

**EXPERIENCES OF FAMILY MEMBERS CARING FOR FEMALE
PATIENTS WITH A CO-MORBID DIAGNOSIS OF BIPOLAR AND
SUBSTANCE ABUSE ADMITTED IN A PSYCHIATRIC HOSPITAL IN
THE WESTERN CAPE.**

By

UWARREN SEPTEMBER



**UNIVERSITY of the
WESTERN CAPE**

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degree of**

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Supervisor: Dr A. Beytell

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Dedicated to my **Grandmother** for supporting and believing in me and trying her best to invest in my education.

To my late brother, **Shawn September** who challenged me in completing this degree, I hope to make both of you proud.



“SUCCESS IS NO ACCIDENT. It is hard work, perseverance, learning, studying, sacrifice and most of all, love of what you are doing”.

- Pele

DECLARATION

I declare that experiences of family members caring for female patients with a co-morbid diagnosis of bipolar and substance abuse admitted in a psychiatric hospital in the western cape is my own work, that it has not been submitted for any degree or examination to any other university and that all the sources I have used or quoted have been acknowledge as complete references.

Uwarren September



Signed: _____

Date: 27 November 2015

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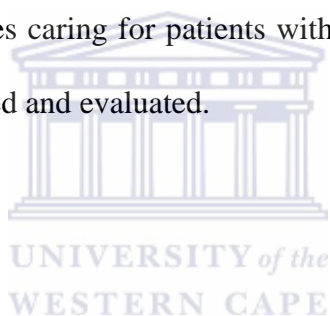
ABSTRACT

Caregivers of people with psychiatric illnesses experience challenges, which contribute significantly to their burden of care and can result in health and mental health problems. The researcher was interested in the lived experiences of caregivers, which resulted in the following research questions: What are the lived experiences of caregivers caring for a co-morbid bi-polar and substance-abuse patient, and what context and situations contribute to the problems? The goal of this research was to explore the experiences of family members caring for relatives admitted in a psychiatric hospital, and the contexts in which these occurred. The objectives were to explore and describe the lived experiences of family members caring for a relative with a co-morbid diagnosis of bi-polar and substance abuse, as well as the situations or contexts in which these experiences occur. These objectives were followed by the last objective of the research, which was to make recommendations to the multi-disciplinary teams (MDTs) on services for family members caring for such a relative.

A qualitative, phenomenological research approach was used for this study with explorative and descriptive research designs. The population for the study comprised families in the Western Cape caring for female relatives admitted to a psychiatric hospital with co-morbid bipolar and substance use disorder. The researcher purposively selected relatives of female in-patients admitted in a female admission ward. Families were chosen whose members were admitted for more than three months. In-depth phenomenological interviews were done with six participants until data saturation was reached. Phenomenological data analysis, focusing on the textural (lived experience) and structural (context in which it was experienced), were followed after data collection.

Findings comprised a composite description of the phenomena of both textural and structural description. The findings of this research resulted in conclusions and recommendations for MDTs and social work on interventions for family members caring for a family member with this mental condition.

Findings from this study conclude what was found in the literature regarding challenges in the system leads to caregivers feeling burdened with their mentally ill relative, and that resources and support are lacking in communities. This led to recommendations aiming at MDTs, government and social workers working in institutions, to align with community social workers in order to strengthen working relationships with the aim of providing the necessary support services to families caring for mentally ill relatives. Future research suggestions are also aimed at supporting families caring for patients with a mental illness for which reasons for re-admissions will be assessed and evaluated.



Keywords: Family, Caregiver, Co-morbidity, Diagnosis, Bipolar disorder, Substances, Abuse, Psychiatric hospital.


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CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Globally, one out of four people suffers from mental disorders in both developed and developing countries. The four leading causes of mental health disorders are depression, alcohol abuse, schizophrenia, and bipolar disorder (National Alliance on Mental Health of Greater Chicago [NAMH], 2013). A survey of South African Stress and Health (SASH) indicated that 16.5 per cent of the population of South Africa suffers annually with a common mental illness like depression, anxiety, and other somatoform disorders (Halliwell, Main & Richardson, 2007). In the Western Cape Province, more than 22 per cent of all disability is due to emotional and intellectual disability (Corrigall, Ward, Stinson, Struthers, Frantz, Lund, Flisher & Joska, 2007). The prevalence of substance abuse and mental illness is high, and 60 per cent of the patients making use of psychiatric services in the Western Cape abuse substances (Botha, Koen, Oosthuizen, Joska & Hering, 2008). A survey conducted by Weich and Pienaar (2009) at Stikland Hospital in the Western Cape confirmed the above statistics by indicating that 51 per cent of in-patients were diagnosed with substance-use disorder. However, eight per cent of these patients were substance-induced psychiatric disorder, one per cent was diagnosed with a substance induced mood disorder, and seven per cent were diagnosed with substance-induced psychotic disorder.

The magnitude of the burden on families who care for patients with psychiatric illness is emphasised by the Mental Health Foundation when they indicate that about 450 million people globally have a mental illness, and about one in four families has a relative with a mental disorder or behaviour problems (Mental Health Foundation cited in Halliwell *et al.*, 2007). Taking care of a person with a mental illness can cause tremendous stress in families' life, which can contribute to feeling burdened with their relative (Uys & Middleton, 2014).

1.2 LITERATURE REVIEW AS ORIENTATION TO THE STUDY

In the following text, the researcher provides an orientation on the co-morbid diagnosis of bipolar and substance abuse and the influences on people caring for them.

1.2.1 Families/caregivers' experiences caring for people with mental disorders

Maji, Sood, Sagar and Khandelwal (2012) describe family burdens as problems, difficulties, or events that affect the life of a mentally ill patient's family. A heavy burden for caregivers of patients with bipolar mood disorder is evident. A longitudinal study conducted on family burden amongst relatives of patients with bipolar affective disorder during the mania phase at admission and four weeks after discharge, found that more than 90 per cent of family members reported severe subjective (rated by relative) and objective burden (rated by interviewer) on admission; not one of the families was free of strain. Severe burden was rated in a quarter (23%) of family members, while subjectively, none of the family members reported severe burden. Initially, most of the family members experienced severe strain, and it is evident from this study that the burden decreases with time when caring for patients.

A longitudinal study conducted by Herua and Ryan (2004) concluded that caregivers of patients with mood disorders where there were fewer rewards, had a higher subjective burden and family functioning was weak. Overall, family functioning, except for behaviour control, was unchanged after a year, and was in the unhealthy range of all dimensions of life. A further study indicated that patients had an effect on the sense of burden experienced by caregivers when daily life and performing tasks were executed. Researchers conclude by suggesting that support to patients with mental illnesses may reduce the sense of burden by families (Fujino & Okamura, 2009).

1.2.2 Socio-economic factors influencing caring for people with mental disorders

The Burden Disease Reduction project in the Western Cape highlighted the correlation between mental health and other socio-economic obstacles including poverty, unemployment, alienation, teenage pregnancies, domestic violence, and poor family functioning. This contributes to the wish to integrate mental health intervention methods with other poverty and development strategies (Flisher, Corrigan, Bradshaw, Schneider, Lund, & Stein, 2008). The social environment of families has an impact on their functioning when they are caring for a mentally ill patient. Poor resourced families staying in a neighbourhood with insufficient housing, schools and services, are likely to experience poor health, low education levels, and no occupational attainment. This contributes to the burden of caring (Thompson, Petticrew & Douglas, 2003; Saegert & Evans, 2003). Unemployment or having a low income, low level of education and/or having no skills are factors that contribute to having high risk of experience a mental illness (Meltzer, Singleton, Lee, Bebbington, Brugha & Jenkins, 2002). People experiencing financial problems can be both a cause and a consequence of mental health issues (Mental Health Foundation cited in Halliwell *et al.*, 2007).

1.2.3 Co-morbidity: Mental illness and substance abuse

In order to explain what co-morbidity is, Nora and Volkow (2010) explain that we first need to understand that drug addiction is a mental illness, and that mental disorders are usually associated with substance abuse, smoking and unprotected sex. This association results in high risk behaviour and injuries, which are major factors contributing to the Burden of Disease in the Western Cape. Nora and Volkow (2010) found that many people diagnosed with a mental illness abuse substances. These authors suggest that patients who are diagnosed with a mood or anxiety disorder are more vulnerable to becoming dependent on drugs and vice versa. A research study conducted by the Medical Research Council (MRC) in 2005 as cited in Corrigan *et al.*, (2007) concluded that substance abuse, as well as mental illness

correlate with less capital, and a very high percentage of community violence. The Western Cape has the highest number of premature deaths because of homicides, road accidents and suicides of all provinces in South Africa, and 58 per cent of homicides and 57 per cent of road accidents in South Africa are associated with alcohol abuse (Bradshaw, Nannan & Laubsher, 2004; MRC, 2005).

1.2.3.1 Co-morbidity between bipolar disorder and substance abuse

Bipolar disorder is a severe and often chronic disorder with lifetime prevalence rates of bipolar spectrum disorders of up to 6.5 per cent of the general population. Patients frequently report co-morbidity between bipolar disorder and substance-use disorders. The rates of alcohol and other substance-use disorders are significantly higher in persons with bipolar disorder than in the general population, and are usually associated with mortality and morbidity (Vornik & Brown, 2006).

A Brazilian study examined the impact of alcohol abuse and dependence on bipolar disorder patients, and found that the clinical severity, functional impairment and quality of life were poor. There were a high number of suicide attempts, and the functioning of the patient psychosis within the first episode, depressive symptoms, earlier age, and lower education were associated with alcohol dependence (Cardoso, Sant'Anna, Dias, Andreazza, Cerese'r, & Kapczinski, 2008). Research that was done to determine the lifetime prediction of suicide attempts in co-morbid substance use and bipolar disorder patients, found a 39 per cent lifetime rate of attempted suicide by bipolar people with co-morbid substance use disorder, and a 23 per cent rate in patients without co-morbid substance use disorders (Dalton, Cate-Carter, Mundo, Parikh & Kennedy, 2003). Another study of patients with manic symptoms found that they were at greater risk for later onset alcohol, cannabis, and benzodiazepine dependency. Alcohol and benzodiazepine dependency were both predicted by bipolar II

disorder. In contrast, major depression was only predictive of benzodiazepine dependency later in the patient's life. There is, however, a lack of information about underlying mechanisms and important implications for prevention between the different patterns of association in mood disorders and substance use (Merikangas, Herrell, Swendsen, Rossler, Ajdacic-Gross & Angst, 2008).

1.2.3.2 Effects of co-morbid mental illness and substance abuse on family caregivers

A family taking care of a relative, who is diagnosed with a mental illness, is usually doing it because of the emotional connection they have with each other, and they may feel obliged to take care of their relative. Families are often uneducated, uninformed and ignorant with regard to mental illness as well as the specific diagnosis of their relative; this often results in families feeling stressed, burdened, and not wanting to take responsibility for their relative (Uys & Middleton, 2014).

Families experience problems caring for a mentally ill relative because of behaviour changes of the relative, especially when there is co-morbidity between substance abuse and mental illness. Diagnosis, help-seeking behaviour and treatment, are difficult, and the family has to deal with behaviour of such a patient. The family experiences a crisis, in many instances without assistance on how to deal with it. This results in stress and worry. The needs of the mentally ill member become paramount, but the needs of other family members are also important (Flisher *et al.*, 2008; Uys & Middleton, 2014).

1.2.4 Mental Health legislation, policies and treatment contributing to the burden of family caregivers

Governmental psychiatric hospitals care and rehabilitate people in need of care, and when these patients are discharged, they receive community-based care in residential facilities and on a primary healthcare level (Mental Health Care Act [MHCA], 2002; Uys & Middleton,

2014). Community mental health services, which include out-patient services, day centres, hospital diversion programmes, crisis teams, group homes, halfway houses, and case management services, are crucial in mental health (Corrigal *et al.*, 2007; World Health Organisation [WHO], 2003).

Before the Mental Health Care Act (MHCA) of South Africa (2002) was amended and evaluated, behaviourally disturbed and substance-induced psychosis, were assessed at community health clinics. The Mental Health Care Act (2002) changed this situation; it states that behaviourally disturbed individuals should be admitted in a district hospital for a 72-hour observation period before referring to a psychiatric hospital. However, when patients are discharged from a psychiatric hospital and relapse within three months, they do not have to go for the 72-hour observation at a district hospital, but can be admitted directly into a psychiatric hospital.

The logic behind integrating mental health into general medical services was that this would contribute to reducing the stigma associated with seeking or receiving treatment. There is a need for general practitioners to accurately identify and treat mental disorders at a global level (Kohn, 2004). This has been confirmed by studies in South Africa where in some settings, 37 to 53 per cent of primary clinic attendees were found to have mental illness, but detection of these disorders by clinic staff was between zero to one per cent (Carey, Stein, Zungu & Seedat, 2003). It was suggested that mental health services should be integrated into existing healthcare programmes such as human immunodeficiency virus (HIV) programmes, home-based carer programmes and training, be offered to staff (WHO, 2003).

Inefficiency, stigmatisation of users and their families, human rights violations, and increased disability of clients associated with admissions, have been cited as reasons why community-based instead of institutional care is important (Corrigal *et al.*, 2007). De-institutionalisation

and integration into general medical services with units/wards in general hospitals, is part of reforming the mental health service delivery system as stated above. In order for this transition to be effective, alternative care arrangements should be in place before patients are discharged (Corrigan *et al.*, 2007; WHO, 2003). De-institutionalised programmes have not developed accordingly, which has resulted in an increase of homeless people and prisoners, who remain mentally ill. While it has been suggested that resources be introduced to support community and primary mental-health services, this development has not been forthcoming (Corrigan *et al.*, 2007; WHO, 2003). This results in poor services to families' physical, emotional, and social needs. The consequences of inadequate legislation and resources allocated to specialist mental-health services results in low income, emotionally stressed families, which experience poor quality of life (Swartz, Breen & Flisher, 2005).

Lund, Kleintjes, Kakuma, and Flisher (2010) found that there is a lack of treatment for mentally ill patients because financial assistance remains a developmental area for mental healthcare users and their families. These authors also mention that there is a lack of reliable data that can be used to plan proper services, and assess and redress current inequalities experienced by the population affected by mental health. The result is that mental healthcare is mainly provided by hospitals, and the needs of mentally ill patients and their families are not met. Although policy and legislation are available, they are not appropriate or effective.

1.3 PROBLEM FORMULATION

It is clear from the literature that policy and legislation, prescribing de-institutionalisation, and care for patients with a mental illness on a community-based instead of institutional based level, have an impact on the caregivers. Caregivers experience a variety of challenges when caring for their patients, especially those with co-morbid substance abuse and bipolar disease.

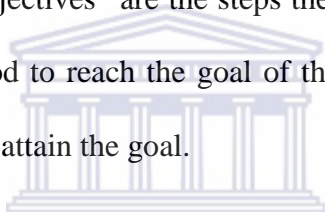
Those challenges contribute significantly to the burden of care and can result in mental health problems in caregivers.

The researcher asked the following research questions when the abovementioned factors were considered:

- What are the lived experiences of caregivers caring for a co-morbid, bipolar and substance-abuse patient?
- What are the contexts or situations contributing to this?

1.4 THE GOAL AND OBJECTIVES OF THE STUDY

According to the Oxford Advanced Learner's Dictionary (2006), the "goal" of a study is what the researcher intends to achieve, and gives direction to the study. De Vos, Strydom, Fouché, and Delport (2011) add that "objectives" are the steps the researcher undertakes at grass root level within a certain time-period to reach the goal of the study. The objectives can also be what the researcher has to do, to attain the goal.



1.4.1 The goal of the research

The goal of this research was to determine the lived experiences of family members caring for co-morbid bipolar and substance-use disorder relatives admitted in a psychiatric hospital and the contexts in which those occur.

1.4.2 The objectives of the research

1.4.2.1 The objectives to attain the above goal included:

- To explore the lived experiences of family members caring for a family member with a co-morbid diagnosis of bipolar and substance abuse;
- To explore the situations or contexts in which these experiences occur;

- To describe the lived experiences of family members caring for a family member with a co-morbid diagnosis of bipolar and substance abuse;
- To describe the situations or contexts in which these experiences occur;
- To give recommendations to multi-disciplinary teams (MDTs) on services for family members caring for a family member with a co-morbid bipolar and substance-abuse diagnosis.

1.5 ORIENTATION TO THE RESEARCH METHODOLOGY

The researcher discusses only an introduction to the research methodology in this chapter and then will focus in more detail on it in Chapter 3 (Research methodology) of the study.

1.5.1 Research approach and design

The researcher used the qualitative research approach, which provided insight into the participants' perspectives and subjective personal data about their experiences while caring for a family member with a co-morbid diagnosis of bipolar and substance abuse (Green & Thorogood, 2009). Applied research was carried out in the study because it will contribute to improvement of intervention with families of patients with a co-morbid diagnosis of bipolar and substance abuse. Explorative research was used as the researcher explored new topics in order to understand the actions of the participants (De Vos *et al.*, 2011). Descriptive research, which focused on the “how” and “why” questions to describe the experiences accurately, was used regarding the findings of the research (De Vos, Strydom, Fouché, & Delpont, 2005).

1.5.2 The research strategy of inquiry

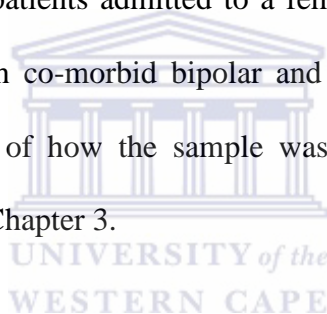
Phenomenological studies, as indicated by De Vos *et al.*, (2005) aim to explore and understand the meaning that people gives to their everyday lives, and focus on “what” people experience and “how” they experience it. Therefore, the researcher employed phenomenology

to explore the lived experiences of family members caring for a family member diagnosed with co-morbid bipolar and substance-use disorder.

1.5.3 Research population and sampling

A population is the entire set of individual who are the focus of the research (Bless, Smith & Kagee, 2006). The population of the researcher's study consisted of families caring for female inpatients in a psychiatric hospital in the Western Cape. The patients had been diagnosed with co-morbid bipolar and substance-use disorder.

Non-probability purposive sampling was employed, in which each element of the population in the sample was not known to the researcher (Bless *et al.*, 2006). The researcher purposively selected relatives of female in-patients admitted to a female ward, in a psychiatric hospital, which had been diagnosed with co-morbid bipolar and substance-use disorder in Western Cape. An in-depth description of how the sample was selected will be described in the research methodology chapter, Chapter 3.



1.5.4 Methods of Data Gathering

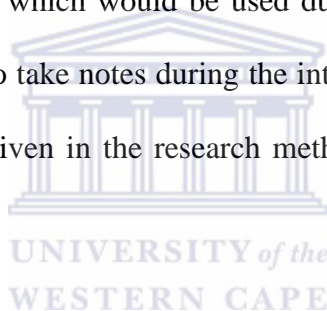
In-depth interviews focusing on the textural and structural description of the experiences were proposed for phenomenology by Creswell (2013). The location where the interviews were conducted was an office at the hospital where the patients were based. The duration of the interviews was 45 minutes to an hour (De Vos *et al.*, 2005). The researcher explained the interview process to participants, using the information sheet (**See Appendix D: Information sheet**) and obtained their permission for the interview and the use of an audio recorder, using the consent form (**See Appendix E: Consent form**). After collecting the data, the data was transcribed word for word (**See Appendix F: Transcription of an interview**) from the audio

recordings for the purpose of data analysis. The researcher used the following two questions and probed to obtain rich data (Creswell, 2013).

- Will you tell me about your experiences taking care of your relative who has a mental illness?
- In what situations did you experience this?

1.5.5 Pilot study

A pilot study involves testing the study by using a small sample of the community for whom the research is planned, and allowing the researcher to identify possible difficulties that might occur during data collection (Bless *et al.*, 2006). An interview was conducted with a family member who was not one of the participants, which allowed the researcher to practise the interview skills and techniques, which would be used during the interviews. The researcher also evaluated the time it took to take notes during the interview. A more in-depth discussion on the pilot interview will be given in the research methodology chapter (Chapter 3, 3.4.7: Pilot study).



1.5.6 Data analysis

Creswell (2009) describes data analysis as ‘unpacking the information collected from the participants’ when the researcher has done an analysis of the data. Phenomenology uses specific data analysis, which will be discussed in Chapter 3 (Research methodology) of the study (See 3.4.8: Data analysis).

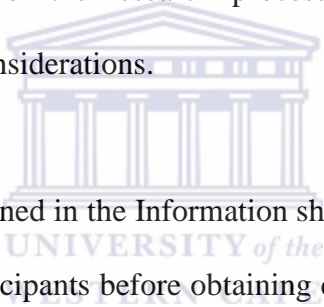
1.6 TRUSTWORTHINESS OF THE STUDY

As cited by Lincoln and Guba (1985), characteristics such as truth value, applicability, consistency and neutrality are of the utmost importance to assess trustworthiness during the research study. Information was obtained from caregivers who care for female patients diagnosed with co-morbid bipolar and substance-use disorder having been admitted in a

psychiatric hospital in the Western Cape. **Credibility, confirmability, reflexivity** and **bracketing** were used to ensure trustworthiness in this study and will be discussed with more detail in Chapter 3 (See 3.5: Trustworthiness) (Moustakas, 1994).

1.7 ETHICAL CONSIDERATIONS RELEVANT TO THIS RESEARCH

Ethics were implemented thoughtfully by the researcher, considering the vulnerable situation of the people with mental illness, as well as their families. Permission was obtained from the Ethics Committees of the University of the Western Cape (**See Appendix A**), the Western Cape Health Department (**See Appendix B**) as well as by the research and ethics committee of Lentegeur Psychiatric Hospital (**See Appendix C**) in order to conduct this research study. Data was elicited from participants, who are human beings with basic human rights, and who contributed towards the value of the research process. During this research study, the researcher adhered to various considerations.



The purpose of the study as outlined in the Information sheet (**See Appendix D: Information sheet**) was explained to the participants before obtaining consent from them in the shape of a consent form and they were informed about the expected duration and procedures of their involvement (**See Appendix E: Consent form**). The possible risk and benefits of the research were explained. The research might contribute to emotions and identification of challenges, but the researcher had a psychologist on standby if such a situation should occur, and would have referred to the appropriate resources when necessary.

The participants were informed that they could withdraw from this study at any stage of the research process (De Vos *et al.*, 2011). Confidentiality was maintained and the information was protected and not available to anyone else than the researcher and his supervisor, who committed themselves to regard this information as confidential. Confidentiality implies that

only the researcher should be aware of the identity of participants (De Vos *et al.*, 2005). The researcher assigned pseudo names to protect the identity of the patient, as well as the family (Bless *et al.*, 2006). The information collected was kept in a safe place at all times.

1.8 CONCEPTUALISATION

Conceptualisation can be either conceptual clarification or definition of key concepts, which the researcher focuses on in this section. However it can also mean the integration of the research into the broader knowledge that exists, which is the literature and research methodology, which other researchers used (Mouton, 2002). The conceptual clarification listed below is important, as it gives an overview of the meanings of terms relevant to this specific study. The conceptualisation of the study within the broader framework of knowledge was done in sections 1.1 (Introduction) and 1.2 (Literature review as orientation to the study), as well as the methodology of this chapter (See 1.5: Orientation to the research methodology) and Chapter 3 (Research methodology).

A **family** can be described as a social institution with many social functions. In its nuclear form, a family consists of a mother, father and offspring. The concept “family” may also refer to the extended family which includes the grandparents, cousins and adopted children. The family should provide emotional support, nurturance and financial support. A family can also be a group of people who are usually related to each other and live together. It is the foundation on which societies are built (Zastrow, 2007).

A **caregiver** is a person or a relative, responsible for looking after another person who cannot look after himself or herself in some or all respects. The term describes a range of relationships in which one person cares for another, sometimes singly, sometimes in conjunction with others (Collins, 2002).

Co-morbidity is illness that takes place in two people at the same time. Co-morbidity implies that there are interactions between the illnesses, and both disorders can affect the course and prognosis of the illness (Nora and Volkow, 2010).

A **diagnosis** is the act of discovering or identifying the exact cause of an illness or problem (Hornby, 2006).

Bipolar disorder is episodes in a person's mood and activity levels that are being disturbed. Bipolar mood disorder can also be described as a mental health condition that involves extreme moods, such as feeling very depressed to feeling very energetic, irritated or extremely excited (WHO, 2010).

Substances include chemical, psychoactive substances that are prone to being abused, including tobacco, alcohol, over-the-counter drugs, prescription drugs and substances (Drugs and Drug Trafficking Act, 1992).

Abuse is the sustained or sporadic excessive use of substances and includes any use of illicit substances and their unlawful use (Prevention of and Treatment for Substance Abuse Act of South Africa, 2008).

A **psychiatric hospital** is an institution, facility, building or place where persons with a mental illness receive care, treatment, rehabilitation assistance, therapeutic interventions or other health services (Uys & Middelton, 2014).

1.9 CHAPTERS TO FOLLOW

A guide to the chapters that will follow is given below as it provides an overview of the work being done throughout this research study.

- Chapter 1: This chapter presents an orientation to this particular study.

- Chapter 2: Will provide a description of the literature relating to the research topic.
- Chapter 3: The research methodology will be discussed in detail in this chapter.
- Chapter 4: The empirical research findings are presented in detail in this chapter (objectives three and four of this research).
- Chapter 5: This chapter encompasses the conclusion and recommendations to multi-disciplinary healthcare team members (objective 5 of the research).



CHAPTER 2

CO-MORBID BIPOLAR AND SUBSTANCE-ABUSE DISORDER

2.1 INTRODUCTION

This chapter encompasses the literature review of the study. Qualitative research starts with the selection of a paradigm or theoretical framework, and the literature review is then described within this framework. Phenomenology begins with a clear paradigm before data collection, but the literature review is only done after the data is collected (De Vos *et al.*, 2011). The research process starts with the orientation to the study and the bio-psycho-social paradigm as background. The process of data collection and analysis was done before he did the literature review in this chapter. This was done to avoid “bracketing” of the researcher’s own experiences and not being influenced by literature but rather focusing on the participants’ experiences.

This chapter provides an overview of co-morbid bipolar and substance abuse in a bio-psycho-social model. In order to understand the context of this study, the bio-psycho-social model is used as a theoretical framework throughout this study. The focus of this chapter is divided into the three elements of the model. The biological element refers to the physical or mental health condition; the psychological component recognises that personal/psychological factors also influence a person’s functioning, and the social factor recognises the importance of the social context on functioning. Furthermore, important literature will be added related to legislation, services and resources, as well as the present service provision and its impact on institutionalisation and deinstitutionalisation.

2.2 THE BIO-PSYCHOSOCIAL MODEL (BPS)

In order to understand the BPS model as a theoretical framework in the context of this study, a theoretical overview will be provided with a holistic focus on the biological, psychological and social elements of this approach. The BPS model enables a disease to be seen as the result of interacting dimensions such as the cellular, tissue, organismic, interpersonal and environmental aspects. Engel in Fava and Sonino (2008) explain that the study of every illness should include the individual, his/ her body and his/her environment. This component is important in this study as it deals with the experiences of family members caring for an individual member who has been diagnosed with co-morbid bipolar and a substance-abuse disorder.

Engel and Engel (2001) explain that the BPS model stems from the general systems theory, and maintain medicine must include the psychosocial dimensions (personal, emotions, family and communities) in addition to the biological aspects, which include both disease and illness of all patients (Gatchel, 2005) by integrating these components, science and the humanistic connects. Engel objects to the medical model and proposes that the patient, the social context in which he/she lives, and the wider society should be included as a basis for understanding the determinants of disease, as well as treatment and healthcare, in order to deal with the disruptive effects of illness. This requires a BPS model.

The BPS model forms the basis of the World Health Organisation's International Classification of Functioning, Disability and Health (ICF), which is now widely accepted as the framework for disability and rehabilitation. Day-to-day functioning and disability are dependent on the dynamic interaction between the individual's health condition and contextual factors that include both personal, psychological, social and occupational factors (WHO, 2001).

Cohen and Brown-Clark (2010) propose that clinicians should recognise the centrality of relationships in providing healthcare, and use self-awareness as a diagnostic and therapeutic tool. They also claim that the clinician should determine which social domains are important in understanding and promoting a patient's health and providing multi-dimensional treatment.

Mental illness affects more than one aspect of a person (Dombeck & Wells-Moran, 2006). Recognition of the understanding, patient's beliefs, feelings, thoughts and health behaviour is necessary to understand the patient's condition, and therefore a move from a disease model to a BPS model of care is essential. This model acknowledges the importance of psychological and social factors, as well as the physical impact of living with a disease. For example, physical impact can include symptoms of pain, stiffness and fatigue. Psychological effects may include feelings of frustration and low mood, and give rise to concerns about the future, while social implications can include concerns about work, role within the family, and continuing to engage in valued leisure activities (Ryan, Hassell & Dawes, 2003). The psychological component of the BPS was, for Engel, connected to psychoanalysis. This model was not meant to incorporate psychology in the broad sense (such as behaviourism, social psychology or experimental psychology); rather, in the 1950s, when psychoanalysis was at the peak of its influence, psychology constitutes psychoanalysis. Although the BPS is viewed with extreme reverence among practitioners of social work, Engel put little emphasis on the social component of the model, except as related to the doctor-patient relationship primarily (with some secondary interest in the healthcare system as a whole). Little discussion can be found in Engel's main writings about the impact of society as a whole, or the larger roles of class or poverty or race, as is often the case in social work interpretations of the BPS (Shorter, 2005).

The BPS model focuses on disease and illness, and illness is viewed as the complex interaction of biological, psychological and social factors (Gatchel, 2005). Disease is defined as an objective biological event involving the disruption of specific body structures or organ systems caused by anatomical, pathological, or physiological changes. In contrast, illness refers to a subjective experience or self-attribution that a disease is present (Gatchel, 2004a, 2004b; Turk & Monarch, 2002). Therefore, as stated by Gatchel (2004b), illness refers to how a sick person and members of his or her family live with and respond to, symptoms of disability. In order to fully understand a person's perception and response to pain and illness, the interrelationships among biological changes, psychological status, and the socio-cultural context, all need to be considered (See Figure 2.1: Conceptual model of the bio-psycho-social). The basic idea behind the BPS model was a rejection of biomedical reductionism. The view was that illnesses are multi-factorial, with many causes; Engel held this to be the case for most medical illnesses, and his followers specify that it is true for all, or almost all, mental illnesses, certainly the standard psychotic and mood conditions. This is still the basic presumption of most persons in the field of psychiatry (Engel & Engel, 2001).

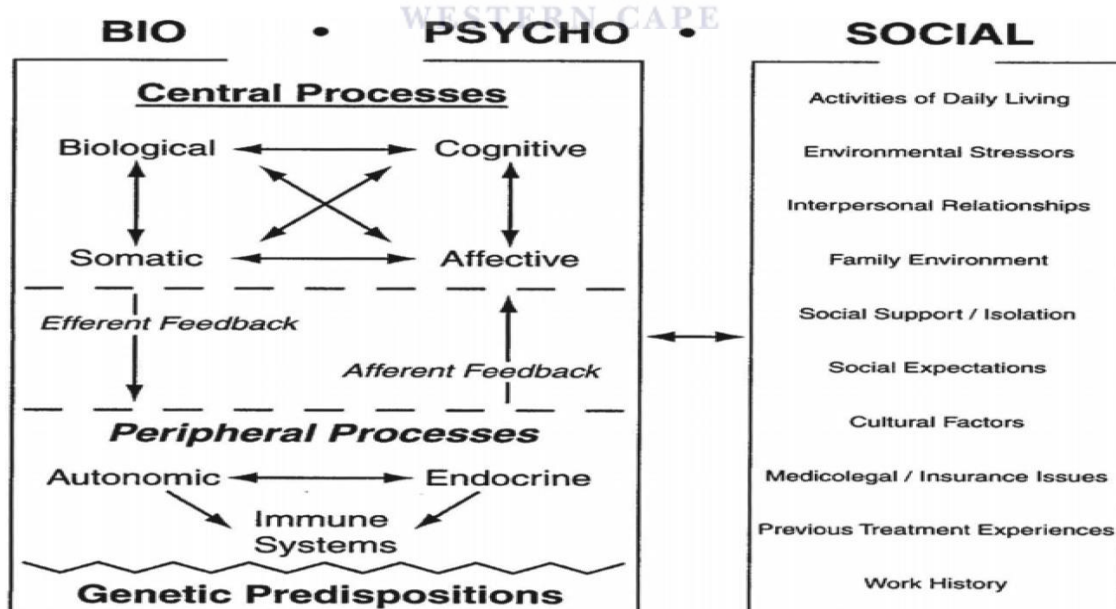


Figure 2.1: A conceptual model of the bio-psychosocial interactive processes involved in health and illness (Gatchel, 2004b).

2.3 BIPOLAR MOOD DISORDER (BD)

Bipolar disorder (BD) is a highly complex and heterogeneous psychiatric condition characterised by both a variety of symptoms and marked variability in its course. For example, a patient with BD can experience episodes of depression, hypomania, mania, or psychosis, and even a mixture of emotional states, or cycle rapidly between them. Marked variability exists between patients in terms of the length, number and type of episodes, severity and type of symptoms, and the degree of inter-episode recovery experienced (Michalak, Murray, Young & Lam, 2010).

BD, also called ‘manic-depressive disorder’, is a chronic biological disease, not a character defect or a moral failing. People with this illness experience changes in their mood and their ability to think and to function. At other times they can be completely without signs or symptoms of their illness. Depression is the most common mood in bipolar disorder but people also experience periods of euphoria and irritability. It is not unusual for these mood states to overlap and profoundly disrupt a person’s work, school, home and social life. The risk of suicide in this illness is very high, but it does decrease with treatment (Angst, Stassen, Clayton & Angst, 2002; Pompili, Harnic, Gonda, Forte, Dominici, Innamorati, Fountoulakis, Serafini, Sher, Janiri, Rihmer, Amore & Girardi, 2014).

BD is a recurrent severe mental disease with a prevalence ranging from 1.3 per cent to 1.6 per cent to 3.8 per cent (Angst *et al.*, 2002; Pompili *et al.*, 2014). A 2005 report agrees with above statistics on National Co-morbidity Survey Replication (NCS-R) that estimates data of bipolar disorder affects about 5.7 million American adults, or about 2.6 per cent of the population 18 years and older (one-year prevalence). The same study noted a lifetime prevalence of 3.9 per cent, suggesting the chronic nature of this illness (Kessler, Demler,

Merikangas, Walters, & Chiu, 2005; Kessler, Berglund, Demler, Jin, Merikangas, Walters, 2005).

Bipolar disease is a mood disorder. According to the WHO, mood disorders are one of the most important worldwide health issues of the 21st century (Boyd, 2007). Mood disorders encompass a large group of disorders in which pathological mood and related disturbances dominate the clinical picture. Mood disorders are best considered as syndromes consisting of a cluster of signs and symptoms sustained over weeks to months, which represent a marked departure from a person's habitual functioning, and tend to recur often in periodic or cyclical fashion.

These disorders virtually always result in impaired interpersonal, social, and occupational functioning. The field of psychiatry considers major depression and BD to be two separate disorders (Sadock & Sadock, 2003). Miklowitz (2011) argues that BD is not “only a brain disease” or “only a psychological problem”. It can be both of these things. Most professionals think of the cycling of BD as reflecting a complex interplay among the following factors:

- **Biological/ Genetic** vulnerabilities, which include inheriting a propensity for the disorder from one or more blood relatives, abnormal functioning of brain circuits involving neurotransmitters such as dopamine;
- **Psychological** agents such as one's beliefs about relationships;
- **Social/Stress** agents, which include events that bring about either positive or negative changes, such as transitions in a living situation or job, or more chronic problems, for instance severe family conflicts or taking care of someone who is seriously ill.

Despite the growing efficacy of available pharmacological tools, bipolar-affective disorders have continued to be a significant source of morbidity and mortality, doing serious harm to the quality of life of sufferers. They are the sixth most major cause of disability worldwide, and being serious and chronic as they are, represent a heavy financial and social burden—both direct, for hospitalisations and consumption of medical resources, and indirect, such as days missed from work and loss of productivity (Colom & Vieta, 2006). Relationships are another area which can be seriously affected, but the National Institute of Mental Health (NIMH) (2010: 2) emphasises: “Bipolar disorder can be treated and people with this illness can lead full and productive lives”. It is important that patients and caregivers must never lose hope.

2.3.1 Biological factors

The exact cause of bipolar disorder is not known. Several findings have highlighted the shared genetic or neuro-biologic underpinnings of the illness. More than two thirds of people with bipolar disorder have at least one close relative (parent or sibling) with the disorder or with unipolar depression ((NIMH) Genetics Workgroup, 1998). Haycock (2010:57, 62) agrees, and mentions that as scientists learn more about BD, it becomes clearer that multiple factors appear to cause and increase the risk of having this illness.

First-degree biological relatives of someone with bipolar I disorder have a 4–24 per cent chance of developing bipolar I disorder, a 1–5 per cent chance of developing bipolar II disorder and a 4–24 per cent chance of having unipolar depression (American Psychiatric Association, 2000). When one identical twin has bipolar disorder, the other twin is 7 to 8 times more likely to have it than a fraternal twin (Kieseppa, Partonen, Haukka, Kaprio & Lonnqvist, 2004; McGuffin, Rijdsdijk, Andrew, Sham, Katz, & Cardno, 2003). Depressive symptoms are the most common in bipolar disorder. They can appear identical to those of a

person with unipolar depression. More than 10 per cent of patients with depression will go on to experience a mania or hypomania episode in the next decade (Akiskal, Maser & Zeller, 1995). Unlike unipolar depression, which is more common in women than men, bipolar I disorder is equally common in men and women (American Psychiatric Association, 2000).

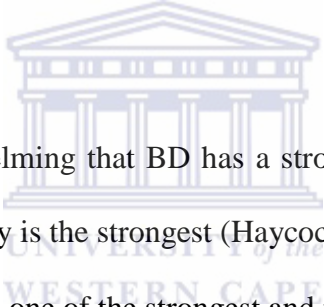
Factors suggestive of bipolar depression include an onset before the age of 25, a parent or sibling with bipolar disorder, a history of psychotic depression, postpartum depression, multiple recurrent depressive episodes, or a history of mania or hypomania induced by antidepressants. Bipolar depression is often associated with “atypical” symptoms including hypersomnia (excessive sleepiness) and hyperphagia (excessive eating). Depression frequently occurs with partial or complete mania symptoms such as racing thoughts, irritability, impulsivity, and psychosis (Perlis, Brown, Baker & Nierenberg, 2006). Among patients who have major depression, about four per cent bipolar disorder are more acute, severe and psychotic episode predicts bipolar I disorder, and mood liability or temperamental instability predicts bipolar II disorder, which about nine per cent patients with major depression develop (Akiskal, Maser & Zeller, 1995).

An unavoidable poor outcome of this illness and its recurrent nature has put BMD among the most debilitating disorders, and has lead researchers to pay more attention to its treatment. Based on the results of different studies, this disorder stands at the 6th or 7th place among other debilitating disorders worldwide (Calabrese, Hirschfeld, Reed, Davis, Frye & Keck, 2003; Chisholm, Ommeren, Ayuso-Mateos & Saxena, 2005; Simon, Ludman, Bauer, Unützer & Operskalski, 2006).

As befitting an illness with such harmful sequelae, there is great interest in refining our understanding of the aetiology of the disease. Research from twin and adoptive studies

consistently indicates a strong and compelling influence of genetics on BD. Despite consistent evidence from twin, adoption, and family studies supporting the role of genes in BD, the precise molecular bases for the disorder seem complex and are poorly understood. Although some chromosomal regions have more consistent support than others, to date no specific gene has been identified that is known to contribute incontrovertibly to the aetiology of BD (Hayden & Nurnberger, 2006). Merikangas and Peters (2010) also mention, in this regard, that although there have been many studies designed to identify candidate genes underlying BD through either linkage (segregating within family) or association (differences between cases and controls), there are still no replicated genetic markers for BD.

The researcher consulted the following resources, and all the authors agree that genetic vulnerability is very important:

- 
- The evidence is overwhelming that BD has a strong genetic component. Of all the risk factors, family history is the strongest (Haycock, 2010).
 - A family history of BD is one of the strongest and most consistent risk factors for the development of this disorder (Merikangas & Peters, 2010).
 - Epidemiological and genetic evidence suggest that BD has a strong hereditary component and that prevalence is relatively insensitive to variations in personal or social adversity (Vieta, 2009).
 - Studies of unipolar and BDs in families consistently show that these illnesses are strongly familial (Lewin, 2003).
 - It is not unusual for BD to be associated in families with other kinds of mood disorders, particularly various forms of depression. Geneticists usually establish that an illness is heritable, through family studies and twin studies. The average rate of mood disorder among first-degree relatives of bipolar persons is about 25 per cent.

The conclusion from various studies is that BD is 79–93 per cent heritable, meaning that most of the variation in risk for the disorder is due to genes. The hypothesis that a person’s genetic inheritance or biological vulnerabilities interact with specific environmental conditions to produce BD is just that – a hypothesis. Although a number of genes have been found to be associated with BD, no single gene provides an adequate explanation. Researchers suspect that many genes—each with a quite small effect – contribute to a genetic vulnerability for the illness. We know that BD involves changes in circadian rhythms; people with the disorder can have recurrences following a single night’s sleep loss. Recent evidence suggests that genes that control our circadian rhythms (“clock genes”) may be involved in the risk of BD and its recurrences (Miklowitz, 2011).

- Adoption studies have also produced data supporting the genetic basis for the inheritance of mood disorders. The inheritability of BD I is apparent because about 50 per cent of all bipolar I disorder patients have at least one parent with a mood disorder, most often major depressive disorder. If one parent has BD I, there is a 25 per cent chance that any child will have a mood disorder; if both parents have BD I, there is a 50 –75 per cent chance that their child will have a mood disorder (Sadock & Sadock, 2003).
- The risk to relatives of those individuals with BD is significantly greater than the risk for those individuals without BD in the family history. The risk of developing BD is greatest when the disorder is present in first-degree family members; namely: mother, father, or siblings (Hines-Martin & Thomas, 2003).
- As in the case of most neurobiological illnesses, science does not have a definitive answer for this question of aetiology. Perhaps more so than for any other disorder, there is mounting evidence that most individuals inherit bipolar illness. Studies of

twins, family histories and adoptions, support a genetic causation hypothesis. Genetics may explain causation in several, but not all, cases; multiple neurological pathways may lead to developing bipolar disorders. The NIMH (2010) indicates that studies of identical twins have shown that the twin of a person with bipolar illness does not always develop the disorder (Taylor, 2006).

In conclusion, a patient's biological predispositions affect his/her psychological and emotional reactions to stress. Recognising that the patient may be biologically and genetically vulnerable, and that certain factors are stressful, is the first step in learning skills for managing the disorder. Bipolar symptoms have a way of recurring when a person least expects them. This is because genetic and biological vulnerabilities are still present, even when medications and psychotherapy control a person's symptoms (Miklowitz, 2011).

2.3.2 Psychological factors

Extreme fluctuations of mood are characteristic of this disorder. Several studies emphasise cognitive impairment in bipolar, in particular, problems with memory and executive function, attention and verbal skills. Impulsivity and excessive risk-taking are common, especially during episodes of mania. People can find themselves acting in ways that are not characteristic for them and do not represent their personal values. Excessive spending, sudden travel, uncharacteristic substance abuse and sexual promiscuity, are common expressions of bipolar impulsivity (Nordenson, Gruber, & Yurgelun-Todd, 2004).

The average age of onset of bipolar disorder is in the teen years to early twenties. The first episode can be either a depressive or a manic episode. Transitioning from a manic/hypomania episode to a depressive episode, or from a depressive episode to a manic/hypomania is considered one "cycle" of bipolar disorder. The episodes in each cycle

can vary from mild to severe in intensity. They can be interspersed with long periods of euthymic mood, or be followed immediately by another mood cycle. Disability in functioning is usually related to how frequently people cycle, and how severe their symptoms are during their cycle (Kessler *et al.*, 2005).

Proportion of time spent in various mood states: people with bipolar disorder suffer reoccurring mood symptoms throughout their life. One study tracked patients' moods weekly for over a decade for the two major types of the illness (bipolar I disorder and bipolar II disorder). In this study, most of the time symptomatic was spent depressed and a minority of time was spent either manic or hypomanic (Judd, Akiskal, & Schettler, 2002).

Behaviour and actions are often impulsive and pleasure-seeking. When manic, patients can participate in uncharacteristic overspending, promiscuity, substance abuse or other impulsive behaviour. Judgment may be affected by perceptual disturbances such as auditory hallucinations, thought problems such as paranoia, flight of ideas (ideas that change so rapidly that they are confusing), or false beliefs (e.g., that one is more powerful, famous, or successful than in reality). Over half of patients who have bipolar disorder experience psychotic symptoms at some time during their illness. Bipolar disorder can be a debilitating disease with a high risk of completed suicide (19 per cent) (Goodwin & Jamison, 1990).

People with this disorder rate their illness as "severe" 83 per cent of the time, much higher than they rate the severity of other mental illnesses (22%) and have trouble functioning in many areas of life (Kessler *et al.*, 2005; Ei-Mallakh & Karippot, 2005). Treatment can significantly reduce suicide rates, even in those who are more severely ill (Angst, Stassen, Clayton & Angst, 2002).

2.3.3 Social factors

Environmental factors must play a role in the development of BD, since identical twins are frequently discordant for the condition. Indeed, a growing body of evidence suggests that environmental factors have an important impact on the onset, course, and expression of BD (Vieta, 2009).

Miklowitz (2011) agrees, remarking that most scientists in the field doubt that environmental factors alone can cause BD without the contributing influences of genetics and biology. However, researchers are reasonably certain that stress and trauma affect the course of the illness. Although BD is a biological illness that deserves proper pharmacological treatment; it is also a chronic, complex and recurrent condition with pervasive behavioural, cognitive and emotional symptoms that may be triggered by personal and environmental factors. Impairment in occupational and social functioning is prevalent, even between episodes. The quality of care and subsequent patient outcomes remains sub-optimal. Psychiatric treatment of BD is complicated by the fact that patients vary with respect to the uniqueness of their symptoms, life circumstances and co-morbid psychiatric issues (Colom & Berk, 2010; Kilbourne, Goodrich & Bauer, 2010).

There has been significant improvement in available treatments for bipolar mood disorder (BMD) during the past few years. However, this disorder still causes difficulties for the patients, their families, and the society (Kleinman, Lowin, Flood, Gandhi, Edgell, & Revicki, 2003). Overall, studies have demonstrated that this disease affects patients' entire family, and may weaken its strengths and adaptive abilities (Barry, 2001).

The chronic and recurrent nature of BMD impacts several aspects of patients' lives, from their interpersonal relationships to the quality of their work. As an example, divorce rate is reported to be higher in this patient population (Ghoreishizadeh, Deldoost & Farnam, 2008).

Haycock (2010) states, although the underlying foundation for BD must have been present, some people report that their episodes began when they were under great stress. These stressful events can include childbirth, divorce or breakup of a relationship, loss of a job, death of a loved one, and serious financial difficulties. Medical researchers tend to agree that stress, in a variety of forms, is probably the most important trigger for BD.

Stress can also result from other illnesses and injuries such as multiple sclerosis, epilepsy, and brain injury. Last (2009) and Miklowitz (2011) agree that another major type of stress has to do with on-going relationships. There is no evidence that disturbances in family relationships are a primary cause of BD, but a high-intensity, high-conflict family can increase a person's likelihood of having a recurrence of BD once she or he has the disorder. Conflict-ridden family environments seem to make bipolar disorder more recurrence-prone. There is a possibility that the cycle of BD may also be affected by conflicts with other significant people, such as the person's employer, co-workers, or friends.

Taylor (2006) argues that professionals, patients and families rightfully worry about the relationship between stress and bipolar symptoms. Stress does not appear to be a major factor in explaining why people develop bipolar disorders, nor does it relate to the number of episodes and relapses that are experienced. Mental illness can develop in some people who have not been exposed to any events that others would consider traumatic. Lack of social support has also been connected to increased bipolar episodes. Having supportive friends and family nearby to lend encouragement between episodes tends to reduce stress (Haycock, 2010). An important factor mentioned by Scott and Tacchi (2010), was the finding that non-adherent individuals with BD were more likely to be living with family members who were significantly less knowledgeable about BD and its treatment, and were more critical of the patient than families of adherent subjects. According to findings by the same authors, it does seem that individuals with BD living in highly expressive emotional

environments, particularly if accompanied by a negative affective style of interaction or a high caregiver burden, are at higher risk of non-adherence and relapse. Scott and Tacchi (2010) furthermore refer to the fact that the views of the patient's significant others towards treatment are important, as these may influence the patient's beliefs about his/her problems and/or attitudes towards proposed treatments.

Effective treatment requires a well-informed patient, a supportive family, and an understanding social network. Fast and Preston (2006) emphasise an approach that looks at the whole picture of BD and manages the disorder through a variety of treatment ideas from many different disciplines and health care professionals. A comprehensive treatment plan does not focus solely on one treatment, such as medication. Instead, it examines all the person's needs, from medication, psychotherapy, physical health, and emotional, financial and personal needs. The primary task of the mental health service is the prevention and treatment of mental disorders in the population. However, for most patients, the family is the most important carer, and the caregiving role is associated with a considerable burden. It is more the exception than the rule that the mental health service has developed routines for taking care of the family, who often feel overlooked and forgotten. When the support system contributes to humiliating, invasive, and devaluating experiences for the next of kin, their burdens are intensified (Tranvag & Kristoffersen, 2008).

Available data suggests that the caregiver burden is high and largely neglected in BD, and is a matter of increasing clinical concern. Patients living with an "over-burdened" caregiver may have an increased risk of relapse (Ogilvie, Morant & Goodwin, 2005). The caregiver's burden may influence the clinical outcome of BD (Reinares, Vieta, Colom, Martinez-Aran, Tottent, Comes, Goikolea, Benabarre, Daban & Sanchez-Moreno, 2006). Ogilvie *et al.*, (2005) state that the caregiver burden has been described as the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patient's

significant other(s), for example members of the household and/or the family, although significant others can be considered to include close and supportive friends.

When caregivers of patients with bipolar illness experience a heavy burden, patient outcome is adversely affected. The experience of burden appears to initiate a sequence of caregiver and patient behaviours that affect both clinical course and outcome, in part by reducing medication adherence (Perlick, Rosenheck, Clarkin, Maciejewski, Sirey, Struening & Link, 2004). Like many chronic illnesses, BD afflicts one but affects many in the family. It is important that all those affected receive the help, support, and encouragement they need (Mondimore, 2006). Community support programmes are proposed by McElroy (1987) to relieve some of the burden placed on them.

Family and interpersonal conflicts may be risk factors in the course of the illness. Family members, when describing the emotional volatility of their bipolar partner, sibling, child or parent, tend to emphasise the intimidation they feel in the face of sudden outbursts that they do not feel they have provoked. In the extreme manic states, family members become worried that the patient will hurt him/herself or someone else. Family members and friends will be particularly upset and scared by the patient's suicidal thoughts, if such are expressed to them (Miklowitz, 2011).

When a patient re-enters his/her everyday world following a mood episode, even well-intentioned family members do not know how to interpret the changes in his/her behaviour (for example irritability or lack of motivation). They often mistakenly think that the person is acting this way on purpose, and could control this behaviour if he/she only tried harder. As a result, they become critical, evaluative, and judgemental. They may also mistakenly think the patient cannot take care of him/herself and try to do things for him or her that the person is more than capable of doing (Miklowitz, 2011). Last (2009) also warns that a

caregiver should not be overprotective, always stepping in, because as a result the patient does not use whatever skills he/she possesses, or develop ones for him/herself, and consequently, becomes increasingly dependent and helpless. There must be a balance between protecting patients and trusting them to make their own decisions. Relatives may repeatedly remind the patient to take medications, or go behind the patient's back to talk with the physician (Miklowitz, 2011).

The safe and successful delivery of efficacious treatment for bipolar disorders relies upon the patient's (and often their caregiver's) ability and willingness to accept and engage with the services provided, and to adhere to an agreed regime of medication and/or other interventions that make up the individual's treatment plan. Collaboration between the clinician and patient is a critical first step if patient outcomes are to reflect the goals of both parties (Scott & Tacchi, 2010).

BD presents unique challenges for women. In particular, various stages and events in a woman's reproductive life can affect and are affected by the disorder. Women are more likely to ruminate when depressed, whereas men are more likely to become aggressive or irritable. Women are also more likely than men to have anxiety, panic attacks, body image problems, and eating disorders (Miklowitz, 2011). Mondimore (2006) points to the fact that although women are no more likely than men to suffer from BD, the hormonal changes that accompany menstruation and pregnancy affect the course of BD in women.

Michalak, Murray, Young and Lam (2010) report that a woman who develops BD at the age of 25 may lose 9 years in life expectancy (due to cardiovascular and other medical problems), 14 years of productivity, and 12 years of normal health. Taylor, Steiner and Soares (2009) observe that the role of gender in BD has not been studied to the same extent

as in other chronic mental illnesses, but there are some specific features of BD in women that set them apart from other patient populations:

- Women have a higher incidence of bipolar II disorder.
- Women present with a higher incidence of rapid cycling episodes, mixed states and antidepressant-induced mania.
- Women with BD have higher prevalence rates of alcoholism than women without this disorder.
- The presence of medical co-morbidities such as obesity, migraine and thyroid dysfunction is also common in this population.

Miklowitz (2011) refers to the fact that mood disorders, which are the direct result of substances, are usually short-lived and treated through detoxification and chemical dependency programmes. After explaining what bipolar entails, the researcher presents an overview of substance abuse disorder in the next section of the chapter in order to comprehend co-morbidity between bipolar and substance use disorder, which will be discussed later on in this chapter.

2.4 SUBSTANCE ABUSE DISORDER (SUD)

Substance Abuse can be defined as a maladaptive pattern of substance use leading to clinically significant impairment or distress, manifest by one or more of the following symptoms within a 12 month period: recurrent substance use in situations that cause physical danger to the user, recurrent substance use in the face of obvious impairment in school or work situations, recurrent substance use despite resulting legal problems, or recurrent substance use despite social or interpersonal problems (Diagnostic and Statistical Manual of Mental Disorders [DSM-IV-TR], 2000). The National Drug Master Plan (1999-2004) defines the concept substance abuse as the misuse and abuse of legal substances such

as nicotine, alcohol, over-the-counter drugs, prescribed drugs, alcohol concoctions, indigenous plants, solvents, inhalants, as well as the use of illicit drugs. Substance abuse can be used to refer to any substance that, when taken by a person, modifies perception, mood, cognition, behaviour, or motor functions (DSM-IV-TR, 2000).

Under certain conditions, the use of substances that affect mood and behaviour can be described as “normal” according to statistical frequency and social standards. It is normal to start the day with caffeine in the form of coffee or tea, to take wine or coffee with meals, to meet friends for a drink after work, and to end the day with a nightcap. However, some psychoactive substances, such as cocaine, marijuana, and heroin, are illegal, and are used illicitly. Others such as tobacco (which contains nicotine, a mild stimulant) and alcohol (a depressant) are available without prescription or over-the-counter. Ironically, the most widely and easily accessible substances, tobacco and alcohol, cause more deaths through sickness and accidents than all illicit drugs combined (Hapt, 2005).

Methamphetamine, cannabis, methaqualone, cocaine, heroin and alcohol are the most commonly abused substances in the Western Cape. Methamphetamine, which is commonly referred to as “tik”, has been the primary drug for which a large number of people have sought treatment since 2004. Statistics from the South African Community Epidemiology Network on Drug Use (SACENDU) show that between January and June of 2010, 34 per cent of the population in treatment reported methamphetamine as the primary drug of abuse. This drug first surfaced among gang members involved in criminal activities in the impoverished parts of Cape Town. However, alcohol is the most frequently abused substance with a lifetime prevalence use ranging between 39 per cent and 64 per cent in the Western Cape and second to methamphetamine, 30 per cent of the population seeking treatment report alcohol as their primary drug of abuse. Cannabis is also a widely used illegal substance, with 16 per cent of people in treatment reporting this substance as their

primary drug of use. The prevalence of heroin, as with cocaine, remains relatively low in the Western Cape, reported at 0.2 per cent and one per cent respectively. In spite of these findings, the use of heroin has also increased in previously economically disadvantaged communities in Cape Town, particularly in what is termed the “Coloured” communities (Parry, Plüddemann & Bhana, 2009).

2.4.1 The biological element of substance-abuse disorder

There is currently a better understanding about the biological underpinnings of drug use and addiction. Recent research has focused on neurotransmitters, especially dopamine, and on the role of genetic factors. Neurotransmitters, many psychoactive drugs like nicotine, alcohol, heroin, marijuana and especially cocaine and amphetamines, increase levels of the neurotransmitter dopamine in the brain’s pleasure or reward circuits. They are the networks of neurons responsible for producing feelings of pleasure or states of euphoria (Nestler, 2005; Pierce & Kumaresan, 2006; Zangen, Solinas, Ikemoto, Goldberg & Wise, 2006). Over time, regular use of these drugs reduces the brain’s own production of dopamine. Consequently, the brain’s natural reward system, the “feel good” circuitry that produces states of pleasure associated with the ordinarily rewarding activities of life, such as consuming a satisfying meal and engaging in pleasant activities, becomes blunted (Dubovsky, Grégoire, Nicolis & Rattazzi, 2006). In effect, the addict’s brain comes to depend on having the drug available to produce feelings of pleasure or satisfaction (Denizet-Lewis, 2006). Without drugs, life may seem not worth living.

Changes in the dopamine system may help to explain the intense cravings and anxiety that accompany drug withdrawal, and the difficulty people have in maintaining abstinence. Although investigators highlight the role of dopamine in helping us understand the biochemical bases of substance abuse and dependence, they recognise that other

neurotransmitters, including serotonin and endorphins, also play a role (Addolorato, Leggio, Abenavoli, Gasbarrini & Alcoholism Treatment Study Group, 2005).

Endorphins are a class of neurotransmitters that have pain-blocking properties similar to those of opioids such as heroin. Endorphins and opiates ports the same receptor sites in the brain. Normally, the brain produces a certain level of endorphins that maintains a psychological steady state of comfort and the potential to experience pleasure. However, when the body becomes habituated to a supply of opioids, it may stop producing endorphins. This makes the user dependent on opiates for comfort, pleasure, and relief from pain. When the habitual user stops using heroin or other opiates, feelings of discomfort and little aches and pains may be magnified until the body resumes adequate production of endorphins. This discomfort may account, at least in part, for the unpleasant withdrawal symptoms that opiate addict's experience. This model remains speculative, and more research is needed to document direct relationships between endorphin production and withdrawal symptoms. Evidence links genetic factors to various forms of substance use and abuse, including alcohol abuse and dependence, heroin dependence, and even cigarette smoking (nicotine dependence) (Feng & Macdonald, 2004; Hampton, Bossaerts & O'doherty, 2006; Liu,Wei, Tan, Zhou, Würthwein & Rohdewald, 2004).

Researchers have begun the hunt for specific genes involved in alcohol and drug abuse and dependence. Alcohol dependence has been the area which is dominant in this research. Alcoholism tends to run in families (American Psychiatric Association, 2003). It has been found that the closer the genetic relationship, the greater the risk of alcoholism. However, families share not only common genes but also a common environment. More precise evidence on genetic factors is necessary, and this derives from twin and adoptee studies (Audrain-McGovern, Rodriguez, Tercyak, Epstein, Goldman & Wileyto, 2004; Drakenberg, Nikoshkov, Horváth, Fagergren, Gharibyan, Saarelainen & Hurd, 2006).

Monozygotic (MZ) twins have identical genes, whereas fraternal or Dizygotic (DZ) twins share only half of their genes. If genetic factors are involved, evidence has found that MZ twins have higher concordance (agreement) rates for alcoholism than DZ twins. The results are more consistent for male samples than female samples (Fitz-Gerald & Patrono, 2001).

A limitation of twin studies is that MZ twins may share more environmental as well as genetic similarity than DZ twins, because they may be treated more similarly than DZ twins. Evidence also shows that male adoptees whose biological parents suffer from alcoholism have an increased risk of developing alcoholism even if they are raised in non-drinking homes (Gordis, 1995). Among women, the rate of alcoholism in adopted daughters not living with their parents with alcoholism, are only slightly higher than those of non-alcoholics not living with their parents. This evidence casts doubt on a strong genetic linkage to alcoholism in women (Svikis, Velez & Pickens, 1994). In conclusion, evidence indicates that genetic factors are believed to play a moderate role in male alcoholism and a modest role in female alcoholism (McGue, Bacon & Lykken, 1993).

The question then arises: If alcoholism or other forms of substance abuse and dependence is influenced by genetic factors, what exactly is inherited? Evidence exists on certain forms of dependence and genetic factors. Alcoholism, nicotine dependence and opioid addiction are linked to genes that determine the structure of dopamine receptors in the brain. As noted, dopamine is involved in regulating states of pleasure, so the possibility exists that genetic factors enhance feelings of pleasure derived from alcohol. The genetic vulnerability to alcoholism involves a combination of factors such as reaping greater pleasure from alcohol and a capacity for greater biological tolerance. People tolerating larger doses of alcohol without incurring upset stomachs, dizziness and headaches, may have difficulty knowing when to stop drinking. It follows that people who are better able to absorb their liquor may be at greater risk of developing drinking problems. They may need to rely on other cues

such as counting their drinks, to limit their drinking. People whose bodies more readily control excess drinking may be less likely to develop problems in moderating their drinking (Radel, Vallejo, Iwata, Aragon, Long, Virkkunen & Goldman, 2005).

Whatever the role of heredity in alcohol dependence and other forms of substance dependence, genes do not dictate behaviour and interaction with environmental factors. Research has found that being raised in an environment free of parental alcoholism is associated with a lower risk of alcohol-related disorders in people at high genetic risk of these disorders. Addiction experts believe that multiple genes acting together with social, cultural and psychological factors, contribute to the development of alcoholism and other forms of substance dependence (Dick, Verrier, Harker & Rashiq, 2008).

2.4.2 The psychological element of substance-abuse disorder

The psychological effects of alcohol or other drugs vary from person to person. By and large, they reflect the interaction of the physiological effects of the substances and our interpretations of those effects. People frequently hold stereotypical expectations that alcohol will reduce tension, enhance pleasurable experiences, wash away worries, and enhance social skills. At a physiological level, alcohol appears to have the same effect as benzodiazepines (a family of anti-anxiety drugs), which increase activity of the neurotransmitter gamma-amino-butyric acid (GABA). GABA is an inhibitory neurotransmitter (it tones down nervous system activity), and increased GABA activity produces feelings of relaxation. As people drink, their senses become clouded, and balance and coordination suffer. Still higher doses act on the parts of the brain that regulate involuntary vital functions such as heart rate, respiration rate and body temperature. People may do many things when drinking that they would not do when sober, either because of expectations concerning the drug, or because of the drug's effects on the brain. For example,

they may become more flirtatious, sexually aggressive, and say or do things they later regret. Their behaviour may reflect their expectation that alcohol has a liberating effect and provides an external excuse for questionable behaviour. People are less capable of perceiving the unfortunate consequences of their behaviour. When sober, they blame the alcohol. The drug may also impair the brain's ability to curb impulsive, risk-taking, or violent behaviour by interfering with information-processing functions. Researchers have also found strong links between alcohol use and violent behaviour, including domestic violence and sexual assaults (Abbey, Zawacki, Buck, Clinton & McAuslan, 2004; Fals-Stewart, 2003; Boles & Miottoa, 2003; Marshal, 2003).

Chronic alcohol abuse can impair cognitive abilities such as memory, problem solving, and attention. One of the consequences of alcohol is that it induces short-term feelings of euphoria and elation that can drown self-doubts and self-criticism. As an intoxicant, alcohol also hampers coordination and motor ability. These effects help explain why alcohol use is implicated in about one in three accidental deaths in the United States (Ratti, 2002).

2.4.3 The social element of substance abuse disorder

Substance abuse is a social problem that not only affects the people who abuse the substances, but also has more widespread consequences. A representative study conducted on the South African population reported that 13 per cent of the general population in the country have an untreated substance-use disorder (Myers, Louw & Pasche, 2010). Social problems related to substance abuse are known to be particularly prevalent in Cape Town, the capital of the Western Cape Province, as compared to other parts of the country (Plüddemann, Parry, Donson & Sukhai, 2004). This has resulted in the province experiencing a greater burden of health, social, and criminal problems from the continued substance abuse. These mentioned authors further substantiate that the Western Cape has

high proportions of trauma patients and people arrested, who test positive for alcohol and other illicit drugs. The use of drugs and alcohol is reported to increase the likelihood of unsafe sexual practices, trauma-related injuries, and violent behaviour (Parry, Plüddemann, Louw & Leggett, 2004).

Even though substance abuse is well-recognised as a complex BPS phenomenon, substance dependence is considered as a “family disease”. A substance-dependent person in the family affects almost all aspects of family life, such as interpersonal relationships, leisure time activities, and finances. Substance dependence invariably increases conflicts, negatively affects family members, and burdens the families. The psychological and behavioural impact on others is often far greater than on the substance-dependent family member. Yet, because of the historical emphasis on substance dependence as an individual’s problem, the study of families’ problems and burdens has been relatively neglected (O’Farrell & Fals-Stewart, 1999).

Traditionally, the research on families with substance-dependent members, has examined the family and the family process almost exclusively as an aetiological entity that affects the subject’s substance use (Rosemary & Webster, 1994). The burden is more often related to disruptive activities of the substance-dependent person, and financial difficulties due to loss of income and/or diversion of funds owing to substance dependence. The families of alcoholics, especially the spouses, live under increased risk of stressful life events, medical and psychiatric disorders, and greater use of medical care services (Lennox, Scott-Lennox & Holder, 1992; Holder, 1998; Connorsm, Donovan & DiClemente, 2001; Bhowmick, Tripathi, Jhingan & Pandey, 2001; Ray, Mertens & Weisner, 2007).

Mental disorders and substance use occur together very often, and can interact negatively on one another. Miklowitz (2011) explains that the term “co-morbidity” refers to the co-

occurrence of two or more psychiatric disorders in the same person. Many people have more than one DSM-IV-TR psychiatric disorder (also DSM 5). These disorders need to be considered as a differential diagnosis as either the primary disorder, or in some cases, a co-morbid disorder (Frances in DSM 5, 2013).

2.5 CO-MORBID BIPOLAR (BP) AND SUBSTANCE USE DISORDER (SUD)

Co-morbidity is a term that originated in general medicine to account for the impact of associated clinical entities, and includes disease states but also non-disease states such as pregnancy, in the management and prognosis of the index disease (Salloum, Pani & Cooke, 2010).

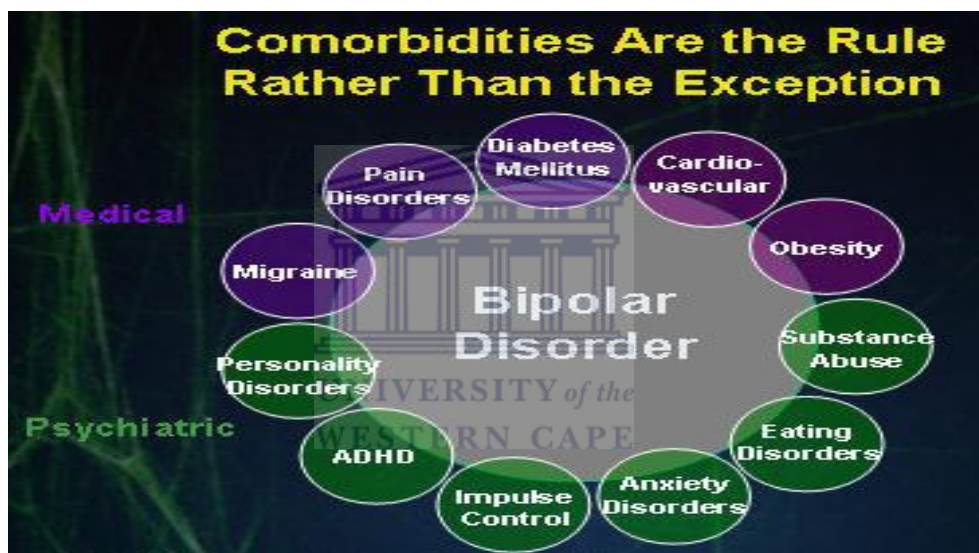


Figure 2.2: Co-morbidity (Ketter, 2013: <http://www.medscape.org>).

Wittchenin, Grabski, Dudek, Datka, Maćzka & Zięba (2008) define co-morbidity as the presence of more than one specific disorder in a person in a defined period of time. This definition extends the concept of co-morbidity to a lifetime perspective, and is the most commonly used in research. The data from both epidemiological and clinical studies indicates that co-morbidity is a common phenomenon among bipolar patients, with a possible negative impact on clinical characteristics of BD. The rates of co-morbidity reported by various authors have been as diverse as ranging from 31 to 68 per cent (Vieta,

Colom, Martinez-Aran, Benabarre, Reinares & Gasto, 2000; Vieta, Colom, Corbella, Martinez-Aran, Reinares & Benabarre, 2001; Suppes, Leverich, Keck, Nolen, Denicoff, Altshuler, McElroy, Rush, Kupka, Frye (2001). In the NCS, all the individuals diagnosed as having bipolar I disorder suffered from at least one psychiatric disorder in their lifetimes (Joyce, 2000).

The risk that a bipolar patient will suffer a substance-related problem is six-fold higher than that of the general population (Colom & Berk, 2010). Regier, Farmer and Rae in Michael, Grunebaum, Hanga, Galfalvy, Matthew, Nathilee, Kanita, Ainsley and Oquendo (2006) and Last (2009) all concur that persons suffering from bipolar disorder have rates of co-morbid substance-use disorders (SUD) as high as 60 per cent. Miklowitz (2011) and Mondimore (2006) found that between 40 and 60 per cent with BD has a long-term substance use disorder, a rate that is much higher than the rate of the general population at 10–20 per cent. The highest incidence of co-occurring SUD among mood and anxiety disorders was associated with bipolar disorder (Grant, Stinson & Dawson, 2004). Compared to non-depressed persons, those with depression have a more than threefold risk of being alcohol-dependent (Lukassen & Beaudet, 2005) and mania is associated with a six-fold risk of SUD. Further understanding of the clinical profile of persons with bipolar disorder who are at higher risk of developing co-morbid SUD, could aid prevention and shed light on the interplay between mood and SUD (Levin & Hennessy, 2004).

The most common SUD appears to be alcohol abuse and dependence. More than any other associated condition, drug and alcohol abuse makes the course of BD much worse (Miklowitz, 2011). Research from the Stanley Foundation Bipolar Network found that the lifetime prevalence rate of alcohol abuse or dependence was 49 per cent for bipolar men and 29 per cent for bipolar women. Women with BPD seemed to be at higher risk for alcoholism

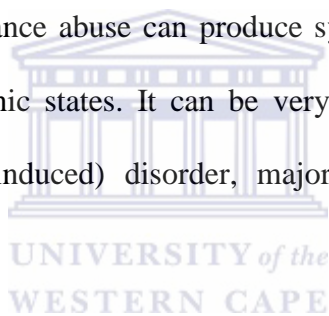
than women in the general population. Whereas alcoholism in bipolar men may have more of a genetic influence, in women the risk may be more of an acquired burden related to depressive illness. Depressive symptoms are especially common in female bipolar patients with co-morbid alcohol abuse (Martin, 2011).

Many people with BD self-medicate with street drugs and/or alcohol. This can make the symptoms worse over the long term (Haycock, 2010). In practice, self-medicating is frequently observed, sometimes because patients cannot obtain their prescribed drugs. Sadock and Sadock (2003) consider that the abuse of substances may be involved in precipitating an episode of illness, or conversely, may represent patients' attempts to treat their own illnesses.

Substance use is associated with poorer outcome of BD, including increased episodes of depression, adherence problems, and delayed symptomatic recovery. Berk, Berk, Castle and Lauder (2008) consider that while some people with BD do not experience alcohol or drug problems, there are many (50–70 per cent of people with BD) whose lives are complicated by alcohol and drug problems because the risks of relapse, mixed episodes, rapid cycling, suicide and violent behaviour increase in people with BD who also display drug or alcohol problems. Bipolar subtypes such as rapid cycling and mixed states (Kupka, Luckenbaugh & Post, 2005) are reported to be associated with co-morbid SUD. A study by Weiss, Kolodziej, Griffin, Najavits, Jacobson and Greenfield (2004) found the bipolar symptoms most associated with co-morbid SUD were depressive symptoms and racing thoughts. One study found that mania complicated by co-morbid alcohol misuse was associated with greater impulsivity, violence, and other drug abuse (Salloum, Cornelius, Mezzich & Kirisci, 2002). Trait aggression has been associated with poor outcomes in bipolar disorder, and specifically, a greater risk of attempted suicide (Oquendo, Waternaux & Brodsky, 2000).

Studies have reported that an earlier age of onset of bipolar disorder (Dalton *et al.*, 2003), particularly in adolescence (Wilens, Biederman, Millstein, Wozniak, Haehy & Spencer, 1999), is associated with a higher risk of SUD. This could be a result of increased impulsivity, which has been postulated as a link between bipolar disorder and SUD (Swann, Dougherty, Pazzaglia, Phamand & Moeller, 2004).

Substance abuse is extremely prevalent among people who have bipolar disorder. The incidence of substance abuse and substance use with BD is similar, because research has also found that at least 60 per cent of people who are diagnosed with BD, abuse at least some time during the course of the illness (Last, 2009; Haycock, 2010). Substance abuse can mask BD. It can worsen the course of the disorder by lengthening mood episodes and increasing their severity. Substance abuse can produce symptoms very similar to those of BD. Stimulants can mimic manic states. It can be very difficult to determine quickly if someone has substance use (induced) disorder, major depressive disorder, BD, or a combination (Haycock, 2010).



Berk *et al.*, (2008) agree, stating that some temporarily altered states which are brought on by taking certain illicit drugs, may mimic episodes of BD, but the effects of intoxication wear off rapidly and do not constitute BD. Substance abuse and anxiety disorders are the most common co-morbidities in BD, and may have a significant impact on its course and treatment (Salloum *et al.*, 2010). Mondimore (2006) advises persons with a mood disorder to scrupulously avoid any and all intoxicating substances in any quantity whatsoever. He also reports on the research finding that persons with mood disorders who also abuse alcohol or drugs have a greatly increased risk of completed suicide. Severe depression complicated by alcoholism or drug abuse has been found to be one of the most frequent diagnostic pictures in study after study of the psychiatric diagnoses of suicide victims. Many

people turn to alcohol or drugs during manic episodes. Substance use problems and addictive behaviours are not essential symptoms of BD, but they can become intertwined with mood disorder symptoms in such a way that each worsens the other (Miklowitz, 2011).

It is important to determine whether the mood symptoms were present before the substance abuse began, or if the mood changes are the result of the substance abuse. If it is clear that the person has both substance abuse and BD, both conditions should be treated simultaneously, without delay. The optimal treatment involves an integration of treatment modalities, rather than merely consecutive treatment with a specific focus on either substance abuse or BD. It can be managed on an outpatient basis, preferably by staff trained to deal with both disorders. Sometimes it will be necessary to admit patients to the hospital or a rehabilitation facility (Kowatch, Fristad, Birmaher, Wahner, Findling, Hellander, & Child Psychiatric Workgroup on bipolar disorders, 2005).

Some psychiatric hospitals in South Africa have started to offer a substance rehabilitation programme for in-patients, because patients with a co-morbid substance abuse problem are often not properly treated at other rehabilitation units – especially if there are no trained psychiatric staff involved (Haycock, 2010). Because of the importance of treatment in co-morbid BD and substance abuse disorder, as well as other psychiatric conditions, the researcher will discuss the current mental health services and implementation of policy and legislation in the following section of this study.

2.6 CURRENT SERVICES FOR MENTAL HEALTH IN SOUTH AFRICA

It is clear that treatment is of outmost importance for patients with the co-morbid diagnosis of BD and substance abuse as well as other mental illnesses. However a gap exists between the burden of mental illness and disability and the mental health resources in South Africa.

The government has an obligation to give resources to the health needs of its people, but it is clear that services for those with mental illness and disability are sadly lacking. Despite South Africa's progressive mental health legislation (Mental Health Care Act 17 of 2002), various barriers exist in financing and providing mental health services. Psychiatric facilities are outdated, with some falling into deterioration, and frequently unfit for human use. There are very few mental health experts, and there is failure to develop essentially critical tertiary level psychiatric services, for example, child and adolescent services, psycho-geriatric services, and neuropsychiatric services. Community mental health and psychosocial rehabilitation services remain undeveloped, and consequently patients are institutionalised without being discharged successfully, into their communities.

Irrespective of the South African Mental Health Care Act (2002), psychiatric services are limited, and policy is not implemented owing to limited resources for mental health from provincial health departments (Lund, Kleintjes, Kakuma, Flisher & MHaPP Research Program Consortium, 2010). There is no national mental health plan and only one out of nine regions at a provincial level has a particular mental health plan. There is no particular spending plan for mental health, either at national or provincial level, and mental health services are supported out of general health spending budgets, where they definitely end up at the bottom of pressing needs when money is allocated (Lund, Kleintjes, Campbell-Hall, Mjadu, Petersen, Bhana, Kakuma, Mlanjeni, Bird, Drew, Faydi, Funk, Green, Omar, & Flisher, 2008).

In a study in all nine provinces, Lund *et al.*, (2010) found that just three regions could report information on mental health expenditure, which was one per cent, five per cent and eight per cent respectively. This is the situation in most middle-income countries, and mirrors the disproportionately low allocation made to mental health irrespective of the high prevalence

of mental disorders and more than 30 per cent of disability-adjusted life-years (DALYs) from these disorders (Prince, 2007).

Research in KwaZulu-Natal indicates gross disparity in the portion of provincial health spending plans to psychiatric facilities (Burns, 2010). Financial plan increases to six psychiatric facilities over the five-year period (2006-2010) went from eight per cent to 25 per cent with a mean five-year increase of 19 per cent and a mean yearly increase of 3.8 per cent. Budget increases to seven general hospitals over the same five-year period changed from 29 per cent to 64 per cent with a mean 5-year increment of 51 per cent and a mean yearly increase of 10.2 per cent. The middle combined spending plan increase for psychiatric facilities was lower than that of general hospitals, which illustrates the vast differences in funding between psychiatric facilities and general health facilities. Research found that four of the six psychiatric facilities encountered a year-to-year drop in spending plan portions within the five-year period; while none of the general hospitals encountered a drop in spending plan during the period. This highlights the fact that psychiatric facilities are not prioritised by governments (Burns, 2010).

South African hospitals have 2.1 beds for each 10,000 population, which is similar to other African countries, but a contrast to European countries that have eight beds for every 10,000 population. Of these 2.1 beds, 1.8 is in psychiatric facilities and 0.3 in general health facilities. This figure represents a little more than 60 per cent of the beds required, according to standards by the South African National Department of Health (National Department of Health, 2004). Accessibility of beds for psychiatric services varies from province to province; for example, KwaZulu-Natal has just 25 per cent of beds required according to standards (Burns, 2010).

Community-based psychiatric services are insufficient. There is just 80 day-treatment facilities in the country (for a population of 47 million) and half of these belong to non-governmental organisations. Likewise, there are 0.36 beds for every 10,000 population situated inside 63 community residential facilities nationwide and, once more, half of these are from the South African Federation of Mental Health (SAFMH). There are limited services particularly for the treatment of youngsters and adolescents. Just 1.4 per cent of outpatient facilities, 3.8 per cent of psychiatric beds in hospitals, and one per cent of beds in psychiatric facilities are for children and youths (Lunt *et al.*, 2010).

Information is not accessible on the number of child and adolescent therapists in South Africa, and the number fluctuates from region to region. In KwaZulu-Natal (which has a population of 10 million) there are just two such specialists in public health. Human resources for mental health care in South Africa are insufficient. As mentioned in Chapter 1 of this study, there are only 0.28 psychiatrists, 0.32 psychologists, 0.4 social workers, 0.13 occupational therapists and 10 nurses per 100,000 of the population (Lund *et al.*, 2010).

South Africa has fewer than 30 per cent of the number of psychiatrists required to conform to national standards of 1 for each 100,000 population. This figure (0.28 for every 100,000 population) is far less than the norm for other middle-income countries, which is around 5 for each 100,000 population, and is much lower than the norm for high-income countries, which are approximately 15 for each 100,000 population. Moreover, most mental health experts have a tendency to be situated inside urban centres, leaving expansive rural areas of the country without such services. From the 32 psychiatrists working in the public health sector in KwaZulu-Natal Province, just six are found outside of the real urban areas (WHO, 2005).

It is clear that resources for mental health care are seriously inadequate in South Africa, and, given the large burden of disease which is undoubtedly increased by socio-economic conditions of poverty, inequality, violence and infectious diseases, there is a considerable gap between needs and services. In the South African Stress and Health (SASH) study, only 28 per cent of adults with severe or moderately severe psychiatric disorders, and only 24.4 per cent of those with mild cases, received treatment (Williams, Herman, Stein, Heeringa, Jackson, Moomal & Kessler, 2008).

A large proportion of the population relies on informal services in the community for mental health treatment. In a sample of patients with first-episode psychosis (FEP), 38.5 per cent had consulted a traditional healer for their psychotic illness prior to making contact with formal psychiatric services. In contrast, rates reported in FEP patients in other countries are a third in Zambia, 24 per cent in Singapore, and 23 per cent in Iran (Mbewe, Haworth, Welham, Mubanga, Chazulwa, Zulu, Mayeya & McGrath, 2006; Chong, Mythily, Lum, Chan & McGorry, 2005; Sharifi, Kermani-Ranjbar, Amini, Alaghband-rad, Salesian & Seddigh, 2009).

Consultation with traditional healers may delay access to care for people with early mental illness, and this in turn may impact negatively on the course and outcome of the illness (Burns, Jhazbhay, & Emsley, 2010). However, traditional healers are more geographically and culturally accessible to many citizens (Mkize & Uys, 1994). In addition to geographical and financial barriers, another major factor leading people to traditional healers is societal stigma associated with the use of formal mental health services (Thornicroft, 2008).

Mental health services and legislation globally propose de-institutionalisation and treatment in the community, as opposed to hospital care (Arvidsson & Ericson, 2005). In principle, the

key argument on which de-institutionalisation is based, is that persons with mental illnesses ought to have the opportunity to experience living in communities with the same rights as people without these illnesses (Magnusson, Severinsson, & Lutzen, 2003). Political interests, to stop the increasing costs, contribute to the decision of de-institutionalisation (Bjorkman, 2000). The advantage of care of mentally ill patients in the community is also debated around the world (Salize, Schanda & Dressing, 2008).

Hospital stays of all types are becoming shorter, and psychiatric hospitalisation is no exception. Patients are discharged as soon as possible and no longer hospitalised in a psychiatric unit for weeks or months. Emphasis is on acute treatment, stabilisation, and discharge. The challenge of transition from hospital to community life is often underestimated. For many patients, being discharged from hospital is just as stressful as an admission, because the hospital has been a protective, structured environment (Surdut, 1998). Hospitalisation provides a person with a much-needed rest or break from the stressors of day-to-day life (Miklowitz, 2011). Re-admission to hospital should be prevented by providing preventative measures such as that the patient and family know the symptoms of the illness and obtain immediate care. Compliance with treatment and avoiding substance use/abuse are also able to delay hospitalisation (Fast & Preston, 2006).

According to mental health policy in South Africa and the Mental Health Care Act (Act 17 of 2002), mental health patients are discharged as soon as possible to prevent institutionalisation and costs. Mental health policy in South Africa has tried to develop appropriate and accessible mental health services for all people in South Africa, which is comprehensive community-based mental health service. This means that the majority of people with mental illnesses should be treated in the community for most of the time during the period of their illness (Thom, 2007: 3). In particular, revision of the Act is required to

address the problems of prolonged institutionalisation and the support of de-institutionalisation processes. In order to prevent this, the involuntary hospitalisation procedure is seen as a problem area and in need of review.

Although de-institutionalisation has advanced at a fast rate in South Africa, improvement of community-based services is still lacking. As indicated in the section above, South Africa is characterised not just by inadequacies in the availability of resources for mental health care, but also by numerous barriers to access mental health services (Saraceno, van Ommeren, Batniji, Cohen, Gureje, Mahoney, Sridhar & Underhill, 2007).

2.7 CONCLUSION

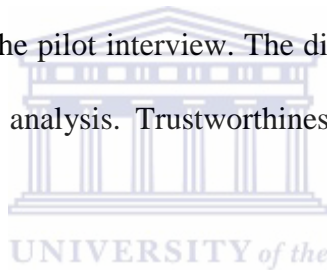
Comprehensive care should be provided at all levels of mental health service delivery. The treatment of co-morbid bipolar and substance-use disorder requires a holistic approach. In psychiatry, a BPS framework is used to ensure that all the needs of an individual are met in terms of an intervention. The BPS model thinks not only of a bipolar disorder, substance abuse and a co-morbid diagnosis of bipolar disorder and substance abuse as biological, but also as psychological and rooted in the social environment.

CHAPTER 3

RESEARCH METHODOLOGY: EXPERIENCES OF FAMILY MEMBERS CARING FOR FEMALE PATIENTS WITH A CO-MORBID DIAGNOSIS OF BIPOLAR AND SUBSTANCE ABUSE

3.1 INTRODUCTION

This chapter describes the research methods and processes followed in this study. The research questions are described followed by the research goal and objectives, which were attained during the research. The search approach, design and strategy of enquiry follow by research methodology follow. The research methodology describes the research setting, population and sampling, the preparation for the data collection, setting up the interviews, conducting the interviews, and the pilot interview. The discussion in the data analysis gives the steps followed during data analysis. Trustworthiness was maintained throughout the research study.



3.2 RESEARCH TOPIC AND QUESTIONS

When a researcher embarks on a research project, the first step is to look for an area of interest and choose a topic from it. Researchers rework and narrow down a topic into a researchable problem and related research questions. Fourché (in De Vos, *et al.*, 2005) supports this viewpoint, and states that we need to find a research problem, and then ensure that it is researchable. It is evident from the literature review that caregivers experience a variety of challenges when caring for a patient with co-morbid bi-polar and substance abuse disease. These challenges contribute significantly to the burden of care and can result in mental health problems in caregivers, as well as the mental ill patient's progress and may result in repeated re-admissions of patients.

The researcher was therefore interested in their lived experiences, which resulted in the following research questions:

- What are the lived experiences of caregivers caring for a co-morbid, bi-polar and substance abuse patient?
- What context and situations contribute to these experiences?

3.3 THE GOAL OF THE STUDY

Fouché and De Vos (in De Vos *et al.*, 2005) state that the term “goal” is synonymous for the terms “purpose” and “aim”. The notion of a goal is the direction which the study follows. The research questions serve as indicators pointing to and explaining or informing the goal of the study, as well as being a guide for the research study (Creswell, 2013). When formulating the goal from a qualitative approach, Creswell (2007: 260-261) advises researchers to keep it non-directional; not to describe cause and effect, but to give a general sense of the main idea using terms such as “explore”, “discover”, “develop”, “understanding”, “describe” and “report”. The goal of this research was to explore the lived experiences of family members caring for co-morbid bipolar and substance-use disorder relatives admitted in a psychiatric hospital.

3.4 THE OBJECTIVES OF THE STUDY

Objectives are the steps one has to take, one by one, realistically at grassroots level, within a certain time-span, in order to attain a goal. The objectives need to be an extension of the goal and must relate directly to it (Fouché & De Vos in De Vos *et al.*, 2005). The objectives to reach the goal in this research were the following:

- To explore the lived experiences of family members caring for a family member with a co-morbid diagnosis of bi-polar and substance abuse;
- To explore the situations or contexts in which these experiences occur;

- To describe the lived experiences of family members caring for a family member with a co-morbid diagnosis of bi-polar and substance abuse;
- To describe the situations or contexts in which these experiences occur;
- To give recommendations to the multi-disciplinary team (MDT) on services for family members caring for a family member with a co-morbid bi-polar and substance abuse diagnosis.

3.5 RESEARCH METHODOLOGY UTILISED DURING THE STUDY

Research is a systematic process to investigate and describe phenomena (Babbie, 2010). The researcher describes the systematic process that was followed in attaining the goal and objectives of the research in the following section of the document.

3.5.1 Research approach

The researcher has used a qualitative research approach during this study. The nature of the information which is required indicates the choice of research approach. Qualitative research is used to explore and understand meaning that people give to their experiences, social contexts, values, opinions and behaviours. These perspectives are explored in depth (Creswell, 2013; Green & Thorogood, 2009). During this research the researcher wanted to explore families and carers' lived experiences when caring for a family member with a co-morbid diagnosis of bipolar and substance abuse by means of in-depth interviews. It was important to get an in-depth understanding of their experiences and the contexts in which these experiences occur. Qualitative researchers participate actively in the research process and are close to the participants therefore it is important to be reflexive about their subjectivity as the researcher indicates in 3.5 (Trustworthiness) in this chapter. Rich, in-depth data is gathered from a limited number of participants rather than large numbers,

which can be generalised as in quantitative research as discussed in 3.4.5 (Sampling) (D’Cruz & Jones, 2006).

3.5.2 The Research Design

Nieuwenhuis as cited in Maree (2007:70) defines a research design as a “plan or strategy, specifying [how and from where participants will be selected] the data gathering techniques to be used and how the data collection will be done”. The researcher employed an explorative and descriptive research design. De Vos *et al.*, (2011) explain that explorative research design focuses on learning about issues that are unknown. The researcher explored a phenomenon to get new knowledge in order to understand the participants who are taking care of a family member with co-morbid bipolar and substance-use disorder admitted to a psychiatric hospital. The researcher also employed a descriptive research design, which is a more intensive examination of specific detail of a situation, social setting or relationship. The researcher provided a detailed description of the lived experiences and contexts of the family member that were explored in Chapter 4 (Findings of the research) where the findings are discussed (Kreuger & Neuman; Rubin & Babbie, as cited in De Vos *et al.*, 2011).

3.5.3 Strategy of Enquiry

The researcher has used a phenomenological strategy of enquiry. Phenomenological studies search for the meaning, structure and essence of the lived experience of individuals or a group around a specific phenomenon (Christensen, Johnson & Turner, 2010). As explained by Van Manen in Creswell (2006) phenomenological studies describe individuals’ lived experiences of a situation or problem and focuses on what participants have in common while experiencing a problem or concern. Moustakas in Creswell (2006) states that the basic purpose of phenomenology is to limit people’s experiences with a phenomenon to a

description of the core problem; therefore this description consists of “what” and “how” they experience it.

Moustakas and Van Manen highlighted two approaches of phenomenology in Creswell (2006) as hermeneutic phenomenology and transcendental or psychological phenomenology. Hermeneutical phenomenology describes the lived experiences of individuals as orientated (phenomenology) and interpreting the texts of life (hermeneutics). In transcendental phenomenology, Creswell (2006) mentioned that the focus is not so much on the interpretations but more on the description of the experiences of the individuals.

A phenomenological study has four main characteristics or procedures, which consist of a phenomenon to study, bracketing of the researchers’ experiences (See 3.5: Trustworthiness), gathering data from several participants who have experienced the phenomenon (See 3.4.6: Methods of Data gathering) and then analysing the data by limiting it to relevant statements and combine it into themes and sub-themes (See 3.4.8: Data analysis; Chapter 4: Findings of the research of this study). The researcher obtained a textural description of what participants experienced when taking care of their relative being diagnosed with a co-morbid diagnosis of bipolar and substance-use disorder and a structural description on how or the context of the experience, which provides an overall picture of the experience of the participants caring for their relative with a co-morbid diagnosis of bipolar and substance use (De Vos *et al.*, 2005; Creswell, 2013).

3.5.4 Research Population

A “population” refers to individuals and/or a group of people who have specific traits, which the researcher wants to include in the study. The research sample derives from the population. It can also be referred to as a group of individuals as determined by the

researcher, with traits and a problem in common. Strategies to recruit participants are determined by the type and amount of data-gathering activities and the characteristics of the population (De Vos *et al.*, 2011; Rubin & Babbie as cited in De Vos *et al.*, 2011).

The selection criteria for participants can also be changed if they are not able to answer the research questions (Mack, Woodsong, Macqueen, Guest & Namey, 2005). Owing to some constraints, the researcher was not able to include the whole population in his study, therefore a sample, which is a subset of the population, was drawn. The population for this research study was all families caring for female relatives with a co-morbid diagnosis of bipolar and substance abuse admitted to a psychiatric hospital in the Western Cape.

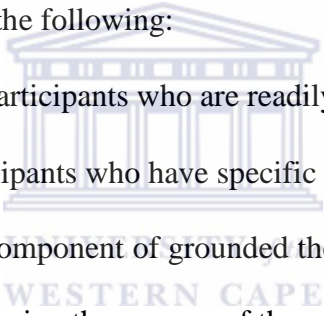
3.5.5 Sampling

Sampling refers to the existence of a population of which the sample is a smaller subset selected from a population which are investigated by a researcher (Henning, Van Rensburg & Smit, 2004). De Vos *et al.*, (2011: 223) maintain the aforementioned description by adding that “sampling means taking a portion or a smaller number of units of a population as representatives of that total population”.

The researcher searched for participants who were information-rich because of first-hand experiences and knowledge of the phenomenon under study (Donalek & Soldwisch, 2004). Given what we have said so far, sampling is a vital part of the research process, and the strategies for choosing a sample will influence both the results and the researcher’s interpretation of these results. The researcher used probability sampling in quantitative research where the population is chosen by the researcher because of common traits that represent the broader society in smaller numbers. This process usually happens when generalisations are made from the small population out of the whole population and are

based on statistical and mathematic formulations. The techniques of quantitative research are usually structured and prescribed (Crookes & Davies cited in Mack *et al.*, 2005).

Qualitative research employs non-probability sampling techniques and it does not mean that the findings of a study will be generalisable, and apply only to the population under investigation, therefore the sample size is not determined by numbers but by the need to fully investigate the problem and to provide rich data. Therefore, much smaller numbers may participate in qualitative research study than in probability sampling. Non-probability sampling is based on the idea of purposive sampling to establish the settings, individuals and/or groups who participate in the study (Mack *et al.*, 2005). In qualitative research as cited by Coyne, Miles and Huberman in Mack *et al.*, (2005) the most frequent non-probability samplings to use are the following:

- 
- Convenience samples - Participants who are readily available and easy to contact.
 - Purposive sample - Participants who have specific characteristics or features.
 - Theoretical samples - a component of grounded theory that enables new or emerging domains to be explored during the process of the research.
 - Selective sampling - the selection of cases prior to the conduct of research.
 - Case sampling - selection of participants within a specific group.

Mack *et al.*, (2005) point out that purposive sampling is the most common sampling strategy to use in qualitative research because it groups participants from pre-selected criteria, significant to the research questions. The objectives of the study determine the sample sizes prior to data collection, depending on the resources and time availability. Purposive sample sizes are mostly determined by data saturation, where new information has no purpose any more for the research question. Therefore, purposive sampling is often most successful in

qualitative research when data is being reviewed, and data analysis has taken place in collaboration with data gathering.

Non probability purposive sampling was used by the researcher in this study. Participants that were unknown to the researcher were selected because they could provide rich information on their lived experiences required for a phenomenological study. Relatives of female in-patients admitted in a female admission ward, in a psychiatric hospital, who had been diagnosed with co-morbid bipolar and substance-use disorder in Western Cape were purposively selected. The researcher ensured credibility of this sample by making use of a maximum variation sample, in which key demographic variables were selected that had an impact on participants' view of this topic. The researcher interviewed individuals until data saturation was reached, and no new information was obtained during the interviews. De Vos *et al.*, (2011) explain saturation as occurring when the researcher begins to hear the same information from participants, and no new information is forthcoming.

3.5.6 Methods of Data Gathering

Collecting data is a process of gathering information on variables, which allow the researcher to answer questions and evaluate the results. The way in which the researcher chooses to collect information also plays an important role in the process of data collection. For example interviews, questionnaires, observations, participations, or reports. Interviews in qualitative research allow the researcher to understand participants' view on a problem or concern and it also allows the participants to express their view from their own perspective in their own way (Stephen, Mary-Lynn & Frances, 2011; De Vos *et al.*, 2011).

Interviews are common in qualitative research, especially phenomenological studies which seek to understand the lived experiences of people. Nicholls (2009) suggested three types of

interviews: structured, semi-structured and unstructured interviews. Structured interviews are pre-determined and are prepared in advance to follow a pre-prescribed format. Semi-structured interviews are most common in qualitative research, and the interviewer conducted an interview based on pre-defined broad questions and themes, with which the interviewee decided if new information was needed or not. On the other hand, unstructured interviews start more with an object and/or idea, and go forward in the direction in which the interviewer and/or interviewee wants to go. Therefore, the researcher used in-depth interviews as a tool of unstructured interviews in phenomenology (De Vos *et al.*, 2005) to understand people's views on their lived experiences caring for a relative with a co-morbid diagnosis of bipolar and substance abuse, admitted to Lentegour Psychiatric Hospital in the Western Cape.

3.5.6.1 Entry into the research site

Creswell (2009) described data collection as information from a qualitative perspective in a natural environment, known to the participant and allowing face-to-face contact and mutual communication. Interviews should happen in a private space where participants feel they are protected, and they should happen in a room where no other people are, in order for the information shared to be kept confidential. The author mentioned that the participants' privacy should be protected at all cost, no matter if the researchers experienced some difficulty in finding such a space even though it meant renting a room. Another option to consider finding a private place for the interview to be conducted in is to make the participants take part in searching for a suitable place where they feel comfortable and that their privacy will be protected. During the search to find a suitable place for the interviews, make sure that you find an appropriate place, especially for male-female interactions. The location where the interview will take place should have enough privacy for the participant to feel comfortable, in order to give honest answers, because the location will have an

impact on the answers from the participant during the interview. Organise the space in order for the participant to be and feel relaxed (Mack *et al.*, 2005; Patton & Cochran in Brikci, 2007).

Interviews were conducted in an office at Lentegeur Hospital where the patients were based, which were known to the participants. An office as defined by Hornby (2006) is a room, set of rooms or a building where people work, a room in which a particular person works or a room or building used for a particular purpose, especially to provide information or a service. The researcher usually utilised the office for consultations with families and patients with regard to issues related to the patient. During the time of being transferred to the pre-discharge ward where the office was based, patients were much more calm, stable, settled and co-operative. Section 4 of The White Paper for Social Welfare (1997: 57) in line with the Mental Health Care Act (17 of 2002) indicates that the above service institutions must render services to individuals, families and societies affected by mental health disorders in a space where patients and their families feel safe and protected. An office based at the hospital was conveniently chosen to conduct the interviews.

3.5.6.2 Methods of data collection

An unstructured interview aims to have in-depth interviews with participants. Only one or two questions were being discussed, which is very limited. The few topics being discussed, carries much more detail. The interviewee may ask questions after the first question by the interviewer, as a response from the interviewee. In-depth interviews were being used to find out more information about a specific topic, but no structured format or plan of the interview was followed as to how the interview would continue. In-depth interviews are more likely to be used in qualitative research methods because it can be satisfactory to the participants and the researcher, and allow the participants to express themselves in their own

way. An in-depth interview is a tool to gain more information in order to get the bigger picture of the participant's perspective on the research topic (Mathers, Fox & Hunn in Mack *et al.*, 2005).

The technique used by the researcher was a motivation to gain more knowledge about what the participants' shares on the topic. The researcher conducted face-to-face in-depth interviews with only the interviewer and the interviewee present in the office at the hospital and the duration of the interview was 45minutes to an hour maximum (De Vos *et al.*, 2005). The researcher provided important information about the study procedure to the participants and included the ethical considerations. The researcher also explained that the information recorded would be accessible after being transcribed. A psychologist was on standby in case an emotional event occurred (Creswell, 2009). As it is important in phenomenology to get the lived experiences from the participant, the researcher guided the interview by probing in order to get rich data until data saturation was reached (De Vos *et al.*, 2011). Two questions were used by the researcher as suggested by Creswell (2013):

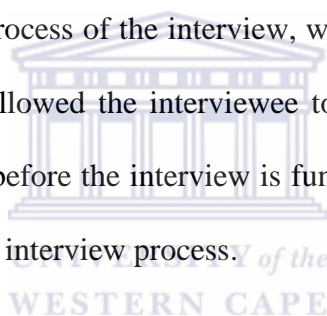
- Will you tell me about your experiences taking care of your relative who has a mental illness?
- In what situations did you experience this?

3.5.6.3 Preparation of participants for interviews

McNamara (2009) placed very high importance on the preparation stage of an interview in order to maintain the focus of the study, which would result in how the interviews would be implemented. Preparation for an interview in qualitative research can alleviate the data collection process, where problems can occur when collecting data (Chenail, 2009). The researcher made use of an office in the pre-discharge ward, where there was less noise and distraction to conduct interviews.

The researcher obtained permission from the area manager to use this office during weekends because of the availability of the family members for the duration of the research study. The researcher made an appointment with the participants and agreed on a suitable time and date for the interview to take place. The in-depth interviews were conducted in English in which the researcher asked two open-ended questions on their experiences of the phenomenon as well as the context in which it occurred. The participants were fully capable of answering the research questions.

Gill, Stewart, Treasure and Chadwick (2008) say participants should be clear about the study before an interview takes place. The researcher should ensure the participants about the ethical considerations and what they entail. This would give the participants some idea of what the study entails and the process of the interview, which had the very important factor of informed consent and also allowed the interviewee to be more comfortable during the interview. Establishing rapport before the interview is fundamental as it can have a positive effect on the development of the interview process.



The researcher explained to the participants that this was a research project being conducted by Uwarren September, a Master in Social Work student at the University of the Western Cape. The researcher invited the participants to partake in this research project because they had experience and knowledge about various challenges in caring for family members with a co-morbid bi-polar and substance-abuse diagnosis. The researcher explained to the participants that the purpose of this study was to explore and describe the lived experiences of family members caring for a family member with co-morbid a diagnosis of bi-polar and substance abuse, as well as the contexts in which they experienced it and to provide recommendations on social work intervention for family members caring for a family member with this illness (**See Appendix D: Information sheet**).

The researcher asked for informed consent verbally during the preparation stage, in which the researcher informed the participants that they could withdraw from the study at any time they wished to do so. Written informed consent was obtained from the participants in form of a consent form (**See Appendix E: Consent form**) on the day of the interview (De Vos *et al.*, 2005).

3.5.6.4 Interviewing skills used during data gathering

a) Starting the interview

In-depth interviews were done in English and took place in the form of a one-one consultation basis, in which the researcher introduced himself and also confirmed the purpose of the interview again as well as the role the interview plays in the research study. During establishing a rapport, and explaining this study, the researcher made the information sheet available to the participant and he explained the process of the interview as well as the ethical aspects. Each participant had a demographic sheet in front of them where their identifying information was on, as well as the research question as suggested by Gill *et al.*, (2008).

Participation in this qualitative research study was completely voluntary as stated by De Vos *et al.*, (2005). Participants could choose not to take part at all. The participants were told if they decided to participate in this research, they could stop participating at any time. Participants were not to be penalised at all. Participants were asked to take part in an interview which would last for approximately one hour. If need arose that participants need assistance, they were to be referred to the relevant person for help. The researcher explained to the participants, should they have any questions regarding this research and their rights as a research participant, or if they wished to report any problems they had experienced related to the study,

they were welcome to contact the researcher and/or his supervisor, as referred to in the information sheet (**See Appendix D: Information sheet**).

b) *Use of specific interviewing skills*

Researchers must have a lot of skills and techniques for the interview to be productive and in order to ensure rich data being collected during the interview. In-depth interviews were conducted in English, by which the researcher made use of interviewing techniques and skills. Maintaining a balance between consistency and flexibility allowed the researcher to elicit the stories of the participants (De Vos *et al.*, 2011). In this research study as suggested by Gill *et al.*, (2008) the researcher made use of attentive listening as a technique to use in unstructured interviews when the participants shared their experiences. Open and emotional body language of the researcher was maintained during the interview. The effective use of silence was seen as positive as it led participants to contemplate their responses. The researcher used reflecting and probing as appropriate remarks or techniques during interviews to elicit individuals' experiences as suggested in phenomenology as the researchers' strategy of enquiry. Responses were clarified and summarised by the researcher during the interviews as the researcher wanted to be clear on certain responses made by the participants (De Vos *et al.*, 2005).

c) *Ending of the interview*

The researcher made the participants aware that a psychologist was available for participants to be debriefed after the interview if the need arose. The researcher assured the participants that all the data collected was handled confidentially and would be tape-recorded. The name of the participant does not appear on the recorder and/or transcriptions of the interview. A code was placed on the collected data and the researcher linked the study to the participant's identity with a code. Codes were

used to identify data collected. No one else other than the researcher and his supervisor had access to the data, which was stored in a safe locked place. The participants' identity was protected during the writing of the research report. As suggested by Gill *et al.*, (2008) the researcher thanked participants for taking part in this study. The researcher asked participants whether they wanted to add something or not, which created a space for participants to think and deal with issues they had not shared with the researcher.

3.5.7 Pilot Study

As stated by Mack *et al.*, (2005) it is helpful to practise interviewing techniques, which were very helpful for the researcher by using the questions through a pilot interview with a colleague. The researcher also made use of pilot interviewing with a family member of a patient in the community who did not participate in the study. The pilot interview did not go too well as the participant was under the influence of alcohol and could not understand the questions posed correctly and therefore the researcher had to explain both questions a great deal. The researcher could not use the information and therefore had to arrange another pilot interview, which went well. The researcher obtained informed consent and followed the same process by explaining the study to the second pilot participant. Conducting a pilot interview was very helpful for the researcher as it made him aware of practical deficiencies that needed attention as well as making the researcher aware of his level of interviewing skills (De Vos *et al.*, 2005). The researcher was calmer during the second pilot interview and could make use of probing after posing the only two questions as suggested by phenomenology studies. The researcher also tested the recording equipment and the batteries before the interview, as suggested by Mack *et al.*, (2008) in order to avoid equipment failure.

3.5.8 Data analysis

Before data is analysed, the researcher has to transcribe the information collected from the participants into words in order to organise and describe the data. The data collected, was ordered, which brought structure and meaning to the information. Phenomenology uses specific data analysis, which was followed by the researcher during this research. The researcher described the personal experiences of the phenomenon under this study, then developed a list of significant statements and then grouped the statements into themes and sub-themes.

A description of “what” the participants in the study experienced with the phenomenon was made, with verbatim examples (textural description) and followed by “how” the experiences happened (structural description) where the focus was on the context or setting in which it was experienced. Finally, a composite description of the phenomenon incorporating both the textural and structural description was written (Henning *et al.*, 2004; De Vos *et al.*, 2005; Creswell, 2013). The researcher also used an independent coder, who contributed to rich findings and to the credibility of the study. The independent coder used the same method of analysis as the researcher, and they met afterwards to discuss the data in order to get rich information.

3.6 TRUSTWORTHINESS

In qualitative research, trustworthiness is established when findings reflect the meanings as described by the participants. The research results should reflect that the researchers are listening to what the participants are saying (Lietz, Langer & Furman, 2006). Nieuwenhuis (2007) agrees by stating that the researcher is the data-gathering instrument. Lincoln and Guba as cited (in De Vos *et al.*, 2005) uses characteristics such as credibility, conformability, and reflexivity as criteria to assess trustworthiness in this study, which can

be valuable contributions towards the researcher's study. The researcher has to bracket in phenomenology. This is where the researcher discusses personal experiences related to the phenomenon in order to set aside or bracket these experiences in order to focus on the participants' experiences. The researchers' experiences working in the field of mental health and his own personal experiences were written in the reflective journal, and after data analysis he had to reflect if it was his or the participant's experiences (Creswell, 2013).

3.6.1 Credibility

When speaking about validity and reliability, it is usually experienced in research that it is credible and trustworthy (Nieuwenhuis, 2007). Credibility is achieved through prolonged engagement, meaning staying in the field until data saturation occurs with member checks when information is checked with respondents (Guba & Lincoln in D'Cruz & Jones, 2006). The researcher had spent time in the specific unit in the psychiatric ward where the families were interviewed. He had done interviews until data saturation was achieved, and after the interview the data was checked with the participants to ensure it was correct. Reflexivity, which will be discussed later in the section, is also a measure to ensure credibility. The independent researcher assisting with the data analysis contributed to peer examination, which is a form of credibility.

3.6.2 Confirmability

In order to achieve confirmability, it is important to illustrate and/or interpret the findings from the data and not from the researcher. Qualitative researchers make use of the concept confirmability instead of objectivity (Shenton, 2004). The researcher ensured **confirmability** through believing that participants gave credible, honest and subjective information about caring for their relative with bipolar and substance abuse disorder. An

independent researcher did data analysis with the researcher, also contributed to confirmability, as well as reflexivity and bracketing.

3.6.3 Reflexivity

Lietz *et al.*, (2006) explained that reflexivity is an active acknowledgement by a researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience under study. Patton (2005: 65-66) emphasised “reflexivity as important to self-awareness, political/cultural consciousness and ownership of the researcher’s own perspective. It should include reflection on culture, age, gender, class, social status, education, family, political orientation, language and values.” The author posed reflexive questions. The researcher should ask the following questions about the participants: “How do they know what they know? What shapes and has shaped their worldview? How do they perceive me? Why? How do I know? How do I perceive them?” The following questions should be asked about those who receive the study (audience): “How do they make sense of what I give them? What perspectives do they bring to the findings I offer? How do they perceive me? How do I perceive them?” The researcher should ask the following questions as a qualitative researcher: “What do I know? How do I know what I know? What shapes and has shaped my perspective? With what voice do I share my perspective? What do I do with what I have found?” The researcher consequently made field notes during the interviews and reflected on his own experiences before data analysis, and answered the questions during and after the research when the report was written.

3.6.4 Bracketing

Bracketing was of utmost importance in phenomenology during this study in which the researcher puts his own experiences aside (Moustakas in Creswell, 2013). This was important as the researcher works in the field of mental health, and the researcher’s own

experiences should not affect those of the participants. The researcher had not done an in-depth literature review before the study and worked inductively, and was therefore confident that the findings were a true reflection of the participants' experiences and not the researcher's own. The researcher also used a reflective journal where he reflected on his personal experiences.

3.7 CONCLUSION

This chapter discussed the research methodology followed during this research study. A qualitative research approach was used as it helped the researcher understand the actions of the participants pertaining to their experiences of taking care of co-morbid bipolar and substance-use disorder relatives admitted in a psychiatric hospital. In-depth interviews were conducted and rich data was gathered. Therefore phenomenology research was the best approach to use during this study, as it gave the lived experiences of the caregivers of patients with a co-morbid diagnosis of substance abuse and BD. The rich data contributed to a better understanding from the perspective of the participants, without influence from the researcher. The fact that bracketing and reflexivity were used strengthens the fact that it was the voices of the participants and not the researchers.

The research findings of this study are discussed in Chapter 4.

CHAPTER 4

RESEARCH FINDINGS REGARDING THE EXPERIENCES OF FAMILY MEMBERS CARING FOR FEMALE PATIENTS WITH A CO-MORBID DIAGNOSIS OF BIPOLAR AND SUBSTANCE ABUSE

4.1 INTRODUCTION

This chapter will provide the findings of data analysis from family members' experiences caring for female patients with a co-morbid diagnosis of bipolar and substance use disorder. The goal of this research was to determine the lived experiences and contexts in which they occur, of family members caring for co-morbid bipolar and substance-use disorder relatives admitted in a psychiatric hospital. The objectives of this research, which are addressed in this chapter, are:

- To describe the lived experiences of family members caring for a family member with a co-morbid diagnosis of bi-polar and substance abuse;
- To describe the situations or contexts in which these experiences occur.

Phenomenological data analysis was done as described in the research methodology chapter, Chapter 3 (See 3.4.8: Data analysis). The “what” that was experienced by participants, with verbatim descriptions (textural descriptions), followed by “how” the experiences happened (structural description) are the focus of this chapter. Coding was done during data analysis of the textural and structural description of experiences, which resulted in themes and sub-themes as indicated in Figure 4.3 (Themes and sub-themes as a result of data analysis). A literature review in phenomenological studies begins with a clear paradigm, in this study the bio-psycho-social model, but a literature review is only done after data analysis (See 2.1:

Introduction of Chapter 2). The researcher has done the initial literature review in Chapter 1 followed by the data collection and analysis, and the literature review in Chapter 2, and this chapter followed after the findings were finalised. Findings in phenomenological studies need to be related to an existing body of theory and research (Leedy & Ormrod in De Vos *et al.*, 2011). This is done in this chapter where new literature is introduced after the discussion of the specific themes and sub-themes.

4.2 BIOGRAPHICAL PROFILE OF PARTICIPANTS

The demographic details of the participants (family members) who took part in this study are presented in **Table 4.1**.

Table 4.1 Demographic details of participants

Participant	Gender	Age	Home Language	Years' Experience caring for the patient	Number of re-admissions of patient	Relationship with patient
A	Female	59	English	18	5	Mother
B1	Female	70	Afrikaans	17	2	Grandmother
B2	Male	77	Afrikaans	17	2	Grandfather
C	Female	35	English	27	3	Daughter
D	Male	61	English	13	8	Father
E	Male	47	Afrikaans	5	2	Husband
F	Female	46	Afrikaans	15	1	Mother

It is clear from **Table 4.1** that both men and woman can be caregivers of patients. The participants, who were the primary caregivers of the patients, included two mothers, a father, grandmother, grandfather, daughter and husband. Most of the caregivers who took part in this study were over 40 years of age. Their home language was Afrikaans or English. Most of the participants experienced caring for their relative for more than 10 years and one husband cared for his wife for five years. Only one patient was admitted once, and the others more than once. Three patients had two readmissions, one had three re-admissions, one had five re-admissions, and a patient cared for by the father had eight re-admissions. Re-admissions in bipolar disease can be an indication of how patients function at home,

heavy caregiver burdens, their environments, and their ability and willingness to adhere to medication, as indicated in Chapter 2 (See 2.3.2: Psychological factors; 2.3.3: Social factors). Fast and Preston (2004:197) remark that “re-admission to hospital can be prevented by implementing aspects such as knowing the symptoms of the illness and obtaining immediate help. Compliance with treatment and avoiding substance use/abuse are also able to delay hospitalisation”.

Table 4.2 Demographic details of patients being cared for by participants of the study

Patient followed by participant	Gender	Age	Home Language	Number of family member living together before last admission	Re-admissions	Current Primary caregiver after discharge
M (A)	Female	33	English	6	5	Boyfriend
C (B1)	Female	19	Afrikaans	3	2	Grandmother
C (B2)	Female	19	Afrikaans	3	2	Grandfather
C (C)	Female	57	English	4	3	Still in hospital
D (D)	Female	37	English	3	8	Father & Step Mother
C (E)	Female	37	Afrikaans	3	2	Still in hospital
C (F)	Female	29	Afrikaans	5	1	Mother

Table 4.2 above gives demographic details of relatives of the participants. All the relatives of the participants were female patients who were cared for (See 2.3.1: Biological factors; 2.3.3: Social factors) and were older than 18 years, only two being not yet 21. Language use of the relatives was the same as the participants. All the patients lived with more than one person in the house, apart from the caregiver. All the households had between three and six members living in the house. The burden affected the family functioning. As discussed in Chapter 1 (See 1.2.1: Families’ experiences caring for people with mental disorder) in households one might find that the caregiver did not have the energy to perform daily life tasks because of the burden being experienced. The year’s experiences of being cared for as well as the re-admission rate stayed the same as indicated in **Table 4.1** (Demographic details of participants).

4.3 THEMES AND SUB-THEMES FROM DATA ANALYSIS

In this particular study the researcher only indicated themes and subthemes a further clustering of categories will be address at a late stage where a follow-up study can be done as recommended (See Chapter 5,5.4: Recommendations and Conclusion). During data analysis, four major themes were found. Themes one and two are textural descriptions, and themes three and four are structural.

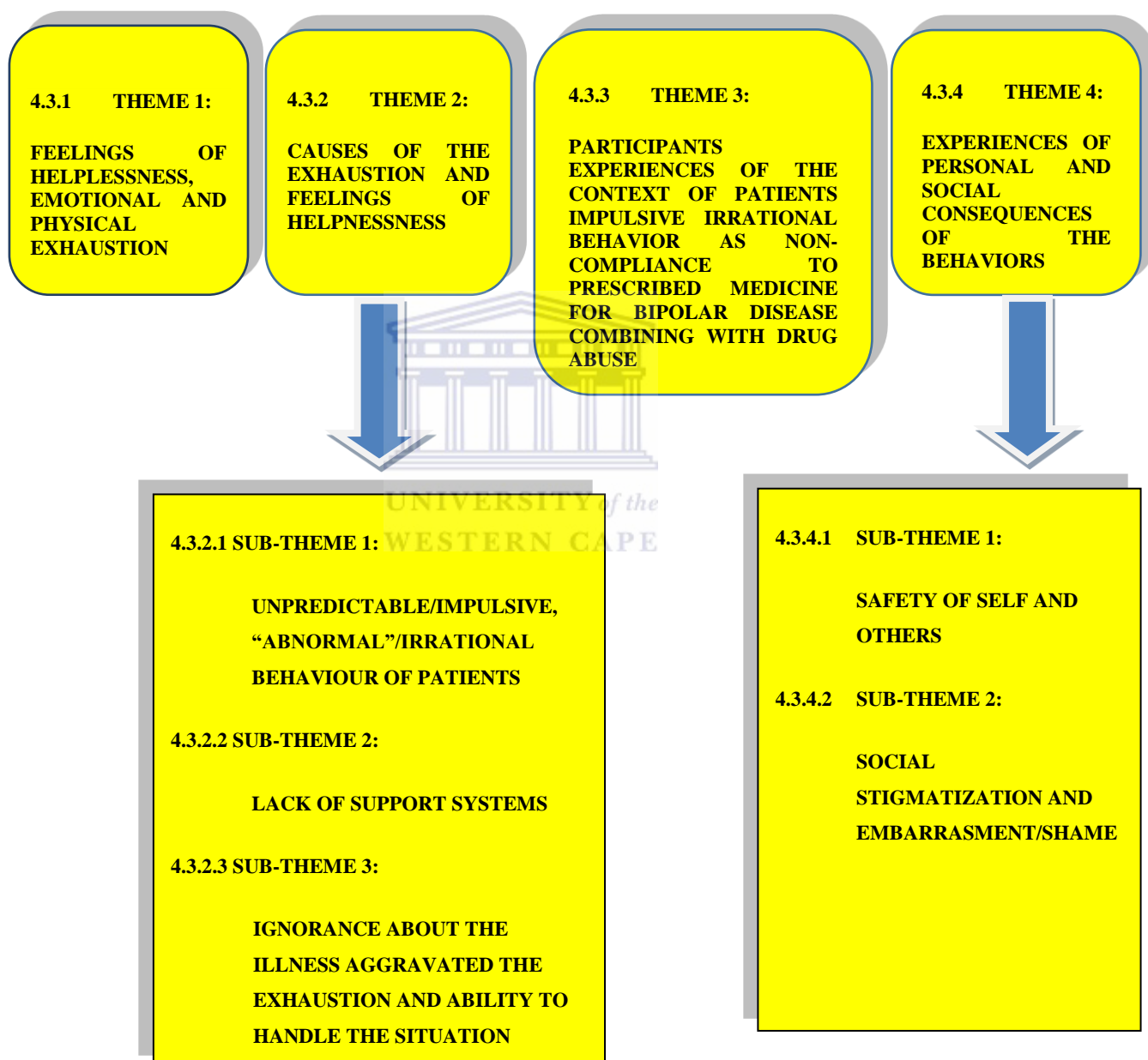


Figure 4.1: Clusters of common themes and sub-themes emerging from the meanings and reflections.

4.3.1 Theme 1: Feelings of helplessness, emotional and physical exhaustion

It was significant that all participants first and very strongly verbalised their feelings of helplessness, with emotional and physical exhaustion (See 2.3: Bipolar disorder; 2.3.2: Psychological factors of bipolar).

Taking care of a family member with BD causes both **objective and emotional burdens**. Caregivers have to compete with various kinds of stress relating to their relative's disorder, symptoms and disruptive behaviours, as well as the stigmatisation by society of persons with mental disorder and their relatives. To live with a person with BD together with the frustration of living daily with such a person can be exhausting. The unpredictable behaviour and change in moods intrude into households and can be a great stress in relationships, which may lead to outbursts (Perlick, Rosenheck, Miklowitz, Kaczynski, Link, Ketter, Wisniewski, Wolff & Sachs, 2008; Mondimore, 2006; Also see 1.2.1: Families' experiences caring for people with mental disorders).

When caregivers become over-sensitive and concerned, they may **experience changes in their moods** and therefore must give attention to their mental well-being. The consequence of taking care of a person with BD may be **burnout**. The carer may not be able to look after someone if he or she experiences burnout (Last, 2009; Fast & Preston, 2004; Haycock, 2010). Through depletion of resources, Spaniol (1987) agrees that long lasting **stress by families can cause loss of energy**, which can result in burnout (See 2.3.3: Social factors of bipolar disorder).

The following responses from the participants support the above authors by indicating feelings of hopelessness; depression, anxiety, and frustration are intrinsically related to exhaustion and helplessness and the **life stage and kinship** of the participants to the patient.

Participant A (Mother) - “A child with bipolar and to the substance that she’s using and the drugs, and having a drinking, is a very very bad situation. Due to that, at all times, I just don’t know which way to turn... don’t know any more what to do. I, **I really just break down and cry, because it’s my child**”.

Participant B (Grandparents) –“Dit maak jou so moedeloos, sal die Here jou nie maar liever wegvat nie. **Want jy kan nie meer op jou ouderdom...** Ons weet nie meer wat met hierdie kind nie”. (This is making you so exhausted, won’t the Lord rather take you away. Because you can’t deal with this, at this age. We don’t know what anymore with this child).

It is therefore evident that the intensity of the emotions expressed in the statements above, reflecting on the experiences over the years, feelings of hopelessness, depression, anxiety and frustration were intrinsically related to exhaustion and helplessness and the **life stage and kinship** of the participants.

Children may go away and spend some time alone, just enjoying them in order not to be burned with the experience he or she had when growing up taking care of the ill parent. In a case study, a daughter reported that the unpredictability of looking after her mother was the worst part, because she never knew what to expect when getting home after school or coming from elsewhere (See 2.3.3: Social factors of bipolar disorder), which led to her experiencing hatred towards her mother for letting her down. Child-headed households might be experienced when a child having to look after the parent. Circumstances outside the child’s control may lead to feeling responsible when incidents occur. People can experience burnout and/or outbursts when taking care of their relative for a long time (See 2.3.3: Social factors of bipolar disorder), which results from being physically tired, emotional and or just having had enough. The carer may just leave his or her relative and does not care anymore (Aiken, 2010; Haycock, 2010; Fast & Preston, 2004; See 1.2.3.2: Co-morbidity between bipolar disorder and substance abuse).

A **daughter** reflecting and correlating with the above authors on taking over the role of mother at the age of twelve expressed unresolved feelings of emotional hardship in the following quote:

Participant C (Daughter) - "It became a **big responsibility** for me as well in the house to look after my brothers and to see that you know that there's food on the table. I mean to make the food and to see that the house was clean, yes that is part of our daily tasks and things but being a 12 year old and looking after two siblings and whilst you are...the one parent is at work and the one parent is ill. Just **wanted to be a child** (starts crying) and, I just wanted to be a child and do my thing, you know, and be with my friends (**cries**). I was always scared, I didn't, and I didn't know how to deal with it. I just wanted my mommy being normal like a normal mother... I at some stage I got **agitated** you know. I don't know how to cope with it, I don't know what to do, **I just got fed-up also about this illness because its making her feels all sorts of things and I don't know how to deal with it**".

It became clear out of above statement that a devastating sense of responsibility can be experienced by **children when looking after their parent** as described in Chapter 2 (See 2.3.1: Biological factors of bipolar disorder), which can lead to feeling guilty for their parent's illness. Feelings of irritation, unhappiness, fright, uncertainty, concern, misunderstanding and frustration may be experienced by children at times.

Being **hospitalised** can be **distressing and terrifying** for both the patient and his or her family (See 2.6: Current services for mental health in South Africa). When a relative gets admitted into hospital this can be a relief for the family, especially when the mood changes are difficult to handle at home and the patient becomes a danger to him or herself and/or to the family (Fast & Preston, 2006; Centre for Addiction and Mental Health (CAMH), 2000).

The following statement supports the above authors by referring to hospitalisation:

Participant D (Father) - “Eventually I said, I say I just can’t do this anymore and that was about a year ago where I then did only what I had to (**referring to hospitalization**)”.

Therefore it can be said from above statement that when caregivers can’t cope with the behaviour of their relative, hospitalisation seems to be the best option of relief for the family.

A family can **experience stressful and sad emotions simultaneously** if a loved one’s ability to function decreases as result of a chronic illness (Last, 2009; Haycock, 2010; Also see 1.2.2: Socio-economic factors influencing caring for people with mental disorders). Roles performed by the ill relative, have to be taken over by the carer, who has to sacrifice the things they used to do together, as well as alter the expectations from the carer’s side. Couples and or relationships that do not have to compete with mental illnesses also experience complications. To have a loved one with bipolar disorder can increase that complexity, especially when the disorder is not treated and/or not treated adequately. The amount of time and energy being spent in taking care of a relative with bipolar disorder can sometimes have an effect on their own well-being and the relationship.

A husband and mother reflect in the statements below on the effects that taking care of their relative have on their emotional well-being:

Participant E (Husband) - “Dit was vir my baie moeilik dat **ek self in die hospitaal beland** het al in Crescent Kliniek vir drie weke omdat ek nie geweet het hoe om dit te hanteer nie”. (It was very difficult for me to handle, that I ended up in hospital myself for three weeks at Crescent Clinic, because I didn’t know how to handle it).

Participant F (Mother) - “Sy willie hoorie, sy willie hoorie sy **maak haar ma siek**” (She doesn’t want to hear, she doesn’t want to hear, she is making her mother sick).

It is clear that from above literature and statements that the difficulties associated with BD have major effects on socio-economic functioning and interpersonal relationships across the life span. People who do not have bipolar disease do not know how awful it is to suffer from the disorder, while the people having the disorder have no clue how bad it is to look after someone who has it (Anti-Otong, 2003; Fast & Preston, 2004; See 2.3: Bipolar disorder).

4.3.2 Theme 2: Causes of the exhaustion and feelings of helplessness

A number of conflicting emotions may appear in family and friends when a relative is diagnosed with BD (See 2.3.3: Social factors of bipolar disorder). **Feelings of helplessness, fear and worry** are experienced by spouses, partners and families of people with BD (Last, 2009; Miklowitz, 2011). Recognising a partner's illness, which has resulted in loss of important aspects of life, may lead to grief over loss. As part of bipolar disorder, a partner may **experience overwhelming emotions, hopeless, puzzled and having bitterness** towards the patient, as well as feelings of **embarrassment and concealment**. Without support, it is possible the caregiver may feel trapped and pressured when looking after their relative with bipolar (Fast & Preston, 2004, 2006; Tranvag & Kristoffersen, 2008; Last, 2009).

Three sub-themes emerged from the data collected concerning the causes of exhaustion and feelings of helplessness by the participants who cared for a relative with BD. The reader will be guided by the statements of the participants as indications of their experiences.

4.3.2.1 Sub-theme 1: Unpredictable/impulsive, "abnormal"/irrational behaviour of patients

The course of the bipolar disorder may risk family and interpersonal relationships. When describing the emotional instability of bipolar by a partner, sibling, child or parent, family have the tendency to highlight the **threats they face during outbursts**, which they felt were

not their fault. Families become worried that their relative could become **suicidal and or homicidal** during extreme manic episodes, and become very emotional and scared if such thoughts are expressed (See 1.2.3.1: Co-morbidity between bipolar disorder and substance abuse). Patients experiencing such an extreme manic state may **say insulting, rude and insensitive things**, and often caregivers finds it very challenging to stay calm, be forgiving, and have patience (Miklowitz, 2011; Haycock, 2010).

The following statements indicate abusive, irrational and uncontrollable behaviour experienced by the participants:

Participant A (Mother)–“We must watch her continuously; she will come and **bath up to five times a day, will let the water run the whole day**. She will walk the whole day up and down to the school to her children. Then the school phones and tell me that she again at school... we are even scared when it comes to the **electrical equipment** and that, because she puts it on and she forgets it... takes handy **Andy and Jik and things and then she puts her children in the water**... she sometimes gets abusive... she will **shout** at me”.

Participant B (Grandparents) - “Dan se ek vir F, dan laat die polisie kry, dan kom sy terug met die hele huis, dan en as ons met haar praat dan se sy vir my sy is 18 jaar oud sy kan maak wat sy wil. Ek se C, maar jy weet jy moet medikasie drink. En dan word sy kwaad vir ons. Hy se toe vir haar, wel as jy nie vir ons wil luister nie, gaan ons jou terugvat Lenteguur toe. Toe **smyt sy die stoele by die huis uit, sy skree op ons**” (Than I said to F, then get the police, than she get back to home, than when we talks with her, she tells us, she is older than 18years old, she can do what she wants to do. I would tell C, you know you should drink your medication. Then she gets angry at us. He said to her, well, if you don't want to listen to us, we going to take you back to Lenteguur then. She then threw the chairs out of the house, and screams at us).

Participants B (Grandparents) – “She is a **compulsive liar and a manipulator**. You cannot control her, it's difficult, but it turns into grief for the parents and for the family. And a question of **verbal abuse, vloek op jou, so en so, partykeer assault, attempted assault**”(A question of verbal abuse, swears at you and so on, sometimes assault, attempted

assault).

Participant C (Daughter) - “She **did weird things** put the light on ... wake up in the middle of the night you know. **Scream she got panic attacks**, constantly or she said it was like a panic attack and she **couldn’t handle crowds and things** and or when the two of us went shopping in the taxi and then she would tell me she just wants to get home”.

Participant D (Father) – “**Irrationality of her behaviour** which was we ... at times we thought it was **...linked to drug abuse and at other times we were convinced it was purely mental illness...** When she’s having an incident she **behaves completely differently to what she would normally behave** ... she has absconded from every single hospital or institution ... located her hiding next to the freeway in the bush which is one of her old tricks and then she would pop out and wave a car down and a woman a white woman long the side of the road gets lifts easily with anybody and that’s the type of fear her parents live with and which is **why we are obsessed with finding her for her safety** and then she is in the back of the van”.

Participant F (Mother)-“Nou was sy op die pad gewees het ek mienma grootmense nou vra sy miskien ‘n stukkie brood... **wil sy nou vir my stiek met ‘n mes** en sy begin maak die kinders senuweeagtig die kleintjie hy’s eintlik nou bang vir haar”.

(And then she maybe was on the road, I mean, the you asks her a piece of bread, then she wants to stab me with a knife and start to make the children nervous, and the little one is already scared at her).

It is clear from the above statements by participants that their ill relatives’ behaviour causes fear and anxiety at times, especially when leaving the ill relative alone at home. The **behaviour** of their relative becomes **abusive, verbally and emotionally**, but the carer does not want to do or say anything because they are concerned about the safety and unpredictability of the patient. During extreme manic episodes, patients often **threaten caregivers of committing suicide or homicide** (See 2.4.2: Psychological element of substance abuse; 2.4.3: Social element of substance abuse).

Men, who are looking after their spouse who has been diagnosed with bipolar, might make more effort to create a support structure, so that women in general are more likely to already have a support structure outside the core family. Relatives and/or families taking care of a patient with bipolar mood disorder usually do not understand the sporadic experiences of bipolar, and are more likely to focus on the behaviour of the patient and the effects it has on the man and make therefore harsh decisions according to what they experience, which can have a negative impact on their relationship (Fast & Preston, 2004; Haycock, 2010; Miklowitz, 2011:28).

One of the participants, who are the husband of the patient, shared the difficulty he experienced looking after his wife with bipolar mood disorder.

Participant E (Husband) - Daar is 'n hele ommeswaai in haar dan's haar hele **gedragsverandering** van, van sy rustig was die rustigste mens dan is ek nou net verkeerd so van rustig af sommer nou na **gewelddadig**, aanvallerig val my nou net aan ek is nou net verkeerd rondom die en rondom daai ek weet nie of dit die bipoler is wat dit veroorsaak nie...dis eintlik waar dinge begin deurmekaar raak het tussen ons die **beskuldigings** die kant toe want ek is nou die beste man die volgende oomblik beskuldig sy my van ek loop in die rondte ek jol in die rondte... na die medikasie na en sy geëet het en dan gee ek vir haar iets om te eet uhm ook dan raak sy rustig en dan laat ek haar 'n bietjie slap dan gaan slap sy as sy daar op staan dan moet ek weer wonder wat gaan nou weer gaan gebeur..."

(There is a whole turn around in her **behaviour** from being the calmest person to being violent and aggressive. Then I am the wrong one around this and around that and I don't know if this is caused by the bipolar or what else... that's where things started to get messed-up between us because of her **accusations**. At times I am the best husband you can get, and then all of a sudden I am the one cheating around. After the medication, and she has eaten... then I would give her something to eat the she gets calm, then I let her sleep a bit, then I started to wonder, what's going to happen next when she wake up).

It is therefore evident from above statement the possibility exists that a partner might stop being involved with his or her ill partner, who does not take care of him or herself, and harsh decisions have to be made with regard to their relationship status. Those decisions

made, may be in the best interest of the partner's emotional well-being. Because of insecurity, partners or spouses are constantly **aware of the stress factors** around them as well as the **changes in their partner's mental state** and often, self-doubt is present.

4.3.2.2 Sub-theme 2: Lack of Support systems

Family is the most important structure for most patients and for family; the caregiving role is a huge burden to be associated with (See 1.2.3.2: Effects of co-morbid mental illness and substance abuse on family caregivers). When caring for and supporting a relative with bipolar cause embarrassment, persistence, and devaluating experiences, the burden is much greater than before (Mondimore, 2006; Tranvag & Kristoffersen, 2008).

Chadda, Singh and Ganguly (2007), as well as McElroy (1987) and Terkelsen (1987) maintain that the seriousness of the illness and the disruptive behaviour of patients are vital predictors, which are associated with high levels of burden. Families find various ways of dealing with the illness, which include finding solutions, support from friends or loved ones, or avoiding the problem by finding a 'solution' – such as substance abuse. When not getting the relevant resources, caregivers experience high levels of burden. It has been reported that caregivers who take on less emotional coping strategies, have a reduction of being burdened, and as discussed in Chapter 1 (1.2.4: Mental health legislation, policies and treatment contributing to the burden of family caregivers), **families therefore need community support systems to lessen the burden** placed on them.

The following participants' stories of their experiences indicate that a lack of support systems aggravates their experience of exhaustion and helplessness:

Participant A (mother)–“You got no family that can help you, not as if they don't want to help you, but my family is scared”.

Participant B (Grandparents) – “Ons het na die buite Maatskaplike Werk toe gegaan, sy kon ons nie veel gehelp het nie”. (We went to an external Social Worker, **but she couldn't help us much**).

Participant C (Daughter) – “It became a big responsibility for me (to look after her) and .to look after my brothers and to see that you know that there's food on the table. I mean to make the food and to see that the house was clean, being a 12 year old, **I had to be an adult then**: do the shopping...”

Participant D (Father) – “She (mother) is unable to cope with any stress or any confrontation at all, so the entire onus or responsibility for D security and safety rested on me. I know on the patient's side as ... side she must feel I am the only person...that actually maintains communication with her from the beginning throughout until I abandoned her”.

It is clear from the above responses of the participants and the literature in Chapter 1 (literature review) that resources are seriously lacking in communities, which often leads to caregivers giving up and become silent. Bipolar disorder affects many people in any family like any other chronic illness; therefore it is important that **the ones affected receive help and support** (See 1.2.4: Mental health legislation, policies and treatment contributing to the burden of disease of family caregivers).

4.3.2.3 Sub-theme 3: Ignorance about the illness aggravates the exhaustion and ability to handle the situation

Caregivers experience many needs while taking care of their relative with a mental illness, such as being able to deal with their emotions with regard to their relative's disorder. Hatfield (1987) states, one of the needs are also **to be educated about the specific illness** of their relative, because the differences in diagnosis and medication often confuse them.

Co-morbidity is one of the concepts that need explanation. **Knowledge is one of the most important things caregivers' needs**, which may add up to how well families do when

caring for their relative and how well their needs for support are met. McElroy (1987), Miklowitz (2011) and Aiken (2010) concur with the above authors by emphasising that **families need to be informed about their relative's illness** as it is expected from them to help with the person's recovery. Families need information about their relative's disorder especially after the experience of a manic episode of their significant other, whether or not hospitalisation is needed. Many misconceptions are gathered by family members about drug treatment and psychotherapy. Caregivers need to understand that their relative's behaviour is to some extent determined by genetic and chemical factors (See 1.2.3.2: Effect of co-morbid mental illness and substance abuse on family caregivers).

The following statements by participants emphasise the need to be educated about their relatives' illnesses.

Participant D (Father) – “There's so much **ignorance** amongst the police that just I don't even think half of them have copies of the latest public health”.

Participant E (Husband) – “Ek weet nie hoe om bipolar te te hanteer nie dit is vir my ook meer dis **ek verstaan dit nie** die gedragsverandering ek weet nie hoe om dit te hanteer nie dit maak my ook gefrustreerd ek weet ook nie eerlikwaar nie ek het gesukkel om dit agter te kom hoe hanteer ek dit want ek ken nie bipolar nie **ek het maar nou begin leer** begin brosjures en goed lees koerante begin kyk toe sien ook bipoler, bipolar oh dis hoe dit lyk dit is hoe dit gehanteer moet word ek het op daai stadium nie geweet nie dit was vir my baie moeilik”.

(I don't know how to deal with bipolar, it is a lot to me, **and I don't understand the change** in behaviour and how to handle it. It makes me frustrated, because it's honestly something I struggle with to adapt to and how to handle it. **I recently started to read and learn** about bipolar on brochures, and newspapers, then I've read, oh this is bipolar and this is a way to handle it. At that stage I really didn't know, and it was very difficult for me).

Participant C (Daughter) – “So it's not mad it's just an illness. **That eventually I came to understand ...By reading up** on it”.

Participant A (Mother) – “**This is not something I know** how to work with, but I’m trying my best, because of the situation she’s in. When Doctor called me in and when he spoke to me, then I only broke down, because I didn’t know it was like mentally something wrong with her”.

Participant B (Grandparents) – “Ek het begin hoor van drugs, **en ek weet nie wat dit is nie**, ek ken dit nie, want ek is al ‘n oumens... Ons het nie geweet daar is vorms wat jy kan invul as hul nou so aangaan en jou mal maak en dreig met allerhande doodmaak stories, en van hulle vriendjies en goed nie. Dat ons ‘n vorms kan invul, en haar byvoorbeeld laat opneem in ‘n plek nie, ons het nie sulke goed geweet nie”. (I started to hear about drugs, **and I didn’t know what it is**, because I am already an old one. We didn’t know that there are forms that one can complete if they are going on like that and make you mad en threatens you with all suicidal and homicidal stories, and of their little friends and stuff... that we can fill out a form, and let he admit in a place for example, we didn’t know about such things).

Participant E (Husband) – “Die mental disability bipolar hoe niemand, Niemand baie mense weet nie eens van bipolar nie **hulle weet nie** wat bipolar is nie hulle weet nie van daai gedragsverandering nie jy word somer onmiddelik gelabel jy’s mal”.
(This mental disability bipolar, no-one, no-one, a lot of people doesn’t even know about bipolar, they don’t know what bipolar is, they don’t know about the change in behaviour, because you got immediately a label that you are mad).

Caregivers of relatives admitted into hospital often build relationships with the multi-disciplinary team with the hope of receiving information, guidance and support. This does not always happen. Families of patients not adhere to treatment, and show disruptive behaviour, experience more stress than others. These families often develop disappointment with professionals for not helping them. It is evident in this sub-theme that the lack of information about the illness from carers and communities and about treatment options aggravates the situation.

4.3.3 Theme 3: Participants' experiences of the context of patients' impulsive irrational behaviour as non-compliance with prescribed medicine for bipolar disease, combining with drug abuse

Problematic family, peer and work relationships may be the triggers of unpredictable behaviour of a patient with bipolar mood disorder. No symptom or factor should be seen in isolation. It is very important to take the context into consideration when assessing a problem as stipulated in 2.2 (Bio-psychosocial model) from a BPS perspective. These factors include financial problems, difficulties related to resuming work or family roles, problems relating to the treatment or medications, or relationships and living situational conflicts (Taylor, 2006; Miklowitz, 2011; Monimore, 2006; Perlick, Rosenheck, Clarkin, Maciejewski, Sirey, Struening, & Link, 2004).

As indicated in 2.3.3 (Social element of bipolar disorder), people with BD often stop their treatment, which can lead to major challenges for caregivers. More than half of the persons diagnosed with bipolar stop using their medications, mostly because of side-effects and cultural beliefs. Unless the patient makes a commitment, no one can force him or her to take responsibility for his or her medication. As pointed out before, patients whose family and/or caregivers are over-protected and more emotionally involved are less likely to continue with treatment.

It is well known that almost 50 per cent of patients with bipolar stop their treatment, although the reasons for this behaviour are unspecific. Substances and other co-morbidities play a role, which is the most common cause of relapse amongst bipolar patients (See 2.5: Co-morbid bipolar and substance use disorder). A patient who does not fully comply with treatment has a higher risk of hospitalisation. It is also reported that between 40 and 60 per cent of patients with bipolar have a long-term substance use disorder as well, and substance abuse can cause similar symptoms to those of BD. It is very difficult to determine whether a

person has been substance induced, has a major depressive episode, a bipolar, or a combination of these. The use of illicit drugs may imitate episodes of bipolar, but the mood disorders which result from substances are temporary (Colom & Berk, 2010; Haycock, 2010; Berk *et al.*, 2008; Miklowitz, 2011).

Last (2009); Haycock (2010); Fast and Preston (2006) support this by confirming that substance abuse is tremendously common among patients with bipolar disorder, and appears in at least 60 per cent of patients during the course of the disorder. These authors agree with the authors in Chapter 2 (See 2.5: Co-morbid bipolar and substance abuse disorder), that these substances can prevent medication from working as it should, and can endorse bipolar and impulsive irrational behaviour.

Statements below indicate that the experiences of carers regarding the context and causes mostly point to not taking medicine for depression, and especially in the case of younger patients, dependence on drugs of abuse with peers.

Participant A (Mother) – “Doctor told me she has to stay on her tablets and things and that will calm her down and things like that. But which **she is not taking it...**”

Participants B (Grandparents) – “Ek was histeries, ek het vir haar gese jy kannie gaan nie. Sy wou nie luister nie en **sy het nie haar medikasie geneem nie. She is a compulsive liar and a manipulator.** Hulle het die vermoë om ‘n “EK” daar te stel, om jou skoon weg te lei van die feit dat hulle nie drugs gebruik nie, uh hulle sal dit ontken, al die pad ontken, al die pad”.

(I was hysterical; I told her you can't go. She didn't want to listen and she didn't take her medication. She is a compulsive liar and manipulator. They have the ability, to put emphasis on the 'I'. To guide you away of the fact that they are using drugs. They will deny it, deny it all the way).

Participant C (Daughter) – “she wouldn’t forget to take it. **I don’t know now when if she’s going to if she comes home how she’s going to cope with taking her own medication** but I’m sure I’ll be able to sort out something ... I’ll be able to get somebody to assist her”.

Participant D (Father) – “I think **catalysed by the fact** that or not catalysed precipitated by the fact that she had been non-compliant with her medication for two days...but it was almost every single time linked to her **non-compliance with her medication**”.

Participant E (Husband) – “As ek by die huis kom dan moet ek nou weer wonder watter gedragsverandering gaan daar nou wees dan moet ek nou wonder nou hardloop ek eers na haar medikasie toe kyk se nee wat die pille is nou te veel jy so dit is hoekom ek se sy seker natuurlik nie haar medikasie gereeld gebruik nie en ek weet nie of dit ‘n impak het op haar admission het hierso. **Sodra sy een of twee glase bier gedrink het** en dis al wat sy drink in elk geval dan lykkit my daar is ‘n hele ommeswaai in haar dan’s haar hele gedragsverandering van, van sy rustig was die rustigste mens dan is ek nou net verkeerd so van rustig af sommer nou na gewelddadig, aanvallerig val...”.

(When I come home, I wonder what kind of change in behaviour will be there. Then I first run to her medication, and then I see, no, this tablets is too much. That’s why I say, she most probably didn’t take her medication regularly which could’ve had an impact on her current admission. **As soon as she drinks one or two glasses of beer**, because that’s anyway all that she drinks, than it looks to me there is a whole change in her behaviour, of being the most calm person, then I am the wrong one, of being calm to violent and aggressive).

Participant A (Mother) – “She’s not taking her medicines, that is what I’m seeing that **she’s not taking her medicines and due to the drugs** and that and at the end of the day, we will just find her, and she might sleep, and she will sleep a whole a few days. Doctor told me she has to stay on her tablets and things and that will calm her down and things like that. But which she is not taking it...”

It is clear from the above participants that patients do not accept responsibility for taking their medication, and the responsibility often lies with the caregiver to remind the patient to adhere to medication. Participants also point out that the inconsistency of taking medication

results from the use of alcohol and/or drugs, which lead to difficulty in becoming stable and can cause greater risk of unpredictable behaviour such as suicide and or homicide.

4.3.4 Theme 4: Experiences of personal and social consequences of the behaviours

Besides the emotional and physical exhaustion that carers experience, their reflections also explicitly and implicitly indicate that patient behaviour threatens their own safety, as well as the safety of others, influence family relationships negatively, and also cause social embarrassment. Two sub-themes emerged from the findings of the participants which highlighted the consequences of patients' behaviour experienced by the participants.

4.3.4.1 Sub-theme 1: Safety of self and others

Disloyalty, reckless spending, violence, carelessness, irresponsibility and breaking the law are experiences that caregivers have to deal with daily when caring for a person with BD. **Attempting suicide and assaulting** another person are among the more common ways in which a person might break the law during a bipolar episode. A follow-up study for over 30 years found that the death rate was very high among bipolar patients, with suicide being the most common cause of death (See 2.3: Bipolar disorder). Up to 59 per cent of patients with BD may display suicidal behaviour and 56 per cent may attempt to commit suicide (Haycock, 2010; Vieta, 2009; Chessick, Perlick, Miklowitz, Kaczynski, Allen, Morris, Marangell & the STEP-BD Family Experience Collaborative Study Group, 2007).

It is evident from the following statements that safety and security are of great concern for the caregiver for both him and or her and for their relative.

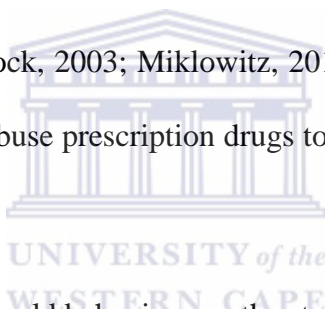
Participant A (Mother) – “ I can't just leave her alone in the house, cause even when I go to church, then sometimes I get a message on the phone or somebody is standing in front of the door and they say, your door is standing wide open. You can't just really, keep on with somebody and **that person is going to hit you** or whatever... she's very strong.... **she**

pulled out my driving gates, my sliding gates at home, the way some came one day to take her to hospital”.

Father about daughter endangering her own life:

Participant D (Father) –“Patient needs security and safety ... inability to look after themselves and her **endangering her own life** by spending weeks and weeks in locations amongst them. I’m certainly not racist but Nigerians they prepared to hide her away and you wouldn’t know she’s in there somewhere”.

In practice it is observed that people with bipolar **medicate themselves with street drugs** and/ or **alcohol** sometimes because patients cannot take prescribed drugs, and this can make the symptoms worse in the long-term. As stated in Chapter 2 (See 2.5: Co-morbid bipolar and substance use disorder), the abuse of drugs may alter an episode of an illness, which may get patients to medicate their own illnesses and will make bipolar disorder worse (Haycock, 2010; Sadock & Sadock, 2003; Miklowitz, 2011). In addition to alcohol, bipolar people may use street drugs or abuse prescription drugs to self-medicate and “manage” their moods (Last, 2009:188).



Grandparents referring to 18 year old behaviour on the streets:

Participants B (Grandparents) – “En ons het tot die wete gekom dat daardie mense, maar erger drug misbruikers is. Hulle het haar geleer. Ek was self **gedreig deur die 28 gang** of wat ookal...”

(And we came to the conclusion, that those people are worse, worse drug abuses. They have taught her. I was also threatened by the 28 gangsters or whatever the case may be).

It is clear from the above correlations that patients do not adhere to medication and that street drugs are the replacement for managing their moods, which makes their conditions worse and causes re-admission to hospital in the long-term.

The risk of suicide is still frequent among patients with BD ranging between 15 and 25 per cent. A suicide attempt of a family member can have lasting effects on the caregiver. The above authors also found that caregivers currently experiencing suicidal ideation, reported health difficulties (Colom & Berk, 2010; Chessick *et al.*, 2007).

Daughter about mother trying to commit suicide:

Participant C (Daughter) – “**She sat with a handful of pills** and luckily I caught her and I sat down with her and I said “mommy, this isn’t the way out...””.

Therefore the researcher can state out of above correlation that watching and or experiences a family member or close relative attempting to or commit suicide can have long-term psychological effects on the carer, which can lead health related issues.

It is important not to forget that BD can occasionally display very sudden behaviour. Aggression and psychosis are two factors which are very complicated to deal with. Learning about the illness enables caregivers to identify the symptoms of new episodes which lead them to intervene more quickly (Mondimore, 2006; Miklowitz, 2010; Haycock, 2010; Also see 2.5: Co-morbid bipolar and substance use disorder).

The following statement indicates that the husband reacted with aggression to a patient’s aggression towards him.

Participant E (Husband) – “dit is nou **my** aggresie teenoor haar aggresie ...” (This is now my aggression towards her aggression).

Therefore, it became evident that families experiences a lot of difficulties adapting to changes in mood, disruptive and or impulsive behaviour of their ill relative and become aggressive and irritated themselves, without being knowing that aggressiveness are not restricted to people living with BD.

Evidence reveals that stressful circumstances and strongly expressed emotions within a family are often the cause of bipolar disorder, and have been described as an important predictor of a setback as stated in Chapter 1 (1.1, Orientation to this study). Thus, BD affects family relationships, and family relationships affect BD. Families usually are unable to control the occurrence when a relative experiences a manic episode. The disruptive behaviour can become intolerable to live with. The fear of new relapses is still present, even though the illness is stabilised because every episode is a stressful event for all family members (Colom & Berk, 2010; Reinares, Vieta, Colom, Martinez-Aran, Tottent, Comes, Goikolea, Benabarre, Daban, & Sanchez-Moreno, 2006; Also see 1.2.1: Families experiences caring for people with mental disorders).

A mother reflected about the effect that her daughter's behaviour had on the family:

Participant F (Mother) – “Skeur familie uitmekaar uit dis mos wat hulle se die tik doen die drugs (coughs). (Tears families apart, this is what they say TIK does, the drugs (coughs)).

It is therefore clear that the illness of a relative extends to the family, and a huge burden rests on them having to taking care of their ill relative.

4.3.4.2 Sub-theme 2: Social stigmatisation and embarrassment/shame

Individuals being labelled as different and/or believed to have negative characteristics which result in negative emotional reactions, discrimination as well as loss of identity has been defined as stigmatisation. The stigmatisation of patients suffering from a severe mental disease, as well as their families caring for them who reported feeling stigmatised, have been observed globally as indicated in Chapter 1 (See 1.2.4: Mental health legislation, policies and treatment contributing to the burden of family caregivers). Stigma involves negative beliefs about certain qualities of a certain group of people.

Caregivers affected by stigmatisation isolate themselves from society and adopt depressive moods which can cause them losing out on opportunities to have valuable resources and enjoyment. Conflicting emotions such as fear, worry, denial, anxiety, hopelessness, anger and even irritability are likely to be experienced by family and friends. One can also be shocked or ashamed by one's relatives' behaviour, especially in public (Gonzalez, Perlick, Miklowitz, Kaczynski, Hernandez, Rosenheck, Culver, Ostacher, Bowden & the STEP-BD Family Experience Study Group, 2007; Berk *et al.*, 2008; Fast & Preston, 2006; Also see 2.3.3: Social factor of bipolar; 2.4.3: Social element of substance abuse disorder; 2.5: Co-morbid bipolar and substance use disorder).

Therefore, the participants below explicitly mention exposure to social embarrassment due to the patient's behaviour. The two men as primary carers (father and husband respectively) and the daughter of a patient, who from the age of twelve was exposed to the bipolar behaviour of her mother.

Participant E (Husband) – “Die mental disability bipolar - niemand, baie mense weet nie eens van bipolar nie hulle weet nie wat bipolar is nie hulle weet nie van daai gedragsverandering nie jy word **sommer onmiddelik gelabel** jy's mal”. (This mental disability bipolar, no-one, no-one, a lot of people doesn't even know about bipolar, they don't know what bipolar is, they don't know about the change in behaviour, because you got immediately a label that you are mad).

Participant C (Daughter) – “It seemed embarrassing because there's constantly there are neighbours, friends in and out and you don't want people to know, what, what is.... You don't want people to know what is happening. **I felt embarrassed** I wouldn't want them to see my mom speaking out of turn to them you know its speaking maybe in a bad way when she's not supposed to”.

Participant D (Father) – “She would assault people and pull plates and cups off restaurant tables and empty out an entire restaurant with a hundred and twenty people”.

It therefore became evident to the researchers that ignorance about the illness and the incidents caused by the impulsive behaviours label the patient and cause social embarrassment for the family. The above themes and sub-themes imply that participants acknowledge that they cannot cope with the behaviour of the patients other than trying to control it with the help of medication, police, and hospitalisation.

4.4 CONCLUSION

The question in phenomenology is: What is the essence of these experiences for the participants? All participants' reflections indicated that the unpredictable, abusive, aggressive, irrational, impulsive and potential self-destructive behaviour of patients leave them mentally and physically exhausted and anxious. The situation is aggravated by a lack of information and skill to cope with the situation, and lack of a social support system. The lack of insight into the situation exposes the family to shame and stigmatisation. The consequence is that coping without institutionalisation and/or social support before and after hospitalisation seems impossible. It is therefore evident that families caring for a relative with a diagnosis of co-morbid bipolar and substance abuse have a great need to be heard and supported.

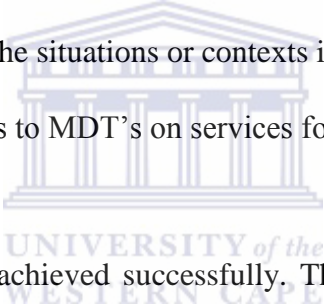
CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

Caregivers experience numerous challenges when caring for a family member with co-morbid bi-polar and substance use disorder, which contributes to the burden of care and also results in repeated re-admissions. The goal of this study was to determine the lived experiences of caregivers in this situation. This goal was achieved through the realisation of the objectives outlined below:

- To explore and describe the lived experiences of caregivers caring for a family member with a co-morbid diagnosis of bi-polar and substance abuse;
- To explore and describe the situations or contexts in which these experiences occur;
- To give recommendations to MDT's on services for caregivers in this position.



The goals and objectives were achieved successfully. The exploration of the experiences was done during the research process described in Chapter 3, and the description of the lived experiences was done in Chapter 4 of this document. The exploration and description of the experiences was done through obtaining a textual description of their experiences and a structural description of the context of these experiences. These processes provided an overall picture of the experiences of the participants caring for their relative with a co-morbid diagnosis of bipolar and substance use. The last objective focused on the recommendations to multi-disciplinary team members with special reference to services for family members. This chapter constitutes the conclusions of the study, followed by recommendations to accomplish the last objective and subsequently the goal of the research.

5.2 CONCLUSIONS

Conclusions will be drawn from the empirical findings in Chapter 4. The themes and sub-themes are illustrated in Figure 4.1 but the researcher deemed it necessary to present it again in Table 5.1 in order to provide the reader with an outline of the conclusions, which will be presented according to these themes and categories.

Table 5.1: Themes and sub-themes

THEMES	SUB-THEMES
THEME 1: Feelings of helplessness, emotional and physical exhaustion.	
THEME 2: Causes of the exhaustion and feelings of helplessness	<p>SUB-THEME 1: Unpredictable/ impulsive “abnormal”/irrational behaviour of patients</p> <p>SUB-THEME 2: Lack of Support systems</p> <p>SUB-THEME 3: Ignorance about the illness aggravated the exhaustion and ability to handle the situation</p>
THEME 3: Participants’ experiences of the context of patients’ impulsive irrational behaviour of non-compliance to prescribed medicine for bipolar disease combining with drug abuse	
THEME 4: Experiences of personal and social consequences of the behaviours	<p>SUB-THEME 1: Safety of self and others</p> <p>SUB-THEME 2: Social stigmatisation and Embarrassment / Shame</p>

5.2.1 Feelings of helplessness, emotional and physical exhaustion

Based on the data provided in this theme, the following conclusions became evident to the researcher:

- All participants experienced feelings of helplessness, emotional and physical exhaustion in caring for their ill relative.
- Young children could take the responsibility to care for their ill parent, which led to feelings of guilt about their parent's illness.
- Unpredictable behaviour and mood changes by the patient disturbed households and caused stress in relationships, which led to outbursts by caregivers.
- Partners took over the roles performed by the ill relative, which had a negative effect on their well-being and relationship.
- Hospitalisation of the ill relative was a relief for the carer and the family members.

5.2.2 Causes of the exhaustion and feelings of helplessness

When a family member was diagnosed with BD, a number of emotions appeared in families. Recognising a partner's illness resulted in loss of important qualities of life, and led to grief over the loss of that person and quality of life. Families experienced feelings of bitterness, embarrassment and suppression of the patient and illness. Caregivers felt pressured and trapped while looking after their ill relative with no support.

The following causes were found, which led to feelings of exhaustion and helplessness by spouses, partners and families of people with BD:

5.2.2.1 Unpredictable/impulsive, “abnormal”/irrational behaviour of patients

- Threats of suicidal and/or homicidal behaviour of patients led to families being worried and anxious.
- It was clear that the behaviour of the ill relative caused fear and anxiety when leaving the patient alone at home.
- Families were verbally and emotionally abused by their ill relative’s behaviour.
- Relationships were being broken and partners became uninvolved with the care of their partners.
- It was found that men, who were looking after their spouse with bipolar, made more effort to create a support structure, meaning that women in general are more likely to already have a support structure outside the core family.

5.2.2.2 Lack of Support systems

- Lack of support systems aggravated feelings of exhaustion and helplessness in caregivers.
- Families were affected by BD urge for help and support caring for their ill relative.
- The burden that caregivers experienced, contributed to embarrassment, persistence and devaluation.
- Families engaged in activities such as substance abuse when there are no solutions and support for them in order to avoid the problem caring for their relative.
- Caregivers experienced high level of burden when not getting relevant resources.
- Participants acknowledged that they cannot cope with the behaviour and would rather prefer assistance of medication, police and hospitalization.



5.2.2.3 Ignorance about the illness aggravated the exhaustion and ability to handle the situation

- Families experienced confusion about the difference in diagnosis and medication of their ill relative.
- Family's needed information about their relative's disorder especially whether or not hospitalisation was needed.
- Many misconceptions existed among family members about the treatment and behaviour of their ill relative.
- Caregivers expect to receive information, guidance and support from the multi-disciplinary team, which does not always happen and in this case resulted in disappointment towards professionals.
- Families of patients who did not adhere to treatment and displayed disruptive behaviour experienced more stress than others.

5.2.3 Participants' experiences of the context of patients' impulsive irrational behaviour as non-compliance to prescribed medicine for bipolar disease combining with drug abuse

In describing this theme, in which participants experienced the context of their relatives' impulsive irrational behaviour, the following conclusions were reached:

- Problematic family, peer and work relationships are the triggers of unpredictable behaviour in a patient with bipolar mood disorder. These triggers include financial problems, difficulties related to resuming work or family roles, and problems relating to the treatment or medication or relationships and living situations.
- Patients are less likely to continue treatment when families or caregivers are over-protective.

- Illegal substances and other co-morbidities are the most common cause of relapse among bipolar patients.
- The use of illicit drugs imitates episodes of bipolar, and prevents medication to work as it should, and endorses impulsive irrational behaviour.
- Non-compliance with treatment has a higher risk of hospitalisation.

5.2.4 Experiences of personal and social consequences of the behaviours

Caregivers reported that patient behaviour threatens their own safety, as well as the safety of others, influences family relationships negatively and also causes social embarrassment. The following conclusions highlighted the consequences of patients' behaviour experienced by the caregivers:

5.2.4.1 Safety of self and others

- As observed, attempting suicide and assaulting another person are among the most common behaviour of a person diagnosed with bipolar.
- It has also been found that people with bipolar medicate themselves with street drugs in order to manage their moods, which makes symptoms worse in the long-term.
- It became clear that caregivers experienced suicidal ideation and reported health difficulties.
- Caregivers found every episode stressful, and even though the illness was stable, the disruptive behaviour was intolerable to live with.

5.2.4.2 Social Stigmatisation and Embarrassment/Shame

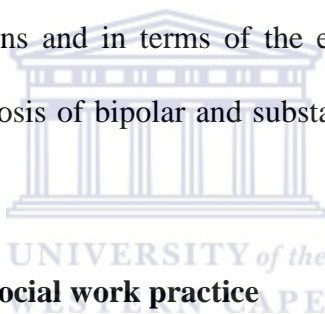
It has been globally observed that patients suffering from a severe mental disease, as well as their families caring for them, report feeling stigmatised.

The following conclusions give an indication on how these caregivers experienced stigmatisation in caring for their relative with a mental illness:

- Caregivers isolate themselves from society, become depressed and experience stigmatisation being associated with a mentally ill relative.
- Caregivers in this study felt exposed to social embarrassment because of their ill relative's behaviour.
- Primary caregivers stated that ignorance about the illness and the incidents causing the impulsive behaviours labelled the patient and caused social embarrassment for the family.

5.3 RECOMMENDATIONS

In view of the above conclusions and in terms of the experiences of families caring for patients with a co-morbid diagnosis of bipolar and substance abuse disorder, the following recommendations are provided:



5.3.1 Recommendations for social work practice

- Social workers need to increase therapeutic intervention services in terms of caregivers of mentally ill patients.
- Increased support services need to be provided by social workers to families using awareness and access to resources and services in communities.
- Generic social workers need to adopt a supportive role in the community through demonstrating support for social workers in specialized organisations. Treatment should be continuous and monitoring is important to prevent relapse.
- Further support needs to be provided by community social workers for social workers in psychiatric facilities with regard to home visits and follow-up services

once patients are discharged back into the community, in order for services to be sustainable.

- Generic social workers need to recognise and prioritise mental health in communities.
- Social workers need to improve communication with families and caregivers in order to establish a working relationship, which will positively contribute to the holistic treatment of the patient.
- Relationships with stakeholders and other role players in the community need to be strengthened among social workers for combating issues regarding service rendering for the mentally ill.
- Social workers should start implementing the bio-psychosocial model in the mental health community in order to understand mental health needs holistically, thus the social worker has a unique role to play in the multi-disciplinary team.

5.3.2 Recommendations for Multi-Disciplinary Teams (MDTs) at psychiatric hospitals

- MDTs are very important in the healing process of the patient and his/her family. Tension among team members should be resolved when treating a patient and his/her family.
- Overlapping roles need to be clarified among members of the MDT in order to prevent role conflict. Each role in the team needs to be acknowledged by the MDT.
- During admission, a guideline should be distributed to patients and their families in order keep record of the history of their episodes, which could save them time during each admission process.
- Patients tend to lose their personal documents (for example identity document, bank cards and curriculum vitae's) during relapses. MDTs can assist caregivers, families

and/or patients in building their own files in order to keep their personal and valuable documents safe.

- The ACT team (Assertive Community Treatment Team) should be more visible and clarify their role in consultation and partnership with other community organisations with regard to discharged patients, as well as support systems in their home and community, which will reduce patients being re-admitted into hospital.
- The MDT should give ongoing support to the needs of the patients and caregivers and should understand the stresses arising from caring for someone with BD.
- Continuous training should be provided to MDTs working with mentally ill patients and their families as part of an integrated treatment plan.
- The researcher recommends that education about stress management and problem solving should be included in the treatment plan of patients and caregivers, as caregivers do not always know what to do when patients become ill and/or act negatively.
- Psycho-education to caregivers should receive more attention with regard to the genetic factors of psychiatric disorders, as well as the difference between an episode and anti-social behaviour in order to know when to admit a patient or to make a case against the patient.
- Psycho-educational programmes should be presented on an ongoing basis to patients and caregivers, in whom their experiences are heard and they are able to tell their stories.
- Education on mental illness and especially the co-morbid diagnosis of substance abuse and mental illness should be provided to schools, other professions, church groups, shelters for homeless people, and traditional healers.

- The utilisation value of social and communication media such as the radio, television, newspapers, cell phones (e.g. Facebook, Twitter and You tube) are highly recommended to contribute to awareness of mental health.
- Support groups for caregivers alone should also be considered, because their needs differ from those of the patients.
- It is highly recommended as part of patients' treatment plans to empower caregivers and patients with regards to budgeting skills in order to teach patients to live within their means. Patients usually go on a spending spree during their illness and lose a lot of money and personal belongings.
- Caregivers must be educated about the procedure to follow when applying for an administrator and/or curator at the Master of the High Court about for patients' assets and financial situations.

5.3.3 Recommendations for government and non-governmental organisations

- Mental health should be recognised by government as a priority in terms of policy, resource allocation and funding.
- Education should be provided by government to stakeholders, role players and the community at large on mental health and the Mental Health Care Act.
- The Mental Health Care Act needs to be reviewed and assessed with regard to its limitations, implications and negative impact on patients, their relatives and the community.
- Implementation of policy needs to be assessed and evaluated with regard to community-based services and further developments required for effective services.
- The need for community care, adequate housing, and better employment support has increased since hospitalisation time has become shorter, due to the changing health system.

- After-hours mobile treatment teams need to be established, because police are not equipped to handle psychiatric emergencies.
- Police need to be educated about their role of assisting and supporting family members in communities on admission of patients. This has become a real challenge for social workers, as family members make contact with social workers to help with the admission of an aggressive patient in the community, especially during psychosis. Therefore more police support is greatly needed.
- Since de-institutionalisation has been advocated by the Mental Health Care Act, caregivers and families have become over-burdened and even mentally unstable or ill. Therefore, long-term in-patient treatment is highly recommended, because the pressure of de-institutionalization and hasty decisions to discharge patients have resulted in social workers having difficulty in finding appropriate aftercare for patients who are chronically mentally ill. As a result patients end up being homeless.
- More specialised mental health social workers need to be employed in mental health (primary, secondary and tertiary care) and at designated community or non-governmental organisations (NGOs). If specialised mental health social workers cannot be found, as it is a scarce source, social workers should be trained in services to patients with mental illness and their families.
- Social workers not working for specialised units as part of a multi-disciplinary team should be incorporated in multi-disciplinary team meetings and case conferences with families and patients when necessary.

5.3.4 Recommendation for higher education and training

- Mental health needs to be incorporated in the curriculum of undergraduate social work students and should include the following modules:

- The mental health context including the cause and onset of the illness.
- Students should be trained on the Mental Health Care Act (17 of 2002) and other policies involving mental health.
- The role of the social worker in a psychiatric facility as part of an MDT.
- Different treatment approaches that are used in the mental healthcare field.

5.3.5 Recommendations for future research

- Reasons for readmissions of patients more than three times a year to a psychiatric hospital needs to be assessed and evaluated. Quantitative, qualitative, participatory action research and evaluation research can be used for this.
- Research needs to be conducted on the effects on a child who has had to grow up with a bipolar parent, especially one who has been diagnosed with co-morbid bipolar and substance-use disorder. Qualitative research will be appropriate for this.
- Research needs to be conducted on the high divorce rate in the bipolar population in which one or both of the spouses are diagnosed with BD. Both quantitative and qualitative research can be used.
- It is important to determine caregivers' perceptions regarding the genetic aspects of mental illnesses, especially if there is more than one family member with the disease, Qualitative research can be done.
- Research on MDTs' needs, fears and frustrations in treating mentally ill patients, their caregivers or families, can be carried out by quantitative and qualitative research.
- Further research is necessary on the specific functions of social work in the field of mental health, specifically on primary, secondary and tertiary level. Models for social work practice on these levels can be created and evaluated.

- Research on the wellness of allied healthcare workers in the field of mental health needs to be done. Quantitative and qualitative research can be used.

5.5 SUMMARY

It is clear that the lack of information on BD, substance abuse and a co-morbid diagnosis by caregivers and communities about treatment options aggravates the situation caring for a relative. The responsibility lies with the caregiver to remind the patient to adhere to medication. There is inconsistency in taking medication as a result of the use of alcohol and/or drugs. These lead to difficulty in being stable, and cause greater risk of unpredictable behaviour such as suicide and/or homicide. Safety and security are of great concern for both patients and for their relative. Family members or caregivers must deal with different kinds of stress related to their relative's illness like symptoms, behaviours, as well as stress relating to societal stigmatisation.

The bio-psychosocial framework allowed the researcher to explore the social context of the caregiver and the patient holistically. The individual functions within a family who functions within a larger community system. This system might be supportive or comprise pathologies.

It was important that the researcher had to become aware of the needs and challenges in the system in order to conclude that resources are seriously lacking in the community, which often leads to caregivers feeling burdened, giving up, and becoming silent. It is hoped that this research study will contribute significantly towards advancing more appropriate health care services to families and carers who tirelessly go out of their way to care for their relatives who are patients with a co-morbidity of mental illness and substance abuse.

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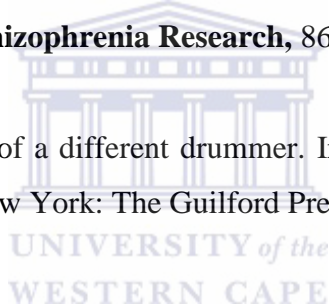
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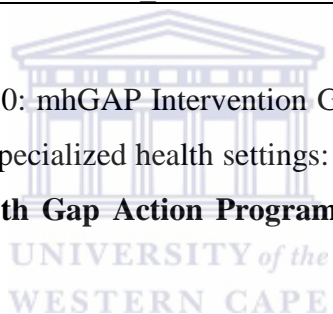
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**APPENDIX A: SENATE RESEARCH COMMITTEE OF THE UNIVERSITY OF
THE WESTERN CAPE**



UNIVERSITY of the
WESTERN CAPE

**OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT**

4 February 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:
Mr U September (Social Work)

Research Project: Experiences of family members caring for female patients with a comorbid diagnosis of bipolar and substance abuse admitted in a psychiatric hospital in the Western Cape.

Registration no: 14/10/50

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

*Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape*

Private Bag X17, Bellville 7535, South Africa
T: +27 21 959 2988/2948 . F: +27 21 959 3170
E: pjosias@uwc.ac.za
www.uwc.ac.za

A place of quality,
a place to grow, from hope
to action through knowledge

APPENDIX B: WESTERN CAPE DEPARTMENT OF HEALTH



STRATEGY & HEALTH SUPPORT

Health.Research@westerncape.gov.za
tel: +27 21 483 6857; fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_2015RP8_650
ENQUIRIES: Ms Charlene Roderick

Highland Drive
Mitchell's Plain
7785

For attention: **Warren September**

Re: EXPERIENCES OF FAMILY MEMBERS CARING FOR FEMALE PATIENTS WITH A CO-MORBID DIAGNOSIS OF BIPOLAR AND SUBSTANCE ABUSE ADMITTED IN A PSYCHIATRIC HOSPITAL IN THE WESTERN CAPE.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries in accessing the following sites:

Lentegeur Hospital

N Jacobs

Contact No: 021 370 1243

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. The reference number above should be quoted in all future correspondence.

Yours sincerely

AD HAWKRIDGE.

DR A HAWKRIDGE
DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 13/4/2015.

CC F VAN DER WAT

CEO: LENTEGUER HOSPITAL

CC S KARIEM

CHIEF DIRECTOR: GENERAL SPECIALIST & EMERGENCY SERVICES

APPENDIX C: ETHICS COMMITTEE OF LENTEGEUR HOSPITAL



Lentegeur Psychiatric Hospital
Co Highlands Drive & AZ Berman
Lentegeur
Mitchell's Plain
7785.

4 December 2014

Lentegeur Hospital Research Ethics Committee

Lentegeur Hospital
Highlands Drive
Mitchells Plain
7785.

To whom it may concern

RE: RESEARCH PROJECT- EXPERIENCES OF FAMILY MEMBERS CARING FOR FEMALE PATIENTS WITH A CO-MORBID DIAGNOSIS OF BIPOLAR AND SUBSTANCE ABUSE ADMITTED IN A PSYCHIATRIC HOSPITAL IN THE WESTERN CAPE.

Principal Investigator/s – Mr Uwarren September

This serves to confirm that the above research project has been granted ethical approval by the hospital Research Ethics Committee

You would be required to submit progress and the final report to the hospital for our records of research conducted at the facility.

Yours Faithfully



Dr P. Smith

Chair – Research Ethics Committee
Lentegeur Hospital.

1st Floor, Admin Building,
tel: (021) 370 – 1105 / 1409 fax(021) 371 - 7359

nadjacob@pgwc.go.v.za

APPENDIX D: INFORMATION SHEET



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2821, Fax: 27 21-959

E-mail: uwarrenseptember18@gmail.com

INFORMATION SHEET

Project Title: Experiences of family members caring for female patients with a co-morbid diagnosis of bipolar and substance abuse admitted in a psychiatric hospital in the Western Cape.

What is this study about?

This is a research project being conducted by Uwarren September, a Master in Social Work student at the University of the Western Cape. We are inviting you to participate in this research project because you have experience and knowledge about various challenges caring for a family member with a co-morbid bi-polar and substance abuse diagnosis. The purpose of this study is to explore and describe the lived experiences of family members caring for a family member with co-morbid a diagnosis of bi-polar and substance abuse, as well as the contexts in which they experience it and to provide recommendations on social work intervention for family members caring for a family member with a co-morbid bi-polar and substance abuse diagnosis.

What participants be asked to do if they agree to participate?

Participants will be asked to take part in an interview which will last for approximately one hour. The interviews will be done privately in an office as arranged prior to the meeting. A tape recorder will be used with your permission. The questions which will be asked are:

- Tell me about your experiences taking care of your relative having a mental illness?
- In what situations did you experience this?

Would participation in this study be kept confidential?

All data will be handled confidential. Your name will not be on the tape or on transcriptions of the interview, which the researcher will use in order to get information for the research. A code will be placed on the collected data and the researcher will be able to link the study to the participants' identity with a code. Codes will be used to identify data collected. No one else other than the researcher and his supervisor will have access to the data and the data which will be stored in a safe locked place. When writing a report or an article about this study, your identity will be protected.

What are the risks of this research?

The research might contribute to emotions and identification of challenges by sharing your experience but you will be referred to appropriate resources. The interview may result in anger and feeling of frustrations.

What are the benefits of this research?

The participant will not directly benefit from this study but, but the outcome of the study will help improving the understanding of others and provide recommendations regarding suitable social work intervention for family members caring for a family member with a co-morbid bi-polar and substance abuse diagnosis.

Do participants have to be in this research and may they stop participating at any time?

Participation in this research is completely voluntary. Participants may choose not to take part at all. If they decide to participate in this research, they may stop participating at any time. Participants will not be penalized.

Is any assistance available if participants are negatively affected by participating in this study?

If need arise that participants need assistance, they will be referred to the relevant person for help. Should they have any questions regarding this research and their rights as a research participant or if they wish to report any problems they have experienced related to the study, please contact the supervisor.

This research is being conducted by the Social Work Department at the University of the Western Cape. If there are any questions about the research study itself, please contact my supervisor Dr. A. Beytell at ambeytell@uwc.ac.za or telephone number (021) 959 22821

or (021) 959 2012. The address is: Social Work Department, University of the Western Cape, Private Bag X17, Bellville 7535.

Should you have any questions regarding this study and the rights as a research participant or if any problems experienced related to the study need to be reported, please contact:

Prof. R. Schenck
Head of Department: Department of Social Work
University of the Western Cape
Private Bag X17
Bellville
7535.
Tel: (021) 959 2011
E-mail: rschenck@uwc.ac.za

Prof. J. Franz (Dean of the Faculty of Community and Health Sciences)
University of the Western Cape
Private Bag X17
Bellville
7535.

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.



Head of Department: Dean of the Faculty of Community and Health Sciences: Prof José Frantz
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

APPENDIX E: CONSENT FORM



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2821, Fax: 27 21-959 2845

E-mail: uwarrenseptember18@gmail.com

Title of Research Project: Experiences of family members caring for female patients with a co-morbid diagnosis of bipolar and substance abuse admitted in a psychiatric hospital in the Western Cape.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name.....

Participant's signature.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study co-ordinator:

Dr A. Beytell (Supervisor)
Social Work Department
University of the Western Cape
Private Bag x17
Bellville
7535.
Telephone: (021) 959 2821
Cell: 0827761717
Fax: (021) 959 2845
Email: ambeytell@uwc.ac.za

APPENDIX F: TRANSCRIPT OF AN INTERVIEW

Transcript 1: Participant A

1	Halo mev, mev ek het nou vir u verduidelik waarom die studie
2	gaan neh, I just want you to tell me about your experiences caring
3	for for M?
4	Well mr S, I can only say from my side, from my point of view
5	that, having a child with bipolar and to the substance that she's
6	using and the drugs, and having a drinking, is a very very bad
7	situation. Due to that, uhm, there is, not only times, at all times,
8	there isn't, I just don't know which way to turn. Because it's very
9	difficult in a situation that, uhm, you try your best to speak softly
10	to her, or or explain to her but there's nothing that you can get
11	through to her, nothing... she will maybe just look at you or she
12	will just walk pass you, or shout at you, whichever way it might
13	work out, but there's nothing that I can get through to her. Even
14	for that matter, if she doesn't even used the drugs for that matter,
15	shes also got her ways and means, she will just go and curl herself
16	up the whole day on the bed and you can ask her if she want to eat
17	something or anything like that, nothing nothing like that.
18	Now what does that do to your experience?
19	Well what I can just say is that... for me personally, I, I really just
20	break down and cry, because it's my child. And knowing that two
21	of us are mostly of the time alone because her children is at school
22	and my youngest daughter that stays with me is at work or was at

23	school still that time, so the two of us are alone and then we have
24	no conversation. I would, she come pass, and maybe i would ask
25	her do you want something to eat or where do you come from
26	now, or maybe she didn't come home the night maybe, that I just
27	want to know what, maybe, that she won't answer me on anything,
28	and it's very hartsore, because it really... emotionally it really
29	touches me.
30	What, what is very hartsore, what is the the the situations that
31	make it so hartsore?
32	Well we have got no communication with one another, that is the
33	thing, there's no communication at all. There's no communication
34	at all, uhm, even when it comes to her children, where I spoke to
35	them and even where it came to the case, uhm, there's no income
36	really, there's no income what i can really say that comes in
37	properly from my side and with hoping to adopt them to ask them
38	how do they feel about me taking them over as a mother would...
39	yes they are 100% with me but their heart is that their mother must
40	be their first priority. And then we land up crying with one
41	another. Because, especially with the little one, the older one, well
42	the little one doesn't really understand yet, but the older one says
43	mom that we still want my mommy.
44	mmmmmm
45	And to me it's a lot of things because uhm, I feel i raised them
46	alone, not for anything, uhm my hearts go out for her children, that
47	she at least have, be a mother to her children (Crying). It does

48	break me, it does a lot to me.
49	Ohk, What is the situations in which that experiences occur?
50	Yes, to that, to that now really, this is the reason why, I uhm, that
51	is the reason why, because she's not taking her medicines, that is
52	what I'm seeing that she's not taking her medicines and due to the
53	drugs and that and at the end of the day, we will just find her, and
54	and she might sleep, and she will sleep a whole a few days or
55	whatever and things like that. she will say theres nothing wrong
56	with her, she will say nothing is wrong with her. it feels, it makes
57	me feel bad. Because i know something is wrong with her. That is
58	the point, there is definitely something wrong with her, because
59	what she does in the house when we now definitely knows that
60	something is wrong with her, she will let the water run the whole
61	day. She, we must watch her continuously; she will come and bath
62	up to five times a day She will walk the whole day up and down
63	to the school to her children. Then the school phones and tell me
64	that shes again at school. Or she will to and get food at the centre
65	sometimes, its, i don't know if some people give her or what but
66	then she'll make up a little food... she is very concerned about the
67	children for that matter.
68	mmm mmm
69	Very much concerned. And she make up little food packets and
70	she that they get the food but when i look at it... i don't know if
71	somebody, i don't know if she took it out of the bins or what she
72	did, i don't know. Because im too scared to look at it, because i

73	don't know how shes going to react with me. Because she she does
74	sometimes gets abusive, not actually i wont say abusive, but she
75	will shout at me and that... because of the state that shes in that i
76	am scared that she might, she will, she turns around and she makes
77	as if she wants to hit me, thats what she does. And i mean, u, you
78	cant temp to something and know that the person in their mental or
79	in their wrongness that they are not right.
80	mmmm
81	I mean you cant just really, uh how can i now say keep on with
82	somebody and that person is going to hit you or whatever. You
83	know, 'cause shes very strong. Thats how come, i must get, i ask
84	the doctor how we going to get her to hospital, because she pulled
85	out my driving gates, my sliding gates at home, the way some
86	came one day to take her to hospital.
87	Now now what happens... or what is the situations... nou wanneer
88	gebeur dit dat sy daardie gedrag openbaar?
89	Mnr S, dai is biekie baie difficult vir my because, i really don't tell
90	lies now, i really cant explain, sometimes you really forgets about
91	these things the way it goes... it was the same. It was the same
92	same situation one night, my son ask me mommy what are you
93	going to say at hospital, as we going on, as we are speaking now,
94	its, you know its things that somebody must really be there to see
95	the things that we going through with her. Its like... it its things
96	that she just, things that she will say to you or or or do... now as
97	soon as you, as I've said she will let the water run, it sound

98	something maybe stupid to say but this is things that she does, she
99	will let the water runnn i mean you must be clean, you must be
100	washed, you must do your washing and things like that. I do the
101	washing, but besides that, she wil, she will take anything out and
102	she will start washing, but she will run the whole bath. Now if you
103	maybe say something to her, then it's a whole, then it's a whole
104	argument or whatever and the i rather ma keep quiet.
105	Okay. Now what would you say to her?
106	I will speak softly to her, knowing that she's going to flair up... but
107	you can speak softly or you can speak how, she will just shout at
108	you. She will shout at you.
109	mmm, and then after that?
110	Then she will just take a walk. She'll take a walk and then she
111	come back and, and whatever (laughs) she might just take a walk
112	or whatever, and or she will shout in the street, en se my ma is
113	alwee mal, (laughs) die vrou gaan alwee aan hier binne. Mr S
114	(laughs)
115	U kan maar vir my vertel soos in wat u voel... wat u ervaar, hoe
116	ervaar u dit?
117	I, Mr S i don't know anymore what to do. To be honest I really
118	don't know more what to do, because this is just me. Meaning, i
119	don't know, uhm, I raised them alone through the grace of God.
120	Their daddy also didn't work and that... so it was just my children
121	and myself. 'Cause he himself was an alcoholic also. But he is
122	dead today. So i raised them alone, and we didn't have this

123	situation like now. And in our family, she's the only one, from her
124	daddy's side, and from my side of our family. So this is not
125	something i know how to work with, but I'm trying my best,
126	because of the situation she's in. As Doctor told me she has to stay
127	on her tablets and things and that will calm her down and things
128	like that. But which she is not taking and things like that and as i
129	said, i don't know really what trick her so.
130	What happens when she's not using her medication?
131	Then you can see shes going down again. She's starting to go off
132	again. But she will say... she will said that there's nothing wrong
134	with her. I always saw her coming and going, coming and going,
135	but it was a usual thing to me, thinking now that she got the child's
136	father, its after the second eldest daughter, which is now 9years
137	old, that we saw this happened. So it's actually now...
138	So now what happened?
139	She just... my eldest son was in hospital, and i went to go visit
140	him, and then my youngest daughter phoned me to say, mommy,
141	please don't go to R's house, come straight a way home, M got
142	sick. And so when we got at home, we just saw her, talking all
143	wrong things, or i can't even remem... or i just know we still kept
144	her the whole weekend in bed, we mos thinking mos now she's
145	sick, that's the way, and things like that. My son started to ride
146	around and go look for hospital, doctors and he could get... then
147	we wrote to lentegeur, then a sister at lentegeur said that we better
148	try to get her in because, this and that and this and that. That's

149	what happened to her. And then eventually from then we saw her.
150	When we admitted her, it took me a bit, but when Doctor called
151	me in and when he spoke to me, then i only broke down, because i
152	didn't know it was like mentally something wrong with her. That
153	that i didn't know. I really didn't know that. Really... but now I'm
154	getting a bit of peace, because of course she's being a long time
155	now in hospital, and now but that... but to live with her is very bad
156	Mr S, because as i said its not only her she got her children also,
157	and then she disturbs the children also on top of it, and I'm the one
158	that must sit with it. Because what, where do I go to, you haven't
159	got no family that can help you, not as if they don't want to help
160	you, but my family is scared... they say straight out we scared, we
161	don't know what to do with M... we don't know what to say. And
162	when it comes to her children, im always in the middle. I also got
163	a life that i must go and do things. I cant just leave the children
164	alone i also got to go to shops and shopping, or maybe want to go
165	away for the weekend and do something, its most disturbing.
166	Bad?
167	Well i mean, when she now... meaning bad that i cant leave her
168	alone in the house. Ohk, maybe maybe not bad, i cant just leave
169	her alone in the house, cause even when i go to church, then
170	sometimes i get a message on the phone or somebody is standing
171	infront of the door and they say, your dood is standing wide open.
172	Then theres nobody, the children and myself had gone to church.
173	So or maybe bad is not the word that i should use, but i mean,

174	theres theres, i cant leave her alone at home, thats the thing.
175	Mmmm
176	That's why I say, when it comes to my family, they also don't
177	know how to handle her, or whatever and and even from her
178	daddy's side also. I can't leave her alone because of the things that
179	she does. As I've said shell leave the house alone, and we are even
180	scared when it comes to the electrical equipment and that, because
181	she puts it on and she forgets it.
182	And does she do that every time?
183	She does it. She does it every time Mr September. As I've said
184	even to the water... we so scared... when we get at home, even one
185	day the water was running over, she got a plug in her hand basin
186	and the water was running over.
187	a plug?
188	The plug she put in the hand basin and she forgets that the tap was
189	running still. And even when the the, there i can still show Mr S
190	now, i didn't sorted out the things even yet, the way we were
191	moving out of the house and just took the things out of this
192	packing bag. She will like take the the spices and things, or
193	whatever and then she mix the whole lot together. The dry
194	ingredients or things like that, you know, its little things but
195	it'sthings that mustn't be. Its things to her age already that
196	somebody wont do by your full senses for that matter. Under the
197	blood of Jesus Lord for what i am saying now. But its true, we
198	wont go and do and take all different spices and just throw it

199	together, it mustn't be. Where she doesn't worry. Even when it
200	come to the food stuff mr S, she will mix anything, thats her way
201	and things like that. To her its just the right watt hats shes going to
202	do things. She takes, you know Mr S what she does, she takes
203	handy andy and jik and things and then she puts her children in the
204	water. Its just things as as im going on that i can recall. Then the
205	little one will run out and they will say mom mom, my mommy
206	throw, my ma het alwee dai goed ini bad gegooi,
207	And then?
208	Then she wants to bath the children in the water Mr S. Mr S, i get
209	so cross or, as i said, to try and keep the peace that she doesn't flee
210	up or get cross or might get hold of me or whatever, i just go to the
211	bathroom and empty the water or tel the children just to come out.
212	But it affects me, it does because, as i say i don't know more what
213	to say i don't know more what to do. I just break down and cry
214	sometimes Mr S or sometimes as i said i do stand an skel with her,
215	i don't know, i cant remember sometimes mr S, really things is
216	just, things is really just too much. Her behaviour with me is very
217	bad, because sometimes she doesn't understand me when i speak
218	to her. When i try and speak to her, as i said, then she screams at
219	you and that.
220	mmm, and then?
221	but then i keep quiet, because as ive said, i am mmm. She shouts at
222	you as if she wants to get hold at you, that is the thing mr S that i
223	don't know if... thats why i rather ma keep quiet because on

224	account the way, when she shouts at you or whatever.
225	mhhh, Ja neh...
226	When i heard the Doctors said to me, about her and her mental
227	illness, and things like that, uhm, there wasn't any thoughts that
228	came through my mind to maybe have a guilty feeling, of
229	anything. What hurt me was, i know she was the child that always
230	used to wake up in the morning when her daddy used to go on
231	with me. I could wake her up in the morning. And that actually
232	broke me down, thinking that uhm getting the age of 18, so it
233	made me thought of...
234	When her daddy does what?
235	when he was mos a alcoholic... and then he wake us up in the
236	night, wake me up in the night and wanted money for wine, and
237	things like that... but there was a time when i tried to put him out...
238	then he use to come and i put him up with the law and that... then
239	he use to come and bang on the doors or and than she was the
240	quickest one that i could wake up. So that made me also felt bad.
241	Did she maybe, did all that things maybe came together. As ive
242	said besides her childs father that kept her hostage also, so that, in
243	fact i, i spoke to the doctor and i said to him, that is what happened
244	if he said its like at the age of 18 already that she was diagnosed
245	with it. But its not to say that only at the age of 18, it was like
246	before that, but that was actually, according to Doctor, they find
247	out that it was actually like at 18 that it is that it really took over.
248	But as i said its not really that i feel guilty about it, the only guilt

249	that i feel is, the hurt and pain all that she went through, through
250	the years with her father and myself, with her daddy been drinking
251	and. She was the child, when we use to wait for the police van, and
252	things like that, and i in the one corner, she in the other corner, so i
253	feel that is all things that broke her down man, and that is actually
254	that hurts me, that, i always thinks of that things. And it hurts me
255	because i know shes not a child like that, she wasn't a child like
256	that. Shes a child, shes a very good child (Crying). Shes not what
257	she is today. And i can see shes not the child like she used to be
258	although i know shes here or there (crying)...
259	Take your time
260	Shes really not... shes not 100% like she used to be.
261	Take your time aunty.
262	Shes a very good child. She was a child that will do anything for
263	me. If she was in this house, this whole house would been the way
264	we wanted it to be. And especially when it comes to my youngest
265	daughter, she cant handle it, because she said mommy, as a young
266	girl, i thought M was my mommy, and as i got older, i realised that
267	she wasn't my mommy and i dint know how this break her down,
268	because this is the way she feels about her sister. And her children
269	is in such a state that they really want their mother like they
270	know.... she no more like she used to be... and its too much for me,
271	i cant handle it anymore thats the reason why i moved out of my
272	house. Think and hoping, she might think to really try and bring
273	herself together and somehow she will pull herself together, i don't

274	know... that is just my heart's desire that she will get herself
275	straight again (Crying) and hoping for the best for her. My other
276	sons, they also don't want to... not to say that they don't want to
277	help. The eldest son always helped, but because they also don't
278	know how to handle her. They try but they will just say, mommy
279	we don't know really what more to do or how to help her. The
280	reason why i move out of my house, thinking, because maybe she
281	will come to her senses, to realise that uhm, what is going to
282	happen to her, if something might happen to me one day. Meaning
283	that, if i must die, where is she going to, because she knows right
284	well, she goes to families to help, and they might help a night over
285	or what, but people don't take you in for nothing. And thats the
286	reason, and i, i myself personally had her grant taken off, because
287	she doesn't use it for anything also, that was also one of my things.
288	But i 100% hope to help her again, so that she can get her money
289	and get herself into a place, and things like that. But that is
290	actually the reason why, and i don't want her now to know where
291	im staying because, im not there to punish her, or whatever but,
292	just trying to see if that will help her, if she, uhm will come to her
293	senses, and she must take her medicine and get herself back on to
294	her feet again and whatever. But as i said, this time i can see
295	through the years that she has been at lentegeur, she definitely
296	doesn't look to me 100% now. She looks well and good but the
297	way she is speaking, i know how she is, is like her mind slips, and
298	she will speak about things over and over and over again, that is

299	what she is doing now. So im really looking, helping or asking
300	people to see where can i... i wouldn't like to see her go on the
301	road, but hoping and trusting there can be a place for her where
302	she can stay forever. That is my hearts cry out for her. It was too
303	much for me to see her suffering like that, that is why i made the
304	move to move to my daughter rather that she don't know where im
305	staying. She asked me that she wants to come to me, and i said i do
306	sleepin work, so she knows she cant come to me, but, the reason
307	why i moved is to get peace, peace for myself, that is actually the
308	main point.
309	Aunty, dankie. Is daar enige iets wat my antie vir my will vra of
310	by add?
311	There's not really anything, sometimes then you forget what you
312	want to say. But i think at this moment i feel a bit better and i want
313	to thank you also for having this conversation with me and your
314	concern actually about her also and im just hoping and hoping for
315	the best for her.
316	Baie dankie dat Aunty Joan deelgeneem het. As daar enige iets is
317	wat Antie Joan nog wil weet en onthou, u kan altyd my laat weet
318	en nog agterna vra. Ma baie dankie vir u deelname.

Key: Participant was very emotional during the interview.

- **Participant A:** Mother of the patient (Pink)
- **Researcher:** Black (W)
- **Patient:** M

APPENDIX G: VERIFICATION BY PROFESSIONAL EDITOR

HELEN ALLEN

**Accredited Professional Text Editor, SATI
Plain Language Practitioner**

**34 Heritage Village
Tzaneen 0850
Cell : 072 1966900
Home : 0877 509638
Email : helanallen11@gmail.com**

24 November 2015

VERIFICATION

TO WHOM IT MAY CONCERN

I am a professional text editor, accredited by the South African Translators' (and Editors) Institute (SATI), and a full member of the Professional Editors' Guild (PEG).

I wish to confirm that on 24 November 2015, I completed a linguistic edit of a Master's Thesis (full) by

Uwarren September

Titled

Experiences of family members caring for female patients with a
Co-morbid diagnosis of bipolar and substance abuse
Admitted in a psychiatric hospital in the Western Cape



H P Allen (Mrs)