed with the caring experience, ranging from high blood pressure, heart attacks, panic attacks, anxiety to lack of energy, tiredness, abandoning one's physical self.
Participants verbalised a need to look after themselves 'as a person' instead of neglecting themselves to the caring role (Dunne & Rogers, 2013).	One participant claimed that she did not have the energy to take care of her basic physical needs such as basic hygiene and doing for her medical appointment.
	The following themes emerged under the superordinate theme 'Searching for Meaning and Peace'
	Acceptance
	One of the outcomes of a search for meaning was the perception of one's strength and one's ability to cope with the difficult situations. This perception was noticed to emerge in participants who showed that they accepted the situation as it is.
	Being hopeful and looking at life positively also emerged in the participants who showed that they accepted the situation with the spouse with BPD.
	The value of commitment, that is marriage being a commitment emerged to be a factor that influenced a participant to accept his spouse with BPD.
	Spirituality
	Faith strongly emerged as a coping mechanism by most of the participants.
	On the other hand, one of the participants negotiated only once with a higher power. This experience of caring for her husband with BPD actually made her lose faith.

Findings extracted from available literature	Findings from the present study
	Dedicating time to oneself
	Time alone and practicing hobbies were other coping mechanisms that the participants used to help them find peace during difficult times.
	Work, alcohol, friends and going out were also mechanisms used by another participant to be able to cope with his spouse with BPD.
Carers pointed out that to cope with the stress of caring, respite is an important option (Dunne & Rogers, 2013).	
Family members posited that they are exhausted with the pains and difficulties of caring for their relative with BPD. Thus, family members feel burned out, they want to live their life and be joyful (Buteau et al., 2008).	All the participants were craving for a joyful life. Caring for their spouse with BPD was stressful. Thus, the participants verbalised their need to find peace.
Family members mentioned that they felt most hopeful when they found possibilities for treatments (Buteau et al., 2008).	
	The following themes emerged under the super-ordinate theme 'Supportive Relationships'
Carers struggle when family and friends do not understand the situations brought about by a relative with personality disorder (Dunne & Rogers, 2013)	One of the participants who was reluctant to ask for family support because of the fear of being judged for her husband's behaviour, felt isolated. Thus, reflecting the stigma that BPD has in mental illnesses.
	Most of the participant mentioned support from family members and friends. Hence, carers rely for support on family and friends.
	Support Groups and Non-Governmental Organisations (NGOs)
	One participant raised the need for support groups with talks from people that have been in similar situations.
All the carers that participated in the study were not aware of the support available (Dunne & Rogers, 2013).	The interviews also reflect the lack of awareness of the local NGOs services available. Therefore, this confirms the limited information that the relatives receive.

Findings extracted from available literature	Findings from the present study
One participant claimed that being involved in a support group made a difference for herself in dealing with her daughter with BPD. The support received helped her significantly to cope with the arising situations (Dunne & Rogers, 2013). In addition, family support programs gave family members a sense of hope because they meet people who are dealing with the same issues. When people feel that they are not completely alone helps them to cope better (Buteau et al., 2008).	One of the participants who attended NGO support groups for relatives with mental illness and perceived this support as beneficial.
Carers of people with BPD may need more individualised and diagnosis-specific support rather than general mental health support groups (Dunne & Rogers, 2013; Lawn & McMahon, 2015).	
	Health Professionals
Some carers who had helpful encounters with health professionals posited that this eased the high demands of their life as a carer (Dunne & Rogers, 2013). The carers that were supported perceived BPD education as the most helpful. This was followed by support from mental health professionals, counselling for the carers, support groups and GPs (Lawn & McMahon, 2015).	Two of the participants felt satisfied with the support that they received from health professionals and acknowledged this. The participants that had the multi-disciplinary team involved and felt supported had a positive attitude towards the health professionals and the services that they received when their spouse needed an admission to a psychiatric hospital
Results showed that the participants perceived that they were not taken seriously by service providers when reaching out for support, there was no support available for carers and also report financial burdens which hindered the carers from accessing support (Lawn &McMahon, 2015).	The lack of support from health professionals to spouses of people with BPD emerged. Furthermore, one participant (who used the private sector for psychiatric consultations), showed his concern about the fees paid and they are not noticing signs of recovery with the treatment.
When in crisis, carers sought help at the emergency department instead of communicating with their relative's psychiatrist. The carers did not seek support for themselves (Lawn & McMahon, 2015).	One participant talked about the need to have support when the family is in crisis. The participant expressed his frustration that at the emergency department there was no one immediately available to talk to the psychiatric patient and the family in a crisis.

Findings extracted from available literature	Findings from the present study
Family members struggle without support from health professionals. Family members want to receive a feeling that there is something to be done for their sick relative. Hence, carers want support and a sense of hope (Buteau et at., 2008). Caring for a daughter with BPD resulted in burden in parents. In an attempt to allow themselves a relief from the intensity of caring, the parents suggested to have access for short-term respite services (Griffin, 2008).	Most of the participants expressed their need for support from health professionals. One of the participants expressed a sense of hope when his spouse sees another psychiatrist or is started on a new oral treatment.
Participants believe that nursing staff does not have adequate knowledge about dealing with the whole situation of having a relative with BPD. they perceive this inadequate knowledge as a leading factor to their experiences of maltreatment and bad encounters with the health services (Buteau et al., 2008; Ekdahl et al., 2011).	One participant expressed his frustration towards the health care system especially at the time of crisis, as they expected to be supported by health professionals specialised in psychiatry. This negative encounter resulted in having a bad experience with the healthcare system and thus, losing trust in health professionals.
Even though carers are highly involved in the service user's life, the participants felt uninvolved, overlooked and ignored by health professionals (Dunne & Rogers, 2013). Participants felt unsupported and were left alone struggling in crisis (Buteau et al., 2008). Participants described that they were not involved in the care, and when they asked for participation, they felt that they were looked upon as an obstacle or a troublesome SO (Ekdahl et al., 2011). Some participants posited that they felt that there was lack of understanding. This was highlighted with stigmatising comments about the BPD symptoms exhibited by the sick relative (Dunne & Rogers, 2013). Ineffective coping strategies by relatives was related to the limited knowledge and information availability to educate the family members of effective coping with their relative with BPD. In addition, the carers claimed that their coping would significantly improve if they had people to turn to for advice, having the right information on managing their sick relative, and knowing how to handle difficult situations (Kay et al., 2018; Dunne & Rogers, 2013).	Carers that were not involved by health professional in the care of their spouse, felt isolated and invisible in this process.

Findings extracted from available literature	Findings from the present study
Participants pointed out that limited information led to losing trust in health professionals. In fact, every time something happened to their sick relative, decreased their trust in health professional's ability to keep their relative safe (Ekdahl et al., 2011).	One of the participants verbalised that he was not given any information about his wife's condition. The only time that a doctor spoke to him was to give him the full responsibility of his wife while she was out of hospital.
Most of the participants have researched for the diagnosis themselves using books and internet (Dunne & Rogers, 2013; Buteau et al., 2008).	Participants were not aware of the diagnosis. The participants claimed that they did not receive enough information. The carers claimed that they looked for the information on the internet themselves. Only one of the participant knew about his spouse' diagnosis but had no information about it. Participants expressed their need for more information from health professionals.
Carers reported that they were not involved in decision making about treatment and care issues Discharge plans were made without involving the family. In addition, the treatment appeared to be ad hoc for the caregivers. The participants expressed that they needed more meetings with health professionals to provide them with knowledge, understanding and support for their everyday caring for their BPD relative (Lawn & McMahon, 2015; Dunne & Rogers, 2013; Griffin, 2008).	Most of the participants claimed that they were not involved in the care plan of their BPD spouse. In addition, the medications were mentioned by two caregivers that does not seem to work on their relative. One of the carers verbalised his concern on medication reliance for BPD and believed that the medications were given ad hoc.
	The participants that were more knowledgeable about mental illnesses were both sufferers of a mental illness themselves and thus could associate with their spouse with BPD more.
Hopelessness was a driving factor for the carer's information-seeking. Family members wanted a sense that there is hope in BPD (Buteau et al., 2008).	A sense of hope was elicited from the interviews as the participants look for the information themselves and go to doctors and other health professionals.

Table 5.1 showed that the findings of the present study contributed to the existent literature by providing an in-depth exploration of the spouse's lived experiences of caring for their relative with BPD. The findings of the present study helped to provide meaning to some of the results extracted from the literature. For example, in one qualitative study (Buteau et al., 2008), the researchers found that family members felt hopeless in caring for their relative with BPD and this was influencing their coping mechanism. In fact, the participants in this study posited that they were in burnout. Conversely, the present study showed that most of the participants found meaning of their experience through faith and this was a factor that helped them in being

hopeful. A relationship with God was found to provide most of the participants with strength and support (Baldacchino et al., 2014). Furthermore, this positive relationship with God is reported to lead religious people to have a peaceful life and accept their situations (Bassett et al., 2008; Tanyi, 2002). The values of commitment and marriage were also factors which helped the participants to find ways to cope during this experience. These factors were not observed to emerge from extant literature. Thus, the present study might reflect the influence an aspect of Maltese culture on the participants. In fact, Abela (2016), stated that marriage is perceived as a sacrament and the Catholic Church has a big influence on family life in Malta. In addition, the Maltese perceive that in marriage the most important value is the constant commitment to one's partner, even if this involves self-sacrifice and the importance given to the values of faithfulness and love. Furthermore, another coping mechanism observed was the participant's perception of their own resilience and perceived ability to cope with difficult life situations. These coping mechanisms were observed to emerge from the participants that verbalised that they accepted the life situation as it was. Moreover, another notion that emerged from the participants that showed acceptance of the situation was that they were hopeful and looking at life positively.

The Person-centred Practice Framework (McCormack & McCance, 2017) and the Common Sense Model (CSM) (Leventhal et al., 1980) are applied in the next section to explore study findings.

5.2 The Person-centred Practice Framework

The Person-centred Practice Framework by McCormack and McCance (2017), is used in the discussion provided in this chapter. This framework is relevant when discussing humanistic caring practices and complex person-centred practices. It also emphasises on the importance of competent health care professionals to successfully manage different contextual and attitudinal factors that are present within the healthcare environment, while keeping the person, that is the spouse caring for a relative with BPD, at the centre of the caring interactions. Utilising the person-centred practice framework, the health professionals, including nurses, have the opportunity to enhance and enrichen the care experience of both themselves and the family members of the patients.

5.3 The Common Sense Model

The Common Sense Model (CSM) by Leventhal et al. (1980), will also be used to discuss the mental representations of the participants regarding their experience in caring for their relative with BPD. This theory is often used in studies to interpret the perceptions of carers. Leventhal et al. (1980), posited that when individuals are faced with a threat e.g., illness, they develop organised patterns of beliefs or mental representations about the condition. These mental representations help people to understand and make sense of the threat (the diagnosis of their relatives having BPD). In addition, these mental representations determine how they respond to the threat. Thus, these mental representations guide people to develop coping strategies that will impact on various outcomes such as quality of life. Petrie and Weinman (2006) posited that these mental representations are influenced by the person's own knowledge about the condition and past experiences of themselves and others with similar symptoms. Leventhal et al. (1997), described the various domains making up illness representation:

1- *Identity*: the label given to the condition and the symptoms that go with it (e.g., BPD).
2- *Cause:* the individual's perceived cause of the condition (e.g., stress, over thinking, or child hood trauma).
3- Time-line: the belief about the length of time the condition might last (acute or chronic).
4- *Consequences*: the belief of how this condition will impact on the individual not just physically and socially (e.g. emotional, spiritual, psychological).
5- *Curability / Controllability*: the perceived belief whether the condition can be cured or kept under control and the degree to which the individual can achieve this.
6- *Illness Coherence:* the perceived knowledge the individual holds about the condition (Leventhal et al., 1997).

In addition to the development of cognitive representations following a threat, individuals also experience an emotional response to the perceived threat and they develop coping strategies designed to reduce the emotional response experienced. In addition, Petrie and Weinman (2006) add that an individual continuously appraises the efficacy of the coping strategies implemented and thus the process is dynamic and not static.

In the present study, the perceived threat for the participant was to live with their relative with BPD, as highlighted by statements such as "*I didn't know what kind of human I am going to*

find in the house" (Kate, p. 5, line 175). The open-ended questions used in the interview of my study, explored the lived experience of spouses of individuals with BPD.

The following section discusses an objective outlined in the study, that of exploring the impact of caring on the spouse.

5.4 The Lived Experience of Spouses living with their relative with BPD

Various researchers (Marcos et al., 2007; Steed et al., 1999) have stated that people who considered that a mental illness has severe consequences, are likely to report poor psychosocial adaptation, decreased psychological wellbeing and decreased social functioning. Hence, the importance of understanding the illness perceptions of these carers, a task undertaken by the present study.

The informal carers in my study and in extant literature talked about their worries causing stress and anxieties. These worries related to the risk of suicide, self-harm and other behaviours associated with BPD and that have a psychological impact on the carers. Furthermore, caring for a person with BPD had an influence on relationships, both on the relationship between the caregiver and the affected individual and relationships in the family. The emotional domain was also affected negatively with the emotional burdens being described by Bauer et al. (2012) as multifarious. The current study also contributes to the general literature by demonstrating that physical changes in the carers amongst which grey hair, high blood pressure, weight loss and lack of energy are all attributed to the stress of caregiving. However, further research is recommended to evaluate the association of physical symptoms and psychological distress in caregivers.

 The carers in the present study also searched for meaning and peace and this was achieved in various ways such as acceptance, spirituality, commitment, resilience and hobbies. However, in addition to these, the current study and the extant literature showed a need for more support and information giving from the health professionals to the informal carers as a source of hope which will help them cope better with the experience of caring. The benefits of support groups were also noted both in the literature and in the present study.

The following section examines in further detail the findings of this study on the impact of caring in relation to extant literature.

5.4.1 The Impact of caring for a relative with BPD

5.4.1.1 The Psychological Impact

The participants in my study described their constant worries about their ill spouse. They expressed themselves as feeling constantly on edge, stressed and anxious. In fact, my study showed that the two main concerns for the participants were the risk of suicide and the impulsive behaviour of their relative. The stress that suicidality puts on the carers was often highlighted in my study more than in the existent research. The participants conveyed their fears of death and of losing their loved one with suicide. It was noted that the participants were worried and anxious as they had no control over their spouse's impulsivity and suicidal thoughts. This increased stress about the risk of suicide in my study, may have resulted from the stigma towards mental illness and suicide or from the participant's past experiences. One of the participants in the present study emphasised that he was worried about suicide due to its unpredictability. His perception was influenced from a past experience of a friend who committed suicide after her work duty without warning anyone. This finding concurs with the CSM by Leventhal et al. (1980), which states that individuals develop cognitive and emotive representations from their personal experience e.g., having a friend who has committed suicide. This experience has influenced the carer's views regarding the probability that his wife will commit suicide.

In the present study it was noted that the participants were more direct at pointing out that suicide was their main concern. On the other hand, the extant research describes the participant's constant worries that something bad might happen to their ill relative. For instance, participants in a study by Griffin (2008), described that the participants experienced chronic stress in association with witnessing their daughters repeatedly self-harming. These parents were moreover not only traumatised, but one of them was also diagnosed with posttraumatic stress disorder as a result of witnessing her daughter self-harming (Griffin, 2008). Ekdahl et al. (2011) explained that in order to cope such carers resorted to "life tip toeing" to avoid upsetting their ill relative and associated this behaviour to caring for a person with BPD because of the emotional dysregulation, impulsivity, self-harming and suicidality.

The unpredictable behaviour resulting from the BPD left the participants feeling unsafe with their spouse. This unsafe feeling was well highlighted by one participant using the phrase *"I didn't know what kind of human I am going to find at home"* (Kate, p. 5, line 175). Moreover, the present study identified metaphors used by the participants to describe aspects of their relative's behaviour that were associated with animals and the demon, such as "*He was like having a demon in him*" (Kate, p.7, line 242) and "*Tame with me, God forbid having a clash with her... She is not afraid of anyone*" (Mark, p. 4, line 73). Hence, this study contributes to the extant literature as the excerpts reflects that the participants associate the behaviour of a person with BPD with the aggressiveness of animals or being possessed by supernatural forces. Furthermore, participants showed grief in seeing the person they loved change and disappearing because of the mental illness. This reflects that the illness deprives the individual with BPD from the human nature. The present study with a sample of spouses obtained, complements the findings of existent research where the participants expressed the pressure, anxiety, emotional burden and stress of all the family members resulting from the behaviour of a relative with BPD (Bailey & Grenyer, 2014).

Another finding in the present study which contributes to the results of the existent research was the participants' constant worrying about their spouse who does not show improvement in symptoms even though their relative took the prescribed oral treatment. In fact, Ekdahl et al. (2011), posited that the participants were frustrated seeing their relative not recovering despite all the efforts. One of the participants in the present study was frustrated with the health care system's approach towards the treatment of BPD which focus mainly on oral treatment. In fact, research shows that psychological therapies are the treatment of choice for BPD. Randomised controlled trials (RCT) showed some of the effective psychotherapies for BPD which include dialectic behavioural therapy (DBT), mentalization-based therapy and transference-focused therapy (Grenyer, 2013). Hoffman et al. (2007), also recommend the FC program as it addresses the needs of the affected family members. Research showed that this program offers hope in improving the carer's grief, depression, burden and improve mastery in caring for their relative with BPD.

The CSM posited that the perceived belief whether the illness can be cured or kept under control is one of the components of illness representation which influences how people respond to the threat (Leventhal et al., 1997). Hence, it is possible that the participants perceived that since treatment was being taken, consequently one would expect to see an improvement or the

disease to be cured. This cognitive perception in turn, influences their emotional response with feelings of frustration and worry and lack of control over the situation.

This section discussed the psychological impact of caring for a relative with BPD. The present study also confirmed the impact of caring on relationships as evident in literature. Hence, the following section discusses the impact on relationships in detail.

5.4.1.2 Impact on Relationships

There is a dearth in literature which presents research on the impact of caring for a BPD person on relationships. Most of the research available studied family members (Bailey & Grenyer, 2014; Bauer et al., 2012; Buteau et al., 2008; Dunne & Rogers, 2013; Ekdahl et al., 2011; Kay et al., 2018; Lawn & McMahon, 2015). Additionally, another study by Griffin (2008) was intended to be a study of family members who had an adult daughter or sister receiving treatment for BPD, but only parents were nominated for this study. Only one research by Bouchard et al. (2009), studied couples with one partner having BPD. The study by Bouchard, et al. (2009) focused on the quality of relationships by studying both the affected women and their spouse/partner. In addition, the couples with the women diagnosed with BPD were compared with the non-clinical couples. The study was quantitative whereas, the present study is an IPA and thus explores and interprets the experience of the informal caregivers in more detail. The present study contributed to research as it had a relatively homogenous sample of spouses living with their husband/wife with BPD. The present study extended the findings by Kay et al. (2018), who found that the family life was affected, the home environment was characterized by chaos and family dysregulation as a result of a family member with BPD. Furthermore, the present study found that the relationships between the family members are affected because the caregivers were focused on their spouse with BPD who requires more attention and care. One participant (Gary) verbalised that he had to abandon the leisure time

with his daughter and the time to help his daughter in her studies, another participant (Katie) talked about abandoning her friends and family because of the high demands of care and attention the sick spouse requires from the carer.

Moreover, Bauer et al. (2012), in their research found that the overall burden is more extensive when the carer of a BPD individual was a spouse or partner. This may be because they live together and share their life with the BPD person. In addition, carers living with a BPD spouse experience specific burdens which include doubts about the relationship, fears of ending the relationship, cheating and problems with the sexual relationship. In the present study, since the fear of suicide was the main factor dominating the interviews, suicide emerged again as an impact on the relationship between the carer and the spouse with BPD. The fear of suicide left the participants with a feeling of insecurity with their spouse. Participants elaborated that with this fear on their mind, they could not have a peaceful relationship as they would never know what their partner might be thinking about. This is in agreement with the CSM (Leventhal et al., 1980) which states that the individual has their own beliefs about the consequences of the condition and how this impacts on them (social, physically, psychologically, emotionally and interpersonal). Hence, it is possible that the participants' responses and reactions are influenced by the perception or mental representation of suicide, as a consequence of the condition.

The behaviour of a relative with BPD was another feature that both in the extant literature and the present study, was found to impact on the relationship between the carer and the sick person. Research showed that BPD decrease the quality of relationships and cause attachment insecurities which result in low marital satisfaction (Bouchard et al., 2009). This was further explained by one participant (Gary) in the present study by stating that the family bond was lost as a result of the changes in his wife with BPD. Gary, verbalised that the changes in his wife's behaviour and her impulsivity resulted in instability between the couple, as this makes Gary feel insecure. Furthermore, the participant explained that BPD was a wedge between the couple and thus it did not allow them to be close to each other. In fact, the participant commented that the behaviour of his wife confused him because of the unpredictability of her behaviour. This confirms the research findings which stated that the unpredictable behaviour of BPD individuals caused confusion and destruction of relationships between the affected person and the family members (Kay et al., 2018). Furthermore, another participant (Mary) in the present study who herself had struggled with a mental illness pointed out that even though

she was satisfied with the opportunity to pay back her husband for caring for her in the past, she posited that mental illness was the causative factor that the relationship between herself and her husband was never stable and was also the factor that triggered her husband's mental illness preventing them from leading a normal family life. This is in accordance with the CSM (Leventhal et al., 1984) which states that there is a relationship between the illness cognition (the cause, that is, the individual's beliefs for the development of the illness) and the health outcome. This relationship is mediated by coping. Thus, the way a person understands the relationship between the cause of the illness has a significant impact on the individual's coping strategies.

Furthermore, another research study (Dunne & Rogers, 2013) found that carers may also respond by walking away when they are faced with overwhelming pain and stress. In fact, Bouchard et al. (2009) in a study on couples where the woman had BPD, demonstrated that general avoidance of communication was a contributing factor to low relationship satisfaction. This was also extended in the present study, where one of the participants (Mark) commented that the aggressive behaviour of his wife with BPD led him to avoid his wife as much as possible. Mark was avoiding and walking away from his wife to avoid conflicts which could not be resolved amicably because of the impulsive reactions of his wife. In addition, another participant Gary, also responds by walking away from his wife as a way of coping with the overwhelming situations at home. This was further explained by noticing that the carers take actions which result in loss of their own identity so as to avoid conflict with their spouse having BPD. This was very evident when one of the participants (Mark) stated that his wife used to kick him out of the house at night and then she phones him up to return again. The participant commented that he experienced this for a very long time and kept doing it to keep the situation calm and avoid further conflicts with his spouse.

The present study extends previous research by Bailey and Grenyer (2014), which showed that caring for a relative with BPD is a high burden for the carer. Results showed that partners changed their role from a husband to that of a father-like figure and were doing things which they never imagined to be doing for another adult. This also emerged in the present study where one participant (Katie) pointed out that she was not only the wife but also a baby sitter, a nurse and a carer. Furthermore, participants in the present study expressed feelings of invalidity and worthlessness in the relationship with their spouse, basically being devoid of an

identity. Hence, this demonstrates that caring for a relative with BPD is life changing. As Dunne and Rogers (2013) found in their study that caring becomes a full-time role which in turn, impacts on the carer's life style, work and leisure.

Hence, caring for a relative with BPD has an impact on relationships and indirectly influences the social aspect of the carer. The next section discusses the social impact.

5.4.1.3 Social Impact

The present study contributed to the available research that being a carer of a relative with BPD is life changing. Research reported that people with BPD cause anxiety and erratic behaviour in their relatives and thus the carer's social life is decreased (Bailey & Grenyer, 2014). In fact, most of the participants in the present study pointed out that the unpredictable behaviour of their spouse stops them from having a social life. Some of the participants (Mark, Katie and Brian) claimed that they felt isolated caring for their spouse. On the other hand, one of the participants (Gary) pointed out that as a result of this stressful experience he needed some friends to go out with them so that he could then cope with his wife. Thus, as the participant pointed out, this experience led him to change his priorities, the family was his priority but now because of the burden created with the experience of living with a wife with BPD, now going out with friends was being considered as more important so he could cope.

While this section discussed the social impact, one must also consider the emotional impact of caring for a relative with BPD. This is discussed in the following section.

5.4.1.4 The Emotional Impact

The findings of the present study illustrate how the participants experienced different emotional reactions in their experience of caring for their spouse with BPD. The findings reflect one of the central beliefs of the CSM that illness representations are highly individualised. The CSM (Leventhal et al., 1980), posited that the cognitive representations of an illness that are formed by individuals predict both their practical and emotional responses to a health threat such as the amount of distress experienced by an individual. Emotional representation of illness captures feelings such as depression, anxiety and anger associated with the illness (Diefenbach

& Leventhal, 1996).   Persons living with the same illness can have different emotional representations of a condition. Thus, people experience different emotional responses (Petrie & Weinman, 2006).

Three participants (Maria, Brian and Mark) in the present study verbalised that they were emotionally destroyed to see their relative being admitted to hospital. Furthermore, it was noted that the participants were influenced by the traumatic experience of the admission process. One of the participants (Brian) expressed his frustration towards the way they were treated at the casualty department and expressed his anger in relation to the lack of communication from health professionals at the casualty department when he presented with his wife to be seen by a mental health professional. The participant was focused on reporting the most unprofessional aspects that they experienced throughout the admission process. Most of the participants (Brian, Gary and Mark) expressed their frustration at the health care services and verbalised that they felt inadequate in the care process as they were not involved, were not given information about their relative's care process and felt unsupported. Hence, this reflects that there was a lack of authentic engagement, where according to the person-centred practice framework (McCormack & McCance, 2006), the experience should be a unique interaction with that person at that time, based on their own values and beliefs. However, this should not only be associated with the health professional's competence but also with components within the care environment which may also have a significant effect on the practitioner's ability to engage with the individuals. This further reinforces the need that health professionals possess skills that enable them to manage the care environment in order to heighten the outcomes for service users, such as ensuring a good care experience.

Moreover, extant literature also demonstrates that caregivers reported not being understood by the health professionals. This lack of understanding was highlighted by stigmatising comments such as "*It's just her behaviour*" (Dunne & Rogers, 2013, p. 645). Such unhelpful comments show that the health professionals are not understanding the concerns and burdens of the caregivers. The person-centred framework (McCormack & McCance, 2006), points out the importance of strong interpersonal skills, where effective communication requires a combination of verbal and nonverbal skills. The way that we, professionals communicate with people is based on our perceptions both at an individual level and also in relation to the label we provide to an illness. This will then influence what is said, how it is said and the language used. Poor communication can result in increased vulnerability experienced by the families and their relative as a patient. In addition, to the importance of interpersonal skills, the person-

centred framework also points out the importance of self-reflection in health professionals to increase one's self-awareness and to understand one's own behaviour. As professionals, one should be able to reflect in action and on action and learn from this self-reflection. Therefore, developing self-awareness is a process of lifelong learning and personal growth. Hence, knowing one-self and self-reflections are important characteristic of the person-centred framework. Hence, the prerequisites of the person-centred practice framework are attributes that enable health professionals to build a positive relationship with the caregivers.

Moreover, one of the participants (Mark) expressed deep sadness when he talked about watching his wife in the ward walking around with the toilet paper roll. The participant verbalised that this image had a negative impact on him. This scenario describes a dehumanising experience of a hospital stay for Mark. Furthermore, one participant (Brian) expressed a lot of anger towards the health care system and he perceived the treatment that they received as experimenting on a "lab rat" without proper communication. The person-centred practice framework (McCormack & McCance, 2006), posits that there is a need that professionals develop advanced communication skills and be involved in important conversations and shared decision making with the family and person receiving care. This is the only way that health professionals ensure that the holistic needs are identified as through advanced communication the health professional is dealing with what is important for the person. According to the person-centred practice framework competence in health professionals is more than simply undertaking a task. Competence reflects a holistic approach that includes knowledge, skills and attitudes. Thus, health professionals need to continue to learn and develop, and acquire skills that enables them to actually provide person-centred care.

Guilt was another emotion that was evident in the study participants. One of the participants verbalised repetitively that she felt guilty and responsible for her husband's mental illness because she believed that her husband became unwell as he was tired taking care of her when she was suffering from a mental illness. Another participant (Katie), felt guilty and blamed herself for allowing herself to be in this situation and to lose control over her life. The participant was overwhelmed with the experience of caring for her husband with BPD. Hence, this is in agreement with the CSM (Leventhal et al., 1997), which states that the person develops a cognitive representation of the perceived cause of the condition. Guilt was also evident in the research by Griffin (2008), where the participant were all parents. The parents blamed themselves for their daughter's BPD. Parents try to understand the situation and reflect painfully on their own life and their parenting with the result of feeling guilty for their

daughter's mental illness (Griffin, 2008). Parents also questioned themselves whether they could have done something earlier and stop the development of BPD in their daughter. Furthermore, Ekdahl et al. (2011) reported that guilt was reinforced with the perception that parents contributed to the development of BPD. Greyner (2013), showed that BPD is caused by a combination of biological factors (genetic) and early environmental influences, such as negative childhood experiences.

As discussed in the previous sections, suicide and its impact on the participants came out as fear. Fear was an emotion that was evident both verbally and non-verbally when the participants talked about their spouse' suicide threats and the resultant need for an admission to hospital. The fear experienced was evident on the participants as they revealed their experience while talking about emotionally painful events. While describing the experience one of the participants (Katie) was crying, while the other participants showed the fear that they experienced in their facial expressions. Fear was expressed while the participants were describing the way that they felt until they knew that their spouse was still alive. Furthermore, one of the participants (Katie) expressed a range of emotions ranging from anger, fear, frustration, and guilt, as she was confused whether she should intervene and do her best to stop her husband from attempting suicide or to step back as she was not responsible for his choices. This created intense emotions in the participant. In fact, this was also elicited from the existent research where the parents felt torn between wanting to care and support their daughters or to step back and let the daughters be responsible for their actions. However, the latter created intense fear of the possible consequences (Griffin, 2008). Thus, the current study extends the literature by showing that this feeling of wanting to intervene while stepping back and the intense fear of the consequences of the latter hold also for spouses as carers of people with BPD.

Research found that the emotional burdens in carers are various and of different types. In fact, according to Bauer et al. (2012), 96.6% of the participants named one or more emotional burdens and 50% named three or more. 50% of the participants named their fear that their relative self-harms or commits suicide as an emotional burden. Thus, the present study confirms the findings and as discussed in this section, gives qualitative details on the emotional impact of caring for a relative with BPD in the light of the CSM and the person-centred Practice framework.

Another contribution to the literature is about the physical impact of caring, which is outlined in the following section.

5.4.1.5 The Physical Impact

Available research did not go into detail into the physical influence of caring. However, the, results still showed that the carers had limited time for themselves because caring for their relative with BPD was a full-time duty. In fact, the participants recognised the need to look after themselves as persons instead of neglecting themselves to care for their ill relative (Dunne & Rogers, 2013). The present study gives further details on the participants' perceived physical impact as a result of caring for their spouse with BPD. In fact, study participants verbalised how the experience of living with their spouse with BPD, had a negative effect on their physical wellbeing. The participants expressed this experience which left them tired, not only psychologically tired but also physically tired. One of the participants described the physical changes that she noticed, such as grey hair, high blood pressure, lack of energy to have a shower and not washing her hair for several days and neglecting her health. The participant pointed out that caring for her spouse consumed all her energy as she had to focus only on him and thus, she put the needs of her body aside. In addition to this, the participant not only noticed her physical changes, but she expressed that her confidence in herself changed. The participant verbalised that at times she blamed her physical self (e.g. the shape of her body) for her husband's behaviour (i.e., he might not like her anymore). Thus, the participant felt so worthless living in this situation, that she ceased self-care.

Another participant (Gary) also pointed out about the burden of this experience and verbalised that he was exhausted and in burnout and he could not take any more of his wife's behaviour. This participant pointed out that he stopped practicing his hobbies and noticed himself that he had limited energy and was sleeping more than before. Hence, the present study showed that these results are in agreement with the CSM, where the belief of the consequence of an illness has an impact on the functional capacity of the individual (Hagger & Orbell, 2003). Fortune et al. (2004) reported that there are a number of significant associations between illness perceptions. In fact, in their study, women with a strong illness identity were more likely to perceive depression as chronic and with more serious consequences. Furthermore, women who

perceived their depression as chronic were less likely to view depression as potentially curable or controllable. These tend to have more severe personal consequences.

While two of the participants (Gary and Katie) perceived the physical changes in them as a consequence of this caring experience, another participant (Mark) pointed out that while the stress of this experience might have been a contributing factor to his heart attacks, however he also acknowledged his unhealthy lifestyle which might also contribute to the physical changes. Nonetheless, an interesting notion was that the participant perceived himself as physically strong and thus he did not give much importance to his physical changes.

The physical symptoms described by the participants in the present study might be indicative that the carers are psychologically distressed. Hence, the present study might shed light for future research to investigate whether caregivers of people with BPD score high for psychological distress. Scheirs and Bok (2007) conducted a quantitative study, comprising 64 persons, out of which 44 were women (biologically related to the BPD person, often being parents) and 20 men (mostly biologically unrelated, being spouses). The mean age of the participants was 44.8 years. The participants scored high on all symptom dimensions of the symptom Check List (SCL-90). Depression, had the highest score in caregivers of BPD people compared with the general population. In fact, the study showed that caregivers of individuals with BPD, suffered more from a variety of psychiatric conditions than the general Dutch population. Schier and Bok (2007), concluded that it was unclear whether the high rate of distress in caregivers resulted from exposure to their relative's behaviour or from the mechanism of assorted mating, that is, choosing a partner who is highly similar to oneself with regard to the level of distress or well-being.

This sections provided a rich discussion on the impact of caring for a relative with BPD. The next section will discuss the findings in relation to a search for meaning in the carers, which is another objective outlines in this study.

5.4.2 A Search for Meaning

The CSM posited that illness representations and the emotional responses to these representations direct people to reduce the dangers of the symptoms and guide them to develop coping strategies to reduce the emotions (Petrie & Weinman, 2006). Thus, the coping strategies used by the participants will be discussed in the light of the available research.

One of the mechanisms that was observed in the present study was acceptance. Most of the participants showed that they accepted the situation as it was. Together with accepting the situation, it was observed that the participants perceived the need to 'protect' their spouse and help her to cope with the illness. These participants perceived themselves as resilient people and able to cope with difficult situations. This could be associated with a stoic vision of life and learning to handle suffering can be interpreted as strength and resilience. Fenech and Scerri (2013), in their study reported that acceptance helped the caregivers of individuals with severe mental illness to start tolerating aspects which were unchangeable about their relative's mental illness.

Two of the participants (Mark and Brian) described searching for a cause of BPD and identifying perceived stress as a causative factor. This is in agreement with the CSM (Leventhal et al., 1997), who states that the individual's perceived cause of the condition (e.g. stress or childhood trauma) guides people to develop their coping strategies. These participants were also very supportive for their wife and were involving themselves in housework to reduce their spouse's stress. Petrie and Weinman (2006), stated that causal beliefs are important as these influence the type of treatment that people perceive as necessary to control an illness. Scerri et al. (2019), conducted a cross sectional survey with 94 Maltese individuals and examined the illness perception of informal carers of persons with depression. Results showed that the causal attribute that was most strongly endorsed by the participants as a cause of depression was "stress and worry" (n=88 [93.6%]). Petrie and Weinman (2006), argued that the identification of stress as a major cause for depression maybe the result of the perceived harmful factors associated with a hectic lifestyle. Furthermore, French et al. (2001), stated that stress as a causal trigger holds a dual purpose, there being an external uncontrollable element and an internal controllable element. Therefore, this implies that the individual avoids blaming oneself or others, while at the same time seeking to control a recurrence.

Furthermore, it was noted that the participants that showed acceptance of the situation, talked more positively about the future. Moreover, all the participants were noted to mention the commitment that they have in their relationship with their spouse and this helped them to accept the situations and find means to cope with this experience. In fact, Lawn and McMahon (2015), posited that the results obtained from their quantitative study demonstrate that the caregivers have a good understanding and empathise with their relatives with BPD. The researchers posited that the carers are particularly empathic with the negative experiences of their relatives.

This might be because the carers are the ones that are confronted first by the emotional turmoil that BPD brings to their life and to their ill relative.

Another important contribution to the literature was the element of spirituality as a coping mechanism. Faith strongly emerged as a coping mechanism for most of the participants, however, one participant questioned why God would allow such a situation to happen. In fact, this participant verbalised that she lost all her faith and bargained only ones with God or a higher power to help her. On the other hand, Mary spoke about the Religious meaning of this difficult experience and considered it as God's will. Hence, one's religious belief could provide a positive meaning to a difficult experience. Fenech and Scerri (2013), in their study found that the participant's religious beliefs helped them to give meaning to their situation and provided solance. Zauszniewki et al. (2010), posited that positively re-interpreting a situation will promote one's well-being.

The notions of "acceptance" and "spirituality" in carers of persons with BPD that emerged from the present study contributed to the extant literature, where Baldacchino et al. (2014) in their qualitative study reported that spiritual coping enhances acceptance and adaptation to a meaningful situation in life. Furthermore, the use of spiritual coping strategies, including religious strategies were found to increase hope and encourage a positive outlook toward life. The study by Baldacchino et al. (2014), was a descriptive sequential explanatory study which investigated the use of spiritual coping strategies of three cohort groups of Maltese older residents. A purposeful convenience sample was recruited from four private homes (2 in Australia [n=30], 2 in Malta [n=43] and 2 state residences in Malta [n=64]). The residents (n=137; men= 103, women = 34), mean age was 72.8 years and all participants were Roman Catholics. Phase I of the study involved the collection of quantitative date using the Maltese version of the Spiritual Coping Strategies scale (Baldacchino & Buhagiar, 2003), while phase II involved the collection of qualitative data using face-to-face interviews and focus groups to explore the use of spiritual coping strategies and their contribution towards coping with institutionalisation.

In addition to spirituality in the present study, hobbies were identified by the participants (Mark and Brian) as a self-empowering means to find a positive meaning in their life. In fact, Mark verbalised that having some time alone in his office focusing on some mechanical problems, distracts him from the daily thoughts and difficulties of life. Work, going out with friends and alcohol use were also mentioned as a means of coping through this difficult situation with the

family. Corbin et al. (2013), states that high levels of stress are associated with high levels of alcohol consumption to cope with negative emotions.

Gary also verbalised that his colleagues at work and his friends were a means of support for him due to the burden of caring for this wife with BPD. This confirms the findings by Dunne and Rogers (2013), who found that participants need someone to turn to for advice. In fact, results showed that coping would significantly improve in carers if they had people to turn to for advice, if they had the right information on how to manage their ill relative and if they knew how to handle difficult situations (Dunne & Rogers, 2013). In fact, Highet et al. (2014), posited that informal caregivers predominantly experience distress and perceive themselves as lacking the skills and knowledge to provide effective care for their ill relative. Caqueo-Urizar et al. (2014), stated that the demands faced by caregivers have a detrimental effect on their own health. Nevertheless, carers claimed that they struggled more when their family and friends do not understand the situations brought about by their relative with BPD (Dunne & Rogers, 2013). This was confirmed in the present study, where one participant verbalised that she did not look for support from her family as she did not want her husband to be judged because of the BPD. This participant felt isolated caring for her husband with no support networks. The fear of being judged reflects the stigma that BPD has in mental illness. On the other hand, the other four participants in the present study, mentioned their family members and their friends as support sources, which help them cope with the difficult situations.

Most of the participants expressed their need for support from health professionals to help them cope in difficult situations. On the other hand, two of the participants who received the support from the health care professionals, not only acknowledged it but also felt satisfied with the support that they received especially when they were in crisis. Research showed that when in crisis the carers did not communicate with their relative's psychiatrist but sought help from the emergency department. In addition, the carers were found to be searching for help only for their relative and were not seeking support for themselves (Lawn & McMahon, 2015). In the present study, one of the participants who searched for support from the emergency department, felt frustrated because of the environment which was not suitable for people in a mental health crisis and was further frustrated that there were no mental health professionals to talk to them when they were in crisis. Hill (2003), emphasis on the need for support networks and education of the 'hidden patient' because the informal caregivers suffer the burden of chronic and long-term illness of their ill relative. Thus, this highlights the need for treatment plans that take into account the human context of suffering, that is the emotional and social aspect of the caregivers

and not only the biomedical diagnosis and symptoms of the sick person. This will not only promote health of the individual patient but also the wellbeing of the informal carer.

The person-centred practice framework delineates the importance of practitioners being sympathetically present by recognising the value and the uniqueness of a person. In this manner they can appropriately respond to the important agendas in the life of a person and thus the practitioner will be maximising the individual's coping resources (McCane & McCorrmack, 2017). Thus, the carers and their relatives need to be accepted and understood by health professionals. In addition, health professionals need to work with caregivers and their relatives' beliefs. Establishing a therapeutic relationship enables people to have a good care experience under their challenging situations. person-centred practice ensures a good care experience for the persons receiving care that reflects the evaluation of care received (McCane & McCormack, 2017).

Furthermore, a study by Dunne and Rogers (2013) showed that carers were not aware of the available support for them. This was also confirmed in the present study where only one of the participants (Mary), was aware and used support services. Mary made use of one of the local NGOs which offers support for relatives of people with a mental illness. In Malta, there are three non-governmental associations that offer support to the relatives with mental illness. The support services for family members are offered by the MHA, Richmond Foundation and the St Jeanne Antide Foundation. The MHA was sent up by family members of people with mental illness to offer support and advice to other families. The Richmond Foundation is run by health professionals and offers support services to relatives and people with mental illness. St Jeanne Antide Foundation is a social work service to support vulnerable people and their families in the community and enables the people to better manage their situations with the ill person.

Brian, in the present study stated that as a carer, he needed to hear the experience of other family members who passed from the same experiences and needed to know how they coped. The participant perceived people in similar situations to be more understanding of the pain and suffering involved to live with a relative with BPD rather than health professionals. According to Dunne and Rogers (2013), participants can perceive attending support groups as a positive experience as it helps them cope significantly with the arising situations between the parent and the daughter with BPD. This result was also evident in the present study with a sample of spouses (representing caregivers), where Mary had a positive experience and received support

and knowledge from the support group and other participants (Mark, Brian, and Gary) verbalised their felt need for support from support groups. However, research also showed that the carers of people with BPD may need more individualised or disease-specific support rather than general mental health support groups (Dunne & Rogers, 2013; Lawn & McMahon, 2015). Leventhal et al. (2003), states that social information has powerful effects on the behaviour of people even when the information does not come from health professionals or other trusted social contacts. This is in view that people often select targets for social comparison who are in a more disadvantaged situation than themselves. This downward comparison makes them feel better. According to Dibb and Yardley (2006), this type of social comparison and downward comparison is common in people with chronic conditions. Social comparison can be important for the caregivers to maintain a positive view of their situation by focusing on dimensions on which they perceive themselves as more fortune than others. Furthermore, social comparison can also reduce feelings of anxiety and isolation when experiencing unusual situations.

Furthermore, Lawn and McMahon (2015), found that GPs were perceived to be an important source of support for carers. Moreover, the participants reported that BPD education was a helpful form of support. In addition, parents also suggested that they needed access to short-term respite services to allow themselves some relief from the intensity of caring for their daughters with BPD. Thus, respite was suggested to help them cope with both their sick daughters and the other family members (Griffin, 2008). Jeon et al. (2005), in their literature review on respite care for people affected by severe mental illness (SMI), posited that there is a significant lack of empirical studies examining the effectiveness of respite care settings. There is a particularly no evaluative research on respite care for people with SMI and their families. Jeon et al. (2005), posited that the lack of recognition of caregiver roles in mental illness and their special needs may be a leading factor for the lack of availability of appropriate respite care services. On the other hand, the fluctuating nature of mental illness and unpredictability of the need for care makes it more difficult for the caregivers to plan the use of respite services. Moreover, the persistent and florid symptoms and behaviours of SMI (such as schizophrenia and depression) may limit the possibility of finding appropriate respite. SMI may demand more skilled staff and resources than other respite care for physical disabilities. Such limitations make it more difficult to have respite care for people with SMI and this in turn, poses severe constraints on the caregivers lives (Jeon et al., 2005).

The participants in the present study not only verbalised their need for support from health professionals but also verbalised that they want to have knowledge about their spouse's condition. The participants claimed that the information that they knew was from searching the internet. Obtaining information from the internet might be a disadvantage as the quality of the information obtained cannot be ascertained. In addition, the caregivers might not fully understand the information and this may cause unnecessary anxieties for the carer. On the other hand, if caregivers are provided with reliable sources of online information and forums, these may provide helpful resources for the caregivers to utilise when needed. Goldner (2006), argued that health professionals need to educate individuals about how to evaluate the content of online information. Most of the participants in the present study were not aware of the diagnosis. Only one of the participants (Gary) mentioned the diagnosis of BPD and verbalised that he did not know what it meant. The participant added that he was aware that BPD was more than depression because he observed that his wife's behaviour was not only of a depression. In fact, this can be interpreted in the light of the CSM (Leventhal et al., 1980), which describes that when people have symptoms they strive to find a label for the illness.

Two participants (Mary and Katie) in the present study that showed more knowledge about mental illness were both persons who had a mental illness themselves and thus they extrapolated their knowledge to interpret their spouse's symptoms. Furthermore, the participants looked for information themselves to help them interpret their spouse's symptoms, took their spouses to different doctors and other health professionals, and felt hopeful for a better outcome, every time their spouse commenced on a new oral treatment.

Kay et al. (2018) found that ineffective coping strategies by the carers were related to the limitations in knowledge and information to the family members on ways to effectively cope with their relative with BPD. However, these findings contradict the results found by Hoffman et al. (2003). Hoffman et al. (2003), conducted a quantitative study with thirty-nine participants, seven patients and thirty-two family members. The family members consisted of 22 parents (16 mothers and 6 fathers), 6 husbands and 4 partners. The age of the family members raged from 28 to 77 years, with an average of 51 years of age. 47% of the family members were college graduates. Results showed that high levels of knowledge about BPD on the part of the relatives was associated with higher scores of burden, depression and psychological distress compared to the family members who knew less about BPD. Therefore, as opposed to the results presented by Kay et al. (2018), Hoffmann et al. (2003), found that the family members did not benefit from being more knowledgeable about BPD. However, one

must note that this study did not indicate whether the knowledge about the disorder led the participants to poor emotional well-being or whether the most burdened, depressed and psychologically distressed family members were more motivated to learn about the disorder. Another factor which might had an impact on the participants was the source and quality of information that the family members obtained. Furthermore, it was not known whether the information was well understood and applied by the relatives. Therefore, in view of these limitations the researchers recommend that the quality and sources of information or misinformation must be considered in more detail in studies on the knowledge of family members about BPD (Hoffman et al., 2003). Hence, this further emphasises on the importance of providing the family members with information about their relative's condition and ensuring that they understood the information given or providing them with reliable sources of information on the internet. Thus, ruling out misinterpretation of information in carers.

Ekdahl et al. (2011), posited that limited information, together with misinformation between the health professionals led the participants in their study to lose trust in the health professionals. In fact, the participants claimed that every time that something happened to their sick relative, e.g. their relative was sent home without the parent's involvement in the decision and s/he self-harms at home, this led the caregivers to lose trust in health professional's decisions (as their decisions were not justified to keep their sick relative safe). Furthermore, carers reported that they were not involved by health professionals in decision making about treatment and care issues. In addition, carers were not involved in discharge planning. Participant felt that the treatment to their relative was prescribed ad hoc. Moreover, the participants felt that there was a need to have meeting with health professionals which provide them with knowledge, understanding and support for their everyday caring for their relative with BPD (Lawn & McMahon, 2015; Dunne & Rogers, 2013; Griffin, 2008). The person-centred practice framework (McCormack & McCance, 2006) emphasis on the importance of the service users and staff involvement in decision making which has a direct impact on them.

Research (Dunne & Rogers, 2013) also showed that even though the carers were highly involved in the patient's life, they felt uninvolved and ignored by health professionals. These results were all confirmed in the present research and the participants who were not involved in the care of their spouse, felt isolated and invisible in the process. On the other hand, the two participants (Mary and Katie) that had the multidisciplinary team involved and felt supported by the health professionals, had a positive attitude towards the health professionals and the health care services and felt grateful that they found support when their spouse needed an

admission to a psychiatric hospital. In fact, one of the participant claimed that she was gratified that her husband found health professionals that were not judgemental and supported them. Thus, this is in agreement with the person-centred practice framework (McCance & McCormac, 2017), which suggests that health professionals be sympathetically understanding in caring, this in turn enables people to have a positive experience. Furthermore, the person-centred practice framework also mentions the importance of self-reflection in health professionals, which encompass exploring personal meanings, beliefs and values that may influence how health professionals practice and interact with the people with BPD and their family members.

In fact, available research showed that the carers who had positive and helpful encounters with health professionals verbalised that the encounters eased the high demands of their life as carers, e.g. "*I've been lucky because my daughter's key supporter has been very willing to engage with me*" (Dunne & Rogers, 2013, p. 645). On the other hand, some of the participants posited that they felt that there was lack of understanding from the health professionals. In addition, this lack of understanding was highlighted with stigmatising comments about their sick relative with BPD, e.g. "*There's been a lot of stigma and a lot of unhelpful comments about 'it's just behaviour' which has been very, very difficult both for her and for us*" (Dunne & Rogers, 2013, p. 645). In another study, the participants believed that maltreatment and the bad encounters with the health services were the result of the staff having inadequate knowledge on dealing with the whole situation of having a BPD persons and their family members (Ekdahl et al., 2011). The present study and the existent research shows that it is essential to build more humane relationships. Thus, there is a need for more communication-centred approaches to deal with carers of people with BPD.

The results from the present study and from existent research may indicate that the treatment for BPD people must involve the affected individual and their family members. In fact, research shows that there are few interventions which address the requirements of the affected family. Hoffman et al. (2007), in their study found that FC was a successful program for the relatives of people with BPD because it focused on teaching the family members to manage their own emotions, that is allowing them to act more and react less. FC also focuses on emotional self-management as so the relatives feel less invalidating. In addition, the program allows the carers to be more mindful to their sick relative and so they will be able to listen,

understand and accept more their relative's experience. Furthermore, the carers will be able to provide more validating responses to their relative with BPD. The participants of FC program showed that the levels of burden, grief and depression were decreased and mastery was increased.

Flynn et al. (2017), conducted a non-randomised controlled study and compared the 12-week FC program with a 3-week optimised treatment as usual (OTAU) program (psychoeducation). A long-term follow-up was carried out for the participants who completed the FC program. This study was done in Ireland. The participants that were offered the OTAU program were waiting to start the FC program. The OTAU program consisted of 3 sessions, where the participants were offered information about BPD and the dialectic Behaviour Therapy (DBT) model. Post-intervention data was gathered on the same day of completion of the programs. At 3-months following completion of the FC program, the participants were reminded to return the data. Furthermore, long-term data was collected after 19 months following completion of the FC program. 51 participated in the FC program and 29 participated in the OTAU program. Out of the 29 in OTAU, 22 participated in the post-intervention assessment, 7 did not complete the program. Out of the 51 in the FC program, 35 completed the post-intervention assessment, 12 participants did not complete the program and 4 did not return the data at the post-intervention. Results showed that FC program significantly improved the participant's total burden and grief. In addition, the improvements were maintained even at follow-up of the FC participants. However, one must note that while the carers were following the FC program, the individuals with BPD were following a DBT program. Furthermore, the FC program was not delivered by trained family members, but was delivered by clinicians. These may all have an impact on the positive results obtained. The researchers, acknowledged that due to the difference in the duration of the two programs, the results cannot be compared. The lack of significant improvements with the OTAU showed that 3 sessions of psychoeducation are too limited to provide benefits to the carers. This may also suggest that psychoeducation only is not sufficient for change and therefore the other two components of the FC program, i.e. skills training and support are important factors for change. Mainly the 3-week OTAU program addressed the key challenges that were identified for that cohort in the study (i.e., being overlooked by health services, managing perceived discrimination against carers of BPD individuals, addressing inadequate support services for carers of individuals with BPD). Although this FC program was not actually compared in this study, the researchers highlighted the benefit of interventions that support families affected by BPD (Flynn et al., 2017).

Since research showed that caring for a BPD is associated with burden, Grenyer et al. (2019) conducted a RCT of group psychoeducation compared to waitlist. The participants in the waitlist were then offered the program at a 3-month delay. Group psycho-education focus was on improving the relationship pattern between the caregiver and their relative with BPD, psychoeducation about the disorder, peer support, self-care and skills to reduce burden. The interventions were designed to focus on the relationship between the carer and the relative with BPD especially when emotions are high. The key principles of the interventions were teaching carers 1) skills to relate with their relative (effective communication skills that are non-judgemental, validating attentive and appropriate); 2) skills to remain calm during distress (carer attends to relationship needs by increasing calmness and reducing reactivity, mindful responses through understanding fears, anxieties and emotions); 3) attending to the caregiver's own needs (e.g. staying connected with friends and family, engaging with carer organisations, taking breaks from caring); 4) setting boundaries (being assertive and setting boundaries and ground rules for the relationship); 5) skills to develop crisis plans (safety plans such as engaging the health services when a relative's mental health problems escalates). 68 caregivers were randomised into interventions group (N=33) and waitlist (N=35). The participants were partners/spouses (n=4, 12.1% carers intervention group and n=6, 17.1% waitlist group), parents, other family members, unpaid support persons and friends of individuals with BPD. Participants were mostly parents (75.8% in intervention group and 71.4% in waitlist). Caregivers were asked to respond to a questionnaire before and after the program. The measures used evaluated the impact on carer functioning and burden and the impact on the interactional environment. The instruments used were: McLean Screening Instrument for BPD carer version (Zanarini et al., 2003), Burden Assessment Scale (Reinhard et al., 1994), Dyadic Adjustment Scale (Sabourin et al., 2005), Family Empowerment Scale (Kaien et al., 1992) and Mental Health Inventory – 5 (Berwick et al., 1991). The interventions were delivered in the form of groups of 6-8 participants, with 2 facilitators and was designed only for caregivers (relatives with BPD did not attend the groups). The interventions involved 16 hours of face-to-face contact over 10 weeks. Most of the caregivers allocated in the intervention group (n=28, 85.4%) completed the program and follow up (only 1 did not complete the program). After 10 weeks, the caregivers in the intervention group reported improvements in interactions with their relative, higher family empowerment, reduced expressed emotions (criticism and over involvement) and improved perceived carer's ability to play an active role with service providers. These results were sustained after 12 months. 96.5% found the interventions helpful in improving their knowledge and understanding about BPD. Analysis of the waitlist group

was only possible on completion of the 10-week program but was not possible as at 12-month follow-up (post-test) as the control group were already participating in the intervention group. In addition, the researchers (Grenyer et al., 2019), recommended the exploration of program outcomes for homogenous samples of carer groups. This is in view that nature of spousal carers may be different from other carer groups. Lawn and McMahon (2015) argued that one reason for this might be because their relationship is an intimate and a chosen relationship and thus the results might be different from a relationship between parents and a person with BPD.

Grenyer (2013), posited that for effective treatment of BPD it is important to focus on supporting the families, partners and carers of the people with BPD. This is in view of the interpersonal nature of BPD which result in the family members and carers to feel burdened by their relative's symptoms. Furthermore, the carers need to learn effective ways to communicate and cope with living with their relative with BPD. Thus, BPD programs must take these recommendations into consideration to maximize their effectiveness.

To conclude, educating the carers, involving them in care and communicating with the carers while sympathising with them during the difficult experiences may result in a more supporting environment for the family members of persons with BPD. Furthermore, providing the spouses and family members with the necessary support information and support systems in place (including local NGOs) may be helpful to improve their coping strategies and reduce the burden of caring for their relative with BPD.

5.5 Conclusion

The findings of the present study contributed to the existent literature by providing in-depth exploration of the spouses' lived experiences of caring for their relative with BPD. Whilst most of the quantitative and qualitative research available had samples of mixed family members, the present study focused on the spouses living with their husband or wife with BPD. Therefore, the present study further contributes to literature focusing mainly on the impact of caring and the coping strategies of the carers. The findings were discussed in the light of the available literature and both the CSM (Leventhal et al., 1980) and Person-centred Practice Framework (McCance & McCormack, 2017).

The following chapter provides a summary of the research findings together with the strengths and limitations of the study. In addition to my learning experience, it also presents the recommendations for clinical practice and for future research.

CHAPTER 6: CONCLUSION

6.1 Introduction

This chapter provides a brief summary of the research study carried out among spouses living with their relative (husband/wife) with BPD. This chapter also presents the strengths and limitations of the study. Recommendations for clinical practice and future research will also be presented.

6.2 Summary of the Research Study

The literature (local and international) targeting the lived experiences of spouses living with their relative (husband / wife) with BPD is scarce. In fact, only one quantitative research focused on the spouse as a caregiver of the wife with BPD. In fact, Bouchard et al. (2009), recommend that further research is required on couples when studying BPD. International research is mostly based on informal caregivers of people with BPD, where the samples consist mostly of parents, spouses, siblings and extended family members collectively. It was noted that there is no local literature on the topic. Therefore, it may be argued that these studies fail to address the impact of caring for a relative with BPD on spouses living with their affected husband/wife. Hence, I decided to conduct this qualitative phenomenological study to address the gap in literature in relation to the experience of spouses living with their relative with BPD and thus provide an in-depth exploration of this phenomenon. Moreover, I aimed to provide a voice for this group of informal carers, who until now have lacked the opportunity to voice their experience and concerns. Semi-structured interviews were used to gather data from a purposive sample of 5 spouses (two females and three males) living with their wife/husband with BPD. The data was analysed using IPA as described by Smith et al. (2009). Three super-ordinate themes emerged: 'An unsettled existence', 'Searching for meaning and peace 'Supportive relationships'. The themes extracted were then discussed and compared with the extant literature in the light of both the CSM (Leventhal et al., 1980) and the Person-Centred Practice Framework (McCormac & McCance, 2006).

In the first super-ordinate theme 'An Unsettled Existence', the participants expressed their view about the impact of living with their wife/husband with BPD. The participants recalled the psychological impact characterised by constant worrying, stress and anxiety in relation to their

spouse's argumentative and aggressive behaviour, impulsivity and unpredictable nature of the symptoms. In addition, the participant's showed that suicidal threats and the risk of suicide exhibited by their spouses with BPD was a common concern which resulted in uncertainty and unsafe feelings in the relationship between the couple. Thus, the participants talked about the impact of BPD on the relationships with their wife/husband and the other family members. Moreover, the participants expressed that this experience required changes and adjustments in their social life. The participants had an opportunity to express their emotional impact while describing their experiences and verbalised their anger, frustrations, guilt and fears associated with caring for their spouse with BPD. The participants also identified physical changes that they associated with this life experience, such as lack of energy and skin changes.

In the super-ordinate theme 'Searching for Meaning and Peace', the participants expressed how they searched for both meaning and peace in an effort to interpret and cope with their experience. The findings in the present study differed from the extant research, as the findings showed that acceptance and resilience were important strategies to achieve meaning. In addition, religious beliefs and marriage commitments were factors that helped the participant to find solace and meaning. Another coping strategy which the participants used to help them cope with their difficult and stressful experiences were the time that they dedicated to themselves practicing their hobbies. This contrasted with the extant literature as results showed that carers wanted respite support and felt better when they found new possibilities of treatment for their affected relative.

The super-ordinate theme 'Supportive Relationships' incorporates aspects of support from family members, health professionals, support groups and NGOs. Furthermore, the present study confirms findings from extant literature regarding that informal carers need more information BPD and a need for the carers to be involved in the care planning of their affected relative. Another common finding in the present study and extant literature was the lack of knowledge of informal carers about diagnosis and the availability of support (support groups and NGOs). The present study that enhances the extant literature as the participant expressed their need for more support from health professionals. furthermore, it was noted that the informal carers interpreted support from health professionals as beneficial.

The present study had its strengths and limitations as outlined in the following section.

6.3 Strengths and Limitations

This section outlines the strengths and limitations of this research study.

6.3.1 Strengths

This study had a number of strengths which are worth to point out.

- This is the first local study that explores the experience of informal caregivers, focusing on spouses of individuals BPD. The results obtained from this local study may also contribute to the dearth of international literature on this particular topic. This study provided an in-depth account of the impact of living with a spouse with BPD, as well as contributed to the extant literature by providing insight into the impact of caring, the search for meaning and provided a voice for the caregivers about their needs for support.

- Consistent with the methodology of IPA, this study had a reasonably homogenous sample of five participants for the purpose of providing an in-depth exploration of the lived experience of caring for a spouse with BPD. Conducting face-to-face interviews ensured confidentiality. This approach enabled the caregivers to voice their experiences and thus, this led to the collection of rich data. Prior to starting the actual interviews, a pilot interview was conducted with one caregiver. This provided the researcher with an opportunity to test the interview guide, provided knowledge of the possible duration of the interview and an opportunity to practice my interviewing skills.

- The researcher aimed to reduce the risk for any possible bias. Hence, a reflective diary was kept with the researcher's reflections before, during and after the research project. In addition, the researcher's academic supervisor conducted mini audits of the data analysis to further reduce the risk of researcher's bias.

6.3.2 Limitations

The limitations of the present study included:

- The fact that this was the researcher's first attempt in IPA research, and thus considering herself as a novice researcher, is considered as a limitation. Nevertheless, conducting the pilot interview, helped the researcher to instil confidence and improve the interviewing skills.

- Three of the interviews were conducted in the Maltese language as the participant's preferred language and mother-tongue. Although a professional translator was engaged to ensure that the translations remain faithful to the original excerpt, some profound meanings or metaphorical phrases may not have a corresponding English version. Therefore, to minimise this limitation, the excerpts are presented in both the Maltese language and translated in the English language. Two participants used the English language during the interview (English speaking participants), thus translation was not required.

- Qualitative research does not provide generalizable findings. Thus, the findings may not be a representation of all the caregivers' experiences caring for their spouse with BPD in Malta.

- IPA is concerned with capturing the essence of the phenomenon being studied which involved gathering a detailed description of the phenomenon (Smith et al., 2009). There is a possibility that the participants were not able to recall correctly the specific details of past experiences. Hence, while acknowledging this as a limitation, the researcher used prompts to ensure that the maximum details are gathered during the interviews. In addition, while acknowledging this limitation, the study provides a detailed account of an under researched topic.

- There was a possibility of social desirability bias in the participants' responses. The participants might have not been completely honest in their responses, especially if they were worried that their answer would put them in a negative light. To minimise this

bias, the researcher ensured the participants about confidentiality and informed the participant that there is no right or wrong answer to the questions asked. Furthermore, the researcher maintained a non-judgemental approach during the interviews.

Conducting this study, enabled the researcher to have a learning opportunity both in the research field and in the topic. My learning experience is pointed out in the following section.

6.4 My learning Experience

The researcher will refer to Bloom's Learning Theory (Bloom et al., 1956), while describing the learning experience whilst conducting this research study.

- As a novice researcher, conducting this study helped me to increase my knowledge on phenomenological research, conducting face-to-face interviews and understanding the ethical issues that are involved to carry out a research study. Furthermore, as a charge nurse, I have gained more knowledge on the experience of informal caregivers living with their spouses with BPD. I have more knowledge and awareness of the caregivers' burdens, their needs and their coping mechanism in difficult situations. This enables me to provide person-centred practice.

- Conducting this research study, I became aware of the importance to comprehend the meaning behind the peoples' words and to appreciate the use of certain language components such as metaphors and repetition of words when people want to emphasise something in their discourse. For example, I can better understand how such carers interpret their lived experience and their search for meaning.

- I have understood the importance of referring to the existent literature in order to gain insight and make sense of the participants' lived experiences. This process involved learning to evaluate the literature as well as critique. This will also be of benefit in my work setting as existent literatures guides me to practice evidence-based nursing care.

- Keeping a reflective diary helped me to improve my analytic skills. The reflective diary helped me to analyse my own preconceptions and beliefs, (named 'knowing self' in the Person-Centred Practice Framework), which may have an influence on the data collection process, data analysis and in my interactions with the informal caregivers.

- I have also improved my synthesis skills as I learnt how to build up emergent themes and then the super-ordinate themes from the interview transcripts.

- Evaluating my performance at the end of each interview, enabled me to improve my interviewing skills across the interviews. Using my experience at work where through my communication skills, I manage conversations and assessments with patients, I was able to achieve in depth interviews with the participants. Additionally, I also noticed that my ability to evaluate my work improved over time as I was working on and writing the research study. I was using my critical skills better when discussing and interpreting the findings of the study and extant literature.

In addition, to my learning experience, this research study provides a number of recommendations for clinical practice. These are presented in the next section.

6.5 Recommendations for Clinical Practice

The following outlines the recommendations from this research study for clinical practice.

- Caregivers commented on the lack of information provided by health professionals since they felt that they were not involved in the care of their relative. This contributed to anger and frustration in caregivers. The caregivers were not aware of the diagnosis of their relatives and what BPD really signifies. Thus, caregivers need to be provided with knowledge about their relative's condition. Nevertheless, the caregivers need to have the opportunity to ask questions and clarify their concerns with the health professionals. In addition, encouraging family involvement during ward rounds and family meetings with the multidisciplinary team helps to achieve shared decision-making in mental health.

- Caregivers felt dissatisfied and traumatised with the admission process of their relative. Participants verbalised their need for support and communication with health professionals when they are in a crisis with their relative having BPD. Hence, clinicians should ensure that communication with the caregivers is a unique interaction based on their own values and beliefs. Moreover, from the findings it is recommended, that health professionals engage in meaningful conversations as suggested by the Person-centred Practice Framework. Furthermore, health professionals must work towards ensuring that the relatives receive a good care experience (McCormac & McCance, 2006).

- Participants in this study negatively commented on the frustrations that they felt when in the emergency department, in the presence of persons with other conditions other than mental health issues and with no one available immediately to talk to them. Hence, there is a need to enhance the availability of a multidisciplinary psychiatric team at the emergency department. Currently the psychiatric crisis team at the local general hospital consists only of psychiatric doctors. However, the management is exploring the possibility of having psychiatric nurses available at the emergency department of the local general hospital for psychiatric emergencies. Thus, this study further recommends the introduction of this service.

- Locally, there exists support groups organised by NGOs. However, most of the participants were not aware of these services. Actually, most of the participants verbalised that they require support from other families that managed to cope with similar situations. On the other hand, the participant that received support from support groups acknowledged its positive effect. Thus, it is recommended to increase the awareness of the available local services and to refer the caregivers to support services. Increasing awareness of the services may be achieved through the use of social media, media educational programmes and providing leaflets to the caregivers.

- Research (Hoffman et al., 2007) showed that programmes for family members such as FC are successful programmes for relatives of individuals with BPD. The programme focuses on education of caregivers about how to managing their own emotions (to act

instead of reacting), emotional self-management (feeling less invalidating), teaching the carers to be more mindful and to listen, understand and accept more their sick relative, and teaching the carers to provide validating responses to their relative. To date, such a program is not available locally. Hence, in view, of the research which showed positive results for carers following such programmes, and the present study demonstrated that the participants were emotionally impacted by the experience of living with their spouse with BPD, then it is recommended that the local mental health system takes into consideration to introduce and pilot such a program.

6.6 Recommendations for Future Research

- This study was conducted with caregivers only. Therefore, it would be interesting if a study is conducted to explore the lived experience of people with BPD and that of couples. Consequently, this will provide a more detailed explanation and thus provide a better understanding of both the caregivers and the people with BPD.

- Continued research should utilise different methodologies such as mixed methodology to continue exploring the implications and satisfaction rates of caregivers living with relatives with BPD. Increased knowledge in these areas would enhance health care professionals' efficacy in this area and ensure a good care experience in this group of individuals.

- Conducting a longitudinal study where the researcher follows the experience of the participants from the period of diagnosis (of their relative) onwards, with a follow-up at 6 months and 12 months following initial contact would provide an in-depth exploration of how perceptions of the caregiver might change along this time period.

- Although eligible criteria for this study included spouses living with their relative with BPD, future research would benefit from conducting similar studies on other groups of caregivers (such as parents and daughters/sons) since this might provide a different exploration of the impact of caring and their coping strategies.

6.7 Conclusion

BPD is a common mental disorder which is associated with high rates of suicide, severe functional impairment, comorbid mental disorders and intensive use of treatment (Leihsenring et al., 2011). Thus, BPD is defined as a disorder that not only affects the person with the disorder but also those around them. Griffin (2009), suggests that in view of the interpersonal nature of the difficulties of the disease, there is a need for interpersonal and relational approach to treatment. Therefore, the treatment approach should include the family members.

Hence, health professionals should be aware of the importance of communication with the family members and caregivers of people with BPD and to involve them in decision-making. Moreover, as existent research and the current study provided a deep understanding of the caregivers' need for support and knowledge from health professionals as the burden of care for their relative with BPD has an impact on their psychological well-being, physical changes, social and inter-relationships. Furthermore, the present study explored the carers search for meaning throughout their experience and which empowered them in their lived experience with the person having BPD.

The current study provides a rich and intimate understanding of a phenomenon which was rarely explored, and thus contributes its findings to the existent literature. This dissertation provides an in-depth exploration into the lived experiences of spouses living with their wife/husband with BPD. The findings of this study and their implications are meant to offer nurses and other health professionals an opportunity to understand the impact of living with a person with BPD and their coping strategies. This might in turn contribute to the development of appropriate interventions as recommended by the current researcher.

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APPENDIX A: INTERMEDIARY LETTER

01st May, 2019,

Dr ▓▓▓▓▓▓▓,

Consultant Psychiatrist,

Mount Carmel Hospital.

Re: Research Project 'The lived experiences of spouses/ partners caring for individuals with Borderline Personality Problems'

Dear Dr ▓▓▓▓▓▓,

My name is Thekla Janice Micallef, I am a charge nurse currently working at Mount Carmel Hospital. I am presently reading for a Master of Science degree in Mental Health Nursing at the University of Malta. As part fulfillment of my study requirements, I am expected to conduct a research study. I intend to explore the lived experiences of spouses and partners, who have been providing care to their relative with borderline personality problems. This will be done by conducting an initial in-depth audio-recorded interview with five to ten informal carers. This will be followed up by a second interview, to explore in further detail any salient points previously raised by study participants. The duration of the first interview is expected to be about 1 hour and this will be followed up approximately six weeks later by a second interview which should last about 40 minutes in duration. The inclusion criteria for my research are adults i.e., eighteen years and over and who are interested in sharing their experience of caring for their partner/spouse with borderline personality problems.

I am requesting that you approach potential participants and provide them with an information letter describing the present study. The details of those individuals who are willing to participate can then be passed on to the present researcher. In this manner, I will not be aware of any participants approached and who may have declined to participate. The data collected from this study will solely be used for research purposes and all the data will be stored in an encrypted format. Confidentiality will be maintained during data collection and data analysis. It is anticipated that data collection will commence by June 2019 and any personal data will be destroyed on completion of this study.

I am aware that I have to strictly adhere to ethical guidelines, especially relating to informed consent and confidentiality and that I have to consult my research supervisor, Dr Josianne Scerri, throughout the research process. Moreover, I will be seeking approval for this study from the University Research Ethics Committee.

Your support for this research project is greatly appreciated. If you wish to clarify any issues about this research project, you can contact me on ▓▓▓▓▓▓ (email:

██████████████████████) or my supervisor Dr Josianne Scerri on ████████ (email: ███████████████████).

Thekla Janice Micallef

Student Researcher

_____ _____ _ ____

Dr Josianne Scerri

Dissertation Supervisor

██████████████████
██████████████████
██████████████████

Dr █████████

Consultant Psychiatrist

Participants` Information Sheet

Dear Participant,

My name is Thekla Janice Micallef and I am currently reading for a Masters Degree in Mental Health Nursing at the University of Malta. As part of my course requirements I am conducting a research study entitled, **"The Lived Experience of informal carers of individuals with Borderline Personality Problems"**. The aim of this study is to explore the meaning that informal carers attribute to the experience of caring for their relative with borderline personality problems. Your participation in this study would help us gain a better understanding about your experiences in caring for a person with borderline personality problems which include the impact of caring for a relative with BPD and your perceived needs and concerns. We will also explore how you cope with the situations and challenges that you encounter. The benefit of your participation in this study is that you will help shed light on the needs of informal carers and this may assist in the improvement of practice. Furthermore, all data collected from this research shall be used solely for the purpose of this study.

You are being invited to participate in an interview to explore your experience as an informal carer. The interview will take approximately 1 hour and will be held at a time and place most convenient for you. You are not obliged to answer all the questions and may withdraw from the study at any time without giving a reason. Withdrawing from the study will not have any repercussions on the quality of formal care being provided to your relative. Unless you have any objections, this interview will be audio-recorded. I can assure you that confidentiality will be maintained throughout the study and that your identity and personal information will not be revealed in any publications, reports or presentations arising from this research. All data collected will be pseudonymised meaning that the transcripts will be assigned codes and that this data will be stored securely and separately from any codes and personal data. This data is only accessible to the researcher, the academic supervisor and the examiner(s) for assessment purposes. The coded audio-recordings, and transcripts will be stored on the researcher`s personal computer in an encrypted format and the hardcopies will be stored in a locked cupboard using codes only.

In the event that you feel distressed due to participation in the interview, the service of a healthcare professional, Dr ▮▮▮▮▮▮▮▮ will be available at no financial cost on your part.

If you are willing to participate in the study you can provide your details to ▮▮▮▮▮▮▮▮ or ▮▮▮▮▮▮▮▮ and I will contact you to set up an appointment. You can resolve to contact me directly on my mobile number or on the email address provided in this letter.

A copy of the information sheet and consent form will be provided for future reference. As a participant, you have the right under the General Data Protection Regulation (GDPR) and national legislation to access, rectify and where applicable ask for the data concerning you to be erased. Once the study is completed all data collected will be erased.

Whilst thanking you for your time and consideration, should you have any questions or concerns do not hesitate to contact me on ▮▮▮▮▮▮ or by e-mail

██████████████████████ or my supervisor Dr Josianne Scerri on ███████ or by e-mail ████████████████████.

Yours Sincerely,

_____   _____

THEKLA JANICE MICALLEF   DR JOSIANNE SCERRI

Researcher   Research Supervisor

The Lived Experience of informal carers of Individuals with Borderline Personality Problems

I, the undersigned, give my consent to take part in the study conducted by Thekla Janice Micallef. The purpose of this document is to specify the terms of my participation in this research study.

1.	I have been given written and verbal information about the purpose of the study and all questions have been answered.

2.	I understand that I have been invited to participate in an interview, in which the researcher will ask questions to explore the meaning I give to living with my relative with borderline personality problems.

3.	I am aware that the interview will take approximately 1 hour. I understand that the interview is to be conducted in a place and at a time that is convenient for me.

4.	I am aware that this interview will be audio recorded and transcribed (written down as it has been spoken).

5.	I am aware that all the data collected will be pseudonymised, meaning that the transcripts will be coded and that this data will be stored securely and separately from any codes and personal data.

6.	I am aware that the researcher, academic supervisor and examiners are the only persons who have access to this data for verification purposes.

7.	I am also aware that the coded audio-recordings and transcripts will be stored on the researcher`s personal computer in an encrypted format and material in hard-copy form will be placed in a locked cupboard and kept until results are published.

8.	I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research

9.	I also understand that I am free to accept, refuse or stop participation at any time without giving any reason. This will have no negative repercussions on my relative and that any data collected form me will be stored anonymously and erased at the end of the research project.

10.	I also understand that my contribution will serve to improve the mental health services especially the services for the relatives of individuals with borderline personality problems.

11.	If I feel that the interviews have distressed me in any way, a health professional, Dr ▓▓▓▓▓▓ will be available to provide a service at no financial costs on my part. Distress may be present since talking about the experience might cause emotional distress.

12.	I understand that under the General Data Protection Regulation (GDPR) I will have the right to access, rectify, and where applicable ask for the data concerning me to be erased.

13.   I also understand that once the study is completed and results are published, all data will be erased

14.   I will be provided with a copy of the information letter and consent form for future reference.

15.   I have read and understood the points and statements of this form. I have had all the questions answered to my satisfaction, and I agree to participate in this study.

Participant: _____

Signature: _____

Date: _____

Formula ta' informazzjoni għall-Parteċipanti

Għażiż/a Parteċipant/a

Jiena Thekla Janice Micallef, fil-preżent qed insegwi Masters Degree F'Mental Health Nursing fi hdan l-University of Malta. Bħala parti mir-rekwiżiti tal-kors, qed nagħmel riċerka bit-titlu, **"The Lived Experience of informal carers of individuals with Borderline Personality Problems"**. L-għan ta' dan l-istudju hu li nesplora xi tfisser l-esperjenza ghal-persuna li tiehu hsieb il-qarib taha (jew il- qarib tieghu) li tbaghti min problemi ta' personalita'. Is-sehem tiegħek f'dan l-istudju jista' jgħin biex nifhmu aktar l-esperjenza tieghek, li tinkludi l-impatt li jhalli fuqek meta tiehu hsieb il-qarib tieghek bi problemi ta' personalitan kif ukol nifhmu fil-fehema tieghek liehma huma il-bzonnijiet u l-affarijiet li jinkwetawk. Nesploraw ukol il-mod kif wiehed ikampa meta jaffacja sitwazzjonijiet diffikultuzi. Li taqsam l-esperjenza tieghek jista' jkun ta beneficju wkoll ghaliex tkun qed tghin biex nifhmu aktar il-bzonnijiet tal-familji b'esperjenzi simili u b'hekk ikun jista' jitjieb is-servizz li naghtu. Kull informazzjoni miġbura tintuża biss għall-għan jew l-għanijiet ta' dan l-istudju.

Bħala parteċipant/a inti se tintalab tieħu sehem f'intervista sabiex nesploraw l-esperjenzi tiegħek. L-intervista se tieħu madwar siegħa u ssir f'post u f'ħin li jkun konvenjenti għalik. M'intix obbligat/a li twieġeb il-mistoqsijiet kollha u tista' twaqqaf l-intervista fi xħin trid mingħajr ma tagħti l-ebda raġuni. Dan mhux ħa jkollu riperkussjonijiet negattivi fuq il-kwalita' ta' kura li tinghata lil-qarib tieghek. L-informazzjoni migbura mil-partecipanti li jiddeciedu li ma jiehdux sehem f'dan l-istudju tigi mhasra. Sakemm m'għandek l-ebda oġġezzjoni, din l-intervista se tiġi rrekordjata bl-awdjo. Nassigurak li se tinżamm il-kunfidenzjalità matul l-istudju kollu u l-identità tiegħek u kull informazzjoni personali miġbura mhumiex se jiġu żvelati mkien fit-teżi, ir-rapporti, il-preżentazzjonijiet u/jew il-pubblikazzjonijiet li jistgħu jirriżultaw minnha. L-informazzjoni li tkun mizmuma se tkun biss f'forma anonima. Kull tagħrif miġbur se jiġi psewdonomizzat, jiġifieri it-traskrizzjonijiet kollha se jkunu protetti permezz ta' sistema ta' kodiċi u miżmuma separatament mill-informazzjoni personali. Ir-Riċerkatur/ir-Riċerkatriċi, is-Superviżur/a akkademiku/a u l-Eżaminatur/i biss ser ikollhom aċċess għall-informazzjoni miġbura u dan bi skop ta' verifika. L-awdjo rrekordjat u t-traskrizjonijiet se jinħażnu fuq il-kompjuter personali tar-Riċerkatriċi f'forma encrypted. Barra minn hekk, il-materjal stampat se jinqafel f'post sigur u prottett permezz ta' kodiċi.

F'każ li tħoss li l-intervista ħolqitlek diffikultà u tixtieq li tiddiskuti x'qed tħoss ma' professjonista mill-qasam tal-kura tas-saħħa, Dr ███████ se jkun qed jipprovdi servizz ta' għajnuna mingħajr ħlas min-naħa tiegħek.

Jekk tixtieq tipparteċipa f'dan l-istudju inti tista' tagħti id-dettalji tiegħek lis ███████ jew lis-███████ u jiena naghmel kuntatt mieghek biex naghmlu appuntament. Inti tista' taghzel li tikkuntatja lili direttament fuq in-numru tal-mowbajl jew fuq l-indirizz eletroniku imnizzel f'din l-ittra.

Se tingħata kopja tal-ittra ta' informazzjoni u tal-formola ta' kunsens sabiex tkun tista' taċċessahom fil-futur. Barra minn hekk, skont l-Att Dwar il-Protezzjoni u l-Privatezza tad-Data u l-Liġi Nazzjonali li timplimenta u tisppecifika skond ir-Regolamenti, inti għandek id-dritt li taċċessa, temenda u tħassar kull informazzjoni li tikkonċernak L-informazzjoni personali kollha se titħassar hekk kif jintemm dan l-istudju ta' riċerka u jkunu ppubblikati r-riżultati miksuba.

Grazzi ħafna tal-ħin u s-sehem tiegħek f'dan l-istudju. F'każ li jkollok xi mistoqsijiet jew tixtieq tiċċara xi ħaġa, tista' ċċempilli fuq ███████ jew tibgħatli email fuq ███████. Tista' wkoll tikkuntattja lis-superviżura Dr Josianne Scerri fuq ███████ jew billi tibgħat e-mail fuq ███████.

Dejjem tiegħek

Firma: _____   Firma: _____

THEKLA JANICE MICALLEF   DR JOSIANNE SCERRI

 Riċerkatriċi   Supervisura

FORMULA TA' KUNSENS TAL-PARTEĊIPANTI

The Lived Experience of informal carers of Individuals with Borderline Personality Problems

Jien, hawn taħt iffirmat/a, nagħti l-kunsens tiegħi biex nieħu sehem fl-istudju mmexxi minn Thekla Janice Micallef. L-għan ta' dan id-dokument hu li jiġu speċifikati t-termini tal-parteċipazzjoni tiegħi f'dan l-istudju ta' riċerka.

1. Jien ingħatajt informazzjoni miktuba u verbali dwar l-għan tal-istudju u l-mistoqsijiet kollha twieġbu.

2. Nifhem li se nkun qed nipparteċipa f'intervista, fejn ir-Riċerkatriċi ħa tesplora l-valur li wiehed / wahda jagħti lil l-esperjenza li jagħddi minnha meta jkollok il- qarib tiegħek tbagħti min problem ta' personalita'.

3. Naf li l-intervista se tieħu madwar siegha. Nifhem, li l-intervista se ssir f'post u ħin konvenjenti għalija.

4. Jien konxju/a li din l-intervista se tkun qed tiġi rrekordjata permezz ta' tagħmir tal-awdjo u se ssir traskrizzjoni (jiġifieri kitba ta' dak li ntqal kelma b'kelma) fl-intervista.

5. Naf ukoll li kull tagħrif miġbur se jiġi pseudonomizzat, jiġifieri it-traskrizzjonijiet kollha se jkunu protetti permezz ta' sistema ta' kodiċi u miżmuma separatament mill-informazzjoni personali.

6. Naf ukoll li r-Riċerkatriċi, is-Superviżura akkademika u l-Eżaminaturi huma l-uniċi persuni li se jkollhom aċċess għal din l-informazzjoni għal skop ta' verifika.

7. Barra min hekk, naf li l-awdjo rrekordjat u t-traskrizzjonijiet se jinħażnu fuq il-kompjuter personali tar- Riċerkatriċi b'forma encrypted. Barra minn hekk, naf li l-materjal stampat se jitqiegħed f'post sikur u se jinżamm sakemm joħorġu r-riżultati.

8. Naf li l-identità tiegħi u l-informazzjoni personali mhuma se jinkixfu mkien fit-teżi, fir-rapporti, fil-preżentazzjonijiet u/jew fil-pubblikazzjonijiet li jistgħu jirriżultaw minnha.

9. Nifhem ukoll li jien liberu/a li naċċetta, nirrifjuta jew inwaqqaf il-parteċipazzjoni f'kull ħin bla ma nagħti raġuni. Dan mhux ħa jkollu riperkussjonijiet negattivi fuq il- qarib tiegħej. Nifhem ukoll li la darba nirtira minn dan lis-studju, l-informazzjoni miġbura se tinżamm b'mod anonimu.

10. Nifhem ukoll li l-kontribuzzjoni tiegħi ser isservi biex jittejeb is-servizz tas-sahha mentali ghal-familjari ta' nies li jbghatu min problem ta' personalita (borderline personality).

11. Jekk inħoss li l-intervisti ħolquli diffikultà u nixtieq li niddiskuti x'qed nħoss, naf li Dr ████████ se jkun qed jipprovdi servizz ta' għajnuna mingħajr ħlas min-naħa tiegħi.

12. Nifhem ukoll, li skont l-Att Dwar il-Protezzjoni u l-Privatezza tad-Data, jien għandi dritt li naċċessa, nemenda u nħassar kull informazzjoni li tikkonċernani.

13.   Naf ukoll li meta jintemm l-istudju u r-riżultati jkunu ppubblikati, l-informazzjoni miġbura titħassar.

14.   Fl-aħħar nett, naf ukoll li se ningħata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex inkun nista' naċċessahom fil-futur.

15.   Jien qrajt u fhimt il-punti u d-dikjarazzjonijiet f'din l-formula. Inħossni sodisfatt/a bit-tweġibiet li ngħatajt għall-mistoqsijiet li kelli, u qed naċċeta minn jeddi li nipparteċipa f'dan l-istudju.

Parteċipant/a:_____

Firma:_____

Data:_____

Firma: _____   Firma: _____

THEKLA JANICE MICALLEF   DR JOSIANNE SCERRI

 Riċerkatriċi   Supervisura

APPENDIX C: INTERVIEW SCHEDULE

English Version: Interview Guide

The lived experience of informal carers of individuals with borderline personality problems

1. Can you tell me about yourself?

    Prompt: How long have you been caring or your partner / spouse?
    How did this change you?

2. What do you know about the diagnosis of your partner / spouse?

3. Can you describe your experience in living with your partner / spouse?

    Prompts: Can you tell me more about your thoughts?

                    What were your reactions to this experience?

4. How did caring for your partner / spouse with a mental illness affect you quality of life?

    Prompts: How do you feel this experience affected your emotions?

                    How did this experience affected you psychologically?

                    What type of physical changes do you notice due to this experience?

                    How do you describe your social life before the taking care of you spouse and now?

5. When did your partner / spouse start showing symptoms that worried you?

6. Can you tell me about your feelings and emotions while living and caring for your partner?

7. How has living with someone with your partner with a mental health condition affected your life?

8. How did this experience affect you spiritually?

    Prompts: And Financially?

9. What was it like when you first started living with her / him? And How is it like now?

10. How do / did you manage to cope?

11. What helps you keep going on in life?

12. What support or other needs can help you / could have helped you?

13. Is there anything else that you would like to add?

APPENDIX C: MALTESE VERSION

Gwida Ghall-Intervista

<u>The lived experience of informal carers of individuals with borderline personality problems</u>

1. Tista' tghidli xi haga dwarek innifsek?

   Prompt: Kemm ilek tiehu hsieb il-mara / partner tieghek?
   Kif bidlek dan?

2. X'taf dwar id-diagnozi?

3. Tista' tiddiskrivi l-esperjenza tieghek li tghix u tiehu hsieb lis-sieheb / siehba tieghek?

   Prompts: Tista' tghidli aktar fuq il-hsibijiet tieghek?

                 X'kienu ir-reazzjonijiet tieghek ghal din l-esperjenza?

4. Kif affetwatlek il-kwalita' tal-hajja tieghek?

   Prompt: Kif kont thossok / Kif affetwatek emozjonalment?

                 Kif affetwatek din l-esperjenza psikologikament?

                 X'tip ta' tibdil fiziku tinnota fik min din l-esperjenza li tiehu hsien lis siehba / mara tieghek?

                 Kif inbidlet il-hajja socjali tieghek min qabel ghal wara li l-mara siehba tieghek bdiet tbaghati bi problem ta' sahha mentali?

5. Meta kien li s-siehba / sieheb tieghek bdiet turi sintomi li nketawk?

6. Tista' tighdli aktar fuq kif hassejtek u l-emozjonijiet tieghek meta tghix / tiehu hsieb lis-siehba tieghek?

7. Kif affetwatlek hajtek il-fatt li tiehu hsieb lil xi hadd b' kundizzjoni tas-sahha mentali?

8. Kif affetwatek spiritwalment din l-esperjenza?

   Prompt: U finanzjarjament?

9. Kif tiddeskrivi d-differenza min meta bdejt tiehu hsieb il-persuna qabel? U x'hini l-esperjenza illum?

10. Kif irnexxielek tkampa?

11. X'jighek tibqa ghaddej fil-hajja?

12. X'sapport jew ghajnuna ohra jista' jghinek / kienet tkun ta'ghajnuna?

13. Hemm xi haga ohra li tixtieq izzid?

Thekla Janice Micallef

████████████

███████

████████████

October, 2018

████████████

Director

Mental Health Services

Re: Research project: 'The lived experiences of spouses / partners caring for individuals with Borderline Personality Problems'.

Dear Dr ████,

My name is Thekla Janice Micallef, I am a charge nurse currently working at Mount Carmel Hospital. I am presently reading for a Master of Science degree in Mental Health Nursing at the University of Malta. As partial fulfillment of my degree requirements I am expected to conduct a research study. I intend to explore the lived experiences of spouses / partners who provide care to their relative with Borderline Personality Problems. This will be done by conducting an initial in-depth audio-recorded interview with five to ten caregivers. This will be followed up by a second interview to explore further in depth any salient points previously raised.

I am aware that I have to strictly adhere to ethical issues especially related to informed consent and confidentiality, and that I have to consult my research supervisor, Dr. Josianne Scerri throughout the research process. Moreover, I will be seeking ethical approval from the University Research Ethics Committee.

Participants will be recruited via an intermediary who is a psychologist currently working in Mount Carmel Hospital and a psychiatric nurse

currently working at Haven (Paola Mental Health Clinic). The intermediary will approach potential participants and provide an information letter explaining the nature of the present study. The intermediary will then provide me with contact details of any participants who accept to be involved in my study.

I am therefore asking your kind permission to allow me to access participants in the manner described. Your support for this research study is greatly appreciated.

Whilst thanking you in advance, should you require further details regarding my study, please do not hesitate to contact me on ███████ (email: ██████████████████████████) or my supervisor Dr. Josianne Scerri on ████████ (email: ████████████████████████).

Yours Sincerely

Thekla Janice Micallef   Dr Josianne Scerri

M.Sc Mental Health Nursing Student   Research Supervisor

APPENDIX E: ETHICS APPROVAL

To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

Acceptance   **Refusal**   **Conditional acceptance**

For the following reason/s:

Signature   Date   20|6|2019.

To be completed by University Research Ethics Committee

We have examined the above proposal and grant

Acceptance   **Refusal**   **Conditional acceptance**

For the following reason/s:

Signature   Date

February, 2019

Re: Psychologist Agreement

I, the undersigned declare that the research study entitled **'The lived experiences of informal carers of individuals with Borderline Personality Problems'** was described to me in detail by the researcher Ms Thekla Janice Micallef. As a professional psychologist, I understand that the study participants may experience some psychological distress during the interview for which help may be needed. In view of this, they will be offered the opportunity to be referred to me for counseling. This would incur no financial cost to the participants or researcher.

Thanking you for your co-operation and availability,

Name of Researcher: Thekla Janice Micallef

Contact Details: ████████

Email: ████████████

Researcher's Signature :   ████████████

Research Supervisor: Dr Josianne Scerri

Contact Details: ██████

Email: ████████████

Research Supervisor Signature: ████████

Psychologist's Name & Surname: Dr Michael Galea

Contact Details: ████████████

Email: ████████████

Psychologist's Signature: ████████

Date of agreement: _____