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UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

The lived experiences of caregivers: psychological and social implications of caring for patients with Bipolar Disorder

Research Report

Submitted in partial fulfilment of the requirements for

the Degree of Master of Arts in Social and Psychological Research (PSYC7022)

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By

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Masters in Social and Psychological Research – Research Report Declaration

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Date: 15/03/2023

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Abstract

Due to the nature of the illness, bipolar disorder (BD) has detrimental effects on the diagnosed patients as well as their caregivers (Hajda et al., 2016). Vast amounts of research have been published on the impact and implications experienced by caregivers of mentally ill patients however, a majority of research assessing the psychological and socio-economic status of the caregivers has been quantitative in nature (Sharif et al., 2020). This study sought to understand the psychological and social implications of caring for a patient with BD, with a specific focus on caregivers in the Gauteng region. The middle-class was chosen as Ayalew et al. (2019) found that the higher the caregiver's income, the fewer implications they experienced as a caregiver. A phenomenological framework was used to conduct this study. The qualitative method of data collection was face-to-face, in-depth interviews with six participants (two males, four females), who were selected using purposive sampling. The interviews were transcribed verbatim, and the data analysed by means of Interpretative Phenomenological Analysis.

For the caregivers in the current study, managing the patient's unpredictable behaviour and dealing with the varying symptoms of the disorder presented a challenge. They described the caregiving role as an emotional rollercoaster, signifying the chaotic, up-and-down nature of the disorder. Being a mother-caregiver led to shared experiences among the caregivers, with similar implications being expressed. Being a wife, however, presented significantly greater caregiver implications. The male caregivers have adapted to their roles better than the females. The theme of financial implications was interesting in this study, as these implications varied among the respondents. The researcher found it interesting that five of the participants spoke about neglecting their needs without any probing, yet they also acknowledged the importance of self-care and being aware of their mental state. The participants in this study expressed the need for support groups, which are lacking in the country. Whilst the findings of this study

were in line with much published research, the researcher notes that there is a scarcity of literature covering some of the themes and subthemes presented, and therefore further research should be conducted. This research was approved by the Ethics Committee (Protocol number: MASPR/21/07).

Keywords: caregiver, psychological, social, implications, bipolar disorder, Gauteng, middle-class

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Definitions of Concepts

In order to provide context for this research project, a brief description and conceptualisation of the main concepts will be presented.

Caregiver

The term 'caregiver' is assigned to an individual who cares for another, defining the role of the individual and, to some extent, creating a new identity for them (Vargas-Huicochea et al., 2018). In this study, the caregiver is the individual who is primarily involved in caring for the patient with bipolar disorder. For the purpose of this research, it is proposed that caregivers are primarily family members. This is due to the fact that literature has shown that since the South African Mental Health Act of 2002 advocated for the deinstitutionalisation of patients with mental illness, these patients ended up in the care of their family members (Lekoadi et al., 2019; Mokwena & Ngoveni, 2020; Ntsayagae et al., 2019; September & Beytell, 2019).

Implications

The researcher opted to use the term 'implication' instead of 'burden' in this study. The researcher recognised that exploring psychological and social implications would be similar to exploring subjective and objective burden, as first defined by Hoenig and Hamilton in 1966, however the term 'burden' was rejected by the researcher for the purpose of this study. In 1996, Szmukler et al. advocated for the rejection of 'burden' when referring to the experience of caring for mentally ill patients. The researchers claimed that it was not possible to operationalise the term and further criticised the underlying assumptions that caregiving is only a negative experience for the carers (Szmukler et al., 1996). In most current literature published about caregivers of bipolar disorder patients, the researcher noted that burden seemed to be the

predominant term used. As such, the intention of the researcher is to highlight that there may be other ways to understand the experience of caregiving.

Bipolar Disorder

Bipolar disorder (BD) is characterised by fluctuating periods of mania (or hypomania in some cases) and depressive episodes (Burke, 2015). The Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-5) (American Psychiatric Association [APA], 2013) differentiates between seven subtypes of BD, however the two most frequently seen and diagnosed are bipolar I disorder and bipolar II disorder. To be diagnosed with bipolar I disorder, the patient must meet the specified criteria for a manic episode. These patients will almost always experience hypomanic or major depressive episodes before or after their manic episode (Burke, 2015). A bipolar II disorder diagnosis requires the presence of a hypomanic episode (current or past) as well as a major depressive episode (current or past) (APA, 2013; Burke, 2015). For the purpose of this study, the two main subtypes of BD will be focused on.

Chapter One: Introduction and Background of the Study

1.1. Introduction

The World Health Organisation (WHO) (2019) has found that the implications of mental disorders is continuously growing around the world. Living with a mental disorder significantly impacts the health, socio-economic status, and human rights of those with mental disorders (WHO, 2019). The WHO (2019) makes reference to many mental disorders, of which bipolar disorder (BD) is one. Determining the exact prevalence of BD in South Africa is challenging as there remains a scarcity of literature and recently updated statistics. The 2004 South African Stress and Health (SASH) study conducted by Herman et al. (2009) is the main source of data regarding the prevalence of mental health disorders in South Africa. The researchers found that the lifetime prevalence of mood disorders in South Africa was 9,8%. However, the researchers made use of the DSM-IV, which classified both major depressive disorder and BD under the category of mood disorders, therefore not allowing for an accurate representation of the prevalence of BD alone (Herman et al., 2009).

Being diagnosed with a mental disorder causes clinically significant impairment in several domains of the patient's life (APA, 2013). However, much research has found that it is not only the patient who is affected by their illness but also those living with them, such as their family caregiver (Ntsayagae et al., 2019; Sharif et al., 2020; Sharma et al., 2016) and even the community in which the patient lives (Fekadu et al., 2019). Just as with the other mental illnesses, BD affects not only the patient but those living with them too (Lekoadi et al., 2019).

Research has shown that 90% of BD patients have multiple episodes during their lifetime (Nolen-Hoeksema & Marroquín, 2017). Every time a patient relapses (returns to a manic/depressive state), the family equilibrium becomes unbalanced, and they have to adjust to the patient's current state (Reinares et al., 2016). Due to the unpredictable nature of BD, caregivers tend to neglect their needs, as well as the needs of the rest of their family (Reinares

et al., 2016). It has been shown that being a caregiver for a BD patient has a negative impact on most, if not all, domains of the caregiver's life such as social and leisure activities (Yadav et al., 2018), relationships (van den Heuvel et al., 2018), mental health (Baruch et al., 2018), family environments (de Souza et al., 2016), marriage (Grover, Aneja et al., 2019), and physical heath (Vargas-Huicochea et al., 2018). Being a caregiver is often not chosen, nor is it planned for, leaving the caregiver very little time to adjust to their new role. Furthermore, the role of the caregiver is not fixed; the course of the patient's disorder determines the role of the caregiver (Kızılırmak & Küçük, 2016).

1.2. Problem Statement and Research Rationale

Due to the nature of the illness, BD has detrimental effects on the diagnosed patients and their caregivers (Hajda et al., 2016). Vast amounts of research have been published on the impact and implications experienced by caregivers of mentally ill patients however, a majority of research assessing the psychological and socio-economic status of the caregivers has been quantitative in nature (Sharif et al., 2020).

Research has shown that how the caregiver experiences the caregiving process depends largely on their socio-demographic profile (Dadson et al., 2018; Grover, Avasthi et al., 2017; Mulud & McCarthy, 2017). In essence, the experience of psychological and social implications when caring for a patient with BD is determined by the caregiver's age, gender, ethnicity, social support (or lack thereof), religious/cultural affiliation, and the severity of the patient's disorder (Shah et al., 2010).

To the researcher's knowledge, there is a scarcity of research focused on caregivers of BD patients in South Africa, particularly in Gauteng. South African-based studies come from disciplines such as social work (van der Walt & Carbonatto, 2019) and nursing (Lekoadi et al., 2019). Furthermore, the South African literature published in this field of study focuses on

caregivers in rural settings caring for patients who utilise government resources (Mokwena & Ngoveni, 2020; Ntsayagae et al., 2019; September & Beytell, 2019).

Based on the above, the researcher identified a gap in the literature. As such, this study sought to understand the psychological and social implications of caring for a patient with BD, specifically focusing on caregivers in the Gauteng region. Furthermore, the research was conducted on middle-class, urban, caregivers by recruiting participants through gatekeepers (specialist psychiatrists and psychologists) in private practice. The middle-class was chosen as Ayalew et al. (2019) found that the higher the caregiver's income, the fewer implications they experience as a caregiver. Utilising the interpretative phenomenological analysis approach in this qualitative study, the researcher was able to gain an in-depth understanding of the lived experiences of these caregivers. Caregivers in urban settings possess different socio-demographic variables than those caregivers in rural settings, and hence, it is important to allow these participants to voice their experience of caregiving.

1.3. Research Aim

The aim of this study was to explore the lived experiences of caregivers regarding the psychological and social implications of caring for patients with bipolar disorder, particularly in Gauteng, South Africa.

1.4. Research Question

How do caregivers experience the psychological and social implications of caring for patients with bipolar disorder?

1.5. Significance of the Study

Due to the lack of qualitative research on the lived experiences of middle-class caregivers of BD patients in the Gauteng region, there have not been many opportunities to understand the implications of caregiving, from their perspective. The intention of the researcher is to add to the existing literature on caregivers while presenting findings from a population who, to the researcher's current knowledge, have not yet been studied. Furthermore, by using the term 'implication' instead of 'burden', it is the intention of the researcher to present a different perspective on the experience of caregiving. As Vargas-Huicochea et al. (2018) so rightfully conclude, it is important to recognise that caregivers are "individuals with their own experiences and feelings, with a socio-cultural baggage that permeates the meaning they assign to life and to the illness as a life event" (p. 214).

1.6. Overview of Research Study

Chapter One - Introduction and Background of the Study

This chapter introduces the current study and presents the aim of the dissertation. Current gaps in literature and a justification for conducting the research are presented. The significance of the study is highlighted.

Chapter Two - Literature Review and Theoretical Framework

The literature review provides insight into the phenomena being investigated and how the topics of the study are related to each other. The theoretical framework of the study is delved into.

Chapter Three - Methods and Ethical Considerations

Chapter three presents the paradigm of the dissertation, the research design, information on participants, an explanation and justification of the data collection method and procedure, a description on the data analysis method used, and ethical considerations.

Chapter Four - Findings and Discussion

This chapter includes the presentation of the findings from the data collected during the interview process. The findings are based on codes that emerged when the researcher conducted interpretative phenomenological analysis, and excerpts from the transcribed interviews are presented. The findings of the study are then supported or contradicted by research presented in the literature review. In order to discuss the findings, the researcher presents a critical reflection.

Chapter Five - Conclusion, Limitations, and Recommendations

Chapter five presents the researcher's concluding remarks, the limitations of the current study, and recommendations for possible areas to study in the future.

Chapter Two: Literature Review and Theoretical Framework

2.1. Introduction

Mental illness has been found to cause significant psychological and social problems in the lives of the patient's family members (Iseselo et al., 2016). Being the caregiver of a patient with bipolar disorder (BD) is an important, yet challenging task (Vargas-Huicochea et al., 2018). While it has been found that caregiving does have some rewards, caring for a person with a mental illness has profound psychological, social, physical, and economic implications for the well-being of the caregiver (Ntsayagae et al., 2019; Sharif et al., 2020). These implications faced by the caregiver have been found to "disrupt their biopsychosocial integrity" (Sharif et al., 2020, para. 1) making for a very stressful experience (Ntsayagae et al., 2019; Sharif et al., 2020; Sharma et al., 2016). The purpose of this literature review is to cover various concepts that have been found to be related to the psychological and social implications of being a caregiver. The theoretical framework underpinning this study will be presented.

2.2. Psychological Implications

Fekadu et al. (2019) found that one's psychological well-being is significantly impacted when caring for a person with a mental illness. When considering the psychological implications of caring for BD patients, researchers found the following areas of concern: a decreased quality of life (von Kardorff et al., 2016); symptoms of distress, poor health, chronic medical conditions, increased use of antidepressants and tranquilisers (Yadav et al., 2018); feelings of being unwanted, burnout, uncertainty (Akbari et al., 2018); feelings of fear, helplessness, frustration, anguish (Morrison & Stomski, 2017; Ntsayagae et al., 2019); and being stigmatised by the wider community (Iseselo et al., 2016).

Caregiving is an exhausting process for the caregiver, and providing long-term care for the patient has been found to cause significant stress for the caregiver (Lekoadi et al., 2019).

BD patients face many behavioural problems placing added stress on South African caregivers, which has significant implications for their mental health (Lekoadi et al., 2019). Similar findings were reported by Kızılırmak and Küçük (2016), who found that the challenges faced by caregivers in Istanbul put them at a high risk of developing mental disorders such as anxiety and depression.

2.2.1. Depression

Caring for a patient with a serious mental illness has a multidimensional impact on the caregiver's life, often resulting in the caregiver experiencing psychological difficulties (Fekadu et al., 2019). Research has shown that caregivers experience considerable stress and feelings of powerlessness and despair. The resultant development of mental health problems such as depression affects caregivers across the globe with studies in Norther Sweden, Saudi Arabia, and Iran producing similar findings (Graneheim & Åström, 2016; Sharif et al., 2020; von Kardorff et al., 2016). Furthermore, research has found that it is common for caregivers to experience depression when they lack social support (Graneheim & Åström, 2016). Liang et al. (2016) found that the difficult behaviours patients display, such as physical and verbal aggression, are contributing factors to the development of depression in Chinese caregivers.

Lekoadi et al. (2019) claim that caring for BD patients puts the South African caregiver at risk of developing clinical depression. Research shows that the significant challenges caregivers face lead to a high percentage of caregivers experiencing depression and anxiety in countries such as Iran, America, and Brazil (Akbari et al., 2018; Perlick et al., 2016; Souza et al., 2017). Statistics regarding depression among caregivers have been well cited in current literature (Jeyagurunathan et al., 2017; Kızılırmak & Küçük, 2016; Liang et al., 2016; Souza et al., 2017; Vermeulen et al., 2015). Perlick et al. (2016) state that depression in caregivers

presents a serious concern, as one-third to one-half of BD caregivers in America meet the diagnostic criteria for depression or at least report symptoms of depression.

2.2.2. Anxiety

Baruch et al. (2018) stated that caregivers of BD patients are at an increased risk of developing mental health problems such as anxiety. Besides the Vermeulen et al. (2015) international study, there is a scarcity of literature related specifically to anxiety in caregivers. However the theme does appear in studies on the subjective implications experienced by caregivers, which will be presented below.

Vermeulen et al. (2015) conducted a global survey with the primary aim of assessing the experiences of family caregivers caring for relatives who had been diagnosed with a severe mental illness. When looking at the emotional implications caregivers experience, they used anxiety as a criterion. They found that 38% of the caregivers felt unable to cope with the constant anxiety of caregiving. One-third of the family caregivers reported that they lacked sleep because of stress and worry (Vermeulen et al., 2015).

In their study on caregivers of BD patients in Mexico, Vargas-Huicochea et al. (2018) found that participants reported symptoms of anxiety and depression due to the impact of being a caregiver. Similarly, Jeyagurunathan et al. (2017) found that 12,7% of the primary caregivers in their Singapore-based study had symptoms of anxiety. It has been found that higher anxiety levels experienced by the caregiver are as a direct result of longer contact time between the patient and caregiver (Souza et al., 2017).

2.2.3. Psychological Distress

In a study conducted by Sharif et al. (2020), Saudi Arabian caregivers reported developing mental disorders and psychological distress as a consequence of caregiving. Baruch

et al. (2018) claim that caregivers of BD patients experience noteworthy psychological distress. A high demand for care by the patient, and family dysfunction contributes to the psychological distress experienced by the caregiver (Fekadu et al., 2019; Koutra et al., 2016).

Due to the unpredictable behaviour in many individuals with BD, Malaysian and Iranian caregivers have reported that they remain in 'stand-by' mode so as to cope with the behaviours (Mulud & McCarthy, 2017; von Kardorff et al., 2016). This 'stand-by' mode is often described as a heightened sense of awareness experienced by the caregiver, where they must remain alert and pre-empt possible behaviours that the patient may display at any given moment (Mulud & McCarthy, 2017). The erratic and impulsive behaviour may be challenging for the caregiver to cope with, and is often distressing to them (Mulud & McCarthy, 2017; September & Beytell, 2019).

Siddiqui and Khalid (2019) found that the quality of the Pakistani caregiver's life is compromised by the psychological distress they experience. The reduction in quality of life has also been attributed to the financial, social, and emotional difficulties that come with being a caregiver in Singapore (Jeyagurunathan et al., 2017), as well as the fact that Iranian caregivers use much of their time and energy to care for the patient (Akbari et al., 2018).

Other factors that have been found to lead to caregivers experiencing psychological distress are the symptom-severity and level of functioning of the patient (Hegde et al., 2019), not being ready to take responsibility for the patient (Rahmani et al., 2018), and a lack of support from family members, spouses, friends, mental health professionals, and the community at large (Hegde et al., 2019; Rahmani et al., 2018; September & Beytell, 2019).

2.2.4. Caregiver Support

Ayalew et al. (2019) state that an important predictor of the implications faced by the Ethiopian caregiver is their social support. It has been found that caregivers experience fewer

implications when they have better social support, and vice versa (Ayalew et al., 2019; Mulud & McCarthy, 2017). In their study, Mulud and McCarthy (2017) found that the Malaysian caregiver's marital status was a significant predictor of the implications they faced, as caregivers who were married (not to the patient) reported fewer implications than those who were divorced, widowed, or separated. The researchers concluded that receiving support or assistance from a spouse may be beneficial as a source of financial, as well as practical, support for caregivers (Mulud & McCarthy, 2017).

Granek et al. (2018) found that parental support, and the support of friends, are vital for the caregiver in Israel. The researchers note that partners of patients with BD require emotional and practical support from their parents and parents-in-law to cope with the patient. Friends help the caregiver feel accepted, listened to, and provide other forms of practical and emotional support (Granek et al., 2018).

When assuming the role of a caregiver, individuals often have to balance the disruption brought about by the disorder and the realisation that many of the support systems they have relied on in the past are no longer available to them (Shamsaei et al., 2015). This is often because the usual sources of support – extended family, friends, and co-workers – have limited knowledge of the illness, and therefore tend to stigmatise the patient and/or the caregiver in Iran (Shamsaei et al., 2015).

2.3. Social Implications

In their research, Fekadu et al. (2019) found that caring for someone with a severe mental illness has a profound socio-economic impact on the caregiver, including divorce, problems with family cohesion, treatment-related costs, and unemployment. Similarly, Vargas-Huicochea et al. (2018) found that the areas most impacted in the lives of Mexican caregivers

of BD patients were relationships, the caregiver's personal growth and autonomy, and the financial implications of caregiving.

It has been found that caregivers often feel isolated and lonely (Graneheim & Åström, 2016; Vermeulen et al., 2015). Kızılırmak and Küçük (2016) state that in Istanbul, most patients live at home and spend most of their time there, and the caregiver consequently becomes less productive and withdrawn from society. Mulud and McCarthy (2017) found that caregivers in Malaysia spent between four and eight hours of their day caring for the patient. The more time caregivers spend caring for the patient, the less time they have to engage in social activities and their leisure time reduces, therefore making the implications of caring greater for the caregiver (Mulud & McCarthy, 2017).

Similarly, Ntsayagae et al. (2019) claimed that the caregiving role comes with numerous sacrifices in the sub-Saharan African caregiver's social and occupational life. These sacrifices further include the financial implications of supporting the patient. It has also been found that caregivers in Iran withdraw from society due to the stigma they face as a result of their association with a BD patient (von Kardorff et al., 2016).

2.3.1. Stigma

While it is well known that considerable stigma is associated with the mentally ill, it is essential to note that the stigma extends beyond the patient and falls onto the caregiver. The level of stigma experienced by the caregiver considerably impacts their experience as a caregiver in Malaysia (Mulud & McCarthy, 2017). The stigma experienced by caregivers adds to their already challenging task as a caregiver (Mulud & McCarthy, 2017; Siddiqui & Khalid, 2019).

Iseselo et al. (2016) claim that there is a relationship between the social support Tanzanian caregivers receive and the stigma associated with having a mentally ill relative.

Their study showed that families hide the patient to avoid being stigmatised (Iseselo et al., 2016). Sharif et al. (2020) found that stigma towards the caregiver came from family members more than from Saudi-Arabian society. Research has found that caregivers experience social ostracism and stigma from their family as well as the wider community (Graneheim & Åström, 2016; Marimbe et al., 2016; September & Beytell, 2019; von Kardorff et al., 2016).

On the other hand, however, Nawura et al. (2019) found that in Arabian cultures, caregivers are often the subjects of ostracism and blame not due to the patients behaviour or diagnosis, but rather if the caregiver is perceived to be neglecting their family member who has been diagnosed with BD or schizophrenia. In line with this, Ghannam et al. (2017) state that this stigma is related to both religious and cultural beliefs that imply that Jordanian family members are obligated to take care of their relatives, regardless of the possible social, economic, or psychological implications this may have on them.

Caregivers are often blamed for the patients illness; they are generally the first ones who notice the patients behaviours, and this disruption to the family causes much confusion and worry (Graneheim & Åström, 2016). Family members tend to place blame on the caregivers for noticing these behaviours until such a time that they accept the diagnosis (Graneheim & Åström, 2016). This blame takes on different forms, however, is often linked to the cultural beliefs of the family and society. Caregivers in Zimbabwe are accused of bringing the illness into the family home with husbands blaming their wives for the child's mental illness (Marimbe et al., 2016). Iranian caregivers express that the process of hospitalisation itself tarnishes the families reputation and causes family caregivers to be blamed for the patient's illness (von Kardorff et al., 2016).

Stigma experienced by caregivers can be associative/courtesy stigma and affiliate stigma (Goffman, 1963; Mehta & Farina, 1988). Associative/courtesy stigma occurs when the caregiver is stigmatised because they are associated with a patient suffering from a mental

illness. On the other hand, affiliate stigma is when the caregiver becomes affected by the stigma regarding mental illness in society (Grover, Aneja et al., 2019; Grover, Avasthi et al., 2017).

Affiliate stigma is said to comprise of three interlocking components; affective, cognitive, and consequent behaviours. Being affiliated with a stigmatised mentally ill individual elicits feelings of helplessness (cognitive component) and unhappiness (affective component) in caregivers (Grover, Aneja et al., 2019; Grover, Avasthi et al., 2017). Affiliate stigma leads to caregivers concealing the patient's diagnosis from family members, withdrawing from society, or even moving away from the patient (consequent behaviours), which has detrimental consequences for the patient (Grover, Aneja et al., 2019; Grover, Avasthi et al., 2017). The results of Grover, Aneja, et al.'s (2019) study revealed that one-third of caregivers in North India experienced courtesy or affiliate stigma when caring for a patient with BD.

2.3.2. Financial Implications

Addo et al. (2018) claim that caregivers in sub-Saharan Africa incur substantial direct and indirect costs when caring for mentally ill patients. Being the caregiver for a family member diagnosed with a mental illness has been shown to have moderate to severe financial implications for the family, with 85% of caregivers in Masa'Deh's (2017) Jordanian study reporting financial implications.

Studies in Mexico, Tanzania, and Zimbabwe have found that the reasons BD caregivers face such severe financial implications are due to: treatment-related costs, a lack of productivity on the patient's behalf, the debt the patient acquires when they are in a manic state (Vargas-Huicochea et al., 2018), and the caregiver leaving their job, or having limited time to work, to assume the caregiver role (Iseselo et al., 2016; Marimbe et al., 2016). Caregivers have reported

using the money they make from their limited working time to care for their relative (Iseselo et al., 2016).

Data collected by Kızılırmak and Küçük (2016) revealed that the majority of the caregivers in Istanbul had financial problems and were unemployed. Similarly, Ghannam et al. (2017) found that among their Jordanian caregiver sample: 70,9% were unemployed, 10,2% worked full time, 9,2% were retired, and 6,1% worked part-time jobs. The researchers concluded that caregivers who left their jobs to care for the patient were confronted with significant financial challenges and consequently had a poor financial status. The researchers found that the time the caregivers spent providing care ranged from 1-24 hours per day, with an average of 13,4 hours per day (Ghannam et al., 2017). The loss of productivity due to being a caregiver has significant financial implications for the caregiver and cannot be ignored (Addo et al., 2018).

2.3.3. Family Functioning

Having a family member with a mental disorder presents challenges for the other members of the family, disruptions in the regular household routine, and strained relationships within the family (Iseselo et al., 2016; Kızılırmak & Küçük, 2016; Reinares et al., 2016). According to Koutra et al. (2016), families in Greece adapt to the psychological and physical needs of a mentally ill family member through various dynamic processes.

Episodes of mania present in BD patients cause the homeostasis of the family to become unbalanced. Caregivers become responsible for multiple tasks and struggle to maintain the shifting roles in the family (Sharif et al., 2020). Research in sub-Saharan Africa shows that having a mentally ill family member means family plans are made around the patient, daily routines and chores are no longer executed, family members are exposed to new emotions, and the caregiver has to change their lifestyle in order to assume the caregiving role (Iseselo et al.,

2016; Ntsayagae et al., 2019). Furthermore, long-standing family roles are challenged, causing disagreements between family members and ultimately weakening family relationships (Iseselo et al., 2016; Ntsayagae et al., 2019).

During the initial stages of the disorder, it is common for the entire family to support the patient by reorganising the family dynamics and routines to accommodate the patient. As time goes on and the disorder becomes established, research has shown that many family members are no longer willing to be so accommodating and distance themselves from the patient, leaving one person behind to take on the role of the caregiver (Vargas-Huicochea et al., 2018).

2.4. The Relationship Between the Caregiver and the Patient

With the deinstitutionalisation of mental health care users, the responsibility of caring for the patient in all their stages has shifted to the caregiver (Tan et al., 2012). Greater implications for the caregiver have been linked particularly to social support and the presence of closer family ties between patients and caregivers in Ghana (Dadson et al., 2018). When caring for a family member with a mental illness, parents, siblings, spouses, and children all have their own perspectives and experiences (Rahmani et al., 2018).

The research on the relationships between caregivers and patients is somewhat contradictory, with some research indicating that relationships get stronger, and others indicating a weakening in the relationship. While there is limited research on the rewards of caregiving, Bauer et al. (2015) found that caregivers in Germany experience increased cohesion and relationships with patients and family members, and praise from patients and others for the caregiving. Similarly, Graneheim and Åström (2016) found that caregivers in Northern Sweden enjoyed their relationship with their mentally-ill family members. The researchers found that the caregivers in their study felt a great sense of responsibility for the patient,

however, they did not blame them for their mental illness (Graneheim & Åström, 2016). Mulud and McCarthy (2017) shared similar findings, where less severe implications were reported when the Malaysian caregivers realised that their loved ones' conduct was brought on by the illness rather than by the patient's personality.

On the other hand, it has also been found that maintaining a meaningful relationship with a loved one who suffers from a mental illness is a challenge for caregivers (Graneheim & Åström, 2016). When the relationship with the patient becomes particularly challenging, the caregiver may experience thoughts of escaping the situation. However, they realise that running away is not an alternative as they cannot give up on their loved one (Graneheim & Åström, 2016). Research shows that female caregivers in India are more likely to have problems regarding the quality of their relationship with the patient, whereas male caregivers experience more constraints on their autonomy (Yadav et al., 2018). According to a study conducted in Germany, a significant predictor of constraints on their autonomy was the leisure time sacrifices that males had to make once becoming a caregiver (Bauer et al., 2011).

2.4.1. The Parent-Child Relationship

An important predictor of the implications of care is the caregivers' relationship to the patient (Ayalew et al., 2019; Dadson et al., 2018). Compared to being a parent, being a patient's spouse, brother, son or daughter, or other relative increases the strain on the caregiver. Viewed alongside other carers, parent caregivers in Southwest Ethiopia experience higher levels of satisfaction and engagement while giving care (Ayalew et al., 2019). Similarly, Jeyagurunathan et al. (2017) found that compared to spousal caregivers, parent caregivers in Singapore experience fewer psychological implications when caring for their children. They state that the differences seen between the two caregivers could be due to the fact that spousal caregivers may have lost the person they confide in, their source of financial support, the person with

whom they share household responsibilities, and the person who helps them raise their child/ren (Jeyagurunathan et al., 2017).

Alzahrani et al. (2017) do not agree with this, as they found that being a female (mother, daughter, or spousal) caregiver and caring for a younger patient increases the implications the Saudi Arabian caregiver faces. In line with this, Andershed et al. (2017) state that mental illnesses are often life-long conditions, and for Swedish parent-caregivers, dependence is markedly different than if they were caring for a child without a mental disorder. These parents often take on significant responsibilities that affect their quality of life and life situations (Johansson et al., 2015).

While there is limited research on the relationship between child-caregivers of patients with BD, it has been found that the children of parents with BD in Germany experience significant implications and are at a particularly high risk of suffering from psychosocial difficulties if they are the patient's only caregiver (Bauer et al., 2015). Fekadu et al. (2019) claimed that children of parents with severe mental illnesses are at a high risk of developing mental and physical illnesses due to the stigma, financial challenges, genetic vulnerability, and psychological implications of caring for their parent. The researchers found that caring for a parent with a mental illness has long-lasting implications for the child-caregiver impacting their health and relationships in adulthood (Fekadu et al., 2019).

2.4.2. Marital Relationships

For spouses of mentally ill patients in Jordan, the inability of the patient to fulfil sexual requirements, the poor quality of the marriage, and the lack of affection are the causes of spouse-related caregiving implications (Ghannam et al., 2017). Furthermore, it has been found that married Indian caregivers have limited support outside of their marriage, making for a challenging caregiving experience (Yadav et al., 2018).

Bipolar disorder has implications for all relationships in the patient's life, and Naqvi et al. (2021) state that marriage is no exception to this. The divorce rate in the BD patient population is extremely high, which clearly indicates that this disorder brings about challenges in interpersonal connections (Granek et al., 2016). It has been found that being a spousal caregiver of a patient with BD in Israel and Pakistan has severe emotional implications, often in the form of the caregiver feeling: anxious, lonely, helpless, frustrated, resentful, and hypervigilant (Granek et al., 2016; Granek et al., 2018; Naqvi et al., 2021). Spouses also experience fear of relapses and are concerned about the patient's future (Granek et al., 2016; Naqvi et al., 2021).

Granek et al. (2016) aimed to understand the impact that BD has on spousal-caregivers and their marriage in Israel. The caregivers expressed that being married to a patient with BD involved much self-sacrifice. The spouses described sacrificing things that gave them pleasure in life (such as their hobbies), and feeling as though they have neither the time, nor energy, to consider their own needs and goals. Overall, most partners felt that their life was centred on the patient and their care (Granek et al., 2016).

According to previous studies conducted in India and Italy, most caregivers for family members with chronic illnesses, particularly the elderly and those with mental illness, are women (Plank et al., 2012; Sharma et al., 2016). Caring for a mentally ill husband may present a different experience for a female spousal caregiver when compared to caregivers who have different relationships to the patient (Sharma et al., 2016; Tan et al., 2012). Additionally, caregiving responsibilities are intricately linked to the ordinary day-to-day activities of female spousal caregivers, such as parenting, working, and maintaining a home (Rahmani et al., 2018).

In their study, Rahmani et al. (2018) found that wives of mentally ill husbands in Iran experience a deterioration in their emotional connection with their husbands over time. They reported that the wives emotionally distanced themselves from their husbands and experienced

internal resentment towards them when subjected to coercive conditions in their marriages. Such conditions included Iranian wives being treated like slaves, being accused of things they did not do, being on the receiving end of their husband's hostility, and being required to ask permission to leave the house to engage in leisure time activities (Rahmani et al., 2018). Naqvi et al. (2021) state that wives in Pakistan feel anger towards their husbands with BD when they are experiencing manic episodes. This is particularly true when their husbands go from being loving and supportive to being angry and distant, making them unrecognisable to their wives (Naqvi et al., 2021).

Rahmani et al. (2018) found that having children made the caregiving experience more challenging for the Iranian wives. However, the most significant issue in their life was financial strain because their mentally ill husband frequently served as the major breadwinner. The female spouses lost their financial security and now had to juggle various responsibilities (Rahmani et al., 2018). Some female spousal-caregivers have found that making peace with the situation and approaching their husband with BD with patience is the only way to regain emotional stability (Naqvi et al., 2021).

2.5. The Changing Role of the Caregiver

Kızılırmak and Küçük (2016) claimed that the caregiving role is often not chosen, and caregivers seldom get time to plan for it, therefore leaving them minimal time to adjust to this new role. According to Pompili (2014), the transition to becoming a caregiver means that the existing relationship between the patient and caregiver is going to change from what it was before the onset of the disorder into a "carer-cared for" (Pompili, 2014, p.5) relationship. It is imperative that the family, and the caregiver in particular, learn how to balance the responsibility of caring and the interference it will cause in their previous routines (Rahmani et al., 2018). It has been shown that caregivers who are not adequately prepared for this

transition, and who are not assessed by healthcare professionals to determine if they are able to take on the role of caregiving, experience severe implications as a caregiver (Andershed et al., 2017; Noohi et al., 2016).

It has been established that caregivers of patients with BD sacrifice themselves and put the needs of the patient above their own (Graneheim & Åström, 2016; Van der Walt & Carbonatto, 2019). Graneheim and Åström (2016) found that Swedish caregivers adapted their lives in order to accommodate the patient's needs. Furthermore, to prevent relapses, the caregivers made sure to create positive life situations for the patients, adding further responsibilities to their caregiving tasks (Graneheim & Åström, 2016). Caregivers in Graneheim and Åström's (2016) study explained that their tasks were to comfort, guide, and protect their loved ones, and they consequently felt that they needed to be rational at all times in order to solve any potential problem the patient may have. This placed considerable pressure on the caregivers, often making them blame themselves when their loved ones relapsed (Graneheim & Åström, 2016).

Lewis (2015) found that caregivers provide tremendous amounts of physical care, medication administration, and emotional assistance during the patient's depressive episodes. Even when the patient was unemployed, caregivers took on the household chores and other duties that the patient typically handled (Lewis, 2015). Rahmani et al. (2018) found that the additional role of caregiving places considerable stress on women who already play multiple roles in their homes, such as being mothers and housekeepers. These wives described being trapped in different roles and saw themselves as the only source of support for the family. Female caregivers neglected themselves, eventually forgot who they were, and experienced a loss of self as a result of taking care of their families, while simultaneously helping their mentally ill husbands (Rahmani et al., 2018).

Being the caregiver of a patient with BD means that one has to balance competing needs and overcome feelings of being needed and rejected simultaneously (Lewis, 2015; van den Heuvel et al., 2018). Lewis (2015) claims that this balancing act makes caregivers feel trapped in their role leading to resentment. Finding the balance between being a caregiver and maintaining their autonomy is challenging for caregivers (Graneheim & Åström, 2016; Shamsaei et al., 2015).

2.6. Theoretical Framework

This research was viewed through the lens of Lazarus and Folkman's (1984) theory of stress and coping, which comprises three main concepts: stress, appraisal, and coping (See Figure 1). The theory has been used as the predominant approach to studying family caregiving (Hegde et al., 2019).

Prior research has made it evident that caregivers face considerable stress during the caregiving process. According to Schulz and Sherwood (2008):

> Caregiving has all the features of a chronic stress experience: It creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance. (p. 23)

The main stressors for caregivers are the patient's behaviours and illness, as well as the disruption in the caregiver's life (Szmukler et al., 1996). Psychological stress will be experienced by caregivers when they feel that the demands of caregiving exceed the resources available to them, which consequently endangers their well-being (Lazarus & Folkman, 1984; Folkman, 2010). Why, then, do some people experience stress while others in a similar situation do not? Lazarus and Folkman (1984) explain:

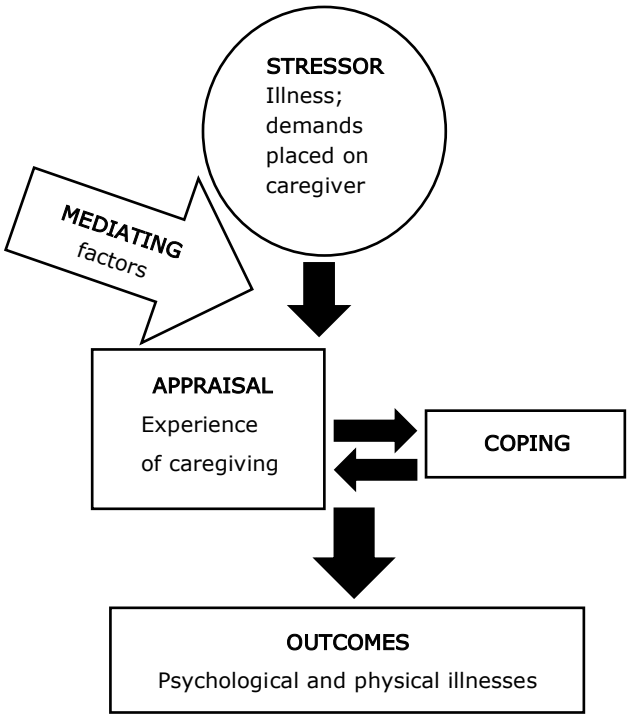
> psychological stress is determined by the person's appraisal of a specific encounter with the environment; this appraisal is shaped by personal factors including commitments, vulnerabilities, beliefs, and resources and by situation factors including the nature of the threat, its imminence, and so on. (p. 289)

Based on the stress-coping theory, how the caregiver interprets their situation ultimately determines the stress level they will experience (Lazarus & Folkman, 1984). In the context of this research, the experience of caregiving is considered as the appraisal of the demands faced by the caregiver (Szmukler et al., 1996). The caregiver's appraisal may be influenced by mediating factors such as the degree of social support they receive, their relationship with their family, and even their personality (Szmukler et al., 1996).

When caregivers are able to manage the demands of caregiving and the emotions they experience as a consequence of caregiving, Lazarus and Folkman (1984) state that the caregiver is coping. Effectively coping with the stress brought about by caregiving will protect the caregiver's mental and physical health (Folkman, 2010). Psychological and physical illnesses are said to be the outcome of an interaction between the caregiver's appraisal and the way the caregiver copes (Szmukler et al., 1996). Due to the nature of this study, the researcher used this model to get a holistic view of the caregiving process, and all the elements that interact to determine the implications faced by the caregiver.

Figure 1

A stress-coping model of caregivers (Szmukler et al., 1996).



2.6.1. Coping Strategies Used by Caregivers

Due to the interactive nature of appraisal and coping in the stress-coping model, and the consequent outcomes thereof (Szmukler et al., 1996), caregiver coping needs to be explored. It has been found that caregivers use various coping strategies to deal with the patient's illness, and the caregiver tasks (Sharif et al., 2020; Van Der Voort et al., 2007). The role of a caregiver differs depending on their relationship with the patient. When looking at traditional gender roles in society, women are the caregivers of the family. However, should the woman become the mentally ill family member, traditional roles will have to switch, having implications for the caregiver (Van Der Voort et al., 2007).

It has been found that caregivers make use of problem-focused and emotion-focused coping strategies (Chakrabarti & Gill, 2002). Problem-focused coping strategies are referred to as constructive coping strategies which the caregiver uses to modify challenging situations.

Such coping strategies include problem-solving, communication, and looking for information. On the other hand, caregivers may use emotion-focused coping strategies, which are less adaptive. When using these strategies, the caregiver is attempting to balance their emotional response to stress by avoiding the situation or simply giving up (Chakrabarti & Gill, 2002).

Which coping strategy the caregiver uses is dependent on various factors. It has been found that coping is directly related to the implications of caring for the patient, the severity of the patient's disorder, the caregiver's expressed emotion (EE), and the support available to them (Chakrabarti & Gill, 2002; Hedge et al., 2019). Caregivers have been found to use maladaptive coping strategies (emotion-focused) when there are high levels of patient dysfunction, high caregiver EE, greater implications of caregiving, and a lack of support (Chakrabarti & Gill, 2002; Dadson et al., 2018; Hedge et al., 2019).

Kızılırmak and Küçük (2016) found that the caregiver's mental health deteriorates as the implications of caring for the patient increases. As their mental health deteriorates, their ability to cope becomes significantly lower, which in turn causes the caregiver to perceive their role as a caregiver as even more challenging (Kızılırmak & Küçük, 2016). Granek et al. (2018) found that caregivers opted to use emotion-focused coping strategies, such as focusing on the positives in the situation and lowering their expectations. Furthermore, the caregivers learnt to take things one day at a time (Granek et al., 2018).

It has been well cited in literature that the way a caregiver copes with their role is gender-dependant. Females have been found to face more challenges when adjusting to their role as a caregiver (Ayalew et al., 2019; Rahmani et al., 2018). The caregiving role is stereotypically a woman's duty (Rahmani et al., 2018); however, the added responsibilities such as being a mother, primary breadwinner, household manager, and main emotional supporter make the caregiving role a particularly challenging one for females, especially if these responsibilities were shared before (Ayalew et al., 2019; Rahmani et al., 2018). When

compared to their female counterparts, male caregivers report significantly fewer implications when caring for a patient with BD (Mulud & McCarthy, 2017).

It has been suggested that male and female caregivers express and handle the implications of caregiving differently, with females opting to use emotion-focused strategies. In contrast, males use problem-focused strategies (Mulud & McCarthy, 2017). Séoud and Ducharme (2015) found that caregivers who utilised problem-focused coping strategies were more likely to develop a resilience towards caregiving. Research by Cassidy et al. (2014) and Scott (2013) found that male caregivers are more resilient than female caregivers, making them less likely to be affected by the caregiving process. It has been argued that resilience may explain how male caregivers are able to cope with the challenges brought about by caring for patients with mental illnesses (Mulud & McCarthy, 2017).

2.7. Conclusion

In conclusion, the above literature has shown that caring for a BD patient has numerous implications for the caregiver. While it is evident that caregivers of patients with BD have received attention in research, much emphasis has been placed on the term ‘burden’, and quantitative studies have dominated this field of study. Furthermore, there is a scarcity of research in South Africa. Utilising an interpretative phenomenological analysis approach in this qualitative study, the researcher intends to add to the current literature by giving South African caregivers an opportunity to share their lived experiences.

Chapter Three: Methods and Ethical Considerations

3.1. Research Design

A qualitative research design was chosen as it allowed the researcher to understand the lived experiences of the participants and interpret these experiences with regard to the chosen phenomenon (Creswell, 2013). The phenomenological theoretical tradition was relevant to this study as it allowed the researcher to gain an in-depth understanding of how caregivers experience the psychological and social implications of caring for patients with bipolar disorder (BD).

Phenomenology involves descriptions of a phenomenon by ordinary people who have experienced the phenomenon (Giorgi, 1979) with the aim of understanding what this experience means to them (Moustakas, 1994). According to Creswell and Poth (2018), phenomenology describes the commonalities in lived experiences among individuals regarding the specific phenomenon under investigation. In studies with a phenomenological underpinning, participants are asked questions regarding 'what' they experienced and 'how' they experienced the phenomenon (Moustakas, 1994). The current study used individual interviews to gather information on the participants' lived experiences.

3.1.1. Interpretive Paradigm

The interpretive paradigm, as defined by Burrell and Morgan (1979), is a relevant paradigm for use in qualitative studies (Alase, 2017), and was used in this research study. The paradigm allows for an interpretive narration of how the chosen phenomenon is subjectively experienced by the research participants (Burrell & Morgan, 1979).

In order to answer the research question, the researcher used an interpretive paradigm to gather data relating to the participants' lived experiences and used that data to construct an understanding of the world through the eyes of the participant (Thanh & Thanh, 2015). The

interpretive paradigm was chosen in order to gain an understanding of the psychological and social implications of caring for patients with BD, from the caregiver's perspective.

3.1.2. Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) was chosen as the research approach for this study. IPA is a qualitative approach that seeks to understand phenomena from a first-person perspective and places value on the subjective experiences of individuals (Eatough & Smith, 2017). IPA is grounded in phenomenology and informed by hermeneutics; the former examines experience from the view of the participants, while the latter is the theory of interpretation (Pietkiewicz & Smith, 2014). In addition, Smith et al. (2009) refer to IPA as being idiographic. The idiographic orientation allows the researcher to examine and analyse the unique contexts underpinning the participants' individual experiences (Pietkiewicz & Smith, 2014).

3.2. Participants

In line with the IPA approach, a relatively homogenous sample was chosen for this study (Eatough & Smith, 2017; Howitt, 2016). It has been suggested that six to ten participants are favourable in IPA studies as this will allow for in-depth engagement with each individual case, while still providing enough data to examine similarities and differences among the lived experiences of the participants (Howitt, 2016; Pietkiewicz & Smith, 2014; Smith et al., 2009). Purposive sampling is recommended in order to create a homogenous sample (Smith et al., 2009). The researcher purposively selected six participants in this study based on the inclusion criteria presented below.

Inclusion criteria: The participant had to: be a caregiver of a BD patient; be over the age of 18; be able to understand and converse in English; reside in Gauteng, South Africa.

Furthermore, the patient whom the caregiver is looking after: may be recently diagnosed or may have a long-standing diagnosis; must have an official diagnosis of BD (diagnosed by a professional). The gender of the participant was not considered as an inclusion criterion as the researcher wanted to include caregivers of any gender.

Exclusion criteria: Participants were excluded from the study if they were unable to provide valid consent to participate in the study, and/or if they were a caregiver of a patient with any psychiatric condition other than BD.

3.3. Sampling and Data Collection Procedure

Participant sampling and data collection commenced after the researcher had obtained ethical clearance from the Ethics Committee (Protocol number: MASPR/21/07). The researcher made use of gatekeepers (two specialist psychiatrists and one clinical psychologist) to find potential participants for this study. The researcher was given a list of specialist psychiatrists and psychologists in private practice to contact by the principal psychologist at Evexia Psychiatric Day Hospital. The researcher emailed the potential gatekeepers and provided a brief overview of her study, and attached the gatekeeper information letter (Appendix C) to the email.

Upon return of the gatekeeper's permission letter, the researcher left participant information sheets (Appendix A) with the gatekeepers to give to suitable individuals, who then had the autonomy to decide if they wished to contact the researcher or not. Participants who contacted the researcher were sent a consent form (Appendix B) via email which had to be signed and returned to the researcher. Following this, an interview was scheduled at a time convenient to both the participant and researcher. Due to the COVID-19 pandemic, the participants were given the option to have the interview via a virtual communication platform such as Zoom, Microsoft Teams, or Skype. Participants were also given the option to meet in

person if they preferred. Prior to applying for ethical clearance, the researcher had secured a private, sound-proof room (Appendix D) at Evexia Psychiatric Day Hospital (Midstream) which would be set up according to COVID-19 prevention guidelines of social distancing and sanitization; both the researcher and participant would wear a mask throughout the interview. However, all six participants opted for online interviews (five were conducted on Zoom and one on Skype).

3.4. Data Collection Tools

When choosing a suitable data collection tool, the researcher kept in mind that IPA requires a method which allows participants to provide rich, detailed descriptions of their lived experiences. Semi-structured, one-to-one interviews are preferred in IPA studies as they allow rapport to be developed while giving participants the space to speak freely (Pietkiewicz & Smith, 2014; Smith et al., 2009). In order to facilitate this process, the researcher set up an interview schedule (Appendix E) with questions to be asked in the interview (Smith et al., 2009). While the majority of these questions are based on the research question and the literature, some questions were guided by Iseselo et al. (2016) and Vargas-Huicochea et al. (2018).

The interviews lasted approximately forty-five to sixty minutes (Alase, 2017) and were recorded with an electronic recording device (participants provided consent for this). The researcher then made verbatim transcripts of each interview (Pietkiewicz & Smith, 2014).

3.5. Data Analysis

Upon completion of the data collection, the researcher analysed the data gathered from the interviews according to the IPA data analysis steps suggested by Smith et al. (2009).

Step one involved the researcher engaging with the original data by *reading and re-reading* the transcripts (Smith et al., 2009). The second step involved *initial noting* by deeply exploring the language used by the participant as well as how they make sense of their experience, while noting anything of interest (Smith et al., 2009).

During the third step, the researcher started *developing emerging themes* by analysing the exploratory comments made in the previous step (Smith et al., 2009). In the fourth step, the researcher *searched for connections across the emergent themes* (Smith et al., 2009). Step five involved *moving to the next case* by repeating steps 1-4 with each individual transcript (Smith et al., 2009). The final step in the data analysis process was *looking for patterns across cases* (Smith et al., 2009).

3.6. Strategies to Ensure Research Worthiness

In order to establish research worthiness in this study, the researcher utilised the following procedures: triangulation; thick, rich data description; peer-reviewing; reflexivity of the researcher (which will be discussed in the subsection 'Role of the IPA Researcher'). The researcher acknowledges that member checking should ideally be used as an additional strategy to ensure research worthiness, however, this was not feasible due to time constraints.

Triangulation is the process whereby the researcher looks for a point of convergence among multiple sources of data (Creswell & Miller, 2000; Schwandt, 2007). The researcher applied one of Denzin's (1978) methods of triangulation to this study: triangulation across data sources (i.e. participants).

In order to ensure that a thick, rich description of the data were provided, the researcher described the participants, setting, and themes of the study in detail (Creswell & Miller, 2000; Creswell & Poth, 2018). In doing so, the researcher "creates verisimilitude, statements that

produce for the readers the feeling that they have experienced, or could experience, the events being described in a study" (Creswell & Miller, 2000, p. 129).

Peer reviewing is a process during which someone familiar with the research reviews the research process and the collected data (Creswell & Miller, 2000; Creswell & Poth, 2018). During the entirety of this research process, the researcher was being supervised by an experienced supervisor with extensive knowledge in the field.

3.7. Role of the IPA Researcher

The role of the IPA researcher is to interpret, understand, and amplify the participants' experiences while affording them an opportunity to tell their stories without fear of judgement (Alase, 2017). It is vital that the IPA researcher bracket themselves while in the process of data collection (Alase, 2017), as well as when designing interview schedules (Smith et al., 2009). The process of bracketing as a researcher means that one has to "set aside our prejudgments, biases, and preconceived ideas about things" we aim to understand (Moustakas, 1994, p. 85). By doing this, the researcher creates a piece of work that tells the subjective lived experiences of the participants, leaving readers with the feeling of "I understand better [now] what it is like for someone to experience that" (Polkinghorne, 1989, p. 46). The interpretive nature of an IPA study requires that the researcher continuously self-reflects and remains aware of any implicit or explicit biases to protect the study's integrity (Alase, 2017).

In order to do justice to the study, the researcher had to be self-aware throughout the entirety of the study. The reason for this was twofold; firstly, as a child-caregiver of a patient with BD herself, she had to make sure to not allow her lived experience to influence the way she viewed the lived experiences of the caregivers in the study. Secondly, the researcher had to create a space where the caregivers in the study felt safe to express themselves without fear of judgement. In order to ensure that the participants did not feel judged, she expressed her role

as a caregiver to the participants at the start of the interviews while explaining the research rationale to them. The reason for doing this was to eliminate the researcher-participant power dynamic and to position herself as a fellow caregiver. The aim was to make sure the caregivers felt understood and heard, and the researcher believes she achieved this as the participants expressed their comfortability in sharing their experiences with a fellow-caregiver.

3.8. Ethical Considerations

To do no harm to the participants, the researcher followed a sound research design and only commenced with data collection after ethical approval had been given (Department of Health [DOH], 2015; Smith et al., 2009). The researcher applied for ethical clearance through the Human Research Ethics Committee (non-medical). Voluntary participation (DOH, 2015; Leedy & Ormrod, 2015) was established by giving participants identified by gatekeepers the opportunity to join the study on a voluntary basis.

Informed consent was gained from participants (Leedy & Ormrod, 2015). The issue of consent was revisited at the start of the interview (Smith et al., 2009). Participants were offered the right to withdraw from the study until the point of final submission (Smith et al., 2009). Raw, unedited transcripts were only viewed by the researcher and supervisor. Thereafter, any identifiable information was disguised by means of assigning pseudonyms so as to afford participants anonymity in all reporting (Smith et al., 2009). Voice recordings uploaded to a computer for analysis were stored in a password-protected folder accessible only to the researcher and were destroyed through deletion after the final submission of the research report (Alase, 2017).

Chapter Four: Findings and Discussion

4.1. Introduction

This chapter presents findings based on the interviews held with the participants. The discussions of the findings are based on the researchers' understanding.

4.2. Participant Demographics

The table below gives an overview of the participants. Four females and two males made up the six participants in this study. The participants come from various occupational backgrounds; some in high-paying jobs and others in more entry-level jobs. This allowed the researcher to explore the financial implications of caring for patients with BD from different socio-economic perspectives within the sample. Half of the caregivers are also the patients' significant other, while two are mothers, and one is an adult child-caregiver. This allowed the researcher to explore different relationship dynamics and support systems. Finally, two of the caregivers are caring for patients who had been diagnosed with bipolar disorder (BD) within a year of data collection. This allowed the researcher to understand the differences in coping styles among the caregivers based on the length of time spent as a caregiver.

Table 1

Demographics of Participants

Caregiver Demographics						
Name[1]	Ella	Liam	Mia	Olivia	Adam	Sophie
Gender	Female	Male	Female	Female	Male	Female
Age	28	61	49	40	35	48
Occupation	Occupational therapist	Engineering manager	Remedial teacher	Teacher	Admin assistant	Student
Race	White	White	White	White	White	White
Religious affiliation	Christian	Nil	Christian	Christian	Christian	Christian
Relationship to patient	Daughter	Husband	Mother	Wife	Fiancé	Mother
Patient Demographics						
Gender	Male	Female	Male	Male	Female	Female
Age	68	45	14	44	34	22
Year of diagnosis	1998	2017	2021	1999	2009	2021

4.3. Emerging Themes and Subthemes

After the data were transcribed verbatim, the researcher created codes which allowed her to determine emerging themes among the interviews. The following themes will be presented below: the ups-and-downs of caregiving; support systems; coping with the patient; social implications; the caregiver-patient relationship; stigma; financial implications; caregiver needs. The sub-themes relating to these themes will be put forward.

[1] All names are pseudonyms so as to ensure participant confidentiality.

Table 2

Themes and Subthemes

Theme	Subtheme/s
The Ups-and-Downs of Caregiving	Anger and frustration Psychological distress Neglected needs and managing competing needs
Support Systems	Lack of support
Coping With the Patient	Gender differences
Social Implications	The impact on the household
The Caregiver-Patient Relationship Stigma Financial Implications Caregiver Needs	

4.3.1. Theme One: The Ups-and-Downs of Caregiving

This theme was explored in order to gain an overview of the various ways in which the caregiving process affects the participants, and to understand the various psychological implications of being a caregiver. Managing the unpredictable and variable nature of symptoms is one of the most challenging aspects of being a caregiver for a person with BD. Participants used descriptive language to express the chaotic, up-and-down nature of the disorder. When asked to explain what it feels like to be a caregiver, the participants described the following:

> *"You know, it is difficult, you do get your ups and downs and you just pick that person up again, and that's not always the easiest…*" (Liam, Husband).

> *"…it's an emotional rollercoaster…cause it's got its ups and downs…"* (Olivia, Wife).

Mia (mother) further elaborated:

> *"…a caregiver also needs to be a plan maker like if plan A is not working, what is plan B and plan C. Ya it's very unpredictable ya, you never know – you never say ya that's the way it's going to be…"*

The lived experiences of the caregivers in this study coincide with findings by Spiers et al. (2023), who found that the cyclical nature of BD places caregivers under significant strain. Furthermore, the unpredictable nature of BD may leave caregivers feeling like they are on a rollercoaster ride, and that they are no longer in control of what is going on around them (Bauer et al., 2012; Mark, 2013). Lekoadi et al. (2019) state that the behaviours displayed by BD patients place the caregiver under additional stress. The unpredictability and lack of control experienced by caregivers creates what Schultz and Sherwood (2008) term a chronic stress experience. If the caregiver is unable to manage the demands placed on them and the emotions brought about by the caregiving experience, they will not be able to cope (Lazarus & Folkman, 1984). In order to minimise the implications of caregiving, it is vital for the caregiver to have social support and implement adaptive coping strategies.

For the two mothers in the study, being the caregiver of their child with BD elicits a wide range of emotions:

> *"…anger and sadness, hopefulness umm… hopelessness and then after, then the next morning when you wake up you are hopeful again…by evening you are hopeless again..."* (Mia, Mother).

> *"It has just been very stressful…there has been a lot of fear…there's hope and then there's hopelessness, there's fighting and then there's I'll give up – this is how it's going to be so it's very push and pull – very radical, it's very up down…"* (Sophie, Mother).

This is consistent with findings by Morrison and Stomski (2017), as well as Ntsayagae et al. (2019), who noted that being a caregiver for a patient with BD elicits feelings of fear, helplessness, frustration, and anguish. When viewing Sophie's (mother) response in isolation, it can be argued that this mother is utilising an emotion-focused coping strategy, as described by Chakrabarti and Gill (2002). In order to balance her emotional response to the up-and-down nature of the patient's behaviour, the mother is inclined to want to give up. Although maladaptive, the need to give up may be this mother's way of attempting to regain some control over her life, and maintain a sense of stability, albeit falsified.

4.3.1.1. Anger and frustration

Feelings of anger and frustration towards the patient were described by the participants in the study. The root of the anger was twofold. Firstly, caregivers were angry that they had to take on additional responsibilities. Secondly, the caregivers were angry because the patient put them in a situation that required sacrifices in their lives:

> *"…he was usually looking basically after himself, making himself a sandwich, um get himself cooldrink or whatever… I needed to do it now for him… and sometimes I felt like cross but he's still big enough to do it himself but he just didn't want to do it himself anymore..."* (Mia, Mother).

> *"...sometimes yes, I do get...angry at my husband for putting us in this situation because you know I can't do the things that I want to do..."* (Olivia, Wife).

Rahmani et al. (2018) state that caregivers who have different relationships with the patient will have different perspectives and experiences. The anger towards the patient in this study is no exception, where the mother caregiver expressed anger at the need to take on more responsibilities. Ntsayagae et al. (2019) found that caregivers in their study experienced frustration when they had to take on additional responsibilities, as this meant that the caregiver had to combine their existing responsibilities with the requirements of caring for the patient.

When considering the anger towards the patient from the perspective of the wife-caregiver, it can be seen that she expresses her anger towards the sacrifices she has had to make and blames her husband (and the condition) for this. Research has shown that spousal caregivers often sacrifice things that give them pleasure in life (Granek et al., 2016), and this may lead to feelings of anger among wife-caregivers (Rahmani et al., 2018).

Interestingly, research has shown that, compared to spousal caregivers, parents experience higher levels of satisfaction and engagement in their role as a caregiver (Ayalew et al., 2019). On the other hand, it has been found that being a female, and therefore a mother-caregiver, increases the implications faced by the caregiver, especially because the patient is largely dependent on them (Alzahrani et al., 2017; Andershed et al., 2017). The researcher is of the opinion that being a mother-caregiver and being a wife-caregiver may in fact have many overlapping, and similar levels of caregiver implications, and as such, this area should be investigated further.

4.3.1.2. Psychological distress

Although psychological distress was not common among the participants, this sub-theme is being presented as literature shows that the caregiving process often causes severe emotional distress in the caregiver's life. This is especially true for female caregivers. Two female-caregivers in the study experience psychological distress as a result of caring for their loved ones:

> *"…I must say now after about…seven months we…are on the right track but ya severe emotional distress...at a stage it was so distressful and I realised I need something, I need to go and see a doctor otherwise I won't be able to survive…"* (Mia, Mother).

> *"…I've been on edge…trying to you know figure things out and make sure he doesn't have that episode again…I'm always scared that it's going to happen again…"* (Olivia, Wife).

In line with the literature, a high demand for care by the patient (Fekadu et al., 2019; Koutra et al., 2016), and feelings of being on stand-by (Mulud & McCarthy, 2017; von Kardorff et al., 2016) contribute to the caregiver experiencing psychological distress. Hegde et al. (2019) found that caregiver distress and the symptom-severity of the patient's disorder are related. It can be argued that these two caregivers experience significant amounts of psychological distress due to the fact that the patient's manic episode was both recent, and the first episode experienced by the caregiver. Although Olivia's husband was diagnosed with BD long before they got married, he had remained stable throughout their marriage. The participant noted that she *"actually forgot that my husband had bipolar till he had his first manic episode that I experienced last year".* In line with literature, psychological implications and distress are

particularly high among those caregivers witnessing psychosis/mania for the first time (Poon et al., 2018).

When viewed through the lens of the stress-coping model, the negative appraisal of their situation as a result of the demands placed on them puts these caregivers in a vulnerable position (Lazarus & Folkman, 1984). Without implementing adaptive coping strategies, these caregivers will likely develop psychological or physical illnesses (Szmukler et al., 1996).

4.3.1.3. Neglected needs and managing competing needs

It has been established that being a caregiver means neglecting one's own needs and prioritising the patient. As such, the researcher explored this to understand how caregivers describe their neglected needs. However, three caregivers presented a different perspective, explaining that life has to carry on:

> *"…life is normal, ah it carries on…*" (Liam, Husband).

> *"…I needed to continue with what I'm good at ya so… ya… you need to continue with your life. You need to find that middle way – how to still go on with your life and to be a caregiver for your bipolar patient..."* (Mia, Mother).

> *"…Umm to be a caregiver, well, I understand that life will not be normal...your life will never be the same as someone else's but that's okay, it doesn't have to be umm you just have to remind yourself it has…to become your normality…and then you get used to it. You know your life's not gonna be worse than before, you just do a few extra things…"* (Adam, Fiancé).

Research has shown that being the caregiver of a patient with BD means that one has to balance competing needs and overcome feelings of being needed and rejected simultaneously (Lewis, 2015; van den Heuvel et al., 2018). Contrary to what has been found in the literature (Graneheim & Åström, 2016; Shamsaei et al., 2015), some caregivers in this study did not struggle to find a balance between being a caregiver and maintaining their autonomy.

When considering Liam (husband) and Adam (fiancé), the researcher would argue that the possible reason for the positive adaptation is gender-related. It is well-cited in literature that men adapt to the caregiving role better than women do (Ayalew et al., 2019; Cassidy et al., 2014; Rahmani et al., 2018; Scott, 2013; Séoud & Ducharme, 2015). This will be discussed in in detail in the *Gender Differences* subtheme. Men often tend to be more resilient, allowing them to cope with their role as a caregiver in a more effective way (Mulud & McCarthy, 2017).

For Mia (mother), the researcher would argue that the participant is attempting to regain a sense of normality and control over her life. She had previously expressed how her life has been overthrown by her son's diagnosis. She also expressed how her son makes it known to her when he is unhappy with something she does, leaving her feeling somewhat worthless. By continuing to go to work and doing what brings her a sense of fulfilment, the researcher would argue that the caregiver is employing a positive, adaptive coping strategy. The act of keeping busy is described as a positive, and common, coping strategy used by caregivers of patients with BD (Hogan & John-Langba, 2016). It is important for caregivers to still feel a sense of worth in their life outside of their role as a caregiver. By teaching them ways to actively seek that fulfilment, it may be possible to lessen the implications faced by caregivers.

While some participants were able to strike a balance between being a caregiver and maintaining a sense of autonomy, it is noteworthy that five of the caregivers spoke about neglecting their needs without probing:

> *"…It feels as if you can't continue with what you want – what is urgent in your life now, he comes first…I want to say I became more of a servant to him…"* (Mia, Mother).

> *"…There was actually a period that was very strained…I was under a lot of pressure and well, your tank is empty, you've got nothing to give anybody else…you sort of get to a place where you are on autopilot…so you lose complete self-awareness. You don't even know what's going on in yourself with you know random even small needs…"* (Sophie, Mother).

As expressed by Mia (mother) and Sophie (mother), it is common for caregivers of patients with BD to sacrifice themselves and put the patient's needs above their own (Graneheim & Åström, 2016; Van der Walt & Carbonatto, 2019). However, what is interesting among these findings is that the two mothers in the study described great self-sacrifice. While there is contradicting research on the caregiving experience from a parent's perspective, the researcher would argue that for these mothers, self-sacrifice was experienced due to the sudden, increased dependence on them. As presented previously, Mia (mother) expressed that her son requires her to perform basic tasks again, which he could do in the past. Sophie (mother) noted that she had to relocate back to Johannesburg to care for her daughter, further stating that *"…it's sort of like having a child again…"*.

The researcher is of the opinion that the mothers in the study may be struggling to adjust to their role. Although the maternal instinct is to care for one's child, both patients are at the

age (14 and 22 years old) where the parent-child relationship would have matured to allow the child to become independent (Louw & Louw, 2014). BD is unpredictable, and neither of these mothers know how much longer they will be the primary caregivers for their children. Resultantly, this may cause increased levels of anxiety, as caregivers worry about the future of the patient, and who is going to look after them when the caregiver no longer has the ability to (Borowiecka-Karpiuk et al., 2014).

Neglected needs were different for Olivia (wife). For this caregiver, neglected needs took on the form of self-sacrifice in order to create a seemingly perfect environment for her husband:

> *"...so I have to make sure everything is perfect for my husband so things don't you know get out of control again. So, that is a challenge for me to keep the peace, to make sure he's okay, to make sure he doesn't get upset..."*

Graneheim and Åström (2016) found that caregivers take on additional responsibilities by creating positive life situations for the patient in order to prevent relapses. The researchers found that caregivers placed considerable pressure on themselves, often blaming themselves if the patient relapses. This literature is substantiated by Olivia's (wife) need to make sure everything is perfect for her husband so that he does not have another manic episode. Rahmani et al. (2018) claimed that the addition of the caregiving role places considerable pressure on women, especially when they already fulfil multiple other roles (such as being a mother and keeping house). Olivia (wife) described a sense of guilt when she did things for herself, which is in line with the neglect that wives in Rahmani et al.'s (2018) study experienced.

Based on the above, it is important for spousal-caregivers, wives in particular, to learn how to effectively cope with their role as a caregiver. Assuming multiple roles is a challenge, and when spousal-caregivers have children, they experience significantly greater implications (Rahmani et al., 2018). Having support systems in place will alleviate the implications of caregiving considerably.

4.3.2. Theme Two: Support Systems

Support systems were explored as a theme because their impact on the coping of the caregiver is well cited in literature. When the participants spoke about support systems, spousal support was mentioned:

> *"…My husband is very supportive, it's something he's never had to deal with in his life…but um he's also now learnt to look out for subtle signs and things…"* (Ella, Daughter).

> *"…I always say if we didn't have each other, if I was a single mom I don't know if I would have made it and if he was a single dad, I don't think he would have made it so because we are such a close family, I think if it wasn't for us being there for one another, um the challenge then would have been so much worse..."* (Mia, Mother).

The views of the participants are substantiated by research by Mulud and McCarthy (2017), who found that caregivers who were married (not to the patient) reported fewer implications than those who were divorced, widowed, or separated. The researchers stated that receiving support or assistance from a spouse may be beneficial as a source of financial and

practical support for caregivers (Mulud & McCarthy, 2017). Ella (daughter) and Mia (mother) indicate that their spouse has played a vital role in supporting them.

The researcher would argue that both of these caregivers still experience implications of caring for their loved ones, however, both are coping with their role better than some other caregivers in the study. This is a clear indication that having a solid source of social support greatly influences the appraisal of the demands faced by the caregiver (Szmukler et al., 1996).

4.3.2.1. Lack of support

For some caregivers, however, family support has not always been available:

> *"…his mother and his sister, they also still – I mean after all these years they still in a bit of denial so one of the situations also that was challenging was that he went on holiday with them…and we thought you know he's with family so he'll be fine, and by the time we got there over the weekend, he was completely psychotic…"* (Ella, Daughter).

> *"…my husband had an alcohol dependency…so he would drink. He wasn't really emotionally available because…he numbed everything…"* (Sophie, Mother).

The lack of family support can be understood from two perspectives. When considering the implications of the lack of familial support on caregivers, research has shown that a lack of social support places caregivers under significant strain (Ayalew et al., 2019; Mulud & McCarthy, 2017). For Ella (daughter), it can be seen that the caregiver cannot trust her family to take care of the patient, which causes severe implications, as the caregiver cannot share responsibilities with the family.

The researcher would argue, however, that the lack of family support should be considered from a different perspective. Much research has shown that BD affects not only the patient, but also all those living with them (Ntsayagae et al., 2019; Sharif et al., 2020; Sharma et al., 2016). It can be seen that Ella's (daughter) family and Sophie's (mother) husband use maladaptive emotion-focused coping strategies (Chakrabarti & Gill, 2002), leaving the caregiver to take care of the patient on their own. While much research has been published on caregiver coping strategies, to the researcher's current knowledge, there appears to be limited published research on how the rest of the family copes with a patient with BD. The researcher believes that a possible area worth further investigation is the coping strategies used by other family members. If these strategies are understood, interventions can be implemented in order to encourage family members to utilise adaptive coping strategies, which would consequently reduce the implications of caregiving for the primary caregiver.

While two of the caregivers had familial support in the past, this support system was no longer available to them, making caregiving a challenging task:

> *"…I needed someone because his parents…moved down to the Cape…just before lockdown…so I had to sort everything out here and I was…reluctant to ask my mom for help because I knew she would have something negative to say the whole time…."* (Olivia, Wife).

> *"…when the parents moved away that was difficult because I mean…to you know take over and I used to get the support from her mom on what to do in certain situations…or I'd be at work that was very difficult…she gets umm panic attacks…she would you know usually call her mom now she calls me and I'm busy with work and like…this is an*

important call I need to answer now and then I try to calm her down…so it's not that easy… without her parent's assistance..." (Adam, Fiancé).

The views of these caregivers are substantiated by Granek et al.'s (2018) research. It was found that partners of patients with BD require emotional and practical support from their parents and parents-in-law. These caregivers feel the lack of this support, and this has placed them both under additional strain. When viewing this through the lens of Lazarus and Folkman's (1984) theory of stress and coping, it can be argued that a lack of social support, compounded with a diminished relationship with their family, will lead these caregivers to have a negative appraisal of the demands they are faced with. The outcome of this appraisal will be determined by the coping strategies employed by each caregiver (Lazarus & Folkman, 1984).

4.3.3. Theme Three: Coping With the Patient

In order to understand how some caregivers handle their role better than others, different ways of coping with the patient were explored. For two caregivers, adaptation was their way of coping:

"...I think a lot of people should pay more attention to the behaviours everyday… if there's a change, change your own attitude…" (Liam, Husband).

"...we needed to adapt quite a lot in the way that we… handle him and the first word that comes to mind is patience…um we need to be patient...we can't fight anger with anger…" (Mia, Mother).

Research shows that caregivers adapt in order to accommodate the patient's needs (Graneheim & Åström, 2016). The researcher would argue that the use of adaptation as a coping strategy could either be destructive or constructive, depending on the context in which it is used. When caregivers adapt as a means of problem-solving, they are said to be utilising a problem-focused strategy (Chakrabarti & Gill, 2002). In this instance, their adaptation would be considered constructive. On the other hand, if adaptation is used as a means to avoid a situation and balance their own emotional response, caregivers are utilising destructive, emotion-focused strategies (Chakrabarti & Gill, 2002).

Interestingly, in line with literature, the male caregiver is utilising a problem-focused strategy, while the female caregiver is utilising an emotion-focused one (Mulud & McCarthy, 2017). The researcher notes that the use of maladaptive coping strategies depends on various factors, one of which is the patient's level of functioning (Chakrabarti & Gill, 2002; Dadson et al., 2018; Hedge et al., 2019). The patient that Liam (husband) is looking after exhibits low levels of dysfunction, which may explain how he is able to implement effective coping strategies. Furthermore, he has been in the caregiving role for a longer period of time than Mia (mother) has, providing another possible explanation for the adaptive strategies (Chakrabarti & Gill, 2002).

What the researcher found noteworthy was that justification of the patient's behaviour was Ella's (daughter) way of coping with the father's behaviour:

> *"…When he's stable again you know, he's not like that and I just sort of try to…justify that persona of him when he's like that and say you know that's part of the condition…he's not purposefully trying to be hurtful or to be difficult…I think that sort of helps to deal with it, but…it still sucks, it's not… a nice experience…"*

Mulud and McCarthy (2017) state that less severe implications were reported by caregivers when they realised that their loved one's conduct was brought about by the illness rather than the patient's personality. Based on Mulud and McCarthy's (2017) research, the researcher would argue that justification should be considered as a coping strategy that would make the caregiving experience less stressful for the caregiver. This is somewhat contradictory to what Ella (daughter) says, as she explains that justifying her father's behaviour helps her cope with the mania, however, the experience remains unpleasant.

When considering this experience through the lens of the stress-coping model, it is important to note that the caregiving experience is considered as the appraisal of the demands faced by the caregiver (Szmukler et al., 1996). As the child of a patient with BD, this caregiver has experienced her father's manic episodes throughout her life. Throughout the interview, she recalled negative experiences brought about by her father's mania. A lack of family support may have contributed to the negative appraisal of the situation for the caregiver. The researcher would argue that taking on the role of her father's primary caregiver without family support caused a significant disruption in this caregiver's life, which is noted as one of the main stressors for caregivers (Szmukler et al., 1996). In lieu of an effective coping strategy, and with the presence of multiple stressors, a lack of support, and a negative appraisal of the situation, the researcher notes that this caregiver is at risk of her mental well-being being affected by caregiving.

The research on child-caregivers of parents with BD is lacking, and the researcher believes that this is an area that is worth investigating.

4.3.3.1. Gender differences

An interesting finding was the contrasting experience of caregiving between males and females. For two females in the study, the need to run away came about unprobed:

"...you know things haven't been easy so ya sometimes I just wish I could just get in my car and just drive and enjoy the drive on my own and not have to worry about anything... but unfortunately that's not...the life that I've been dealt with at this stage so I must deal with it..." (Olivia, Wife).

"...there was many days I thought no I'm going to take him with me and we are going to go away and we are not going to come back..." (Mia, Mother).

When asked about what she wanted to go away from, Mia answered:

"Umm from the situation, from the bad situation at home because some days nothing that you say, nothing that you do is good enough umm... and he will tell you that...."

Research has shown that being the caregiver of a BD patient means that one has to balance competing needs and overcome feelings of being needed and rejected simultaneously (Lewis, 2015; van den Heuvel et al., 2018). Graneheim and Åström (2016) found that when the relationship with the patient becomes particularly challenging, caregivers may experience thoughts of escaping the situation. However, they realise that running away is not an option as they cannot give up on their loved one (Graneheim & Åström, 2016).

While both caregivers expressed the need to escape, Mia (mother) expressed that she wants to take the patient with her, while Olivia (wife) described wanting to be alone. The researcher would argue that these differences may result from the caregiver's appraisal of the demands they are facing. Olivia (wife) has expressed that she has taken on additional responsibilities since her husband's manic episode. It may be possible that the caregiver does

not feel that she has the available resources to deal with the additional responsibilities. The need for solitude may be her way of reducing the demands she is facing.

When considering the need to escape with the patient, it can be said that the mother-caregiver may feel that caregiving for her BD son, as well as fulfilling her other roles (wife, mother to her other child) exceeds her available resources. The possible overwhelming demands placed on the caregiver can be seen when she expresses:

> *"…I needed to guide and to assist my husband as well okay, so it was not only the children, it was my husband as well…like I felt like he needs guidance, what to say to my son…"* (Mia, Mother).

Graneheim and Åström (2016) found that caregivers explained that their tasks were to comfort, guide, and protect the patient. Mia (mother) can be seen to be engaging in these tasks, however, she also feels the need to assist and guide the rest of her family, adding to her responsibilities as a caregiver. It is possible that she may feel the need to escape from her other roles in order to have the resources to care for her son.

On the other hand, the two male caregivers had different experiences:

> *"…For me, it's been able to encourage her to keep going…umm… that's always the most difficult part for a bipolar patient…and she knows that she can't give up because she'll lose me… and she sees me as her only – the only thing worth living for, in her life…*" (Liam, Husband).

> *"...if you are in a relationship and you love them umm you kind of have an advantage because you can do quite a lot for her or him..."* (Adam, Fiancé).

There is a scarcity of research examining the rewards of caregiving (Bauer et al., 2015). Vargas-Huicochea et al. (2018) present an interesting perspective on the potential, underlying rewards of being a caregiver for a patient with BD, which aligns with what the male caregivers in the current study experience. The researchers found that the true power of the caregiver-patient relationship lies in the fact that the caregiver is often assigned the primary task of caring for, and containing, the patient with BD disorder. If we consider it in this way, caregivers find the motivation to endure their role when they view themselves as the sole providers for the patients, and the one who is totally responsible for caring for the patient. When placing themselves in this position of power over the patient, caregivers maintain an attitude of resistance and immutability, bringing about rewards that the caregiver is not always aware of (Vargas-Huicochea et al., 2018). The researcher believes that the caregiver-patient power dynamics are worth investigating further, especially when the caregiver is a male.

4.3.4. Theme Four: Social Implications

Literature has shown that caregivers face many social implications when caring for patients with BD. One such implication is that they spend much of their time with the patient. Participants explained that the patients did not want to be left alone:

> *"...I have to be there for her so she doesn't necessarily want to be alone all the time and I have my hobbies, which are different so we don't always share the same hobbies, which can make it a challenge…because I spend time with her and I'm like okay well I*

don't want to do this, I would rather want to do my own thing and then we have to now kind of like compromise and that can sometimes be a challenge..." (Adam, Fiancé).

This coincides with research by Mulud and McCarthy (2017), who found that the more time caregivers spend caring for the patient, the less time they have to engage in social activities. Adam (fiancé) expresses that the time he spends with the patient leads to self-sacrifice. Interestingly, this was the second time this participant mentioned self-sacrifice in the interview. Research has shown that male caregivers often experience constraints on their autonomy when their partner has BD (Yadav et al., 2018). It can be seen that this is something that Adam (fiancé) does struggle with in his role as a caregiver. Considered through the lens of the stress-coping model, it could be argued that the constraints on his autonomy would be a stressor for this caregiver, as it ultimately causes a disruption in his life (Szmukler et al., 1996). The researcher would argue that the caregiver's compromise in this situation is an emotion-focused strategy, which will ultimately cause the caregiver to have a negative appraisal of his role as a caregiver.

The two mothers in the study explained:

"...I want to say he don't want to be left alone. At the beginning we couldn't leave him alone okay and now he doesn't want to be left alone... I want to say it's time ..." (Mia, Mother).

"...there was a stage where I had to say you have to bath, now I'll sit with you in the bathroom because she just didn't want to be alone and it was – she had this thing about

– she stopped driving even, so umm ya there wasn't – I think that that more fell on me…" (Sophie, Mother).

Reinares et al. (2016) claim that the unpredictable nature of BD makes caregivers neglect not only their needs, but the needs of the rest of their family. Both mother-caregivers experience increased patient demands, primarily related to the time they spend with them. Interestingly, they both expressed how their other children have been neglected since they became caregivers for the BD patient, leading them to feel guilty. Attempting to manage and contain the patient with BD while simultaneously giving attention to the rest of the family is an exhausting process, and without the implementation of adaptive coping strategies, caregivers are at risk of developing psychological or physical illnesses (Szmukler et al., 1996). It is imperative that caregivers and their families are equipped with the information and tools they need to adjust to the patient effectively and adequately.

4.3.4.1. The impact on the household

It has been established that BD does not only impact the caregiver, but also others living with the patient. This sub-theme was explored to understand how living with a patient with BD impacts the household.

The impact on the household is caused by the patients' erratic behaviour, as described by Mia (mother) and Olivia (wife):

"…when I think back at the beginning…our whole uh household was totally on its head... we ran around in this house looking after him…he was in a…very bad state, in a manic depression that we don't want to go through ever again…" (Mia, Mother).

> *"...something made him very aggressive...and I was scared he was going to do something to [caregiver's son] because he wasn't – my husband wasn't himself...I'm very scared at what [caregiver's son] remembers and sees and I don't want him to know his pappa like that because that's not who his pappa is..."* (Olivia, Wife).

The views of these participants are in line with research by Reinares et al. (2016), who found that the family equilibrium becomes unbalanced, and the family has to adjust to the patient's current state every time the patient relapses. As has been established, both of these caregivers have only witnessed one manic episode, which was recent for them. The experience expressed by Olivia (wife) is particularly noteworthy. It has been found that wife-caregivers experience their husbands with BD as becoming unrecognisable during their manic episodes, which results in anger towards the patient (Naqvi et al., 2021). Research has also shown that the aggressive behaviour displayed by patients may lead to the caregiver developing depression (Liang et al., 2016). However, to the researcher's knowledge, the caregiver's fear for their child's safety has not been well researched.

The researcher is of the opinion that this is an area worth further investigation, as the addition of this stressor may potentially have negative implications for the caregiver.

4.3.5. Theme Five: The Caregiver-Patient Relationship

The relationship between the caregiver and the patient is a complex one. As such, this was a theme worth exploring in-depth.

For Ella, being the daughter of a patient with BD means that the parent-child role is switched:

"…It's something where I have to be a bit more mindful of his emotions and his coping strategies…I feel like to a certain extent sometimes the parent-child role, is a bit you know skewed because he can't take on as many responsibilities, so I have to take on a lot more responsibility for him…"

There is a scarcity of research on the implications of being the child-caregiver of a parent with BD. It has, however, been found that children of parents with BD are at a particularly high risk of suffering from psychosocial difficulties if they are the patient's only caregiver (Bauer et al., 2015).

The researcher is of the opinion that child-caregivers require attention in future research, as the impact of caring for a mentally-ill parent has long-lasting implications for the child-caregiver, and impacts their health and relationships in adulthood (Fekadu et al., 2019). For the child-caregiver to effectively cope with their role, attention should be given to ways to support the caregiver, which will ensure that their health and relationships in adulthood are less impacted, essentially reducing the implications of being a caregiver.

When the patient is their significant other, caregivers experience a strained relationship. Adam (fiancé) describes the strain as follows:

"…I'm not just a caregiver, I'm like, in a relationship with her…there's times where it feels like I'm literally a caregiver, and you know it puts a strain on the relationship, because you know I'm gonna be in a relationship with them so I'm gonna do more than just caring and giving, I want to have an actual relationship. So, there's been times where I was like – ah I feel like I'm just looking after someone, I don't want to feel like that. I want to feel like I'm in a relationship with someone..."

The caregiver appears to be battling with the transition to "carer-cared for", as described by Pompili (2014, p.5). When taking on the role of a caregiver for a patient with BD, one has to learn how to balance the responsibility of caring and the interference it is going to cause in one's previous routines (Rahmani et al., 2018). The researcher would argue that this caregiver was somewhat unprepared. He explained that he moved in with the patient very early in their relationship as her parents wanted to see if he could handle her BD. However, her parents lived on the same property during that time, and he had them as a support system. As seen in the support section, the caregiver explains how he took on many additional responsibilities when the patient's parents moved away. He also expressed in the interview that he was required to take on responsibilities that he was not ready for. It can be said that he shared the caregiver duties with the patient's parents, and therefore did not fully comprehend the requirements of the role until he became the primary caregiver.

Interestingly, this participant expressed that being in a relationship with a patient who has BD puts the caregiver in an advantageous position as it allows the caregiver to do a lot for the patient. It could be argued that there is a masculine need to look after their partner, hence this caregiver is experiencing his role in this way.

Olivia, being the only wife in the study, highlights an important impact on the relationship between her and her husband:

> *"…I am the main breadwinner, I am the main decision maker…I am now head of the house…I'm the main everything which is a lot of pressure on me…I do sometimes wish um that I could just take a back seat and he can take responsibility and make decisions and everything because…it's a lot of weight on my shoulders…"*

Olivia's (wife) view is supported by Rahmani et al. (2018), who found that wives experience significant financial strain because their mentally ill husband served as the breadwinner prior to the onset of their illness. The loss of financial security and the need to juggle various responsibilities causes significant implications for female spousal-caregivers (Rahmani et al., 2018). When viewed through the lens of the stress-coping model, the additional stressors placed on the caregiver, the use of an emotion-focused strategy (wishful thinking), and the lack of social support may be why this caregiver has a negative appraisal of caring for her husband. The researcher believes that without intervention, this caregiver is at risk of developing psychological or physical illness as a result of being a caregiver (Szmukler et al., 1996).

An interesting finding is that Liam (husband), Olivia (wife), and Adam (fiancé) all express that they are in a long-term, committed relationship with the patient, and that they do not see their partners in a different light because of their diagnosis:

> *"…So…to me…I still love the same person…I just felt like… I was sorry for her… I mean umm to me personally she didn't change umm… still the person that I love, still the person that I want to spend the rest of my life with…*" (Liam, Husband).

> *"…I don't think it's a sacrifice…I knew he had bipolar before I married him umm it's part of that you know commitment when marrying somebody you know in sickness and in health …"* (Olivia, Wife).

> *"...marriage is long term it's like forever, you can't just like drop out, they wanted to make sure that I don't hurt her and that she doesn't hurt me, either and they wanted to make sure I can handle this..."* (Adam, Fiancé).

It has been established that being married to a patient with BD presents a different set of challenges for the caregiver (Granek et al., 2016), with Pruchno and Resch (1989) claiming that spousal-caregivers are particularly vulnerable due to the fact that they have the most investment in the relationship with the patient. For the spousal-caregivers in this study, the commitment they made to the person was held in a higher regard than the patient's diagnosis. It can be argued that the caregivers have adopted an attitude of acceptance and non-judgement in order to cope with their partner's diagnosis. In doing so, they continue to view their partner as a person, and not as their disorder.

4.3.6. Theme Six: Stigma

Interestingly, the participants in this study have never experienced stigma from the wider community. However, stigma within the family was common for many participants, as explained by Olivia (wife):

> *"...I told my mom then just like two or three days afterwards and she says do you really want to date someone with bipolar and that hurt me a lot because you know I wanted her to be happy for me and I like somebody and…she brings it up often when things go wrong. She says yaaa you knew he had bipolar, and I thought you know it's unfair…to throw that in my face the whole time …"*

In line with Sharif et al.'s (2020) findings, stigma towards the caregivers came from family members more than from society. Iseselo et al. (2016) claim that there is a relationship

between the social support caregivers receive and the stigma associated with having a mentally ill relative. This is in line with what Olivia (wife) experiences in her role as a caregiver, as she explains her mother's disapproval of her relationship. It has been seen throughout the presented findings and discussion that this caregiver has had a particularly negative appraisal of the caregiving process. Mulud and McCarthy (2017), as well as Siddiqui and Khalid (2019), found that the stigma experienced by caregivers adds to their already challenging tasks as a caregiver. It is, therefore, important to educate not only the caregiver, but also the extended family, on BD so as to reduce the stigma associated with the disorder.

For two participants, the stigma that the patient experiences is challenging for them to deal with:

> *"…it was more seeing the stigma that he had to deal with that affect me, than the condition itself…"* (Ella, Daughter).

> *"…when I look at umm people, if you say no your child is bipolar, how they just start treating that person like they're crazy and irrational, even when that behaviour – they've never seen any of the mania or the depression or the psychosis. Umm that is quite a difficult thing to deal with…"* (Sophie, Mother).

It can be said that these two participants are experiencing affiliate stigma, which is the process whereby caregivers are affected by the stigma regarding mental illness in society (Grover, Aneja et al., 2019; Grover, Avasthi et al., 2017). Affiliate stigma may lead to caregivers concealing the patient's diagnosis from family members, among other things (Grover, Aneja et al., 2019; Grover, Avasthi et al., 2017). The researcher would argue that this

concealment places additional stress on the caregiver as they will not be able to reach out to their support system to ask for help and will need to take on the caregiving responsibilities by themselves.

Contrary to research by Singh et al. (2016), which found that parents experienced more stigma than other caregivers, caregivers in this study appeared to be similarly affected by stigma, irrespective of their relationship to the patient. While Grover, Aneja, et al. (2019) found that one-third of the caregivers of BD patients in their study experienced courtesy or affiliate stigma, 5 of the caregivers in this study described being stigmatised. This is an interesting finding as Grover, Aneja, et al. (2019) claimed that higher caregiver stigma was associated with lower caregiver income. As such, it would be expected that the caregivers in this study would not report high levels of stigma since the study focused on middle-class, urban caregivers. The researcher would then argue that, based on the findings from this study, caregiver income may not be related to the level of stigma experienced by the caregiver. This is an area that should be investigated further as stigma causes considerable implications for the caregiver.

4.3.7. Theme Seven: Financial Implications

Financial implications were explored as the researcher wanted to understand whether middle-class, urban caregivers had different experiences from those caring for patients in rural settings. When the participants spoke about the financial implications of caring for a patient with BD, three said:

> *"...the medication it uh is a HUGE amount okay and remember now, it was not only my son that needed the medication, my daughter as well just for her anxiety okay but basically for [patient], medication and then obviously the au pair and ALL the extras*

that we needed…to give the au pair to do things with him to keep him busy during the day that was an enormous amount ya… but by grace, we have survived..." (Mia, Mother).

"…but still does not have a job so financially it's…killing us so ya it's been a very negative experience…I'm very lucky I work at a private school…we do have good salaries but from going from two incomes to just one…I've had to…take money out of my trust fund which I had – didn't want to do and I've had to do it three or four times. So my trust fund which is supposed to be for later on in life is being gobbled up now just for us to live…" (Olivia, Wife).

"…she can't really work permanently, she's at home... before I met her, I always had spare money…at the end of the month then I met her…it becomes really difficult financially to keep up and I just kinda wish that I'd..I made more money to you know keep her happy or to you know to keep her going because I don't have the finances to help and even though I want to…" (Adam, Fiancé).

The views of the participants are substantiated by research by Vargas-Huicochea et al. (2018), who found that BD caregivers experience severe financial implications due to treatment-related costs and a lack of productivity on the patient's behalf.

Mia (mother) presents different financial implications to the other caregivers. For this participant, quitting her job to care for her son was not an option, however, the patient was unable to attend school due to his condition. Therefore, the caregiver had to employ an au-pair to look after the patient while she was at work, incurring considerable financial costs. It can be seen that the financial implications are experienced in a more negative light by Olivia (wife)

and Adam (fiancé). The researcher would argue that since Mia (mother) is married and her husband works full-time, there are two sources of income to sustain the household and provide for the patient. On the other hand, Olivia (wife) and Adam (fiancé) are the sole providers in their homes as the BD partners are unable to work. The patient's loss of productivity places the caregiver under significant strain to take on the responsibility of providing for the household by themselves.

The other three caregivers in the study did not experience financial implications:

"…So, if he is to go on shopping sprees and be a little bit erratic in that sense, um they [patient's mom and sister] always sort of just cover his expenses… which helps us to not have that financial stress…even though he's on pension, he's on quite a good medical aid plan that really covers all his medication, all his doctor's appointments…" (Ella, Daughter).

"…she keeps feeling like she can't go to work and is letting me down or letting us down… financially. Umm…but I don't see it as a problem at all. I – we – I don't earn a bad salary I'll be honest and umm and it's good enough for – to keep us going so you know there's no issues really…" (Liam, Husband).

"…Now we supporting her, she gets an allowance and she's living back with us umm…we paid the varsity and everything and we are in a..fortunate position where we have…– we are in a position to do…you know, more than enough. …" (Sophie, Mother).

The views of these caregivers contradict the majority of the published research, which claims that caregivers experience financial implications as a result of caring for patients with BD (Addo et al., 2018; Masa'Deh, 2017; Vargas-Huicochea et al., 2018). For Ella (daughter), the patient's erratic spending behaviours are covered by his family, thus the caregiver does not take on that responsibility. She explains that his family is in a fortunate position, and therefore is able to cover the costs he incurs without it being an implication for them. For both Liam (husband) and Sophie (mother), caring for the patient is not seen as a financial implication due to the financial position of both caregivers.

It is noteworthy that Liam (husband) has a very different experience to Olivia (wife) and Adam (fiancé), all of whom are caring for their partners with BD. The researcher would argue that Liam (husband) is in a significantly higher paying job than his counterparts, therefore alleviating the financial implications of the patient not working. It can be argued that even among those middle-class caregivers, different income levels greatly impact the implications of caring for the patient.

4.3.8. Theme Eight: Caregiver Needs

In order to understand what caregivers need to make their role more manageable, this theme was explored. The need for support was voiced by the caregivers:

> *"…Definitely a support system. I want to say like we had okay… we had now a very young boy with bipolar disorder but if – I must say, so if it wasn't for the support system um definitely, we wouldn't – we would not been able to survive..."* (Mia, Mother).

> *"…Definitely umm… an – a good support system for the caregiver…I think support is the biggest – support and information… is the biggest need…"* (Olivia, Wife).

> *"…I think definitely support groups. I don't know a lot of support groups like this where we umm caregivers can go and speak umm or even online support groups…"* (Sophie, Mother).

It has been established throughout the results and discussion that support is essential in the caregiving process to help the caregiver effectively cope with the demands placed on them. The need for a support group was expressed, and this is a social support system that the researcher believes will be beneficial to caregivers of BD patients, especially those who lack familial support.

The caregivers explained how important it is for them to take care of themselves:

> *"…Like you see caregivers burn out so often from…a psychiatric condition so I mean really, if you not going to take care of yourself, you going to end up with some or other condition as well… I definitely think like a proper self-care plan or like ways you can – tips and tricks of what you can do…"* (Ella, Daughter).

The caregivers in this study were able to indicate the importance of self-care, however, the implementation is something that is lacking. There is a need for caregivers to learn how to practice self-care so that they are able to meet the demands of their role. Practising self-care will also enable the caregivers to have a more positive appraisal of the caregiving experience, thus making them less likely to develop psychological or physical illnesses as a result of the caregiving process.

The need for information on how to handle the patient was also mentioned by the participants:

> *"...I think uhh…tips and tricks of how to deal with a manic or psychotic phase in the situation…"* (Ella, Daughter).

> *"...like information and stuff on different scenarios, on how to deal with stuff, what to look for, umm and just also making sure that that person is fine as well emotionally, mentally…"* (Olivia, Wife).

> *"...and umm ya just all the information...the positive, the negative, the – all of it – information tools, tools probably, tools for making things easier and then also tips…"* (Sophie, Mother).

Educating caregivers on what to expect during different phases of the disorder will allow them to develop more adaptive coping strategies. By equipping them with the knowledge and skills they require to take care of the patient, and thereby providing them with resources they did not have before, caregivers may feel less overwhelmed by the demands of caring.

4.4. Conclusion

This chapter presented various themes and subthemes that emerged from the interviews conducted with the participants. Some of the themes were predetermined as the researcher set up the interview schedule hoping to elicit specific information. In other words, even though the interview questions were open-ended, they were designed by the researcher in such a way to elicit the participants to discuss themes specifically relating to the psychological and social

implications of caregiving. The two mothers in the study have similar experiences as caregivers, while the only wife in the study experiences significantly greater implications in her role as a caregiver. The two male caregivers have adapted to their roles better than the females, which is in line with published literature. The theme of financial implications was interesting in this study, as these implications varied among the respondents. With no published research on middle-class, urban caregivers of patients with BD in South Africa (to the researcher's knowledge), there is no literature with which to compare these findings. The researcher found it interesting that five of the participants spoke about neglecting their needs without any probing from the researcher, yet they also acknowledge the importance of self-care and being aware of their mental state. The participants in this study expressed the need for support groups, which are lacking in the country. Whilst the findings of this study were in line with much published research, the researcher notes that there is a scarcity of literature covering some of the themes and subthemes presented above, and therefore further research should be conducted.

Chapter Five: Conclusion, Limitations, and Recommendations

5.1. Introduction

This chapter will provide an overall conclusion of the study, recommendations for future research, and limitations encountered while conducting the research.

5.2. Limitations

Some limitations of the study should be acknowledged. Due to the fact that there are more females than males in the study, the study may be seen as stereotypical. A lack of male participants meant that the data became dominated by female experiences. Although there are disproportionately more women among the participants, this reflects the growing importance of caring duties for women in society as a whole. It also highlights the greater need to assist female caregivers and lessen the disparity in the toll that caregiving takes on different genders.

Recruiting participants presented a challenge in this study. Despite reaching out to 15 psychiatrists and psychologists in private practice, only four agreed to act as gatekeepers. The other practitioners failed to respond to the researcher's request for them to act as a gatekeeper. Of the four who agreed, only three returned gatekeeper permission forms (Appendix G, H, I). Furthermore, one gatekeeper referred potential participants who did not meet the inclusion criteria. The use of a different method of recruitment should be considered in future studies.

The researcher acknowledges that the participants do not represent the South African population in terms of race and culture groups, and therefore it is possible that the results are somewhat biased towards a particular population. It will be beneficial to consider caregivers of different races and cultural affiliations in future, as the way we view the world is shaped by such demographic characteristics.

5.3. Recommendations and Implications for Future Research

Upon analysing the data collected for this research, the current study has found some areas that may be worthy of investigating in the future. While there are many commonalities across the caregivers' lived experiences, an important finding from this study is that each carer's experience is unique and complex. Despite the fact that this study represents a wide range of experiences, including bipolar disorder (BD) type (and patient's level of functioning), caregiver gender and role, time since diagnosis, and caregiver age, it may be advantageous for future research to concentrate on more specific experiences in order to better understand how they differ from one another. For instance, future research may concentrate entirely on adult-child caregivers as a specific type of caregiver interaction.

The experience of stigma in this study was contrary to published literature, which found that the experience of stigma is directly related to the caregiver's income (Grover, Aneja, et al., 2019). As such, it was expected that the caregivers in this study would not experience high levels of stigma, yet stigma was prevalent among the sample. It is possible that caregiver income may not be related to the level of stigma experienced. This is an area that should be investigated further as stigma causes considerable implications for the caregiver.

The results of this study found that a position of power was assumed by the male caregivers. The caregiver-patient power dynamic is an area that should be explored further, especially when the caregiver is a male.

A need for support was brought up by the caregivers. The results presented in this study revealed the varying levels of support experienced by the caregivers and the effects of the lack of support. The caregivers highlight the need for a caregiver support group, which is not available in South Africa. This highlights the lack of support from mental health professionals. Caregiver support is an area worth investigating further in future.

Medication, and adherence to medication, came up in several interviews. This could not be explored in this study as it did not align with the research question. However, it would be beneficial to investigate this in the future.

The use of semi-structured interviews appeared to give the participants the space to share their experiences; a space which they have not been given in the past. The current study highlights the need for more research on this group, especially in the South African context where there is a scarcity of literature. Urban, middle-class caregivers should not be neglected, as their experiences are valid, and they face many implications of being a caregiver.

5.4. Conclusion

The current study sought to understand the lived experiences of middle-class caregivers regarding the psychological and social implications of caring for patients with BD, particularly in Gauteng, South Africa. In order to do this, semi-structured, in-depth interviews were used. The data from these interviews were analysed using IPA. This analysis highlighted various themes which the researcher felt were able to fulfil the aim of the research. The data provided interesting insights into how caregivers experience their role, and the various psychological and social implications of caring for a patient with BD.

For the caregivers in the current study, managing the patient's unpredictable behaviour and dealing with the varying symptoms of the disorder presents a challenge. They described the caregiving role as an emotional rollercoaster, signifying the chaotic, up-and-down nature of the disorder. The expressed feelings of anger and frustration, and the reasons for these emotions were different when different relationships with the patient were considered. The only wife in the study expressed anger at the fact that she has had to sacrifice many things in her life, and she blames her husband (and his condition) for this. On the other hand, one mother in the study expressed anger at the need to take on additional responsibilities. Throughout the

findings of this study, the researcher would argue that there are many similarities between being a mother-caregiver and a wife-caregiver and suggests that this should be investigated further as the findings of this study are somewhat contradictory to published research (Ayalew et al., 2019).

The two participants who expressed anger and frustration were also the only participants who brought up feelings of distress in the interview. The researcher previously argued that the feelings of distress for these two women in particular were brought about by the fact that their respective patient's episode was recent. The researcher would argue that attention needs to be paid to caregivers experiencing the patient's mania for the first time. Caregivers are often not equipped to deal with the patient when they are in a manic state and need guidance on what to do in these situations. As has been seen in the public sector (Lekoadi et al., 2019; van der Walt & Carbonatto, 2019), patients in the private sector are also being discharged from hospital and sent back to their family homes while they are still unstable. This has significant implications for the caregiver, especially if they lack the necessary information and education about BD.

When considering the support caregivers in the present study receive, having a solid source of social support greatly influences the appraisal of the demands faced by the caregiver. The caregivers who have social support appear to have adapted to their roles better than those caregivers in this study without any form of social support. This indicates the importance of a support system for the caregiver. While some caregivers experience a lack of support from their families, adding to the implications of caring for the patient, the researcher identified that there is a gap in the literature studying the way other members of the family cope with the patient. This is an area that deserves attention as it will allow for interventions to be implemented that will encourage the rest of the family to utilise adaptive coping strategies, thereby alleviating some implications faced by the caregiver.

The current study found that it is vital for caregivers to have social support and implement adaptive coping strategies to minimise the implications of caring for a patient with BD. Justifying the patient's behaviour was how the daughter in the present study copes with her father's behaviour. The researcher found that literature on adult-children who are caregivers for their parents with BD is scarce. This area should be investigated further as the experience of the child-caregiver in this study is somewhat contradictory to the literature that can be found (Mulud & McCarthy, 2017). Being a child-caregiver with a lack of familial support, and simultaneously navigating the changing parent-child relationship is a challenge for the participant in this study.

Caregivers in the study experienced strained relationships with the patient when the patient was their significant other. For the wife in the study, she became the primary breadwinner, which had severe implications for her and her relationship with her husband. Interestingly, the three partner-caregivers explained that they do not view their partner differently because of their diagnosis, and all value their long-term commitment to the patient. This is contradictory to published literature, which has shown that the divorce rate is high when one is married to a partner with BD (Granek et al., 2016). For the wife-caregiver in the study, it can be argued that she has faced the most significant implications, yet she is firm in her stance that she will not leave her husband. She remains hopeful and explains that she knows who he was and who he can be again.

Stigma from the wider community was not experienced by the participants in the study, however, stigma from the family was common among many caregivers. Stigma was either in the form of the caregiver being warned about the patient's disorder, or alternatively, family members treating the patient differently. Both forms of stigma affected the caregivers, with both having similar end results: a lack of support for the caregiver.

The financial implications experienced by middle-class caregivers varied. Three caregivers experience financial implications yet had vastly different experiences. The researcher argues that the caregiver who has a somewhat manageable experience has a husband who provides a second source of income. The other two caregivers are the sole breadwinners in their homes due to the patient's loss of productivity, and therefore have negative appraisals of their demands. The other three caregivers in the study experience no financial implications, which contradicts most of the published literature (Addo et al., 2018; Masa'Deh, 2017; Vargas-Huicochea et al., 2018). It is noteworthy that the caregivers in this study, albeit all from the middle-class, have vastly different income levels. The caregivers, therefore, experience different financial implications.

In line with literature (Cassidy et al., 2014; Mulud & McCarthy, 2017; Scott, 2013), the males in the current study have adapted to their role more positively than the females have, primarily due to their use of adaptive coping strategies. Interestingly, two females in the present study expressed the need to run away. Both of these caregivers experience challenges with balancing competing needs and fulfilling multiple roles. While one caregiver expressed the need to escape with the patient, the other wants to escape alone. The researcher argues that this is due to each caregiver's appraisal of the demands she is facing, along with her understanding of the resources available to her. It was found that the two males assumed a position of power over the patient. Interestingly, neither male in the study expressed the need for a support system, even though one male caregiver expressed challenges in his role since he lost the support of the patient's parents. The researcher would argue that traditional male gender roles, especially in South Africa, make it difficult for men to ask for help. Although it is clear that the men in the study have adapted well, the fiancé is facing some challenges, especially financially and with his loss of autonomy. It is therefore important not to neglect men when creating interventions for caregivers of patients with BD.

Along with the need for information on how to handle the patient, the caregivers in this study expressed the need for support groups. There is a scarcity of support groups for caregivers of patients with BD in South Africa (Lekoadi et al., 2019), and this is something that should be strongly considered. Caregivers understand the importance of self-care but are unsure of how to implement such self-care routines. Having a psycho-education-based support group may be of significant benefit to this cohort of caregivers, as the implications they face in their role as a caregiver have been shown to be extensive.

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Appendices

7.1. Appendix A: Participant Information Sheet

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

School of Human and Community Development Department of Psychology
T +27 11 717 4503/53 | E psych.SHCD@wits.ac.za |

Participant Information Sheet

Dear Sir / Madam,

My name is Mikaela Nicolau and I am a Masters student in Social and Psychological Research at the University of the Witwatersrand, Johannesburg. As part of my studies, I have to undertake a research project, and I am investigating *"The lived experiences of caregivers: psychological and social implications of caring for patients with Bipolar Disorder"* under the supervision of Dr Mambwe Kasese-Hara.

What is this study about?

The aim of this research project is to explore the lived experiences of caregivers regarding the psychological and social implications of caring for patients diagnosed with bipolar disorder, particularly in Gauteng, South Africa. In terms of the psychological implications of caring for a patient with bipolar disorder, I will ask you questions about the emotions you have experienced as a result of caring for the patient (the topics under investigation here are sadness, anxious feelings, and distress). Regarding the social implications of caring for a patient with bipolar disorder, I will ask you questions about any stigma you may have experienced as a caregiver, the possible financial implications you have faced, and whether there have been any changes in your family functioning since the patient was diagnosed.

What will I be asked to do if I agree to participate?

As part of this project, I would like to invite you to take part in an interview conducted by me. This activity will involve a once-off, online interview. Should you prefer a face-to-face interview, I have organised a private, soundproof room at Evexia Psychiatric Day Hospital in Midstream which will be set up according to COVID-19 prevention guidelines; both you and I will wear a mask throughout the interview. The interview should take around 60-90 minutes.

Would my participation in this study be kept confidential and anonymous?

The interview will be completely confidential as I will not be asking for your name or any identifying information, and the information you give to me will be held securely and will only be accessible by myself and my supervisor. I will be using a pseudonym (false name) to represent your participation in my final research report.

Audio recordings

With your permission, I would like to audio record the interview using a digital device. This recording will be stored in a password protected folder on my laptop and only myself and my supervisor will have access to this recording. It will be deleted after I have transcribed and analysed your interview. The transcription from your interview will be anonymised and I will delete the transcriptions I have made after the final submission of my project.

What are the benefits and risks of this research and may I stop participating at any time?

Your participation in this study is voluntary. You will not receive any direct benefits from participation but there are no disadvantages or penalties if you do not choose to participate or if you withdraw from the study. You may withdraw from this study at any point during the interview and for a week after your interview. You may decline to answer any question you do not feel comfortable answering. If you experience any distress or discomfort at any point in this process, we will stop the interview or resume another time. If you need some support or debriefing following the interview, these are available free of charge at Evexia Psychiatric Day Hospital. Please call the hospital on 012 348 8200 and request to speak to Winston Schoeman (principal Clinical Psychologist). He is aware of my study and will be able to provide you with support or debriefing. If you need emergency support, the Evexia phone lines are operational 24/7, however Winston will not be available to you after hours and you will be referred to the Registered Nurse on call.

Will I receive payment or any incentives for participating in this study?

You will not receive any form of remuneration nor incentives for participating in this study.

What if I have questions?

If you have any questions during or afterwards about this research, feel free to contact me or my supervisor on the details listed below. This study will be written up as a research report, which is due on the 15th of December 2021, and will be available online through the university library website. My study may potentially be published in a scientific journal as well. A summarised version of my study will be made available to you (on request) by June 2022. If you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za

What is the next step?

Should you agree to participate in this study, please contact me and I will send you a consent form which you will need to sign and send back to me. We will then discuss which interview method you prefer (online or face-to-face) and we will set up a time that is convenient for both yourself and me.

Yours sincerely,
Mikaela Nicolau

Researcher details:
Mikaela Nicolau | 1130811@students.wits.ac.za | 082 314 9976

Supervisor details:
Dr Mambwe Kasese-Hara | Mambwe.Hara@wits.ac.za | 011 717 4552

7.2. Appendix B: Participant Consent Form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

School of Human and Community Development Department of Psychology
T +27 11 717 4503/53 | E psych.SHCD@wits.ac.za |

Participant Consent Form

Title of project: *"The lived experiences of caregivers: psychological and social implications of caring for patients with Bipolar Disorder"*
Name of researcher: Mikaela Nicolau

I, …….., hereby consent to participate in this research project. I agree to, and understand, the following:

(Please tick the relevant options below).

	Yes	No
I agree that the research has been explained to me and I understand what my participation will involve.		
I agree that my participation will remain confidential		
I agree that the researcher may use anonymous quotes in her research report		
I agree that the interview may be audio recorded		
I understand that even if I agree to participate now, I can withdraw at any time without any consequences of any kind		
I am not required to answer questions which may make me feel uncomfortable		
I agree that my participation in this study is voluntary		
I agree that participation will not result in any rewards or benefits		
I agree that I may request a summarised copy of this study by June 2022		

Participant's name and surname: ……

Participant's signature: ……

Date: ……

Researcher's name and surname: ……

Researcher's signature: ……

Date: ……

Please note that the researcher will make a photocopy of this consent form so she can keep one (for ethical purposes) and you can keep one (for your records).

7.3. Appendix C: Gatekeeper Permission Letter – Psychiatrist/Psychologist

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

School of Human and Community Development Department of Psychology
T +27 11 717 4503/53 | E psych.SHCD@wits.ac.za |

Psychiatrist/Psychologist
Private Practice
Address

Date

Dear Dr/Madam/Sir,

Re: Permission to get access to potential research participants

My name is Mikaela Nicolau.

I am studying for a MA in Social and Psychological Research in the School of Human and Community Development at the University of the Witwatersrand. I am seeking permission to get access to potential research participants through you.

I am conducting research on "*The lived experiences of caregivers: psychological and social implications of caring for patients with Bipolar Disorder*". Caregivers have been studied for many years, in various ways. Research has shown that the extent to which caregivers are affected by the caregiving process is very much dependent on their socio-demographic variables. To my knowledge, research has not been done on caregivers in the private sector in Gauteng. Conducting research on a different sample of caregivers will allow me to add to the literature from a different perspective. I am approaching you to help me find participants because, as a specialist in your field, I believe that you are able to identify caregivers (they can be parents, guardians, other family members, or even friends) who will be suitable for my study.

I request permission to get access to these caregivers through you. In order to reduce the influence of the underlying power dynamic, I will leave my Participant Information Sheet with you with the hope that you will give the information sheet to any caregivers you feel will be suitable for my study. My information will be on the Information Sheet, allowing the caregiver to contact me if they want to participate in my study.

The research will entail interviewing six to ten adult caregivers (over the age of 18) who are caring for a patient who has a formal diagnosis of bipolar disorder. The patient whom the caregiver is looking after may be recently diagnosed or may have a long-standing diagnosis. The caregiver must reside in Gauteng. If they agree, they will be asked to be interviewed by myself. These interviews will ideally be conducted via a digital communication platform. Should they prefer an in-person interview, I have organised a private, soundproof room at Evexia Psychiatric Day Hospital (Midstream), which will be set up according to COVID-19 prevention guidelines of social distancing and sanitisation; both myself and the participant will wear a mask. The interviews should take between 60 and 90 minutes. The interview will be conducted at a time suitable for both the participant and me. The interview will be audio recorded (the participant will need to give consent for this).

Participants will be asked to give their written consent before the research begins. Their responses will be treated confidentially. Individual privacy will be maintained in all published and written data resulting from the study.

The results will be communicated in my final research report, which will be submitted on the 15th of December 2021, and will be available on the university website. Furthermore, my study may possibly be published in a scientific journal. The research results will also be made available to you and the participants in a summarised form, and should you wish to request this, the summary will be available by June 2022.

I therefore request permission in writing to get access to potential research participants for my research through you. The permission letter should be on your practice's headed paper, signed and dated, and specifically referring to myself by name and the title of my study.

I look forward to your response as soon as is convenient.

Yours sincerely,

Mikaela Nicolau

Should you have any further questions, please feel free to contact myself or my supervisor on the details below. If you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za .

Mikaela Nicolau
082 314 9976
1130811@students.wits.ac.za

Dr Mambwe Kasese-Hara
011 717 4552
Mambwe.Hara@wits.ac.za

7.4. Appendix D: Permission Letter – Research Site (if needed)

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

School of Human and Community Development Department of Psychology
T +27 11 717 4503/53 | E psych.SHCD@wits.ac.za |

Managing Director
Evexia Psychiatric Day Hospital, Midstream
Suite 115, Midstream Hill Medical Park

21 May 2021

Dear Sir,

Re: Permission to use a room at Evexia Psychiatric Day Hospital for research interviews

My name is Mikaela Nicolau.

I am studying for a MA in Social and Psychological Research in the School of Human and Community Development at the University of the Witwatersrand. I am conducting research on "*The lived experiences of caregivers: psychological and social implications of caring for patients with Bipolar Disorder*". I am seeking permission to use a room at your hospital to conduct my interviews should my participants not feel comfortable having their interview over a digital communication platform.

The research will entail interviewing six to ten adult caregivers (over the age of 18) who are caring for a patient who has a formal diagnosis of bipolar disorder. The patient whom the caregiver is looking after may be recently diagnosed or may have a long-standing diagnosis. The caregiver must reside in Gauteng. If they agree, they will be asked to be interviewed by myself. These interviews will ideally be conducted via a digital communication platform. Should they prefer an in-person interview, I would like to ask your permission to use one of your private, soundproof rooms, which will be set up according to COVID-19 prevention guidelines of social distancing and sanitisation; both myself and the participant will wear a mask. The interviews should take between 60 and 90 minutes each.

The interview will be conducted at a time suitable for both the participant and me. Should you give your permission, I will ensure that my interviews are booked well in advance with your receptionist so as to accommodate everyone involved. The results will be communicated in my final research report, however the name of your hospital will not be in my research, unless you explicitly state that you would like the name mentioned in my research.

I therefore request permission in writing to use one of your private, soundproof rooms. The permission letter should be on your hospital's headed paper, signed and dated, and specifically referring to myself by name and the title of my study.

I look forward to your response as soon as is convenient.

Yours sincerely,

Mikaela Nicolau

Should you have any further questions, please feel free to contact myself or my supervisor:

Mikaela Nicolau
082 314 9976
1130811@students.wits.ac.za

Dr Mambwe Kasese-Hara
011 717 4552
Mambwe.Hara@wits.ac.za

7.5. **Appendix E: Permission Letter – Research Site**



Psychiatric Day Hospitals
Just be YOUrself
012 348 8200
info@evexia.co.za

21 May 2021

Mikaela Nicolau
Email: 1130811@students.wits.ac.za
Tel: 082 314 9976

Dear Mikaela Nicolau

In my capacity as the Managing Director, I herewith give you permission to use a room for research interviews at Evexia Psychiatric Day Hospital (Midstream) for your research on *"The lived experiences of caregivers: psychological and social implications of caring for patients with Bipolar Disorder"*.

Furthermore, I give permission for you to use the name of the hospital in your written report and any publications thereof.

Yours sincerely,



Winston Schoeman
MANAGING DIRECTOR

7.6. Appendix F: Interview Schedule

- What does it mean to you to be a caregiver of a person who has been diagnosed with bipolar disorder?
- How have you experienced your role as a caregiver?
    - Follow up: Have you experienced any positive feelings since the patient's diagnosis? If so, what brought about these positive feelings?
- How has your life changed since you became a caregiver?
    - Follow up: What areas, if any, in your life have been the most affected by caring for the patient?
    - Follow up: What challenges do you face as the caregiver?
- How did you feel when you found out that the patient was diagnosed with bipolar disorder?
- How did the rest of your family react when the patient was diagnosed?
    - Follow up: How do your family members help you care for the patient?
- Has there ever been a time, since the patient was diagnosed, where you have felt that people looked at or treated you and your family differently?
- Based on your experience, what do you think a caregiver of a patient with bipolar disorder needs?
- Is there anything else you would like to tell me that you think I haven't asked about in this interview?

7.7. Appendix G: Permission Letter – Winston Schoeman

WINSTON SCHOEMAN PSYCHOLOGIST (PTY) Ltd.

218 Richard Street
Hatfield
PRETORIA
0183

Practice Number: 0815616

Tel: 076 703 5696
E-mail: winston.schoeman@gmail.com

21 May 2021

Mikaela Nicolau

Email: 1130811@students.wits.ac.za

Tel: 082 314 9976

Dear Mikaela Nicolau

I herewith agree to refer, as per your Participant Information Sheet, potential research participants for your research on *"The lived experiences of caregivers: psychological and social implications of caring for patients with Bipolar Disorder"* as per my discretion.

Yours sincerely,



Winston Schoeman

7.8. Appendix H: Permission Letter – Dr M Lombard

Dr Melinda Lombard

MBChB, MMed(Psych), FCPsych

Psychiatrist

Practise number : 0448591

Room 117 MHMP

Midhill Boulevard

Midstream

Tel:0129420818

Fax:0126871555

receptiondrlombard@lantic.net

22/5/2021

TO: WHOM IT MAY CONCERN

RE: PERMISSION TO GET ACCESS TO POTENTIAL RESEARCH PARTICIPANTS

I hereby give permission to get access to potential research participants to Mikaela Nicolau for her research on 'The lived experiences of caregivers: psychological and social implications of caring for patients with Bipolar Disorder'

BEST REGARDS

DR MELINDA LOMBARD

7.9. Appendix I: Permission Letter – Dr CE Schüler

Dr CE Schüler
MBChB (Pret) MMED Psych (Pret)
Psychiatrist
PR: 0018074

320 Grus Street
Waterkloof Ridge
0181

P.O. Box 2592
Brooklyn Square
0075

Tel: 012 346 7723
Fax 086 245 2981
reception@schuler.net.za

21 May 2021

Michaela Nicolau
Email: 1130811@students.wits.ac.za
Tel: 0823149976

Dear Ms Nicolau,

I herewith agree to refer (on my discretion), per your Participation Information Sheet, potential research participants for your research on

The lived experiences of caregivers: psychological and social implications of caring for patients with Bipolar Disorder.

Christian Schüler