

Masters Research Project

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**The experiences of daughters raised by a parent with
bipolar disorder**



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Abstract

This study seeks to explore the challenges and difficulties faced by children raised by a parent with bipolar disorder, with a specific focus on the experiences and memories of daughters of these individuals. Bipolar disorder, previously known as manic-depressive illness, is characteristically referred to as an episodic, yet lifelong and clinically severe affective (mood) disorder. Bipolar disorder is a severe mental illness, which is stressful not only for patients, but also for family members. Very little work has been done to define more precisely the family burden associated with the illness. Studies that do focus on the impact of bipolar disorder on caregivers or families of the patient have looked at the family as a whole. There seems to be a scarcity of research looking at the experiences of children of parents with bipolar disorder. The children of individuals with bipolar disorder are at high risk for developing a range of mental disorders. Overall, parents with bipolar disorder tend to create a familial environment that is unstable and lacking in structure. Therefore in addition to being at genetic risk for the development of mental disorders, are exposed to a stressful familial environment that increases the risk of psychopathology and difficulties. Despite the importance of assessing the impact parental bipolar disorder can have on children, there is a lack of relevant literature.

A non-probability sample of eight female individuals raised by a parent with bipolar disorder was selected from the student population at Wits University. Semi-structured face-to-face interviews were used to gain in depth information regarding the memories and experiences of these individuals. One interview was conducted per participant. Once the data was collected, thematic content analysis was used in order to analyse and draw conclusions from the data. From this method of analysis ten main themes were found, as well as six sub themes.

The findings of this study suggest that bipolar disorder has a profound effect, not only on the individual suffering from the illness, but on their children as well. Manic episodes appear to be a particularly stressful time, featuring with great prominence in the memories of respondents. Participants felt strongly that their family environment was affected by their parent's illness. In general it seemed as if participants with ill mothers described a far more chaotic family environment as compared to those participants with ill fathers. This study also found that knowledge and understanding help these individuals make sense of their parent's illness, seemingly providing a sense of power

and control. A number of participants mentioned the negative effects that stigma associated with mental illness has on the families concerned, often leading to adverse outcomes. In contrast to this, support and understanding by both healthcare professionals as well as the broader community is considered indispensable. The children of patients with bipolar disorder, in addition to being at genetic risk for the development of mental disorders, are exposed to a stressful environment that increases the risk of psychopathology and other difficulties. It is therefore imperative that further research be conducted in this area, as relatively little is known about the long term effects of the parent's illness on their child.

Declaration

This is a research project submitted in partial fulfillment of the requirements for the degree of BA Masters (Psychology) in the Faculty of Humanities, University of the Witwatersrand, Johannesburg, 11 November 2012.

I declare that this research project is my own, unaided work.

Raesah Valli

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Chapter 1: Introduction

Research Aims

This study aims to explore the experiences of daughters who were raised by a parent with bipolar disorder by focusing on:

- The emotional impact of being raised by a parent with bipolar disorder as narrated by participants
- Incidents or memories that stand out during the course of participants' parental illness (manic phases/ depressive phases/ normal mood phases)

This study will also aim to assess if parental gender has an effect on the experience of these individuals. A pilot study showed that caregiver burden is often greater for children when the mother is affected by the disorder as opposed to the father.

Research Rationale

This study is based on a questionnaire-based pilot study, which explored the experiences of individuals raised by a parent with bipolar disorder. The pilot study was limited by its methodology and as a result the richness of experiences could not be explored in depth. Also, findings of the pilot study suggested that there are significant differences in the experiences of individuals whose mothers were ill as opposed to those individuals whose fathers suffered from the condition. It appeared that individuals with an ill mother were more greatly burdened and adversely affected by their parents' illness. It is therefore fitting to explore this issue in more detail through the use of a comparative study. This study will focus on the experiences of the girl child alone and will exclude boy children, so as not to further complicate an already complex relationship. Psychoanalytic theory indicates that boys and girls relate differently to their mothers and fathers (Freud, 1925). A bipolar mother or father will therefore have a very different impact on their daughters versus their sons. Interviews rather than simply questionnaires should provide the opportunity to obtain more rich data and will also provide the opportunity to further explore issues that surface during the interview process.

Although much research has been done in the area of bipolar disorder and the way it presents in those suffering from it, research on the effects on children is limited (Oglevie, Morant and Goodwin, 2005). Bipolar disorder is a chronic illness, the symptoms of which can be very debilitating (Miklowitz & Johnson, 2009). For this reason, many individuals with the illness become very reliant on others for constant support and care. Caregivers are very often family members, like spouses, partners and children (Reinares, et al., 2006). According to Steele, et al (2009) research and interventions tailored towards the psychiatric needs of the children of bipolar parents may result in improved outcomes for both parent and child, as well as in decreased health care costs. Because of the severe and debilitating nature of the illness, bipolar disorder very often affects most aspects of a patient's life and by extension the lives of their families (Dore & Romans, 2001). Children however grow up experiencing their parent's illness often at very vulnerable periods of their development and the psychological impact of this can undoubtedly be profound.

Psychologists often encounter these individuals both during their childhood and as adults, as they have to deal with complex psychological sequelae (Ostiguy, et al., 2008). Psychologists need to understand these complications or even the possible development of frank disorders. A starting point to this understanding is to examine the experiences of such children. This would enable us to better manage these heavily burdened individuals and help make their lives more tolerable and fulfilling.

Chapter 2: Literature Review

2.1 Introduction

According to Oglevie, Morant and Goodwin (2005) bipolar disorder is a severe mental illness, which is stressful not only for patients, but also for their children. Very little work has been done to explore the experiences of family members associated with the illness. Bipolar disorder is a major cause of suffering for patients very often causing severe functional distress and impairment, because of this patients are very often forced to depend on others, often family members, for assistance (Miklowitz and Johnson, 2009). The burden that bipolar disorder indirectly imposes upon families is a matter of clinical concern for healthcare workers (Dore and Romans, 1999).

This study seeks to explore the challenges and difficulties faced by family members of bipolar patients, with a specific focus on the experiences and memories of the daughters of these individuals. In order to do this it is essential that one understands what bipolar disorder is, in terms of its presenting symptoms, prevalence and a etiology as well as how the disorder impairs the functioning of those suffering from it. This literature review will also look at the treatment of bipolar disorder while also looking at aspects like caregiver burden and the impact of mental illness on family relationships. Literature will then focus more specifically on children raised by a parent with bipolar disorder. Thereafter Psychoanalytic theory will be considered in terms of how it can offer explanations for how the experience of an ill parent in early life can affect a child's subsequent development. Existing research in this area will also be considered. This literature review concludes with an exploration of the existing research on the impact of the illness on children raised by a parent with bipolar disorder.

2.2 Understanding bipolar disorder

Bipolar disorder, previously known as manic-depressive illness, is characteristically referred to as an episodic, yet lifelong and clinically severe affective (mood) disorder (Pini, et al., 2005). As stated by Sadock and Sadock (2007) mood disorders are characterized by pervasive disturbance in mood and psychomotor activity as well as cognitive impairment. Also referred to as "affective disorders", Sadock and Sadock (2007) assert "mood disorders" is now the favoured term of the World Health

Organisation (WHO). Official mood disorder categories that are currently in use include major depressive and disorders bipolar disorders as well as their specific variants known as dysthymic and cyclothymic disorders respectively.

Bipolar disorder is characterized by several phenotypes of mood disorders including depression, mania, hypomania or cyclothymia that can present with a puzzling variety of other symptoms and disorders (Pini et al, 2005). According to Sadock and Sadock (2007) a depressive episode consists of a depressed mood or loss of interest or pleasure in daily activities consistently for at least a two week period along with other symptoms such as weight loss or weight gain; insomnia or hypersomnia; psychomotor agitation or retardation; fatigue; inability to concentrate and/ or loss of energy or recurrent thoughts of death or suicide. Manic episodes are characterized by a period of time (at least one week) of highly elevated, expansive or irritable mood. During manic episodes individuals generally display elevated self-esteem and grandiosity; inability to sleep; become increasingly talkative and agitated and may engage excessively in pleasure seeking behaviours. Manic episodes are seen as severe enough to cause marked distress or impairment in the sufferer (Sadock & Sadock, 2007). Hypomania on the other hand also refers to a distinct period of at least a few days of mild elevation of mood, sharpened and positive thinking and increased energy levels but does not include the impairment of mania (Sadock & Sadock, 2007).

Because of the diverse clinical features and courses of this disorder various clinical sub-diagnoses have been proposed. Bipolar I disorder and bipolar II disorders are seen as the best established of these proposed sub-groups (Baek, et al., 2010). A comprehensive clinical evaluation done by Baek et al. (2010) found significant differences in the clinical characteristics of bipolar-I and bipolar-II; therefore asserting that differential diagnosis of bipolar-I and bipolar-II is justified. As indicated by the Fourth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), the diagnostic classificatory system utilised in most epidemiological studies, both bipolar I disorder and bipolar II disorder are defined by a set of specific yet separate symptom criteria (Pini, et al., 2005).

A diagnosis of Bipolar disorder type I necessitates the presence or history of at least one manic or mixed episode. Bipolar I disorder can be diagnosed even if there is a presence

or history of only one manic episode and no past major depressive episodes are present. However, in most cases, individuals who experience one or more manic episodes also experience major depressive episodes (Pini, et al., 2005).

Bipolar disorder type II differs from bipolar type I by presence of hypomanic rather than manic episodes. Hypomanic episodes can be distinguished from manic episodes by a shorter duration (at least four days instead of one week), and less severe levels of impairment which is not severe enough to cause marked deficiency in social or occupational functioning, does not result in psychiatric hospitalization and does not include any psychotic features (Pini, et al., 2005).

The DSM-IV-TR also includes cyclothymia as a bipolar spectrum disorder with hypomanic as well as depressive episodes. However depressive episodes in cyclothymia do not meet the criteria for major depression (Pini, et al., 2005).

2.2.1 Prevalence

All affective disorders:

According to Oglevie, Morant and Goodwin (2005) the World Health Organization (WHO) identified mood disorders in its 1999 annual report as among the most common causes of morbidity and mortality in developed countries. In the Americas they were ranked as the most burdensome disorder, and in Europe as the third most burdensome. Epidemiologic estimates from studies done in Europe suggest that up to 1 million individuals with bipolar disorder live in the UK alone (Oglevie, Morant and Goodwin, 2005).

Bipolar disorder:

South African statistics with regards to prevalence of affective disorders including bipolar disorder are hard to come by as there is a lack of research in developing countries. A number of avenues were utilized in order to obtain statistics on prevalence in a South African context including the South African Depression and Anxiety Group as well as literature on mental illness in South Africa (Gagiano, 2001; cited in Robertson, Allwood & Gagiano, 2002), however no current prevalence rates are currently available. According

to Miklowitz and Johnson (2009), bipolar disorder is reported to affect about 2–4% of the United States population in its various syndromal and subsyndromal forms. However, another United States survey, that made use of the Mood Disorders Questionnaire, suggests that the prevalence of bipolar disorder may be higher than this estimate. The results of the community-based survey indicated that 3.7% of the 125 000 adults screened could likely be diagnosed with either bipolar I or bipolar II disorder (Oglevie, Morant and Goodwin, 2005).

2.2.2 Epidemiology

The epidemiology of bipolar disorders in European studies has been described with a significant degree of consistency across various study designs and countries (Miklowitz and Johnson, 2009). Evidence from community studies supported the clinical description of bipolar disorder as an episodic disorder that typically arises in early adulthood and has a mean age of onset estimated to be between the ages of 20 and 30 (Miklowitz and Johnson, 2009). There is fairly consistent evidence that bipolar I and bipolar II disorders, according to the criteria in the DSM-IV, have an estimated 12-month prevalence of approximately 1%. There is also no evidence of major differences across age groups and gender. This finding is consistent with other studies and reviews (Pini et al., 2005).

2.2.3 Etiology

Like other mood disorders the cause of bipolar disorder is strongly linked to genetics and heritability. This has been confirmed with the use of twin studies (Sadock & Sadock, 2007). Research has however also found evidence to suggest an environmental contribution (Sadock & Sadock, 2007). Findings suggest that many adults diagnosed with bipolar disorder report stressful or traumatic experiences in early childhood or adolescence (Sadock & Sadock, 2007). It is suggested that, as with other mood disorders, environmental factors often interact with genetic predispositions in the development of bipolar disorder (Sadock & Sadock, 2007).

2.2.4 Impairment of functioning

Bipolar disorder is a chronic and severe illness that constitutes the sixth leading cause of

disability amongst the physical and psychiatric disorders worldwide (Reinares, et al., 2006). Individuals suffering from bipolar disorder very often experience severe difficulties in occupational and cognitive functioning. In addition, bipolar patients presented lower rates of autonomy and fewer interpersonal relationships than individuals without bipolar disorder (Vázquez, et al., 2010). According to Vázquez et al. (2010) patients suffering from bipolar disorders have also reported difficulties with their jobs, and around 20% of them have permanent disability. Patients with bipolar often report fewer social interactions with their friends and family and lower interest or pleasure in their leisure activities.

Bipolar disorder can be seen as one of the most costly and debilitating of psychiatric disorders (Henin, et al., 2005). Henin et al. (2005) also indicate that comorbid substance abuse and very importantly suicide risk are other major concerns with regards to bipolar disorder.

A study by Vázquez et al. (2010) asserts that stigma regarding the illness may be associated with levels of poor functioning in bipolar disorder. As defined by this study stigma reflects people's responses to individuals who possess some undesirable or unusual characteristic. It may be expressed as mild intolerance, in ways that are more deeply discrediting, or through overtly prejudicial and discriminatory practices. According to this study higher scores of self-perceived stigma were correlated with lower scores of functioning (Vázquez et al., 2010).

Literature on the degree of impairment caused by bipolar disorder seems to be consistent (Miklowitz and Johnson, 2009). As indicated by Miklowitz and Johnson (2009), bipolar disorder is a highly recurrent, costly, and impairing illness leading to high rates of disability, comorbidity, medical problems, and suicide attempts or completions. The illness has broad-ranging effects on functioning during and between episodes, including impaired work performance, family distress, relationship dysfunction, and low life satisfaction.

2.3 Treatment of bipolar disorder

Guidelines for the treatment of bipolar disorder vary to some extent. Like other mood

disorders the primary form of treatment for bipolar disorder is medication (Barlow & Durand, 2009). According to American Psychiatric association guidelines five types of medication can be used in the treatment of bipolar disorder. These include: Mood stabilizers such as lithium, valproate and carbamazepine, anti-manic agents, antidepressant agents, adjunctive medications and newer atypical medications (Fountoulakisa, et al., 2005). Lithium is often considered the first choice of treatment in all phases of bipolar illness because of its effectiveness in the normalization of mood. Antidepressant medications, although effective in the treatment of bipolar depression, can actually worsen the overall course of bipolar disorder by promoting mania (Fountoulakisa et al., 2005). Bipolar disorder is a complex illness and as such the treatment of the illness is also complex. According to Sachs and Thase (2000) the treatment of bipolar disorder is often a life-long process and important maintenance phase treatment is an under researched area. Adherence to medication regimes is often a problem with bipolar patients. Discontinuing maintenance medications can lead to rapid recurrences of symptoms (Miklowitz, et al., 2004).

Psychoeducation, cognitive-behavioral therapy, and family focused treatment are other options that are said to be successful adjuncts to medications in improving the outcome of the illness (Miklowitz, et al., 2004). Family focused treatment, helps both the individual and their family gain an understanding of the illness, guidance on adherence to medication as well as assistance on how to manage daily stressors and create a familial environment that is conducive to long-term mood stability (Miklowitz et al., 2004). However this form of treatment is often greatly underutilized (Fountoulakisa et al., 2005).

2.4 Caregivers and caregiver burden

Caregivers are those who attend to or provide services to an individual in need, typically one suffering from chronic illness or disability (Steele, Maruyama & Galyner, 2010). As a consequence of deinstitutionalization, families became more actively involved in the care of the patient (Reinares et al., 2006). The effects of the family's attitudes on the patient's illness course have been complemented by research related to the impact of the illness on caregivers (Reinares et al., 2006).

According to Oglevie et al. (2005) caregiver burden can be described as the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patient's significant other(s), e.g. members of the household and/or the family, such as children. Significant others can also be considered to extend to include close and supportive friends. Whereas Reinares et al. (2006) defines caregiver burden as the consequences that living with an ill relative has on caregivers who are usually family members, including children.

2.5 Impact of living with a family member with bipolar disorder on family functioning

A number of studies have been done investigating how mental illness affects and impacts on family functioning. For example a study done by Miller, et al. (1986) found that families of patients with major depression, alcohol dependence, and adjustment disorder reported greater family dysfunction than a control group, however in the same study, families of schizophrenic and bipolar patients did not differ significantly from controls. However, Steele, Maruyama and Galynker (2009) argue that the nature of these studies may not always apply to the case of bipolar disorder because of its chronic, progressive but variable course. There is reason to believe that the experience for those close to patients with bipolar disorder could be very different from that of family members of patients with other mental illnesses (Steele, Maruyama & Galynker, 2009).

In a study done by Dore and Romans (1999) a sample of family members of patients with bipolar disorder were interviewed systematically in order to determine how this role affected them. In this study, family members reported experiencing substantial difficulties in their relationships with the patient when he or she was ill. These difficulties included significant impact on their own employment, finances and other social relationships and in certain instances had legal implications. Violence was a particular concern for family members of both male and female patients, particularly when the patient was manic. According to this study, the mental health of the caregivers involved appeared to be unaffected. Despite their difficulties, the families of individuals with bipolar disorder appeared emotionally committed to the patients and showed considerable tolerance of problematic behaviours. However, a meta-analysis by Steele, Maruyama & Galynker (2009) analyzed 24 papers and found that the majority of papers report the presence of

psychiatric symptoms in family members, such as depression, anxiety and increased mental health service use.

2.6 Children raised by a parent with bipolar disorder

Most studies that focus on the impact of bipolar disorder on the relatives of bipolar patients have looked at the family as a whole (Steele, Maruyama & Galynker, 2009). There are also a number of studies that have looked more specifically at the experiences of the spouse (Lewis, 1998; Fadden, Bebbington & Kuipers, 1987). There seems to be a scarcity of research looking at the experiences of children of parents with bipolar disorder. One study by Ostiguy, et al (2008) investigated levels of stress in the offspring of parents with bipolar disorder as compared to children of parents with no affective disorder. Those with parents with bipolar disorder reported more difficulties in interpersonal and non-interpersonal domains of chronic stress than controls. According to Ostiguy et al (2008) the offspring of parents with bipolar disorder are at high risk for developing a range of mental disorders, as well as other problems such as deviant behaviours and suicidality. Although heritability is an important issue in the etiology of bipolar disorder (McGuffin et al, 2003; Todd et al., 1996), environmental factors also contribute to the development of difficulties in these offspring.

Three recent studies (Bella et al., 2011; Rothen et al., 2009; Manpreet et al., 2007) looked at psychosocial functioning, personality traits and psychopathology in the adolescent children of bipolar parents. All three studies aimed to determine risk factors for bipolar disorder. Findings indicated that adolescent children of bipolar parents showed significantly higher levels of psychosocial impairment, neuroticism, psychoticism as well as Axis I disorders such as major depressive disorder and attention-deficit hyperactivity disorder than control groups.

A number of other studies focus solely on the likelihood of inheriting the disorder from a diagnosed parent (Henin et al., 2005; Singh et al., 2007). These studies tend to focus on biology and genetics and do not explore the lived experience of these individuals.

Overall, parents with bipolar disorder tend to create a familial environment that is unstable and lacking in structure (Romero et al., 2005). This suggests that the children of patients with bipolar disorder, in addition to being at genetic risk for the development

of mental disorders, are exposed to a stressful familial environment that increases the risk of psychopathology and developmental difficulties (Ostiguy et al., 2008).

2.7 Psychoanalytic theory

Psychoanalytic theory can offer explanations for how the experience of an ill parent in early life can affect a child's subsequent development. The object relations theories of Freud and Klein are particularly useful in this regard.

Freud's focus was on the importance of Oedipal issues, a triadic three-person conflict model between the child and both parents, which provides an explanation for intrapsychic functioning (Hook & Watts, 2002 as cited in Hook, Watts & Cockcroft, 2002). According to this theory psychosexual drives and the negotiation of the Oedipal complex influence the development of the personality, neurosis and the nature of the unconscious (Hook & Watts, 2002 as cited in Hook, Watts & Cockcroft, 2002).

Object relations theory, an important part of psychoanalytic theory stems from the theories of Freud (Greenberg & Mitchell, 1983). According to this theory, our psyches or internal world consist of mental representations of important people in our lives, most importantly our parents. These representations are known as internal objects. Object relations theory has been expanded on by a number of theorists such as Klein, Winnicott and Bion and all propose a number of different, and at times contradictory, ideas (Greenberg & Mitchell, 1983). However, some basic principles remain the same and these will be discussed below.

Object relational theories seem to agree that the infant's first relationship is with the primary object, the mother (Watts, 2002 as cited in Hook, Watts & Cockcroft, 2002). From birth the infant is able to relate to objects and actively seeks to form an exclusive relationship with the mother (Greenberg & Mitchell, 1983). The mother-infant dyad, also known as the pre-oedipal dyad, later extends to include a third, the father. It is through the internalization of these initial relationships and interactions that the infant develops her way of relating to other objects. Some aspects of this internalization will be conscious while other parts will remain unconscious (Greenberg & Mitchell, 1983).

According to Freud (1931) (as cited in Saguaro, 2000) male and female development and relationships with their parents in early life differ significantly. While the most important relationship in early infancy does seem to be the mother for both boys and girls in later development relationships with the mother and father change (Freud, 1931, as cited in Saguaro, 2000). The Oedipus complex plays out such that after a period of resistance boys begin to identify more strongly with the father whereas girls will eventually identify more strongly with their mother (Freud 1931, as cited in Saguaro, 2000). This has to be taken into account when looking at the relationship with a bipolar parent. There is likely to be a differential impact on boys and girls. Studies may need to consider the experience of boys and girls separately.

Psychoanalytic theory is relevant in that it proposes that early interactions with ones parents will influence how we relate to others and our world in later life. Therefore, having a mother or father who is ill during a child's early interactions may have serious implications for the infant's later development and object relating in adulthood.

2.8 Existing research in this area

Despite the importance of assessing the impact or burden of parental bipolar disorder on children, there is a lack of relevant literature. There also seems to be a lack of understanding on the specific effects of mania and inter-episodic symptoms, and no existing measures designed to assess this adequately. Measures exist to assess the caregiving burden of patients with depressive disorders, such as the Family Burden Questionnaire (Fadden, Bebbington, & Kuipers, 1987), and schizophrenia, such as the Family Distress Scale (Herz, Glazer & Mostert, 1991). However these may not be appropriate to capture the specific difficulties associated with the cyclical nature of bipolar disorder particularly the stress arising from manic episodes. A result of this situation is uncertainty regarding how best to structure family interventions in order to optimally alleviate caregiver burden (Oglevie et al., 2005).

Qualitative research is therefore a useful starting point. Rose (1998) has attempted to explore the perceptions of family members of bipolar individuals using qualitative methods. However this study again, focused on the family as a whole and was not

specific to bipolar disorder, including family members of individuals with schizophrenia in the sample.

Stern, et al. (2004) used the narrative approach in a study of family members of individuals with mental illness. They argue that the narrative form is a primary means of ordering, structuring, and communicating illness experiences, reflecting some of the processes that caregivers intend to master and understand. In their study they explored how caregivers articulate the consequences of a devastating experience and turn it into a meaningful event that can in some way be incorporated into the course of their own life.

According to Hinshaw (2010) qualitative material can help the next generation of investigators and clinicians address key developmental questions related to etiology, maintenance, prevention, and treatment of the important, fascinating, and devastating condition known as bipolar disorder. He feels that narrative accounts can convey to scholars and scientists a sense of the right questions to ask in future investigations of mechanisms, developmental course, and intervention; they can also inform policymakers of directions for key future initiatives related to bipolar disorder in particular and mental illness in general.

2.9 Theoretical Framework

The biopsychosocial model proposed by Engel (1977) considers illness within a framework of multiple systems and can therefore be seen as a systemic model. According to this framework illness must not only be looked at in terms of biological factors in terms of the biomedical model, but also in terms of the person, the family, the care-giver relationship and the social context. These elements are seen as interrelated where change in one level can affect the other levels, there is therefore continuous and mutual feedback across levels (Ross and Devereil, 2004). The biopsychosocial model also emphasises the role of the family system in the functioning of individuals. It refers to the holistic well being of the family system in terms of the physical, emotional, social, economic, cultural, and spiritual dimensions of the family (Pardeck & Yuen, 2001). By integrating systems theory and the biopsychosocial model one is able to identify and explore the experiences of the caregiver and family, from an interdisciplinary perspective, rather than adopting one single approach that may be flawed or limited in terms of its ability to explore the vital issues this study aims to investigate.

Chapter 3: Research Methodology

3.1 Research Questions

1. How do participants' narratives reflect their experience of being raised by a parent with bipolar disorder?
2. How, if at all, does parental gender impact on the experience of these individuals?

3.2 Research Design

Research for this study was conducted from a qualitative perspective as researchers emphasize the importance of qualitative investigation in this area (Hinshaw, 2010; Stern et al., 2004). Furthermore using narratives in order to explore the “life-stories” and specific life events; particularly around manic and depressive phases; of daughters raised by a parent with bipolar disorder lends itself to a qualitative perspective (Stern et al., 2004). Focusing on specific life events provided insight into the experience and impact of symptoms specific to bipolar disorder such as manic episodes, which many studies have failed to do in the past (Miller et al., 1986). Qualitative methods also provided deeper descriptions and explanations of how these women make sense of the world and their experiences of particular events (Coyle, 2007).

Adult participants were used for this study rather than dependent children/daughters because as a sample they are less vulnerable. Adults were also able to give a retrospective view of their parent's illness and narrate the story of how they grew up under these circumstances in a more eloquent way. Even though adult children/daughters are a less vulnerable population than younger, dependent children/daughters they are still a potentially vulnerable population. The subject matter that was dealt with in this study did raise issues of a sensitive nature. These participants may have, for example, felt emotionally overwhelmed when experiences they had as a child of a bipolar parent are recalled or recollected. If in the unlikely event that any difficulties did arise, participants would have been referred to the Emthonjeni Community Psychology Clinic and were provided with the contact details for Lifeline as both are free counseling services.

3.3 Sample

The sample for this study consisted of eight volunteers. Four of the potential participants were known to the researcher and were asked if they would be willing to participate in the research. The other four potential participants were sourced from the student population at Wits University School of Humanities. A non-probability purposive sampling strategy was used, as only daughters raised by a parent with bipolar disorder were invited to participate in the study. This was in order to keep the sample more homogenous. Notices inviting students to participate in the study were put up on department notice boards. Due to the fact that this is a comparative study attempts were made to include equal numbers of daughters with ill mothers and fathers (four participants with a diagnosed mother and four participants with a diagnosed father), however only three individuals with ill mothers came forward to participate in the study.

Adult children of parents with bipolar disorder were used for this study rather than younger dependent children, who can be considered a more vulnerable sample. Adult participants were also more likely to have experienced a greater variety of their parent's mood symptoms and therefore have a greater range of memories to draw on. All participants were over the age of 18 for ethical reasons. Adult children were also more likely to have had sufficient experience of the symptoms of the illness and are therefore more likely to have memories of both manic and depressive episodes. The sample attempted to be inclusive in terms of race in order to obtain a greater variety of perspectives, adding to the richness of the data.

Only participants who have parents who were diagnosed with bipolar type I disorder and whom a psychiatrist had diagnosed were included in this study. This was to ensure that the parents of participants were not suffering from misdiagnosed schizophrenia or a personality disorder that would confound findings. Bipolar type II and other types of bipolar disorder are often confounded by personality disorders (Mahali, Changappa, Gerson & Goldberg, 2010).

For ethical reasons participants should not have suffered from bipolar disorder themselves. In pre-interview discussion potential participants were asked whether they had suffered from bipolar disorder themselves. None of the subjects had.

Due to the fact that the interview questions were open-ended and attempted to explore the “life-stories” of participants, a large amount of information was collected from each participant. Qualitative research aims to gather rich and textured data and does not aim at generalizability (Zhang & Wildemuth, 2009). Therefore, a sample size of eight was sufficient to ensure that data is rich and contains a large amount of depth so that valid conclusions could be drawn.

3.3.1 Sampling method

The researcher explained the research area to potential participants and they were then invited to participate in this study. The four potential participants that were approached by the researcher agreed to participate in the study. Five potential subjects from the student population at Wits University contacted the researcher. Four of these five potential participants met the criteria for participation and agreed to take part in the study.

3.3.2 Daughters of parents with bipolar disorder

Of the eight participants who took part in the study, all were women who were raised by a parent with bipolar disorder. All participants were over the age of 18. None of the eight participants have been diagnosed with bipolar disorder themselves. Three of the participants were Indian, four of the participants were white and one participant was coloured.

3.3.3 Parents diagnosed with bipolar disorder

All participants’ parents have been diagnosed with bipolar I disorder by a psychiatrist. All participants’ parents have had some form of treatment at some point although they may not have adhered to this treatment for an extended amount of time. Five of the participants had a father with bipolar disorder and three had a mother with bipolar disorder. The nature of the sample is problematic as more participants with an ill father were included in the study as compared to participants with an ill mother. This could not be avoided as only five potential participants responded to the notices inviting students to participate in the study and only four potential participants were known by the researcher. The sample is also not fully inclusive in terms of racial demographics as no

black participants took part in the study.

3.4 Instruments

Open-ended questionnaires were used in order to gain in-depth information regarding individuals' experiences of their parents' illness. This method aimed to gain information that was rich in nature (Mack & Macqueen, 2005). An interview guide was created in order to ensure that all areas are sufficiently explored. The interview guide consisted of four main questions and ten probes. Probes were only be used to gain additional information when necessary. These questions were developed based on findings from the questionnaire-based pilot study, through exploring literature in the area of bipolar disorder and family experiences of mental illness and in consultation with the research supervisor. The interview aimed to explore individuals' memories and feelings around their parents' illness in an attempt to establish "life-stories" of the participants as well as ask participants to consider how their lives would have been different if it was their other parent who was ill instead.

3.5 Procedures and data collection

Each participant was asked to complete a 30-minute interview conducted by the researcher. Interviews consisted of four open-ended questions and ten probes (Hollway & Jefferson, 2000). A qualitative research interview was chosen as an instrument in order to allow each participant to engage in a narrative of her "life-story" and experience with her parent's illness. An interview guide was created in order to ensure that the aims of this study were sufficiently explored.

Interviews were conducted at places where the participant was most comfortable and at a time that was mutually suitable. Once participants understood the aims and procedure of the study written consent was obtained. With the permission of the participant interviews were audio-taped and transcribed for accuracy of analysis and presentation of results.

3.6 Data Analysis

The type of data analysis employed in this study is thematic content analysis. According to Braun and Clarke (2006) Thematic analysis is an adaptable research tool that can provide rich accounts of data. Thematic analysis is used to identify, analyse and report central patterns and themes that are found in the data (Braun & Clarke, 2006). Themes capture important aspects of the data that relate to the research question and represent patterned responses contained in the data set. Various themes arose from the data, which were analysed (Braun & Clarke, 2006). Interpretive phenomenological analysis (IPA) is another qualitative research tool that was used to analyse data. Interpretive phenomenological analysis allows for the exploration of the individual's lived experience and is as such highly appropriate to this study. IPA investigates the way in which individuals make sense of their life experiences and the meanings they place on them (Smith & Eatough, 2007). According to Smith and Eatough (2007) IPA is also well suited to smaller sample sizes as greater emphasis is placed on each individual case.

The stages of analysis are summarised as follows:

“ (a) several close and detailed readings of the data to obtain a holistic perspective so that future interpretations remained grounded within the participant's accounts; (b) initial themes were identified and organized into clusters and checked against the data; (c) themes were then refined, condensed and examined for connections between them; (d) a narrative account of the interplay between the interpretive activity of the researcher and the participant's account of their experiences in their own words was produced.” (Smith & Osborn, 2003 as cited in Smith & Eatough, 2007, p.45).

Interpretation of findings also involved the interpretation of results using a psychoanalytic theoretical perspective. This serves to add further meaning to the findings stemming from the thematic content analysis by providing possible explanations for the results.

3.7 Reflexivity

Reflexivity is a very important consideration in qualitative research. This is due to the fact that the researcher is seen as the main instrument of analysis in this method

(Hollway & Jefferson, 2000). The characteristics and expectations of the researcher may therefore influence the interpretation of the data (Finlay & Gough, 2003).

As a psychology student, familiar with the debilitating nature of mental illness, I may have had certain expectations about my findings that could have lead me to overstate certain perceptions when they might not have been present.

As a researcher I therefore need to understand that my research may not be entirely objective in nature and that my active role in the research process can contribute to the depth and quality of my data, findings and conclusions reached. Throughout the research process the researcher kept a journal in which feelings and thoughts about the research interviews, as well as any feelings or thoughts that arose while writing up the report, were recorded. This allowed the researcher to reflect on personal thoughts and to determine the impact that these thoughts may have had on the research project.

Another important consideration in this regard is the effect this research may have had on the participants. The subject matter being dealt with in this study is of a sensitive nature. For this reason it was essential that all ethical guidelines were followed.

3.8 Ethical Considerations

All participants involved in the study were adequately informed as to what the study entailed. Informed consent was obtained through signed consent forms. This study explores experiences of a sensitive nature and participation may have given rise to emotional vulnerability. As a registered student in clinical psychology I am being trained to deal with these situations and would have been able to deal with any arising emotionality respectfully and sensitively. If any difficulties did arise, participants would have been referred to the Emthonjeni Community Psychology Clinic and were also provided with the contact details for Lifeline as both are free counseling services. None of the participants felt that they needed to make use of these services. Although participants are known by the researcher all information obtained from interviews is and will remain confidential. All participants were free to withdraw from the study at any time. A summary of results will be provided to all participants who are interested. Ethical clearance was obtained from the Human Research Ethics Committee, School of Human

& Community Development (protocol number: MCLIN/12/0101H) on 27/03/12. Ethics clearance is valid until 31 December 2014.

3.9 Credibility, transferability and dependability

The quality and value of qualitative research concepts such as credibility, transferability and dependability should be upheld. Credibility involves establishing that the results of the research are credible and believable (Trochim, 2006). Credibility is usually concerned with the perspectives of the participants in the research, as one of the main purposes of qualitative methods is to describe or understand phenomena from the perspective of the participants (Trochim, 2006). Participants will therefore have access to the research project when it is completed and marked and their opinions and criticism will be taken into consideration.

Transferability refers to the degree to which the results of qualitative research can be generalized to other contexts or settings (Trochim, 2006). Transferability can be enhanced if the researcher effectively describes the research context and assumptions that were central to the research (Trochim, 2006). Material from the literature review describes and explores the assumptions that the research is based on.

Dependability involves the need for the researcher to account for the changing context in which the research takes place (Trochim, 2006). The researcher should describe the changes that occur in the research setting and how these changes affected the way the researcher approached the study (Trochim, 2006). Through the use of a journal the researcher documented thoughts and feelings towards the research as well as made any notes with regards to changes in the context of the study in a way that enhanced dependability of the study and results.

3.10 Conclusion

In conclusion, a qualitative study design, with with semi-structured interviews was used in order to explore the experiences of daughters raised by a parent with bipolar disorder, by looking at their memories and considering effect their parent's illness had on them and consider how they feel their lives would have been different if it was their other

parent who was ill instead. This study design was chosen as it effectively gains in depth information from the participants in an ethical way. As a researcher I am aware that my subjectivities have influenced the results of the study. Through the use of reflexivity I hoped to use subjectivity as a means of enhancing the uniqueness and depth of this study. In addition I continuously considered aspects such as transferability, dependability and credibility to ensure rigour in the quality of this research project.

Chapter 4: Results and Discussion

4.1 Introduction

In order to analyse and draw conclusions from the data, thematic content analysis was used. Steps outlined by Braun and Clarke (2006) were followed and as such ten themes and six subthemes were identified. These themes will be briefly outlined, beginning with the effect of the parent's illness, the prominence of the manic episode stands out here as a notable sub-theme as well as memories of parents' depressive episodes and the description of normal mood phases as short-lived and fragile. Following this, the instability of the family environment, as described by participants will be discussed as they relate to literature gathered on the nature of bipolar disorder.

Most participants narrated their experiences of family relationships or family dynamics when the onset of parental illness. The role of the other parent draws an interesting comparison. Participants with ill fathers tend to idealise the role of their mother whereas those participants with ill mothers tend to see their fathers as absent.

Most participants also discuss sibling dynamics. Both the gender of siblings as well as the birth order of siblings arose as important subthemes in this regard.

All participants discuss the relationship between themselves and their ill parent throughout the interview. In light of this relationship and the experience of their parents' illness participants reflect on how they perceive themselves as a daughter raised by a parent with bipolar disorder. The role of treatment and the importance of knowledge about bipolar disorder also seem to play a very central role in the lives of both the participants as well as their parents. Participants also discuss the negative effects of being stigmatised on the well being of both themselves and their parents and narrated the instrumental role of outside support.

This chapter will discuss these themes by drawing on the literature and the previous research discussed in chapter one in order to make sense of and highlight the meanings behind the themes found in this study.

4.2 The experience of living with an ill parent

All eight participants described growing up with a parent with bipolar disorder as a difficult experience. The level to which this difficulty was expressed seemed to vary a lot

between participants. Overall participants with ill mothers described a greater degree of difficulty as compared to participants with ill fathers:

“It was horrendous! Ya, it was really, really tough” (participant 1)

“It was very difficult. There are times when I feel very angry about the whole situation” (participant 2)

While participants with ill fathers also indicated that their experience of growing up was difficult, this difficulty was described to a somewhat less extreme extent:

“It was an experience that I would say was difficult at times but I don’t really see it as something that was completely devastating” (participant 7)

Participants involved in the study describe, in detail, memories of different moments during their parents’ illness. It is extremely interesting to see what these memories tell us about bipolar disorder as well as consider why these memories prove significant for the participants themselves. This memory describes when a respondent remembers first realizing that something was wrong with her father:

“I came home once and heard my uncle and mother talking about when my father will get discharged from the hospital, I was wondering why he was in the hospital. Apparently he started arguing with the doctors at the hospital and so they admitted him. I didn’t really understand it” (participant 8)

In the above case the respondent was very young and did not understand why her father was in the hospital, she was not told but instead over-heard adults talking about it. It is possible that this memory stands out for the participant because it was the first time that she was made aware of the seriousness of her father’s illness.

4.2.1 Significance of the manic episode

Despite differences in the degree of difficulty expressed between the two groups, all participants seemed to view manic phases as particularly distressing times. The manic episode seems to feature with great prominence throughout all participants’ accounts of

their parent's illness. Manic episodes are described in a lot of detail by all participants and appear to be a very stressful time for the family as a whole.

"I used to really fear the impulsive behaviour in the manic phase the most" (participant 2)

All eight respondents mentioned that the emotions of the parent suffering from bipolar disorder were amplified during this time. Many participants also described their parents as being irritable, easily agitated and short tempered:

"When manic he'd be very likely to lash out" (participant 4)

Other conditions described by the respondents included the high level of energy and the reluctance to sleep during the manic phase of the illness. These behaviours are all outlined as typical symptoms of mania in the work of Kaplan and Sadock (2000). One participant had the following to say about her mother's behaviour during a manic episode:

"She hardly slept at night and was always busy but not doing anything constructive" (participant 2)

Another participant described her mother's manic behaviour as follows:

"When she was high, that how I say it on the high side she became very, very overactive and she'd do things that was out of the extraordinary in terms of like...you know she'd have so much of energy and she had to obviously use this energy so she'd be visiting people, she'd be baking, she'd be cooking she's be making achar and handing it out to everybody because she had so much of energy" (participant 3)

Some participants describe their parent's creativity during manic phases and spoke about how their parents often seemed over stimulated in terms of ideas and innovations, writing poetry at times and engaging in unrealistic business ventures the next. Kaplan and Sadock (2000) describe this sudden onset of creativity that can occur in the manic phase:

“His creativity is definitely enhanced as he begins writing poetry, very good poetry, I might add” (participant 6)

Kaplan and Sadock (2000) describe behaviour during the manic phase as erratic and strange, at times including unusual grooming behaviour:

“My mother would become totally obsessed with looking at herself in the mirror, either brushing her hair into different styles, applying make-up or loads of perfume” (participant 2)

Some participants describe how talkative their parents become during the manic phase; descriptions include how a parent who is usually reserved and quiet suddenly became very loud and talkative (Cassidy, Forest, Murry & Carroll, 1998). During a manic episode the parent is usually very distractible and inattentive:

“He speaks more than he listens during the manic phase” (participant 6)

A highly noticeable feature of the manic episode that stands out in the recollections of all respondents are their parent’s *“spending sprees”* during manic episodes. Uninhibited buying sprees and irresponsible and behaviour with money are characteristic of mania (Cassidy, Forest, Murry & Carroll, 1998). Many participants describe their parents’ reckless spending. During these times the manic parent would spend a lot of money without thinking; buying lots of items, including gifts for the family:

“He would do things, like, go out and buy six leather jackets and for no particular reason... he would go and open bank accounts for all of us for about R30 000.00 and I was about eight” (participant 5)

This reckless and irresponsible behaviour with money would undoubtedly result in financial strain, putting the entire family under stress. Participant 6 also indicated that her father impulsively spent savings, bonds and pension funds, leaving the family in debt that they could not pay. Participant 8 indicates that her father used to impulsively buy cars:

“He would buy cars when he had no money. He would fall ill and go buy cars! He would borrow money so we were owing money” (participant 8)

Interestingly, another participant also indicated that her father would buy cars and bikes when manic, leaving the family in debt:

“Incidents that stand out during the manic phases are always the irresponsible behaviour with money. He spends money usually on bad deals on motorcars and bikes. This money is sometimes accumulated cash or very often loans, which my mother in some way makes sure it is repaid” (participant 6)

She goes on to say:

“My father’s sudden resignation from his well-paid job, his reckless spending of his pension fund and my mother’s home industry as a result” (participant 6)

Her father’s impulsive and irrational behaviour during a manic episode resulted in him spending irresponsibly, losing money and quitting his job (Cassidy, Forest, Murry & Carroll, 1998). By not working these parents undoubtedly place a financial burden on their families in addition to the other difficulties that they have to deal with as a result of the illness.

During a manic episode individuals can become extremely friendly and sociable (Kaplan & Sadock, 2000), at times forming relationships with anyone and everyone:

“My father wanted to entertain and invited lots of guests to our small house they all came, but when he was in a depressive episode the same friends were nowhere to be seen” (participant 8)

“He makes a lot of strange friends-usually shady characters that one would not necessarily trust during his manic states” (participant 6)

Reckless and sometimes dangerous behaviour is also a distressing feature of mania. As indicated by Kaplan and Sadock (2000) during the manic phase individuals can become aggressive:

“My father becomes a hazard on the road with his high speed reckless driving” (participant 6)

Another participant described her mother as becoming quite stubborn and single minded during manic episodes:

“And then also, like with her, once she I don’t know what sort of idea came into her head when she was like in the high where we’d just have to let her do it, you know she just became difficult like I said, if she decided she wants to go on holiday then that was it she’d go on holiday!” (Participant 3)

In contrast one participant described how manic phases often felt like happy times:

“You know the manic phases, I’m just thinking about that it was just really great just really happy. It was just wonderful when she was in those phases. I remember she would often go on spending sprees and that was cool because often we would get stuff (laughs). It was just a sense of fun” (participant 1)

However this participant goes on to describe how these happy times were short-lived and that her mother would eventually become quite irritable and aggressive when manic.

This participant’s response illustrates how disruptive a parent’s mania can be on the entire family with the description of a vivid memory:

“I remember once he took us to Fordsburg and he decided that he wanted to move to Johannesburg. He bought a flat in town and we stayed there for 6 months. He wanted to buy a business in Johannesburg and so he uprooted the family. We didn’t realise at the time that it was the illness” (participant 8)

This childhood memory clearly illustrated how a parent having bipolar disorder can disrupt and destabilize the entire family unit in a very extreme way, especially if it is not understood. Romero et al. (2005) states that parents with bipolar disorder can create a familial environment that is unstable, unpredictable and lacking in structure.

4.2.2 Depressive episodes

Most participants describe depressive episodes less frequently and in less detail than manic episodes. According to participants' descriptions of their parents' behaviour, depressive episodes are often considered the exact opposite of manic episodes. Parents are said to lack energy, be very quiet, very down, disorientated and have little interest in anything including socializing with friends and family:

"...in the lower end then it was also very bad in terms of, she wouldn't be interested in doing anything" (participant 3)

"I mean, I remember that sort of in his depressive state he's quite sort of withdrawn and ja... So when he was in the depressive state you know, it would just be him and me and my mom and he would be reluctant to sort of engage in other activities or go out" (participant 4)

A number of participants stated that their parents slept excessively during depressive phases and sometimes wouldn't get out of bed for days. These symptoms are typical of major depressive episodes (Kaplan & Sadock, 2000):

"...he used to come home and shut himself away in the bedroom. He used to shut himself in the bedroom a lot...it happened often where he would agree to do something like for instance agree to go to a party or go out and at the last minute change his mind and he would lock himself away and nobody could get to him" (participant 5)

As is the case with manic episodes, participants consider depressive episode very distressing. A participant described how emotional lows would lead to crying episodes, where her father would claim that he was useless and had no reason to live:

"During the depressive state he feels worthless, unable to make himself or anyone happy and he sleeps a lot and avoids regular socializing. Although he never spoke directly to me about ending his life, I would see my father cry about having no reason to live" (participant 6)

Another participant described her father's depression as follows:

"We didn't like him when he was depressed, he wouldn't talk, he would get up at night and then sleep a lot, he didn't worry about himself when he was depressed" (participant 8)

Participant 2 discusses how she feared her mother's behaviour in manic episodes more than in depressive episodes until she was told that the depressive phase is more dangerous as it could lead to suicide. This concern is confirmed by Balázs et al. (2004) who assert that risk for suicide is particularly high during major depressive episodes. Fear of a parent committing suicide undoubtedly causes stress for their children, increasing the burden placed on them (Reinares et al, 2006).

It seems that during depressive episodes parents tend to isolate themselves from their families. This may explain why these episodes are described less frequently and in less detail than manic phases as participants have fewer memories of their parents when they were depressed. However, one participant focuses far more on her father's depressive states in her discussion of his illness. This may be because her father experienced more depressive episodes during her childhood than manic episodes. She describes a particularly distressing memory:

"My dad disappeared for hours and we didn't know where he was. He returned hours later, totally disorientated, covered in leaves and twigs. When questioned, his response was that he felt utterly useless. This was very traumatic for our entire family" (participant 7)

This participant goes on to say that she felt responsible for a particular incident as she had an argument with her father a while before it happened. In another incident the participant describes seeing her father cry and become very emotional. This may have been distressing to witness.

Another participant describes a memory of when her father fell into a depressive state:

"Once we were on holiday and there was a car accident and the car was smashed, he suddenly became very quiet and then became depressed" (participant 8)

From this we can clearly see how a stressful situation for the parent can serve as a trigger for either depressive or manic episodes. The etiology of depression as outlined by Kaplan and Sadock (2000) does indicate that stressful life events can trigger both manic and depressive episodes.

4.2.3 The fragility and instability of normal mood phases

Few participants referred to normal mood phases during the interview and had to be prompted in order to describe these periods of their parent's illness. One participant said of her father:

"...you know during normal mood phases he was really just dad!"
(Participant 7)

Two other participants describe normal mood phases positively but both went on to say that they always felt as if these periods would not last:

"...there was also just this feeling of waiting for the crash, this feeling like the happiness would never last" (participant 1)

"There would be days when he would throw us around in the pool and you like, stuff that you would, it was just a good memory you know it would be holiday and you would be fine but it was so quick to shift that there was always a sense even if it was a normal stage you would be a little worried" (participant 5)

It seems that participants' memories of their parents' manic and depressive phases are far more prominent than normal mood phases, which were seen as short lived. Interestingly two participants said that they felt as if normal mood phases would not last long but none of the participants mentioned feeling this way about manic or depressive phases.

In terms of symptomology all participants describe the experience of their parent's illness in a very similar way. Both mothers and fathers with bipolar disorder seem to behave in similar ways with regards to their daughters' memories and descriptions of manic and depressive episodes. Few participants described normal mood phases. However, those that did describe these phases indicated that they always felt as if these more stable periods would never last for very long and would soon be taken over by manic or

depressive phases. What seems to differ between the two groups of participants is the extent to which their parent's illness was experienced as difficult for them. In light of their responses daughters of mothers with bipolar disorder seem to feel that the process of growing up was far more difficult as compared to daughters of fathers with the same illness.

4.3 The unstable family environment

Many participants indicated that their parent's illness resulted in a home environment that was unstable and at times very unpredictable. Interestingly, many participants with ill fathers indicated that they were unaware of and somewhat less affected by their father's illness until they were older. This is in contrast to daughters of bipolar mothers who seemed have been aware that their mothers were ill for as far back as they can remember. One participant who has a mother with bipolar disorder describes her family life as follows:

"...every up the whole family went up. So we were all manic living on cloud nine and then every downer it felt like the whole family was in a depression now. It was just completely crazy...going from periods of absolute enmeshment, no space for me to have my own feelings, my own thoughts to periods of complete disconnect...That was the level of instability and yoh, it was just really crazy and it was really difficult. She was...ya. It's just really hard to speak to and ya just putting it into words...it was just a crazy space and ya. It was just ups and downs...It was real and extremes and with her..." (participant 1)

This participant felt as if her entire childhood was overcome by her mother's illness. She describes the mood of the entire family being predicted by her mother's ups and downs and indicates that there were real extremes in terms of how the family related to each other from one mood phase to the next. She describes her family life as a "crazy space".

Participants with ill fathers described an upbringing characterised by similar instability but a number of these participants indicated that they were unaware of their father's illness when they were young:

“...we thought we had a very normal childhood...And also he was very unstable so you never really knew where you stood. You know he could be in a good mood he could be in a bad mood and it was difficult to figure out what this day was gonna bring and it was also very difficult depending on the time you know he might walk into the house in a good mood and then everything would shift. So ja, it was a tough time” (participant 5)

“And if I sort of look back on my childhood, I don’t remember my dad being around a lot, he was out of house quite a lot, he use to, you know like leave at 7 in the morning and come back home at a about 6 or so. I don’t really remember having that much interaction with him” (participant 4)

From participants responses it seems that those with ill fathers felt that they were more protected and shielded from being exposed to their parents’ illness:

“To be honest it didn’t really affect us, especially when we were young” (participant 8)

On the other hand participants with ill mothers describe a childhood and family environment that was very much dominated by their mother’s illness and did not indicate being shielded from this in any way.

4.4 The role of the healthy parent

All participants made some mention of their other parent during the interview. What was clearly evident was the contrast between the two groups. Those with ill fathers seem to idealise their mothers who appear to have played a central role in keeping the family as contained and stable as possible while those with ill mothers indicate that their fathers were either absent leaving them to care for their ill mothers or alternatively cared for their ill spouse whilst failing to support and care for their children.

4.4.1 The idealised mother

The majority of participants with ill fathers indicated that their mothers played a central role in their fathers' care and served to protect them from being adversely affected by his illness during their childhoods. A number of these participants stated that they were not aware that their fathers were ill while they were growing up as their mothers kept this information from them. These participants seem to feel that this was a good thing and expressed gratitude towards their mothers for "hiding" their fathers' illness from them by trying to keep family life as "normal" as possible:

"My mother hid it from us quite well, I have to say I am very grateful for her...she was the primary caregiver and the primary support through all of his illness. Definitely my mom...So coming from an external point of view people would often say to me your mum had to deal with a lot, you know that sort of thing" (participant 5)

"I never actually knew he was bipolar until I was about 15,16 years old" (participant 4)

"My mum tried her best to keep things as normal as possible for us all and she really did a good job, it was difficult for her too" (participant 8)

This participant goes on to say:

"My mother looked after my father and she had a lot of patience...I think my mother tried to keep things the same for us as much as she could" (participant 8)

One participant in particular seems to idealise her mother to a very great extent and is quite defensive of her claiming that while outsiders may have seen her as domineering she was an amazing caregiver who served to protect her children while still seeing to the healthcare of her husband and keeping the family together despite difficulty:

"My mother tried in every way possible to keep the family stability and "protect" myself and my younger siblings during our formative years...she has always been in the best place to notice changes in

my dad's behavior, help keep track of how effective the medicines were, she learnt the warning signs of like when he would relapse and stuff and she just made the environment we lived in as supportive, easy and free of stress as she possibly could...my mother was really protective of us and took on a huge amount in caring for my father" (participant 6)

This participant made mention of the relationship between her ill father and her mother. A number of studies have looked more specifically at the experiences of the spouse (Lewis, 1998; Fadden, Bebbington & Kuipers, 1987). Although the limitations of this sample do not allow for generalization, it seems as though the wives of ill husbands play a far more central role in their spouses' care and their family's support than the husbands of ill wives. Multiple participants describe their mother as being instrumental in caring for their ill father while still doing her best to protect her children from the effects of the illness:

"In both manic and depressive states my mother becomes his chief enemy because she is the only one who fully understands...and alerts the necessary health care givers. Their constant arguments, people looking at my mother as a dominant, bullying character in our household where in fact she has always been in the best place to notice changes in my dad's behavior, help keep track of how effective the medicines were, she learnt the warning signs of like when he would relapse and stuff and she just made the living environment as supportive, easy and stress-free as she possibly could" (participant 6)

This participant feels that the person most adversely affected by her father's illness is her mother. She states that it is her mother's strong character that has kept their family together. During her father's normal mood phases her parents have a loving, understanding relationship. Another respondent also describes her mother as being very patient and never complaining when the respondent's father was ill.

4.4.2 The absent father

On the other hand the participants with ill mothers indicated that their fathers failed to provide the same function. The daughters of mothers with bipolar disorder who participated in this study indicated that their fathers were largely absent and unavailable to care for them. Two of these participants indicated that their fathers did not take part in the care of their mothers and that this responsibility was left largely up to them, the child:

“My sisters and I would have to take over the running of the household as our dad was always busy or out of town” (participant 2)

“You see why it was difficult not only from her side, it was also difficult in terms of my father and my brothers, you, they didn’t actually accept or they did feel like you know what she was actually going through that, so initially it was very difficult” (participant 3)

The other participant indicated that while her father did play a role in her mother’s care she often felt as if he did this in a way that was to the detriment of herself and her sister, protecting her mother whilst ignoring the impact of her illness on the rest of the family:

“And my dad, I think that my dad is also a huge big problem with growing up with a bipolar parent because his way of handling it is to tell me, “I think you need to go home now, look at the time, it’s time to go” so we’re going to avoid everything. So there’s the sense that dad’s way of protecting us from the mother has never been to protect us or say back off that’s uncool, it’s to keep the mother happy...And I think a lot of it is anger towards him as well” (participant 1)

4.5 Perceptions of the outcome of the self

Whether stated directly or indirectly, all participants reported some emotional impact resulting from their parent’s illness. One participant indicated that she felt sad, helpless and grew up feeling insecure, reporting that she felt as if there was nothing that she could do to help her father. She also reported having to be very careful throughout her

childhood as she was constantly worried that she would do something to make her father fall ill:

“Well it really made me feel very insecure, like you just never knew what could happen next! It also made me feel helpless; there was absolutely nothing I could do to change the behaviour or to control it in any way at all... I always had to tread really carefully”
(participant 7)

Another participant indicated that she tends to attract unbalanced, volatile people into her life now, as an adult. She attributes this to being raised by an unbalanced, volatile mother:

“So I really have a tendency towards attracting people like her into my life so like extremely unbalanced friends, friends who in retrospect I can see the pathology in. So it was like not only this pattern of relating at home but this pattern of relating that followed me into my other relationships. And these extremely volatile really bad, really good but there’s never a balance” (participant 1)

A number of participants reported that they developed certain characteristics as a result of growing up with a parent with bipolar disorder and are affected by this in their adult lives:

“So I think I am very sensitive, you sort of grow up like that because, I had to sort of just do it myself... I am getting older I am sort of having like I would not say having problems. As I got older I started questioning more you know initially I think when you young you just accept it and you do your thing but I think as you get older you sit and you think about it and you question them so I think sometimes when I am having a little bit of difficulties in my life or issues I sort of always, maybe blaming that, maybe it was because of that, this is why I am sort of reacting or doing things in a certain way” (participant 3)

This respondent feels that she developed into a timid and reserved young individual partly because of her father’s illness:

*“I was an extremely timid and reserved young individual partly because of my inherent nature as well as childhood experiences”
(participant 6)*

She stresses the importance of the child, or any other caregiver, caring for his or her own emotional health as well. Asserting that while providing support for your ill loved on is important as he or she cannot take on full responsibility and must not:

“Try to be all and do all for the patient” (participant 6)

With regards to concerns surrounding their own health, a number of participants mentioned how the experience of their parents' illness may make them more vulnerable to emotional and psychological difficulties. All participants were aware of and mentioned their genetic vulnerability to developing bipolar disorder, although none of them are diagnosed with the condition. Heredibility is particularly strong with regards to mood disorders (Kaplan & Sadock, 2000):

“I worry about genes but if it's going to happen it will happen. I try to be health conscious” (participant 8)

One participant does indicate that she fears inheriting the illness:

*“This is a very emotional topic for all us sisters as we constantly fear becoming either manic or depressed. We've told each other that we need to be told immediately and have to accept treatment. I constantly pray that we are strong enough to receive help. I fear what's to become of my family, my partner and myself”
(participant 2)*

As a woman, experiencing the effects a mother's illness has on a home may explain this respondent's fear of developing the illness. Children who are raised by a parent with bipolar disorder not only face a genetic vulnerability to developing a mental illness but, as we can see by the accounts of respondents, are brought up in environments that can be very stressful at times, posing a further risk to their health and normative developmental adaptation (Hall and Webster, 2007).

Responses varied with regards to the nature of the effect of their parent's illness but what became evident was that while many participants report negative outcomes these

participants also describe positive outcomes and appear to have made meaning of the experiences in a way that is helpful to them, this is true across both groups of participants.

Ostiguy, et al (2008) reports that high levels of stress in individuals with bipolar parents can make them more prone to developing a range of mental disorders. One participant reports having suffered from depression during her adolescence. However, interestingly, rather than blaming her father for this, perhaps by thinking that she inherited a mental illness, this participant feels that the fact that her father had a diagnosed mental illness made her feel less alone:

“I think when I was about 14 I had a really bad depression myself and I couldn’t figure out like where does it come from. I just sort of realized there was something from my dad, you know I kind of, it made me feel sort less weird and like less alone” (participant 4)

This is interesting to note as the positive emotional impact that comes from being raised by a parent with bipolar disorder is something that not really discussed in literature on the topic:

“Having a dad with bipolar disorder is not all-in-all a negative experience. There is much to be gained from this experience” (participant 6)

For example two participants reported that living with a parent with bipolar disorder resulted in them taking an interest in studying psychology:

“But it has made me who I am today and there is the flip side to it and I think working with children there’s just this unspoken empathy of “I get it”. That I think is just so soothing. So in so many ways it has given me the tools I need to do my job” (participant 1)

“Well I think it definitely steered what I studied, the field I am in now, psychology”

This participant also credits her father on making her a more understanding and perceptive person due to the fact that she had to deal with the effects of his illness when

growing up as well as be observant and watch for any changes in his mood. She feels that by doing this she learned how to understand people better.

“I also think it, you know I credit my dad with making me aware of things. So, in situations and stuff people can tell you that I pay attention to everything... So, it definitely made me more aware of people and how some people are very inobservant they don't really pay attention to that. So, I think that's definitely something I learned and also to be more understanding” (participant 5)

Some participants also describe how their experiences of supporting and caring for their parents have been very rewarding and fulfilling. They feel that they have learned empathy and are grateful for their health.

Although the experience of being raised by a parent with bipolar disorder can undoubtedly be very emotionally difficult and have negative outcomes with regards to how these individuals view themselves, the findings of this study indicate that the experience can serve to build an individuals' character, provide skills with regards to understanding people and in that sense may indeed have positive outcomes. This appears to be consistent with daughters raised by both mothers or fathers with bipolar disorder.

4.6 The relationship with the ill parent

Overall most participants described strained, difficult relationships with their parents as a result of their illness. The nature of these difficulties did somewhat vary between participants with some describing closer relationships to their parents and others more distant relationships, this did not seem to be affected by the gender of the parent.

However, what did seem to be affected by parental gender was the role that participants played in the care of their parent. Daughters who have mothers with bipolar disorder seemed to take on a more central role in the care of their parent as compared to daughters who have ill fathers. Playing the role of a caregiver undoubtedly changes the dynamics of a parent-child relationship and as was discussed in the interviews participants who had to care for their ill mothers often felt as if the roles were reversed:

And in so many ways it felt like I was the parent to my mother, in so many ways I didn't get to be the little child. Mum was the baby mum was the person that needed to be looked after. It was always about her and her feelings not really about me...ya" (participant 1)

This participant feels as if she was not mothered and had to play the role of her own mother in many ways. Interestingly because she was the only daughter in the family it seemed as if she felt that she had to play the role of a mother to the whole family:

"I think because she had the bipolar I feel she wasn't so involved in my life, she was probably trying to deal with her condition, so basically I feel that I sort of had to fend for myself, you know I just had to look out for myself all the time" (participant 3)

These individuals indicated that they felt as if they missed out on being a child and were not given the opportunity to engage with their mothers in a way that is conducive to healthy development. This participant indicated that her mother's condition felt so overwhelming that at times she felt as if she had the illness:

"It was so bad it was actually like Munchausen's...however you say that, you know the one where the mother puts the disease onto the children. So it was almost like she was keeping me sick so that I would always be around. And I say that more as a symbolic thing rather than an actual diagnosable thing...I really give as good as she gives. You know really aggressive, tears. It was a really, really difficult childhood and you know just trying to come out of that ok...I mean I never got the space to hate my mother, I mean she's so vulnerable she just falls to pieces...Whereas other people's mothers felt so much more robust" (participant 1)

Anger and frustration are other emotions associated with the parent's illness. This generally seems to apply to times when the parent is in a manic state. They may become very selfish and totally inattentive, not listening to anything their child says:

"Usually my mum is the most selfless and giving person I know, but when manic, she only thinks of herself" (participant 2)

When ill the bipolar parent was unable to fulfill his or her parental role. This participant describes how inattentive and preoccupied her mother could be during a manic episode. It is clearly difficult and frustrating for a child in this situation, not to have their parent listen to them when they are emotional or help when they are in need:

"I remember distinctly pouring my heart out to her and begging her to take the medication on one occasion and to stop this behaviour and thereafter she carried on with her normal conversation as if I had said nothing. It was painful and frustrating. I also distinctly remember delivering my first child and my mum being too occupied to help me. I hate admitting it or even thinking it, but just after experiencing one of my Mums episodes, my baby developed colic"
(participant 2)

This participant indicates that in an attempt to care for her mother she became seen as a "bad child". It seems that in this case the lines between parent and child became blurred:

"My mum used to say that I talk down to her and treat her like a child which I had not intended or still don't know if it was her imagination or the truth. All I know was that I had to help her, to help herself. It used to strain our relationship terribly and I felt estranged from her and that I was the 'bad child'...My mum was not in touch with me the way my friend's mums were with them...I still love her with all my heart and soul...to constantly remember that those actions are not my mums" (participant 2)

A number of participants who have fathers with bipolar disorder also described their relationships with their fathers as somewhat negative as well however; these relationships were described as more distant and less confrontational when compared to participants with ill mothers:

"It was very hard to connect with him and even now we don't have a particularly close and strong bond and I think also because his tendency when he is manic he is to lash out and to be sort of very aggressive and narcissistic. I think that that also played a role

because I was very reluctant to confide in him so it sort of, its been quite difficult” (participant 4)

“I remember distinctly a conversation I had with a friend of mine, his father had died when he was younger and he said to me at least he said you have a dad and I said to him it feels like I don’t, it feels like my father is dead. I never see him...” (participant 5)

Some of these participants do, however describe their relationships with their fathers as quite positive:

“We were so worried about him...he was a really good father, he was strict, he didn’t want us to swear or lie, he was a good father. We would laugh, tell stories and it would feel nice to sit together” (participant 8)

These participants indicated that they were often very concerned about their parent experiencing stress. Most participants commented on how manic and depressive episodes were almost always preceded by some stressor in their parent’s life. At times they worried that they themselves may cause the stress.

Reported feelings of guilt come up repeatedly throughout the data. Guilt for not being able to help their parent by not possessing sufficient knowledge regarding the illness, guilt for holding the parent’s erratic behaviour against them and blaming them for certain difficulties. One participant reports feeling guilty about moving out of the country and not being able to support her ill father and caregiver mother as much as she would like to:

“I feel a certain amount of guilt for not being close enough” (participant 6)

Another respondent reported feeling guilty about not speaking to her father for a few days after an argument, as he subsequently had a depressive episode and she blamed herself for this:

“I felt really guilty and responsible for making him depressed” (participant 7)

Of the eight participants, five indicated that, although difficult at times, their relationships with their parents was generally caring and loving. It seems as if these participants feel that when their parents are in depressive and manic phases that they become a different person and are no longer the kind-hearted, loving parent that they know.

4.7 Sibling dynamics

Of the eight participants in the study five discuss their siblings. Interesting dynamics seem to be evident with regards to these relationships within the family. These dynamics seem to be based on two factors, the gender of the sibling or the birth order within the family.

4.7.1 Sibling gender

Participants with female siblings seemed to be able to rely on their sisters for support. This seemed to be the case across the two groups. These participants bring up how as sisters they grouped together and supported each other during the difficult times. This participant describes how her and her sisters bore most of the responsibility for taking care of their mother and for household upkeep as their dad was often busy or out of town. In this case the participant and her sisters had to take over household duties when her mother was ill:

“There were days when my mum would lay in bed all day and sleep saying that she was sick and could not do anything. My sisters and I would have to take over the running of the household”
(respondent 3)

Another participant indicated that he and her sisters tried to help their mother take care of their father as they grew up:

“My sisters and I did try to help when we were older...” (participant 8)

One participant, who has a mother with bipolar disorder, expressed a wish for a sister. She indicated that if she had a sister she may have felt more supported in her care of her mother:

“I’m the only female. I’m not actually sure if it would be different had I had a sister. I actually do question this all the time, in terms of, maybe then it would be different because obviously with brothers they look at things differently and I think as a female you look at things differently” (participant 3)

Another participant who has a father with bipolar disorder indicated that her brother was most affected by her father’s illness, as he was often the target of his aggression. She also felt that her brother might have inherited the disorder from her father:

“My eldest brother had the most effect you know, he was, my dad had, I dunno quite, he didn’t know how to manage his depression and often he would manifest it with aggression and particularly towards my eldest brother My father would often manifest as anger towards them but he left us girls alone mostly...” (participant 5)

However, support from the same sex sibling did not consistent across interviews and may be affected by birth order.

4.7.2 Birth order

One participant felt as if she raised her younger sister along with playing a caring role for her mother:

“...so I was not just mother to my mother but I’ve been my sister’s good enough mommy. So I did a lot of the emotional work for mu sister and in so many was I the cushion between my mother and my sister” (participant 1)

It is however important to note that sibling relationships were not discussed in detail during the interviews and suggested patterns are merely speculation. Further research in this area is needed to establish sound conclusions.

4.8 The role of treatment

Treatment seems to play a central role in managing the illness. On the whole treatment provided relief from the symptoms of the illness for both the parent and the family. The majority of participants see medication as the primary treatment for bipolar disorder. A number of these participants indicate that Lithium is a reliable and effective way of helping their parents and in turn making their lives far easier and worry free. Fountoulakisa et al. (2005) state that medication, primarily lithium, is the first choice in the treatment of bipolar disorder:

*“A little bit of a mood stabiliser would do wonders for her”
(participant 1)*

Many participants discussed difficulties in getting their parents to adhere to medication regimens:

“...they would prescribe him something and he would take it for 3 months and he would feel better and then he'd stop taking it and then he'd get back to where he was. So there was always, I mean I remember there was always medication in the house but he wouldn't take it. He would take it for 3 months and then stop and it... I think it was a sign of weakness to admit that something was wrong so that was his issue, he was not very comfortable in taking medication.” (participant 5)

“No, initially she didn't [take the medication], it was very difficult actually” (participant 3)

Participants whose parents successfully adhered to treatment seem to demonstrate a sense of relief. The illness appears to have affected them far less since their parent began taking appropriate medication:

“I remember wishing that he would just take the medication so he would be normal all the time. Thank goodness he did! He is completely normal now” (participant 6)

*“If my dad had started medication sooner than he did it would have made all our lives much easier. But rather now than never!”
(participant 7)*

On the other hand respondents whose parents refuse to take medication report far more current distress, fear and uncertainty. Adherence to medication regimens or routine can often be a problem in individuals with bipolar disorder Sachs and Thase (2000). These participants do see the value of medications such as Lithium and report wishing their parents would take it regularly:

“My father refuses to take Lithium as chronic medication so the recurrence of the mood swings is inevitable” (participant 6)

The same participant reported that medication is given to her father secretly at times further demonstrating how important medication is in providing relief, not just for the parent themselves but for the entire family.

One participant reports that when she was young her father received shock therapy as a form of treatment. It seems as if this form of treatment had little success. This respondent states that she more recently began to read up and learn about other treatments such as Lithium.

One participant in the sample expressed very negative feelings towards medication as the sole means of treatment. This participant's father is currently suffering greatly as a result of the long-term side effects of Lithium. She feels that her and her family were not sufficiently educated about these side effects and that other possible means of treatment, such as psychotherapy, were never considered or suggested by her father's doctors:

“There was never any therapy, there was never any sort of psychology brought into it, it was all very very psychiatric... in the last few years because his been on this lithium for so long he started to develop renal problems, kidney failure and stuff and ja because a lot of that is contributable to lithium. I mean it frustrated me quite a lot with the lithium, you know if he wasn't so sort of only focused on psychiatric options or treatment you know, things might have been better” (Participant 4)

This participant expressed feelings of anger and frustration at not being provided with adequate information and feels that healthcare workers need to make more of an effort to communicate with their patients and their families. Family focused treatment, helps both the individual and their family gain a better understanding of the illness and also helps to assist with managing daily stressors (Miklowitz et al., 2004). However, according to Fountoulakisa et al. (2005) this form of treatment is often greatly underutilized.

4.9 The importance of knowledge

It is clear that all participants have actively sought information on bipolar disorder in order to help them better understand and care for their parent. It appears that having this knowledge and understanding of the condition provides them with a sense of power and relief, as well as a level of control. This helps in that participants almost seem to fear the illness less and see it as just another illness that can be treated effectively and managed well:

“Knowledge demystifies a scary unknown, changing something that is so overwhelming to something that the families of the ill can and really manage much better from day to day” (participant 6)

All participants agree on the importance of knowledge and understanding but what is interesting is how this has changed over time. The oldest respondent in this study, who is 74 years of age, reports that when her father was first admitted to the hospital for his illness, the doctors didn't know what was wrong with him. As she got older she sought knowledge and now has a far better understanding of the disorder. It is evident when comparing the accounts of older participants to younger participants that there has been a significant social shift in how bipolar disorder is understood; as younger participants seem to greatly rely on their knowledge of the illness for comfort and to keep them from becoming overwhelmed and negative.

Knowledge and understanding has taught these individuals that their parent's illness is not caused by something they did and they realise that they are not to blame:

“Healthcare workers can explain to children that the illness isn't triggered by something they are doing” (participant 7)

All participants stress the importance of education on bipolar disorder. All participants feel that healthcare workers should educate families and help them understand the illness, as this would have helped them cope better at an earlier stage. Families should be taught how to deal with their loved ones in both depressive and manic states and they should be guided towards treatment, which are seen as very effective:

“Health care workers should take the following into consideration: A family member, especially a parent with an , like bipolar disorder, really affects the entire family. For this reason it so important to have support for the sick and for their family. Knowledge is also so so important. It will help you know what your place is in helping your family member get better. Education for the whole family is essential as it helps to manage the symptoms and in making sure the individual is compliant with medications. This will make their overall outcome better and make life less stressful for everyone”
(participant 6)

One participant mentioned that children of parents with bipolar disorder should be told that it is just an illness and nothing to be ashamed of. They should be taught how to approach the situation and how to talk to their parents during both manic and depressive states. One respondent suggested how attending a support group might prove helpful. A lack of knowledge about bipolar disorder is blamed for difficulties in the past and attributed to health in the present. So although there seems to be an effective improvement in family education on bipolar disorder perhaps more is needed (Fountoulakisa et al., 2005).

According to (Miklowitz et al., 2004) psychoeducation and family focused therapy, that provide bipolar patients and their families with an understanding of the illness are effective forms of treatment that can help with adherence to medication as well as assist to create a stress free environment for all members of the family.

4.10 Stigma and support

Stigma is a major concern brought up by many participants. According to their reports society's outlook on mental illnesses like bipolar disorder makes it feel as if families need to hide the condition.

A prominent emotion associated with the parent's illness is shame. This embarrassment seems to stem from the stigma attached to bipolar disorder. Vázquez et al (2010) asserts that stigma surrounding mental illness can often lead to poor outcomes amongst bipolar patients and their families. The community gossiping about the family and their ill parent and not understanding the illness, often referring to their parent as "totally crazy" (participant 7) illustrates such stigma. The embarrassment felt by these individuals undoubtedly seems to stem from society's lack of understanding:

"There isn't a single friend of mine that knows that my father has this illness. There is a certain degree of embarrassment that I always have to deal with mainly because society does not understand this illness" (participant 6)

During the interview one participant of Indian descent discussed whether the stigma associated with mental illness was an Indian thing:

"...you know talk about it and also go and seek help, definitely. Because a lot of people, you know with I'm not sure if it's an Indian thing, you know but when it comes to mental health and when it comes to Indian people they sort of tend to ...there is no such thing, but even if its just like the initial stages, its important that they talk about it and then obviously go and seek help" (participant 3)

However another participant of a different background also discussed stigma in her community and spoke of how she was teased at school for coming from a family that was different:

"I think it would have been more accepted to discuss this sort of thing because it was really kept under wraps a lot of the time. We were told that my dad was sick...we only found out much later but u know when I think of it had been sort of an open thing within the

family that would have been a lot easier and a lot easier to explain to people as well. You know you take a lot of flack in school when you different in anyway but I think knowing at least what is different would have helped us” (participant 5)

Both participants feel that stigma stands in the way of understanding the illness and also prevents families and individuals from seeking the treatment and help that they need. As a result of the stigma associated with mental illness these families and individuals often feel isolated. This is ironic as the majority of participants discuss support from relatives, healthcare professionals and the broader community as essential in making the lives of children with bipolar parents easier:

“And also asking the healthy parent to step in and support. To help support the ill parent in such a way so that they can do what they need to be a good parent, stepping in in a mindful way. A lot of systemic work” (participant 1)

“I think families really need to try and build better relationships with medical healthcare professionals... and sort of try to engage more with that” (participant 4)

“there was not a lot of follow up care for my mother and they did not explain to her exactly what was going to happen you know, it was just a case of ok your husband was bipolar, here is the medication make sure he takes it so there was not a lot of follow up medical care and I think that is an area we definitely lacked in. Both psychologically and medically... Help them to normalize and try to educate them... I'll see you when the script runs out, come back, and that's not the way it should work, it needs supportive care” (participant 5)

4.11 Conclusion

In conclusion this study highlights that bipolar disorder has a profound effect, not only on the individual suffering from the illness, but on their children as well. All participants

involved in this study described the experience of being raised by a parent with bipolar disorder as difficult (Romero et al., 2005).

Manic episodes seem to stand out with most prominence in the memories of respondents. Parents' spending sprees and unpredictable behaviour during these phases cause great distress for participants and their families. These behaviours are all outlined as typical symptoms of mania in the work of Kaplan and Sadock (2000). Depressive episodes were described less frequently possibly because parents seemed to isolate themselves from their families when depressed. However, depressive episodes were also considered distressing particularly because they are linked to fears of suicide. Fear of a parent committing suicide undoubtedly causes stress for their children, increasing the burden placed on them (Reinares et al, 2006). Normal mood phases were considered fragile or unstable and participants felt that these periods were experienced with a sense of non-permanence.

The family environment in general was seen as unstable and filled with many "ups" and "downs" as a result of the ill parent's often extreme and unstable mood state. Participants felt strongly that their family environment was affected by their parent's illness albeit to different degrees. Romero et al. (2005) states that parents with bipolar disorder can create a familial environment that is unstable, unpredictable and lacking in structure. In general it seemed as if participants with ill mothers described a far more chaotic family environment as compared to those participants with ill fathers. In terms of perceptions of the parent who was not ill, two noteworthy themes came up, that of the idealized mother and the absent father. Individuals with ill fathers seemed to consider their mothers as playing a central role in their father's care while also keeping the family together and protecting them from the negative effects of growing up with an ill father. On the other hand individuals with ill mothers described their fathers as largely absent, often leaving them and their siblings to care for their ill mothers.

In terms of participants perceptions of the self all participants felt as if the experience of being raised by a parent with bipolar disorder affects them in their adult lives. Recent studies done by Bella et al. (2011); Rothen et al. (2009) and Manpreet et al. (2007) found that adolescent children of bipolar parents showed significantly higher levels of psychosocial impairment, neuroticism, psychoticism as well as Axis I disorders, such as major depressive disorder, when compared to control groups. Overall most participants

described strained, difficult relationships with their parents as a result of their illness. The nature of these difficulties did somewhat vary between participants with some describing closer relationships to their parents and others more distant relationships, this did not seem to be affected by the gender of the parent. Interestingly, while many consequences of this experience were considered negative, the majority of participants were able to draw on positive outcomes as well, stating that hardships made them develop into more robust individuals.

Most participants mentioned their siblings and the role they played in the family system. Both the gender and the birth order of siblings seem to be significant. Participants with female siblings seemed to feel as if they had more support as the burden of their parent's illness was shared. One participant without any female siblings expressed the wish to have a sister. In terms of birth order older siblings seemed to carry a greater caregiver burden. One participant mentioned having to play the role of a caretaker to her younger sibling as a result of her mother's illness. Steele, Maruyama & Galynker (2009) have looked at the impact of the parent's illness on the family as a whole but to date there are no current studies that consider sibling dynamics.

In terms of treatment, most participants saw medication as the primary choice. When parents adhered to treatment this provided relief from the symptoms of the illness for both the parent and the family. One participant mentioned the side effects of medications and felt that other forms of treatment, such as psychotherapy, are not given enough consideration by healthcare workers. Participants also emphasised the importance of knowledge and understanding in helping them make sense of their parent's illness, seemingly providing a sense of power and control. Finally, a number of participants mentioned the effects that stigma associated with mental illness has on the families concerned, often leading to negative outcomes. A study by Vázquez et al. (2010) asserts that stigma regarding the illness may be associated with levels of poor functioning in bipolar disorder. In contrast to this, support and understanding by both healthcare professionals as well as the broader community is considered essential in making the lives of children with bipolar parents more tolerable and fulfilling.

Chapter 5: Limitations, Implications and Recommendations

5.1 Introduction

This study aimed to explore the experiences of daughters raised by a parent with bipolar disorder. The limitations of this study will be outlined with regards to both conceptual and methodological limitations. Furthermore implications as well recommendations for further studies will be made.

5.2 Conceptual Limitations

Literature on the experiences of individuals raised by a parent with bipolar disorder is very limited, highlighting the need for further research in this area.

Furthermore, very little is known about bipolar disorder in a South African context. The literature utilized in this study is based on research done in other countries, most evidently the United States of America and the United Kingdom. For this reason it is unclear whether the concepts and theories posed in this literature are appropriate for application to a South African Context.

5.3 Methodological Limitations

Many view qualitative research as lacking in value. However, Mack and McQueen (2005) state that qualitative research is valuable as it allows researchers to gain specific information about views, opinions, and experiences. As the purpose of this research was to explore the lived experiences of daughters raised by a parent with bipolar disorder, a qualitative approach was the most appropriate design.

A qualitative approach is also subject to the researchers personal views and beliefs, making it subjective in nature. Throughout this study, a journal was kept in which the researcher kept note of all her feelings, views and experiences regarding the study. As such, the researcher was able to reflect and try and minimise the impact of her subjectivities.

The sample size of eight participants may be regarded as a limitation, as this is a relatively small sample. A larger sample would have provided a wider reflection of individuals' perceptions. However due to aspects such as time, accessibility and financial constraints, it was difficult to attain a larger sample.

As non-probability sampling strategy was used therefore one cannot rule out the influences of extraneous variable. This would have been catered for if random sampling were used, however, because information on patients confidential and in order to avoid the inclusion of misdiagnosed individuals, this sampling method would not have been effective.

The sample included participants who were of different ages, cultural backgrounds (including as Indian, mixed-race and white) and were from different areas of Johannesburg. These aspects may have influenced responses in numerous ways. However, obtaining a sample that was identical with regards to the above-mentioned aspects was not possible. This aspect could be viewed as a limitation, in that these aspects influenced and created disparities in the answers provided. However it could also be seen as a useful aspect in that this study encompasses the views of individuals of different ages, backgrounds, locations and with both mothers and fathers with the illness. This is an aspect that adds to its value as a qualitative study.

This study looked at the effect of parental gender on the experience of individuals raised by a parent with bipolar disorder. For this reason the gender of the child was kept constant and only daughters were used in this study. The perspectives of male children were not explored.

A further limitation of this study is the imbalanced nature of the sample. Despite efforts to include equal numbers of daughters raised by a mother with bipolar disorder as daughters raised by a father with bipolar disorder, only three individuals with ill mothers volunteered to participate in the study.

This study explored the experiences of daughters raised by a parent with bipolar disorder within Johannesburg and surrounding areas. As such, these findings may not apply to other individuals worldwide. This aspect should be kept in mind when reviewing the results.

Complete anonymity was not attained as the interview was administered by the researcher in person. However, all possible steps were taken to ensure that all the participants' identity and information was kept confidential, as they are all referred to by pseudonyms, and no one but the supervisor and researcher has access to the collected data.

5.4 Implications and Recommendations for further studies

In order to produce further research in this area, it would be valuable to address the main limitations of this study. As such, an increased amount of literature regarding family experiences of individuals with bipolar disorder should be included focusing on the experiences of children. Furthermore, a larger sample may also add value to further studies.

This study focused solely on the experiences of female children and further research looking at the experiences of sons raised by parents with bipolar disorder will serve to fill this gap.

Another important variable that could be considered is birth order of the participants. It is highly possible that the eldest child would have played a different role in the family from the youngest and will therefore have different experiences.

Aspects such as religion and culture may have undoubtedly had a great deal of influence on childhood experiences of a parent's illness. Future studies could possibly take this variable into account when doing further research on this topic.

The experience of family members of individuals with bipolar disorder is an under-researched area. This study will hopefully add to the body of research and encourage individuals to pursue further research within this area. In addition, little research has been done on the effects of being raised by a parent with bipolar disorder. This is an extremely important area of research as these effects can have life-long implications for the individuals involved. Therefore it is advised that increased amount of literature, research and publicity should be generated around this topic.

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Appendix A

Interview Schedule

1. What was it like growing up with a mother/father with bipolar disorder?

- How did the illness effect your parent, what were they like when they were ill?
- What incidents or memories stand out during manic phases/ depressive phases/ normal mood phases?
- What role did treatment play in your parent's history?
 - When did they start taking treatment?
 - How were things different after they started taking treatment?
 - Where there difficulties in making sure they adhered to treatment? Were you involved in this?

2. How did your parent's illness affect you?

- What emotional impact did the illness have on you?
- How did your parent's illness affect the rest of your family?
- Who took care of your parent?
- What role, if any, did/ do you play in the care of your parent?
- How do you feel your childhood differed from that of children with parents who were not ill?
- What do you think could have been done to make things easier for you?
- Have you been for therapy yourself? How has it helped you?

3. Do you think things would have been different if it was your other parent who was ill instead? If so, it what way?

4. Overall what is the most important piece of advice you can give health care workers in regards to assisting children of bipolar patients?

Any other comments you would like to make?

Appendix B

Participant Information Letter

To the potential volunteers of research,

My name is Raeesah Valli and I am a Masters student currently studying at the university of the Witwatersrand. I hope to conduct research on the experiences of daughters raised by a parent with bipolar disorder in partial fulfillment of my degree.

My research aims to look at the life-stories of these individuals as they look retrospectively at their experience of their parents' illness. An invitation is extended to you as a potential participant to take part in this research. Participation in this study is voluntary and no one will be advantaged or disadvantaged from participating in this research or choosing not to participate in this research. Confidentiality will be adhered to and you will be able to remain anonymous to readers, as I will not require any personal details such as name or ID number. Due to ensuring your confidentiality, volunteers will not be getting individual feedback.

You will be asked to complete an audiotaped interview conducted by myself. This interview will take approximately 45-60 minutes to complete. Once data is transcribed it will be kept in a secure place for up to three years, thereafter it will be destroyed.

Your participation in this study is entirely voluntary and you may withdraw your participation, or refuse to answer questions I may ask, at any time. If counseling is required after completion of the interview Lifeline is a free telephonic counselling service (0861 322 322) that can be utilized. A psychiatrist will also be available for referrals.

If you require any further details:

My email address is: raeesahvalli@hotmail.com.

My cellphone number is: 0828231790

Contact details for my supervisor, Leonie Human, who is overseeing the project are:

leonie.human@wits.ac.za

Kind regards,

Raeesah Valli

Appendix C

Consent form



*Private Bag 3, Wits 2050,
Johannesburg, South Africa
Tel: 0716888203
Email: 570210@students.wits.ac.za*

Dear Potential Participant,

I am inviting you to participate in this study if you are a daughter raised by parent with bipolar disorder. Should you consent to participate, you will be asked to do the following:

- Complete an interview conducted by myself
- Complete a consent form agreeing to have the interview audio-taped

The interview will take approximately 45-60 minutes to complete. All information disclosed by you will remain confidential. Your participation in this study is entirely voluntary and you may withdraw your participation, or refuse to answer questions I may ask, at any time. If you agree to participate, please complete and sign this form:

Thank you for your time,

Raesah Valli

I, _____ do / do not consent to participate in the research study to be conducted by Raesah Valli.

Signature: _____ Date: _____

Appendix D

Consent form for being audiotaped



*Private Bag 3, Wits 2050,
Johannesburg, South Africa
Tel: 0716888203
Email: 570210@students.wits.ac.za*

Dear Participant,

You will be asked to complete an audiotaped interview conducted by myself. This interview will take approximately 45-60 minutes to complete. The interview for the study requires audiotaping in order to ensure that information is not lost during the research process. Once data is transcribed it will be kept in a secure place for up to three years, thereafter it will be destroyed.

I, _____ do / do not consent to having the interview conducted by Raeesah Valli being audio-taped.

Signature: _____ Date: _____