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Narratives of partners of people diagnosed with bipolar disorder

by

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A research report submitted to the Faculty of Humanities, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Arts in Psychology.

2016



Declaration

I declare that this thesis, entitled 'Narratives of partners of people with bipolar disorder', is my own unaided work. It is submitted for the degree of Master of Arts in Psychology, at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.

Signed this ____ day of _____, 2016.

_____

Mia Emmarentia Pienaar

Dedication

To my father, my mother, my sister and my brother. You know why.

Acknowledgements

To my supervisor, Prof. Tanya Graham, thank you for your gentle guidance. Thank you for teaching me, ignoring my fits of anxiety, challenging me and for laughing with me. Your calmness and warmth has been so appreciated.

To my lecturers and teachers, Prof. Kevin Whitehead, Prof. Jill Bradbury, Prof. Kate Cockcroft, Dr. Vinitha Jithoo, Prof. Garth Stevens; as well as guest lecturers to Wits, Prof. Ian Parker, Prof. Erica Burman, Prof. Ann Phoenix, Prof. Ruthellen Josselson, and Dr. María Elena Torre. You have each in some way poked, prodded, nudged or shaped this research and I thank you for allowing me to learn from you.

To my friends and family, thank you for your support, encouragement and patience. Especially to my mother and father, who gave me everything I needed to complete this research including hugs, cups of tea and opportunities for ranting. My sister and brother, who have been cheering and sympathising and being proud and challenging me from so far away. Robyn-Brooke Labuschagne, thank you for being so understanding and supportive and for buying me sweets. Janine Barnes – my study buddy, my empathiser, my sounding board, I have so enjoyed your company along this road. Cat Coxon, thank you for waking me up with a bunch of lilies. Hannes, your limitless support and encouragement has made these last few months easier. You are all wonderful.

Thank you to Sister Sandra Williams for helping me to reach one of my participants.

In memory of Linda Trump, who gave me a spark of enthusiasm and warm encouragement right at the beginning of this study. She helped me to find my sample, she welcomed me into her support group community and her passion for this field was inspirational. She was a force in community outreach and psycho-education for bipolar disorder, and she will be missed.

Lastly, thank you to my participants for sharing your stories with me. Your openness and your willingness have been a gift, and I hope I can give you something too with this research.

Abstract

Bipolar disorder is a chronic, turbulent mental disorder that is associated with feelings of distress and 'caregiver burden' for those who are close to people diagnosed with it. Although there is a relatively large body of literature on 'caregivers' of people with chronic mental illness, it is argued that this body of research has been reductionist and one-dimensional. Furthermore, the extant research has, in general, treated any person close to someone with bipolar disorder as a 'caregiver', without giving attention to the unique relational dynamics between two people. This is especially true for romantic partners of people with mental illness. This study used a social constructionist approach and a narrative methodology to analyse individual interviews with five people who are or had been in an intimate relationship with someone with bipolar disorder. This study used Bamberg's (1997) positioning analysis to explore the ways in which the participants constructed important characters, their audience and themselves in their narratives of living with someone with bipolar disorder. It was found that there are many more possibilities for dynamics between a person and his or her partner with bipolar disorder than a simple caregiver-care receiver dynamic. It was also found that for the participants the term 'caregiver' is not an appropriate description of their role and position. This research is important as an example of embracing the complexity of family members' experiences of mental illness, and to open the possibility of narrative intervention for partners of people with bipolar disorder.

Keywords: Bipolar disorder, Caregivers, Narratives, Positioning Analysis, Social Constructionism

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Abbreviations

APA	American Psychological Association
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
EE	Expressed Emotion
FFT	Family Focused Therapy
HIV	Human Immuno-Deficiency Virus
MHIC	Medical Health Information Centre
PMS	Pre-menstrual Syndrome
SADAG	South African Depression and Anxiety Group
SAFMH	South African Federation of Mental Health

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Chapter 1: Introduction

> How do we encompass such arrays of complexity? We usually do not. Or rather, we impose meaning and limit what we deal with. (Emde, 1994, p. 721)

Bipolar disorder affects as many as 500 000 people in South Africa (Colin, 2013). This means that there are as many as 500 000 families who are experiencing the effects of the disorder. These could range from witnessing and caring for a person within the depths of a crippling depressive episode, to the anxiety and fear caused by the unpredictability of a manic episode (Judd et al., 2002; 2003). It is imperative that we understand not only the complex, dynamic experiences of people diagnosed with bipolar disorder but also the people caring for them, interacting with them and responding to them.

Bipolar disorder is a pervasive and turbulent mood disorder that, besides for being a distressing disorder to live with, can also be a source of distress for the family members of those who have been diagnosed with it (Judd et al., 2002; 2003). Bipolar disorder has been described as being 'contagious' to family members (e.g. Freeman, 2015) and many relationships have not survived the course of this disorder (Trump & Hugo, 2006). Family members have been identified as especially influential to the development, course and treatment of bipolar disorder (e.g. Barrowclough & Hooley, 2003; Miklowitz, 2007).

There is a large body of research on this topic, but it is argued in reviewing the literature that most of this research stems from a pathologising viewpoint of bipolar disorder and those interacting closely with this population. Most research on this topic has imposed meaning by conceptualising bipolar disorder and 'caregiver burden' from a medicalised, deterministic viewpoint (Ayres, 2000; Henderson & Forbat, 2002). Most research on this topic has limited what it deals with by looking at binaried variables instead of nuanced, participant-constructed meanings (Langellier, 1999; Lavis, et al., 2015).

A social-constructionist approach and the narrative method of inquiry offer a theoretical perspective and methodology that is sensitive to contextually shaped and multi-dimensional experiences (Riessman, 2005) of those people who are or have been in an intimate relationship with a person diagnosed with bipolar disorder. Instead of shying away from complexity, this research highlighted the rich, varied experiences of partners of bipolar disorder. It aimed to

understand how the partners of people with bipolar disorder have, themselves, made meaning of their experiences.

Rationale

Bipolar disorder is a chronic, turbulent and painful mental disorder (Trump & Hugo, 2006). Bipolar disorder is associated with depression, euphoria (Bower, 2000), suicide (South African Depression and Anxiety Group [SADAG], 2013), sub-syndromal symptoms (Scott et al., 2006), multiple relapses (Mazza et al., 2011), and relationship distress and dissolution (Rowe & Morris, 2012). Family members and partners of people with bipolar disorder might experience depression, 'caregiver burden', volatility from the patient (American Psychiatric Association [APA], 2013; SADAG, 2013) and financial, occupational and social strain (Oshodi et al., 2012).

It seems clear why such a mental disorder needs to be researched and understood as well as possible. However, by defining bipolar disorder according to the dominant categorical and descriptive conception of it (Double, 2003) laid out by the Diagnostics and Statistical Manual of Mental Disorders (DSM 5) (APA, 2013), we can only understand it myopically (Parker, et al. 1995). The symptoms identified from categorical and descriptive conceptualisations of the disorder do not give a sense of the lived experience of bipolar disorder (McWilliams, 2009). McWilliams (2009) explains this argument by a comparison with thinking one knows what a piece of music sounds like by knowing the musical notes, instruments and tempo that construct it.

This argument can be extended to researching the people close to a person who has been diagnosed with bipolar disorder. If we start with a reductionist definition of bipolar disorder (Double, 2003) and then try to list the ways in which the symptoms might affect family members of the patient, we will miss out on the complex, dynamic forces that could be influencing the experience of bipolar disorder and we will impose a medicalised understanding on a population who might not experience it as such (Parker et al., 1995). Specifically, when grouping partners of people with bipolar disorder with other family members, the nature of different relationships becomes conflated: a mother-child, sibling and intimate relationship are treated in the same way (Henderson & Forbat, 2002).

In reviewing the literature around the topic of partners of people with bipolar disorder it was discovered that 'caregiver' literature treats its subjects as just that – one-dimensional and peripheral to the disorder, either sufferers of the bad behaviour of their 'patients' or exerting a negative influence on the patient who only wants to get better (Ayres, 2000; Henderson & Forbat, 2002; Lavis, et al., 2015). 'Caregiver' literature has imposed a character definition on a population without considering how family members of people with bipolar disorder might identify themselves or how they want to be understood. 'Caregiver' literature has made the specific relational aspects of an intimate partnership invisible (Henderson & Forbat, 2002).

There has been a well-accepted shift in not identifying people by their diagnosis; not calling a person 'a schizophrenic' but referring to them as 'a person diagnosed with schizophrenia' (Alex, 2012; APA, 2000; Link, et al., 1999; Perry, 2011). This shift has not been extended to people who are in close relationships with the mentally ill. They are referred to as 'caregivers' or 'carers', placing emphasis on their role in terms of a mental illness (Ayres, 2000; Lavis, et al. 2015; Henderson & Forbat, 2002). This ignores many possibilities for the experience of being a relative of someone with mental illness: that the relatives do not view themselves as caregivers, that the 'burden of care' is not fractionally as distressing as watching a loved one experiencing a mental disorder, that they themselves have unfulfilled needs as a consequence of being in an unequally beneficial relationship.

Furthermore, this conception pathologises the 'caregivers' – either blaming them or diagnosing them with 'caregiving sickness' (Perry, 2011). 'Caregiving' in literature is often viewed in terms of the ways in which the 'caregiver' could either contribute to the course of the disorder or what the 'caregivers' could do better to improve the lives of people with bipolar disorder (eg. Rowe & Morris, 2012). Otherwise, 'caregivers' are identified as having 'symptoms' of their role – depression, anxiety and even physical distress (eg. Jeglic et al., 2005). This medicalisation of the experience of having a relationship with someone with a mental illness implies that 'caregiving sickness' could be treated medically – if we treat their depression, anxiety and physical complaints their 'symptoms' should recede (Double, 2003). Concurrently, there is an assumption that being in a relationship with someone with bipolar disorder must have negative effects and these negative effects must qualify as objectively and observably distressing in order to gain attention from research (Aranda & Street, 2001).

This is not to say that the existing literature has not been valuable. It is strongly established that mental illness does not only affect those who have been diagnosed, and has provided concrete information about the social forces that contribute to the etymology and progression of mental illness (eg. Goldberg-Arnold, Fristad & Gavazzi, 1999; Miklowitz, 2007; Yusuf, Nuhu & Olisah, 2013). However, something has been overlooked in this literature – the intrinsic experience of being close to someone diagnosed with a psychological disorder.

This research conceptualises 'caregivers' in a different way. They have been viewed as people who are or have been in an intimate relationship with someone with a volatile set of symptoms (SADAG, 2005), that could be associated with a range of possible experiences and meanings (Ayres, 2000). Because the caregiving role is being problematised this research has explored the experiences of partners of people with bipolar disorder whether or not they are giving care to the patient. This research has conceptualised bipolar disorder not as an isolatable complication for a patient and his or her family, but as a multiply constructed and diversely experienced phenomenon. This research also views the relationship as producing particular ways of experiencing bipolar disorder, dependent on the history and context of the dyad.

Social constructionism offers a perspective that supports this viewpoint. Social constructionism is an epistemology that assumes that reality has been socially constructed; social groups have collectively made meaning of their worlds (Burr, 2003). These meanings are shaped by history, culture, economics and politics and as such become taken for granted 'truths' that can be deconstructed (Burr, 2003). By picking apart the social meaning of phenomena that have been negotiated by the people involved (Roberts, 2000), we can gain access to the perspectives with which people understand and experience their surroundings.

The narrative approach is a social constructionist methodology which is useful in exploring the constructions and meanings unique to individuals who are in a relationship with someone with bipolar disorder. The narrative method of inquiry uses the narrative instinct with which people communicate their experiences to understand how they have made meaning of their experiences (Riessman, 2008). It uses the way in which this meaning construction has occurred as an index for the claims to truth and intentions with which a narrative is delivered (Bamberg, 1997). In this way, the narrative approach allows the researcher to gain a sense of

how the participant wants to be understood and what meaning they have made of an experience (Riessman, 2008).

If the dominant construction of mental illness has positioned family members, and especially partners of people with mental illness as 'caregivers', narrative analysis is one of the ways in which we can 'turn back on' such a construction (Parker, 2013) and interrogate it (Langellier, 1999). By using a narrative approach this research has aimed to understand how partners of people with bipolar disorder construct and make meaning of their experiences, to answer the lack of attention that has been given to emergent understandings of this phenomenon.

Research Aims

Taking existing literature into account, this research aimed to demonstrate the need for broadening the view of people who are affected by mental illness – including the people diagnosed, their families and the larger community. More specifically, this research aimed to illuminate the experiences of partners of people with bipolar disorder without imposing theory, themes or constructions on them. That is, while the existing literature has characterised people related to those with mental illness as 'caregivers', this research aimed to understand how the partners of people with bipolar wanted to be understood themselves. Using a social constructionist perspective, this research sought to be critical of some of the discourses used to talk about mental illness and the family members of people with mental illness. It aimed to explore the narratives of partners of people with bipolar disorder to understand how people specifically in an intimate relationship and specifically living with bipolar disorder construct their experiences. With the aim of pointing to a need for more constructionist and participant-oriented research on the subject of the effect of mental illness in the community, this research offers an exploratory exemplar of the use of narrative inquiry in the context of South African mental health.

Structure of the Report

This introductory chapter provides the reader with a background and context that invites critical engagement with the topic. It delivers a rationale for this study, arguing that a constructionist perspective of a phenomenon experienced by so many people is important to develop our

understanding of it. It states the aims of this research project and the operational definitions of concepts that are central to the investigation of this topic.

Chapter 2 reviews literature on bipolar disorder, family members of people with bipolar disorder and relationships, and introduces the narrative conceptual framework. This literature review describes the presentation, course and treatment of bipolar disorder, and discusses research that contests the dominant descriptive and categorical (McWilliams, 2011) conceptualisation of bipolar disorder. It goes on to consider research on quality of life for both patients and family members of people with disorder, stigmatisation of patients and their relatives and challenges the discourse around 'caregivers'. The literature review then provides a brief overview of relationships comprising a person diagnosed with bipolar disorder and discusses some of the implications of conducting research on relationships. Finally, the social constructionist and narrative theoretical framework is explained and explored.

Chapter 3 describes and explains the methods used in this research project. The research questions are presented, followed by a discussion of the research approach and conceptual framework used. In this section the assumptions of exploratory, co-constructive narrative research will be discussed, providing the reader with an understanding of the theoretical standpoint of this study. The participants, data collection tools and procedures used for this project will be described before an explanation of the way in which the data were analysed. This chapter also comprises a self-reflexive discussion and explains the ethical concerns with which the procedures were chosen.

Chapter 4 presents the analysis and interpretations of the data. This chapter is separated into a section for each of the five participants. Each participant's section is further organised into three sub-sections – one for each level of analysis described in *Chapter 3*.

Chapter 5 gives an overview of the findings and a discussion of the interpretations presented. The overview of findings is a critical engagement with some of the most salient concepts created in the participants' narratives, raising the possible implications of this kind of non-generalisable, constructionist research. The discussion responds to the literature review with what was seen in the data. The strengths and limitations of the research will then be discussed,

followed by suggested directions for future research. A conclusion for this research report will then be presented.

The references to texts used to inform, develop and support this research are presented followed by the appendices, showing the information and consent requests given to the participants, the interview schedule used in data collection, and the ethics clearance given for this research.

Operational Definitions

The following terms have been operationalised for this research:

Narratives: These are the stories provided by the participants. They are temporally-oriented accounts of past, present or even future events (Riessman, 2008). As discussed by Riessman (2008) narratives do not necessarily have to comprise a certain structure, and they do not have to have specific content. Georgakopoulou (2006) describes 'small stories'; stories that are not necessarily autobiographical or representing an experience in its entirety. As such, the narratives to which this report refers may be 'small' narratives of isolated, fleeting episodes or they may be the overarching narrative that the participant provides for living with a person with bipolar disorder.

Partners: In this report a 'partner' will be any person in a long-term romantic relationship with a person with bipolar disorder. This relationship may be marital or not, may be heterosexual or not and may be a current relationship or not.

Bipolar disorder: For this report, 'bipolar disorder' will refer to a diagnosis of bipolar I or II with any specifiers of onset and course, given by a practicing psychiatrist. Because there is a general contestation around the 'shape and form' of bipolar disorder, a person given a diagnosis of bipolar disorder that is contested will still be referred to as bipolar disorder if the referred to person identifies with that diagnosis. For example, in this study, Participant 3's husband's diagnosis of bipolar II disorder has been doubted, but at the time of data collection both Participant 3 and her husband accepted and used the label of 'bipolar disorder'.

Caregiver: The term ‘caregiver’ will be avoided in accordance with the argument around a one-dimensional view of people who have a close relationship with someone with bipolar disorder. Instead the terms ‘family members’, ‘partners’ and ‘caregiving family members’ will be used. However, the term is still used to match the vocabulary of other research when reviewing the literature.

Patient: After careful consideration it was decided that the term ‘patient’ would be used tentatively with the same concern around conceptualising a person in a one-dimensional, and in this case, pathologising way. The preferred term throughout this research report will be ‘a person with bipolar disorder’ but there are times when in service of clarity the term ‘patient’ is used to refer to someone who is being treated for a mental disorder.

Kleinman (1988) cautions the use of the term ‘patient’ because of the connotations of a passive object being subjected to the expertise of the medical health professional, but also points out that efforts to avoid such terms may end up as distractions from the real issue; a compassionate and respectful attitude towards people with mental illness.

Green (2009) suggest using the term ‘mental health service user’ but this term seems like just another, more agency ascribing way of saying ‘patient’. It also still defines a person in terms of the treatment of their mental health condition, and becomes confusing as soon as we start to ask what counts as a mental health service.

This problem reflects a tension within this study that the reader is alerted to. Even though this research calls for a deconstruction of the ways in which we think and speak about mental illness, especially for the relatives of people with mental illness, it still uses terms like ‘mental illness’, ‘patient’ and ‘symptoms’. This is testament to the ways in which medical discourse has been so institutionalised as to limit the possibilities for other ways of conceptualising the people concerned (Mishler, 1984). While I would like to resist such discourses, I cannot do so for the present study without losing my focus on the partners of people with bipolar disorder.

Conclusion

This chapter has provided an introduction, rationale, the research aims, structure, and operational definitions for this research. It has oriented the reader to the topic of partners of people with

bipolar disorder and to the use of a social constructionist perspective in this study to understand these individuals. With a context and background in mind we can look to what has been written on the topics of bipolar disorder, family members of people with mental illness, and the conceptual assumptions of social constructionist research.

Chapter 2: Literature Review

This chapter presents a literature review that has five main subjects. Literature on bipolar disorder and the course and treatment of it will be reviewed to provide an understanding of the characteristics of this mental disorder. It will be shown that bipolar disorder is still poorly understood and the course and treatment of bipolar disorder is far from straightforward. Literature on the quality of life of people diagnosed with bipolar disorder will provide a better understanding of what it is like to live with mental illness. The nature of bipolar disorder is important to keep in mind when trying to understand the experiences of family members of people with bipolar disorder so that we have a vocabulary of the range of potential experiences of it.

Literature on the stigma surrounding mental illness is considered with a view to understanding the social experience of mental illness. A discussion of how patients might experience stigma is followed by literature that explores how the relatives of people with mental illness are affected by stigmatisation.

Focus then shifts to how family members might experience bipolar disorder. Literature on the pivotal role that family members play in the course and treatment of bipolar disorder will be used to enter into a discussion of how family members are positioned within this topic. When reviewing the literature on caregiver burden and quality of life for caregiving family members, the argument will be made that in the literature reviewed there is a positioning of caregiving family members and their experiences as important only in terms of the course and treatment of the patient, rather than an interest in their experiences as intrinsically important. At the same time, the particular experience of the relationship has been lost amongst a reference to 'caregivers' without any recognition of the nature of the relationship.

Focus is then drawn to the literature on intimate relationships and how we might research them. It is argued that relationships cannot be researched as the sum of their parts because a relationship is situated within a context and involves an intersubjectivity that might not be accessible to those outside the relationship.

Lastly, the theoretical framework of social constructionism and narrative inquiry is explained and discussed, with reference to the theoretical assumptions of this research.

By examining these five subjects; the nature of bipolar disorder, stigma, the experiences of caregiving family members, researching relationships, and the narrative framework a context in which this research can be situated is gathered.

The main foci have been integrated somewhat, because there are areas, for example the course and treatment of the disorder which involve the patient and the family members. This is line with the general theme of this research – that the disorder, the people involved and the context in which this phenomenon occurs are intertwined.

Bipolar Disorder

In deconstructing the ways in which a medical perspective has positioned people diagnosed with bipolar, it has been important for this research to first explore how bipolar disorder is understood and in what ways such an understanding can be problematic. Even though this research has not looked directly at the people diagnosed, understanding a diagnosis of bipolar disorder was an important situating tool to be able to contextualise the experiences of their partners.

The DSM 5 (APA, 2013) presents its descriptions of bipolar and related disorders, located between the chapters on other psychotic disorders and depressive disorders. This location represents bipolar and related disorders' relation to psychotic and depressive diagnostic classes with regards to symptomology, family history and genetics (APA, 2013). The bipolar and related disorders are bipolar I disorder, bipolar II disorder, cyclothymic disorder, substance or medication induced bipolar and related disorder, bipolar and related disorder due to another medical condition, other specified bipolar and related disorder and unspecified bipolar disorder. (APA, 2013).

For a diagnosis of bipolar I disorder, a medical practitioner must recognise an episode of mania. This is a discrete period of elevated, expansive, or irritated mood that is persistent and contrary to a baseline of typical functioning for that person. This discrete period must persist for at least one week or for any time if it is required that the person be hospitalised for reasons of safety (APA, 2013). The mood episode may be characterised by heightened goal-directed

activity, grandiosity, a decreased need for sleep, an increase in rate and determination of speech, a feeling of not needing to sleep, flight of ideas, distractibility, psychomotor agitation and excessive involvement in risky activities (APA, 2013). An episode of mania causes marked impairment in the person's ability to function at their usual level, and may include features of psychosis. Only an episode of mania is necessary for a diagnosis of bipolar I disorder, but depressive and hypomanic episodes are common in people with bipolar I.

A hypomanic episode is characterised by the same symptoms as a manic episode but the symptoms do not cause a marked impairment in functioning. A person experiencing a hypomanic episode may not feel distressed, and may even feel very good, but the heightened nature of their mood will be observable to others. A hypomanic episode may still qualify as such if the symptoms are only present for four to five consecutive days (APA, 2013).

In the DSM 5's description of a major depressive episode, a person will display symptoms for at least a two week period that shows a distinct difference from the person's usual level of functioning. Symptoms of a persistently depressed mood, a clear decrease in pleasure or interest in all or most activities, weight loss or weight gain especially due to a loss of or increase in appetite, insomnia or hypersomnia, psychomotor agitation or psychomotor retardation, fatigue, persistent feelings of worthlessness or guilt, diminished cognitive abilities like decisiveness, recurrent thoughts of death or suicide, or suicidality, must be observable by others (APA, 2013).

At least one major depressive episode and at least one hypomanic episode will qualify for a diagnosis of bipolar II disorder (APA, 2013). The APA (2013) reports that often a person will present to a psychiatrist with symptoms of a major depressive episode and will not report symptoms that may constitute a hypomanic episode because those symptoms did not cause the person distress. This makes bipolar II disorder difficult to diagnose. The APA (2013) also suggests that in bipolar II disorder it is not hypomania that causes impairment to a person's life but rather the major depressive episodes, general lability, and inconsistent social functioning. The DSM 5 distinguishes bipolar and related disorders from personality disorders such as borderline personality disorder by stating that mood episodes must be distinct from the person's usual functioning rather than a generalised pattern observable when a personality disorder is present (APA, 2013). Bipolar and related disorders are often co-morbid with anxiety disorders;

attention-deficit and hyperactivity disorder; disruption, impulse-control and conduct disorders; and substance use disorders (APA, 2013).

The possibility of a person with bipolar disorder committing suicide is at least fifteen times higher than people who do not have the disorder (APA, 2013). Because of the high risk of suicide, bipolar disorder is viewed as a life-threatening disorder (Bower, 2000). Besides the threat of physical self-harm, the people diagnosed with the disorder often exhibit themes of substance abuse, bankruptcy, debt and dysfunction in relationships (SADAG, 2013). In both depressive and manic episodes there is often severe social and occupational dysfunction, and mania is treated as a medical emergency (Rodseth, 2011). Depression is often the prevalent mood state (Rodseth, 2011).

Although these conceptions of bipolar disorder are generally the conceptions that diagnosis and prognosis are based upon, there is a growing body of research suggesting that these conceptions are simplistic and inaccurate. For example, Bauer et al. (2005) assessed a treated American out-patient population for the distribution of their depressive and manic symptoms. Because of their results of high co-occurrence of depressive and manic symptoms, they suggest that the categorical conceptualisations of the disorder used by both the DSM-IV-TR and the ICD-10, the systems Bauer et al. (2005) were looking at, are less valid than a dimensional conceptualisation. They suggest that it is not accurate to conceive of the disorder as a swing between discrete mood 'poles'. Instead the disorder is characterised by variations of "admixtures of manic and depressive symptoms, the combination of which is associated with greater dysfunction" (Bauer et al., 2005, p. 88).

Likewise, Johnson et al. (2011) showed that depression and mania symptoms were not negatively correlated in their outpatient sample. If mania and depression occur as separate poles, the presence of symptoms of each pole should be strongly negatively correlated. Furthermore, Johnson, et al. (2011) argue that the generally accepted one-dimensional model of the DSM-IV-TR and the ICD-10 have influenced nomenclature and aetiology of bipolar disorder.

Singh et al. (2013) used the DSM-IV-TR diagnostic criteria for bipolar disorder alongside a semi-structured interview diagnostic tool in an out-patient sample. They found data consistent with claims that bipolar disorder does not occur as a 'bipolar' disorder. Singh et al. (2013) found

higher anxiety levels in those meeting criteria for mixed states than for either depressive or manic states. With their earlier finding that supports the co-occurrence of depression and mania, it is possible that mixed states should not be reduced to a combination of depression and mania, but a state that results in different and even more intense symptoms (Singh et al. 2013).

Before the publishing of the DSM 5, Limandri (2012) pointed to research suggesting that borderline personality disorder could be an unexplored dimension of bipolar disorder because they are co-occurring conditions. Affectivity, instability, impulsivity and behavioural dysregulation – symptoms characteristic of borderline personality disorder are often found in patients with bipolar disorder (Limandri, 2012). The nosological difference between the disorders is that borderline personality disorder is a pathology of personality traits, while bipolar disorder is a pathology of mood state (Limandri, 2012). However, it must be kept in mind that the issue of distinguishing between personality disorders and other psychiatric disorders is still a contentious issue (eg. McWilliams, 2009).

The APA (2013) recognises in the DSM 5 that previous versions have been overly narrow in their diagnostic categories and descriptions. They admit that the diagnostic categories did not capture the clinical reality, gross symptom heterogeneity between cases, and the frequent common symptoms between different disorders. The question remains as to how much the DSM 5 attends to these problems, but the efforts of the APA (2013) do inspire hope for psychiatric diagnosis that is more dimensional and flexible.

While critiques of the arguments around the symptoms and definition of bipolar disorder are beyond the scope of this research, it is important to note that bipolar disorder is poorly understood, and it is likely that we still do not know how little we understand about it. At the same time Roberts (2000) argues that a medical perspective overlooks the person behind the patient – the qualitative human experience of pain and distress, and the capacity for an empathic understanding of those experiences is often ignored because of a focus on delineating the symptoms.

Course and treatment. Bipolar disorder is treated pharmacologically with mood stabilisers and more recently, atypical antipsychotics (Rodseth, 2011). The pharmacological treatment helps to even the extremes of mood states. Co-morbidity with other psychiatric

disorders and/or physical illness is common, making pharmacological treatment far from straightforward (Townsend, Biegel, Ishler, Wieder, & Rini, 2006; Zergaw, Hailemarium, Alem, & Kebede, 2008).

There are many difficulties involved in the treatment of bipolar disorder. Finding the optimal drug for a patient is difficult, especially in light of the procedure of diagnosing bipolar disorder in the first place and because of the vast variations in presentation of symptoms (Rodseth, 2011). Furthermore, the symptoms of bipolar disorder, as well as other factors such as effectiveness of support structures, could confound a patient's ability and motivation to adhere to a strict medication regime (Rodseth, 2011; Trump & Hugo, 2006). In Trump and Hugo's study, 68% of their sample of people with this mental illness discontinued their medication at least once during the course of their treatment.

The high cost of chronic medication and the struggle to get financial support from medical aid schemes (SADAG, 2005; Trump & Hugo, 2006) also makes drug adherence difficult. Another difficulty, often found in chronic medication-takers, is that once the depressive symptoms start subsiding the patient loses the drive, motivation, and/or interest to adhere strictly to their medication regime (Bower, 2000). On the other hand, it has been found that some bipolar disorder patients purposefully stop taking their medication in the hopes of experiencing the pleasurable symptoms of hypomania (Bower, 2000; Mavundla, Toth & Mphelane, 2009).

Furthermore, the side-effects of pharmacological treatment sometimes disable patients. In Trump and Hugo's study (2006) 52% of people with bipolar disorder experienced fatigue and low energy, 51% noticed a lack of concentration, 50% felt they had low libido and 42% had sleep disturbances.

Even with treatment, sub-threshold (inter episode) depressive and mixed mood states often affect a patient's global functioning, social adjustment and subjective well-being (Mazza et al., 2011). This means that inter-episode periods should not be viewed as times of relative health and usual functioning. Treatment for bipolar disorder should therefore be understood as a complex process that should not be taken for granted as straightforward or even present once a person has been diagnosed. Furthermore, social factors affect the course and treatment of bipolar disorder.

It has been well established that the family members of a person with bipolar disorder play a pivotal role in the course and treatment of this condition (e.g. Barrowclough & Hooley, 2003; Miklowitz, 2007; Perlick et al., 2007; Yesufu-Udechuku et al., 2015). Using the systems approach, Barrowclough and Hooley (2003) and Miklowitz (2004) have established that patients who live with a high expressed emotion (EE) (characterised by occurrences of criticism, hostility, emotional over-involvement and other negative emotional communications) family are two to three times more likely to relapse in the subsequent nine months after their release from a psychiatric institution, as are patients who return to a low EE family.

Miklowitz (2007) uses a model to explain that, in high EE families, residual symptoms experienced by the patient feed into a system which results in higher risk of relapse. Residual symptoms lead to negative interactions between family members. These negative interactions influence cognitive reactivity to the patient by the family members. That is, they may respond with fear, hostility, hopelessness, exaggerations and continuous reminders of the patient's past behaviour and generally negative and pessimistic attitudes. At this point, the system can manifest in two ways. Either the high level of EE contributes to a relapse in the patient's hypo/mania or depression, or it contributes to the patient's residual symptoms. If the patient's residual symptoms are increased, the system plays itself out again, ultimately ending in a relapse for the patient.

This is just one conception of the ways in which the family members' emotional states are seen to impact the course of the patient's disorder. Complementing the assertion of the families' roles is research on the effect of family focused therapy (FFT) on the course and treatment of bipolar disorder.

Therapeutic family interventions have been proven to be effective in smoothing out the course of bipolar disorder alongside pharmacological treatment (Miklowitz, 2007). In FFT families are taught to recognise signs and symptoms of the disorder, to develop strategies for providing early intervention of possible relapse and to provide a consistent medication-adherence regime. In FFT the premise is that if there is healthy communication within the family, the patient will experience less emotional stress and therefore decrease their risk of relapse. While there is an emphasis of the interactions of the family, the effects of those interactions, and

psycho-education around healthier interactions, there is no emphasis on individual family members' experiences and difficulties. At the same time, it must be observed that, in these conceptions, a significant amount of responsibility is placed with the family members for the well-being of the patient.

Pollio, North, Reid, Miletic and McClendon (2006) designed a one-day psycho-education workshop for the families of people with severe mental illness. They suggest that this is a practical solution for giving information and support to families who are negotiating an intensive life-load – dealing with the mentally ill family member, the rest of the family, and their own work and social obligations (Pollio et al., 2006). Pollio et al. (2006) reason that psycho-education is effective in providing families with tools to understand mental illness and provide more sympathetic support.

Here, it must be highlighted that in recognising that the emotional states of families comprising a person with bipolar have an impact on the development of the disorder, the emotional states of the family members themselves must not be neglected. Families in distress as a result of the disorder or any other factor must be understood and supported – with a positive effect of efficient and effective support for the patient but not only for that effect.

Quality of life for the patient. Vittersø (2004) defines quality of life as including both objective and subjective evaluations of one's own living. Objective quality of life is any dimension of living that is norm-referenced and based on systems or institutions (Vittersø, 2004). An example would be security from crime, standard of day-to-day living or financial security. Subjective quality of life is a person's appraisal of their life as fulfilling their unique wants and needs (Vittersø, 2004). These definitions can be problematised in a number of ways (see Vittersø, 2004), but to understand the relevant literature the concept can be viewed in its most essential form – a self-evaluation of satisfaction with one's own life.

When comparing the quality of life of people with bipolar disorder and other psychiatric disorders, it was found that people with bipolar disorder experience a significant impairment (Michalak, Yatham, Kolesar & Lam 2006). However, Mazza et al. (2011) found that people with bipolar experience a lower quality of life than a general population, but higher than that of people who have been diagnosed with schizophrenia. While acknowledging that research on

such a slippery concept as ‘quality of life’ in significantly varied populations must be viewed critically, we can, for the moment, accept that quality of life will be reduced in any long-term psychiatric disorder.

In Michalak et al.’s (2006) patient-centred assessment of quality of life, the theme of the patients’ conception of their ‘caregivers’’ proxy needs was established. That is, some patients in the study described feeling that their caregiving family members had a need to care for the patient that was not complemented by the patient’s need to be cared for. Patients reported that their caregiving family members showed over-vigilance for signs of recurrence, a preoccupation with a caregiving role, and reported feeling obliged to provide opportunities for caregiving.

Similarly, people with bipolar disorder expressed feeling that they were more well-liked by friends and family when they were hypomanic (Michalak et al., 2006). They expressed feelings of doubt around whether their friends and partners were initially attracted to their symptoms or their personality. Using this line of thinking, it may be that partners of patients feel a range of emotions when experiencing the symptom-neutral patient instead of the exciting, hypomanic person they may have been attracted to.

When Michalak et al. (2006) discuss the stigma associated with bipolar disorder they raise issues of the complexity of how stigma affects people. For example, their participants expressed concerns around disclosure of their disorder, identity associated with the disorder, marginalisation and stereotyping.

Some patients in Michalak et al.’s (2006) study reported that even if they had disclosed their diagnosis and it had been received well by the community, they felt that their identity was then shaped by their diagnosis. After diagnosis the community identified them as ‘being bipolar’ and being blind to their extra-diagnosis history and future.

Stigma

In his seminal work, Goffman defines stigma as a ‘marking’ of someone who does not live up to societal expectations (Goffman, 1963). A person who does not characterise the perceived normality of a group or context is treated as being disgraceful, discredited, and undesirable in implicit or explicit ways. This treatment prompts the stigmatised to hide this mark in whatever

way possible, in an effort to gain access to unencumbered social intercourse (Green, 2009) and ultimately social acceptance (Goffman, 1963). Importantly, Goffman reminds us that stigma is a matter of perspective. Members of a group will stigmatise those whom they perceive to be 'other', and this perception will be historically, politically and culturally situated (Goffman, 1963). As such we must be aware of the ways in which institutions might practice unintended stigmatisation.

Green (2009) describes Goffman's distinction between being 'discredited' and being 'discreditable'. If a mark of stigma is obvious and external, the person is immediately 'discredited'. For example, a person with a physical disfigurement is stigmatised and discredited upon being seen by others. A person whose mark of stigma is internal or can be hidden is 'discreditable' because the person knows that while the mark stays hidden he or she will be socially accepted, but if the mark is seen the person will be 'discredited' by society. Anticipated stigma (Quinn & Chaudoir, 2009) describes a person's feelings and beliefs around others becoming aware of the mark.

Quinn and Chaudoir (2009) similarly describe concealable stigmatised identities. A person who can conceal their mark takes on the task of keeping that mark hidden on pain of being rejected by society if the mark is seen. Link et al. (1989) explain that because many people have been taught the negative stereotypes associated with stigma before they are marked themselves, they still hold negative stereotypes about themselves and other people who have been assigned the same stigma. This is Goffman's concept of self-stigma, when stigma has been internalised so that a person feels self-hatred, shame, devaluates themselves and has a sense of dehumanisation.

Associative (Green, 2009) or courtesy (Quinn & Chaudoir, 2009) stigma is stigmatisation against people who associate with a person who has been marked, such as the family members of people with mental illness. Depending on the situation, this might also be a concealable stigma and the stigmatisation might have been internalised. So, a family member of a person with mental illness may feel distressed by being treated as discredited when people know about their association with a person with mental illness, they may be motivated to hide their association,

and they may have their own stigmatisation against the person who is mentally ill and self-hatred for their association with that person (Quinn & Chadoir, 2009).

Green (2009) argues that even in research on stigma and stigmatisation, the population that has been assigned the stigma is treated just as such. That is, research treats stigmatised populations as socially deviant, studying the interactions between the 'other' and the 'norm' without critically looking back on why the stigmatised population has been constructed in this way. When Green (2009) explains Goffman's interpretation of stigma, she explains that stigma taints or spoils a person's identity. Once the stigma has been assigned, the person is treated as belonging to the stigmatised group, and the rest of their identity is ignored and dismissed. Transposing this concept back to the body of research on stigma, Green (2009) argues that those who are stigmatised and then participate in research are still treated only as belonging to their stigmatised group.

Östman and Kjellin (2002) conducted a study of 'stigma by association'. Östman and Kjellin (2002) designed a quantitative study to measure the participants' "own objective feelings" (p. 495) around being stigmatised, providing care to people with mental illness and with the aim of assessing psychological factors in these cases. With the report that there were no significant differences in psychological factors related to the patient's demographics, such as type of mental illness and length of time spent giving care, Östman and Kjellin (2002) state:

> This may illustrate that the situation of being a close relative of a person with severe mental illness is in itself a factor of importance, and contradicts the conventional wisdom of anti-stigma initiatives, that members of the public differentiate between illnesses (Östman & Kjellin, 2002, p. 496).

This statement is worrying for several reasons. Firstly, Östman and Kjellin (2002) needed a statistical non-significance to suggest that there may be more to the experience of being close to someone with mental illness than measurable variables. This is confirmation of the argument that a medical model of 'caregiving' has become blind and numb to the people involved (Roberts, 2000). Second, it is not clear what Östman and Kjellin (2002) mean by 'conventional wisdom', or how they have come to understand that 'members of the public differentiate between illnesses.' However, the most worrying point is that Östman and Kjellin (2002) seemed to have identified the stigmatisers as the 'members of the public'. What would that make the

stigmatised? Are they not members of the public? The authors go on to conclude that they have found an association between relatives having symptoms of mental illness themselves and having a higher perception of stigmatisation. If this is true then it is the having of mental illness that makes one more likely to perceive stigmatisation, not the having of mental illness making it more likely to be stigmatised. Assumedly unintended, Östman and Kjellin (2002) have displayed a stigmatisation of the mentally ill and their relatives, the kind described by Green (2009).

According to Kakuma et al. (2010) there have been a number of programmes that target stigma around mental illness carried out in South Africa. Their study (2010) reviewed programmes established between 2000 and 2005. Kakuma et al. (2010) give an optimistic presentation of de-stigmatisation programmes, like those established by SADAG, the South African Federation for Mental Health [SAFMH], and the Mental Health Information Centre (MHIC) all of whom are involved to varying degrees in raising awareness, promoting mental health and well-being and providing information about mental illness.

However, Kakuma et al. (2010) argue that even though there seems to be an encouraging number of de-stigmatisation programmes in South Africa, "one cannot assume that raising awareness about mental illness will lead to a change in attitudes and behaviour" (Kakuma et al., 2010, p. 122). Therefore, it must be kept in mind that there is a far distance to travel between de-stigmatisation programmes and the lived effects of deeply entrenched stigmatisation. This concurs with Green's (2009) argument that research that merely looks at interactions around stigma and describes them does not act against stigmatisation. Perhaps Green's (2009) call for deconstructions of stigmatisation and the institutions maintaining oppressive discourses is a first step in acting against stigmatisation.

Perry (2011) conceptualises stigma in terms of labelling theory, developed by Link (1982) and Link, Cullen, Struening, et al. (1989). When a person is diagnosed with a psychiatric disorder, not only are their identity and behaviours looked at through the diagnosis, but the diagnosis results in feelings of rejection, a loss of status and discrimination in the diagnosed person. These feelings motivate secrecy, withdrawal, isolation and maladaptive interaction strategies which exacerbate symptoms and further feed into negative perceptions of psychiatric

disorders (Perry, 2011). The diagnosis then, becomes not only the label for the pathology but also a cause of on-going nature of pathology.

At the same time, when a 'sick role' is created (by diagnosis of a person) a 'caregiver role' is created as a necessary response. The diagnosed person is given a new role which excuses them from certain social obligations and responsibilities relative to the nature and severity of their illness (Parsons, 1951, cited in Perry, 2011). This means that someone close to the 'sick person' has to manage whatever obligations and responsibilities have been given up.

When the 'sick role' is created, the 'caregiver role' becomes necessary. Not only have we created a new identity for someone with a psychiatric disorder, we have also created a new identity for the people closest to the diagnosed person. If a researcher only sees a caregiving family member as a 'caregiver', the role is taken for granted and the personal experience of this family member is overlooked. The rest of the person's identity is lost. According to Green (2009) then, when we label family members of people with mental illness as 'caregivers' we are stigmatising them.

Poindexter (2002) used a narrative approach to explore one woman's experiences of stigma using five different methods of analysis. Poindexter's participant, Ann, cared for her son, who had contracted the Human Immuno-Deficiency Virus (HIV), until he died in their home. Poindexter (2002) interviewed Ann for a larger study and then identified two narratives about stigma which she analysed as a demonstration of what some different modes of analysis can offer. Poindexter (2002) first analysed Ann's narratives of being stigmatised with a rough transcript and only to comprehend the content. Poindexter then used Labovian structural analysis, a more function-oriented structural analysis (see p. 62), and two co-constructive approaches that emphasised the role of the researcher. With the different methods Poindexter (2002) gained depths of interpretation. Most significantly, Poindexter (2002) foregrounds the emotional experience of being stigmatised. Ann's sadness and rage at her son being treated badly because of his having HIV becomes more and more salient the deeper Poindexter moves with her analyses.

Poindexter (2002) provides a convincing argument for experimenting within narrative approaches to transcription and analysis, but also for the use of narratives in general. Poindexter

(2002) was able to gain perspective on her own influence on the research situation and the emotional context of Ann's stories. Ann's stories became a poignant influence to Poindexter's teaching and practice and as such Poindexter argues that getting in touch with the emotional and the personal are part of the power of narrative research.

Caregiving Family Members

According to Henderson and Forbat (2002), a distinct social category for caregiving has been constructed. This fixed identity is present in most research on family members of people with mental illness with no acknowledgement of the relational dynamic of a care dyad (Henderson & Forbat, 2002). In the first place, the caregiving construct assumes that care happens in one direction, from the active carer to the passive caregiver. This conceptualisation leaves no room for the possibility that in a care relationship there may be reciprocation (Henderson & Forbat, 2002), or even that a person diagnosed with mental illness may offer some form of care to their close ones. In the second place this conceptualisation is closed to the possibility that the relationship is not based on the care aspect – there is caregiving involved but that is not the identifying feature of that relationship (Henderson & Forbat, 2002). As a third point, the caregiving construct often assumes an independence-dependence binary so that dependence becomes a taken for granted assumption of disability (Henderson & Forbat, 2002). Furthermore, even though care is a natural part of any close relationship, this dynamic is isolated and pathologised as a symptom of mental illness (Henderson & Forbat, 2002).

In positioning two people as carer and care-receiver we are reducing the relationship to one of existing because of the requirement of care and disregarding all the possible forces that could hold and bring two people into an intimate relationship. The multiplicity of the relationship becomes invisible along with the emotional experience of the relationship (Henderson & Forbat, 2002).

Even though the conceptualisation of 'caregivers' is problematic, the literature is still valuable in its contribution to what we know about the experience of being close to someone with a mental illness. In Oshodi et al.'s study (2012) it was found that the most common burden of care was a feeling of having to exert a lot of physical effort, while the least common burden of care was a feeling of being in danger. They also found that participants older than 35 years old

experienced more burden than those that are younger than that, and males experienced more burden than females, which they suggest could be because of common cultural notions of gender roles (Oshodi et al., 2012). According to this study, many participants expressed feelings that the patient would be better off dead or wishing that the patient had never been born (Oshodi et al., 2012). This echoes a finding by Östman and Kjellin (2002), who reported relatives of people with mental illness expressing the same wishes, or that they had never met the patient.

Yusuf et al. (2013) similarly found that increased emotional distress in caregiving family members was associated with male caregivers, male patients and residence in a rural area. They also explain the gendered differences in the experience of distress by pointing to incongruence with culturally conceived gender roles and caregiving roles. They argue that people living in rural areas will most likely have inconsistent access to resources, which results in a higher feeling of distress.

Jeglic et al. (2005) suggest that that depression has a 'contagion' effect for the caregiving family members. They argue that perceived negative behaviour in the patient is associated with greater levels of depression in the partner, and hypothesise that this effect is mediated by the subjective levels of caregiver stress and burden. At the same time, depressed partners are less able to respond positively to the patient's positive behaviour (Jeglic et al. 2005). This means that the caregiving family member's appraisal of the caregiving and patient roles influences the extent to which they feel depressed (Jeglic et al. 2005).

Baronet (2003) suggests that subjective burden is mediated by the caregiver's appraisal of their role. For example, interference with the caregiving family member's work, leisure or social activities might result in the caregiver's negative appraisal of caregiving. Likewise, problems in the relationship between the caregiver and the patient might lead to a negative appraisal. The author suggests that a negative appraisal of the caregiving role is associated with high subjective burden and low satisfaction in caregiving (Baronet, 2003).

Perlick et al. (2012) argue that rumination acts as a mediator for the depressive symptoms in caregivers. Their study looked at gender as a mediating variable, but makes an interesting suggestion about the caregiver's ruminating style and level of mastery in terms of their partner's

mental disorder. They found that lower rumination and higher perceived mastery was associated with fewer depressive symptoms (Perlick et al., 2012).

Based on this data as well as Zergaw et al.'s (2008) finding that caregiver burden changes over time, we might infer that a caregivers' experience will depend to some extent on the dynamic nature of the patient's symptoms and psychological status as well as on the dynamics of the caregiver's responses to the patient and their own dynamic life. This points to caregiving partners' experiences as being multi-causal and multi-dimensional, rather than being static, uni-causal and/or independent of personality and time and space considerations.

Mavundla et al. (2009) conducted a study of caregiver experiences in Limpopo, South Africa. Their study is useful for a number of reasons. Firstly, they argue for the importance of qualitative research and emic investigations in less politically and economically developed areas. Secondly, in their results they show important factors presenting in a less developed area that influence the caregiving experience – for example, the nature of extreme financial burden and atrophied mental health programmes. Thirdly, they identify an important mental health system challenge; that insufficiently trained and overworked nurses are often the primary medical health carers in these areas. The authors also talk about the specific cultural conceptions of mental illness and treatment in South Africa.

Oshodi et al. (2012) similarly raise the issue of superstitions and cultural conceptions in views of mental illness. They argue, like Mavundla et al. (2009), that these conceptions affect the care of the mentally ill, and the caregivers themselves. In their study, Oshodi et al. (2012) found that one-fifth of their participants expressed the feeling of not being able to have their own friends, possibly because of the social stigma, but also because of the burden of care.

According to Hook (2002), the unique historical and social context of South Africa has created psychopathology specific to us. That is, it is not a matter of varying prevalences and presentations of mental illness constructed in Western conceptions, but that South African mental illness is unique in its constitution. Hook (2002) argues that more studies need to deconstruct cultural conceptions of mental illness and treatment in South Africa without importing the categories constructed in other places.

Even though these studies (Mavundla et al., 2009; Oshodi et al., 2012) are useful emic investigation, they reproduce the pathologised view of both the patients and the family members involved. Mavundla et al. (2009) argue that the conceptualisations analysed in their study were all negative, despite the neutral presentation of their interview questions, and that this is because of the way mental health is conceptualised. This is a further pathologising of the community which fails to consider that the negative view of mental illness is influenced by the experience of mental illness, and that stigma and marginalisation can be reduced by psycho-education, which will assumedly and insidiously hold the same view. In other words, if the medical community continues to pathologise the experience of mental disorders, psycho-education generated from this area cannot logically solve the issue of stigma. Henderson and Forbat (2002) argue that interventions aimed at psycho-education for caregivers professionalise their role and push the imposition of the medical model into private spaces even further.

In another direction, Townsend et al. (2006) give a useful review of the literature on co-occurring substance abuse and mental illness. However, they also exhibit the general pattern of the existing literature on the families of people with mental illness.

> This conceptual framework proposes that family involvement, hypothesized *to be a function of* the family member's stress and well-being, will have a significant influence on client outcomes. (Townsend, et al., 2006, p. 473, emphasis added).

In this quote we see an acknowledgement of the influence of the psychological status of the family member (the patient) on the families (assumedly 'healthy' relatives). However, we also see that the families' involvement is again only conceptualised as important in terms of the mental status and course of the patient, excluding any acknowledgement of the family (including the patient) that itself, as a unit, as a system, is being affected.

Chen and Greenberg (2004) researched the positive aspects of caregiving. They argued that while the positive gains of caregiving have recently been acknowledged, not enough research has been done on how to facilitate the positive appraisal of the caregiving role. They studied the effects of formal and informal support of the positive perception of caregiving. Chen and Greenberg (2004) found that there were higher levels of perceived gains when there was more positive interaction with mental health professionals, when other family members were involved in giving care to the diagnosed patient, when there was participation in a support group

and when there was perceived reciprocity in caregiving between the caregiver and the patient. Chen and Greenberg (2004) pointed out that there has been too much focus on caregiver burden, but the quantitative methods of their research means that there is no room for the possibilities that participants themselves could raise as significant factors (Stern, Doolan, Staples, Szmukler & Eisler, 1999). At the same time, Roberts (2000) points out that 'the individually meaningful may not be the same as the reproducibly measurable' (p. 433).

A systematic review and meta-analysis of interventions aimed at improving the experience of caring for people with severe mental illness was conducted by Yesufu-Udechuku et al. (2015). The authors found that psychosocial interventions were associated with improvements in the experience of caregiving and quality of life, and were negatively associated with caregiver burden and psychological distress. Their research also suggested the early interventions are more beneficial. Yesufu-Udechuku et al. (2015) showed that there is no evidence to suggest what type of intervention, for example psycho-educational or support groups, is most successful. They argue that research comparing interventions addressing the needs of the patient (psycho-educational) should be compared with interventions addressing the needs of the caregiver (support groups).

Evidence to suggest that early interventions are beneficial is also given by Lavis et al. (2015). Lavis et al. conducted qualitative research with 'carers' as part of a larger study analysing the effects of early intervention services for first-episode psychosis. This research investigated the experiences and affective challenges associated with caregiving and how these factors might intersect with access to early intervention services. They found that many of their participants appreciated these services because of the dissemination of clinical information and a feeling of being valued in the assessment and treatment of their diagnosed relatives. However, Lavis et al. (2015) also found that many of the carers were dissatisfied with the priority status given to their suggestions and observations and felt that there was no room for their own needs and emotions to be attended to. The authors point out an absence of help-seeking behaviour in the family members which they suggest could be because of the ubiquitous focus on the patient. Furthermore, Lavis et al (2015) assert that an absence of help-seeking behaviour cannot be taken as absence of a need.

Lavis et al. (2015) begin the report of this research with a problematic conceptualisation of 'carers'. They acknowledged that these people might not be primary caregivers but did not further acknowledge that these people may not self-identify as carers at all. In their purposive sampling they asked early intervention service users to give the contact information of someone who had supported them (p. 136), so the 'carer' term has been imposed. The term 'supporter' could be more apt here. Lavis et al. (2015) then discuss the implications of this construction of family members as carers.

> …Becoming a carer is not automatic at the moment of a relative's diagnosis but is a complex configuration of social processes, some of which are embedded in existing healthcare structures. (Lavis, et al., p. 140)

Lavis et al. (2015) conclude by calling for research that is genuinely focused on carers, not just as a means to better care for patients.

> Further research is therefore necessary to guarantee that carers are supported *alongside* as well as *through* service users, and to ensure that they are listened to as well as for (Lavis et al., 2015, p. 141, emphasis in original).

Stepping back to see a bigger picture, Steele, Maruyama and Galynker (2010) provide a comprehensive review of literature on psychiatric symptoms in caregivers of patients with bipolar disorder. They point out that the experience of providing care for a person with bipolar disorder may be different to providing care for other mental illnesses because of the significant variation in the patient's functioning, the anxiety around the possibility of future episodes, sub-syndromal symptoms and the high risk of suicidality (Steele, et al., 2010). They found that most research studying caregivers of people with bipolar disorder focused on caregiver burden. They also found that most published interventions were psycho-educational in nature and not targeted at the experiences of the family members of the patients. They suggest that stigma related to mental healthcare could discourage relatives from seeking treatment for their own symptoms of distress. According to Steele, et al. (2010) none of the existing studies reviewed took a history of their participants, the relatives of people diagnosed with mental illness. This means that none of these studies can know if the psychiatric symptoms observed in the 'caregivers' ever preceded the caregiving role. Taken further this means that we can be critical about the claim that it is the caregiver role that has necessarily caused the psychiatric symptoms. The literature has imposed a caregiving role on all family members of people with mental illness because they give care,

without an acknowledgement that there may be much more to living with or close to a person diagnosed with a mental illness.

The Narrative Approach to Caregiving Family Members

There is only a very limited body of literature that has researched the experiences of family members of people diagnosed with mental illness from a narrative perspective. Peljert (2001) analysed the narratives of parents of people with schizophrenia living in a psychiatric residence. She argued that the focus on the burden of care in literature is useful for our understanding of what it is like to be close to someone diagnosed with a mental illness, but that this focus has not provided a multidimensional or holistic understanding.

Peljert's (2000) study is somewhat confusing in its use of narratives, because the data is analysed from a phenomenological hermeneutics perspective. It seems that the study is not based on social constructionist understandings and that the term 'narrative' only refers loosely to the stories that were produced in the interviews, by chance of the narrative instinct (Riessman, 2008). Peljert (2000) exhibits the same use of the term 'caregiver' (eg. p. 195), when the participants in her study are specifically not providing care to their sons and daughters who are permanently residing in a psychiatric residence. Peljert (2000) replicates the findings of the caregiver literature, describing the distress experienced by family members of people with mental illness.

Stern, et al. (1999) used a more generalised sample of family members of people with severe mental illness and used a narrative methodology. They also used the term 'carer' to describe their participants without explaining how they came about assigning this term to the family members. That is, no indication was given whether or in what way these family members could be considered 'carers'. However, Stern et al. (1999) provided interesting insights into the way in which their participants have made meaning of their experiences. They too were able to replicate other caregiver literature in the main themes that were constructed by their participants, from a more recognisable narrative framework than was Peljert's (2000). Additionally, Stern et al. (2000) created a model of the two narrative structures observable in their data.

Stern et al. (2000) found that when trying to understand how family members of people with mental illness make sense of their experiences their narratives were either characterised by a reparation or restitution structure, or a chaotic or frozen structure. The reparation/ restitution structured narratives involved a *platform*, a part of the narrative from which the meaning of their experiences became reconstructed (Stern et al., 2000). This platform became the point at which the illness and its consequences became incorporated into the participants' present construction of their world. Alternatively, participants whose narratives were frozen or chaotic repetitively presented the same themes as if their meaning-making of their experiences was stuck. When looking for coping styles and belief systems in their participants' narratives, Stern et al. (1999) found that the participants delivering a restitution or reparation narrative seemed to have more consistent strategies for adaptively incorporating mental illness and its consequences into their lives than the participants who delivered frozen or chaotic narratives. Stern et al. (1999) provide a convincing argument that narrative research may have therapeutic implications for the family members of people with mental illness, and suggest that their research approach be repeated with larger and more diverse samples.

Another interesting suggestion by the authors is to establish an empirical link between narrative transformations and a concept such as expressed emotion. The bridging of positivist and constructionist approaches is, as discussed by Roberts (2000), a potentially fruitful endeavour; using two contradicting approaches in a complimentary way. Between Stern et al.'s (1999) model of the possible repercussions of storying experiences in a transformative way, and Roberts's (2000) argument for allowing room for the narrative approach alongside evidence-based medicine, the narrative paradigm is demonstrated to be a powerful tool for understanding and supporting the lives of those affected by mental illness.

In Ayres's (2000) narrative analysis of family caregivers she identified four story types. Ayres (2000) argued that because most research on caregiving starts from a position of 'caregiver burden' and the things that make the caregiving experience worse, it is necessary to conduct research with a neutral conceptualisation of how caregiving might be experienced. She analysed the narratives individually and then across-case so as to identify patterns and recurring story structures.

Ayres (2000) identified ‘ideal life’ stories, ‘normal/ordinary life’ stories, ‘life compromised by caregiving’ stories and ambiguous stories. In the ‘ideal life’ stories the participants presented caregiving as a life-changing and even life-saving force. Caregiving was identified as their purpose in life, as the thing they are meant to do with their lives and as something that saved them from the waste of other ways of spending life. In ‘normal/ ordinary life’ stories, caregiving was constructed as a routine part of a life. For these participants caregiving had been incorporated into their lives as a part alongside other parts. Caregiving was seen as a necessary component of having a relationship with the patient without resistance or resentment, but merely acceptance of that necessity. For participants who constructed a narrative of a life compromised by caregiving there was an emphasis on what had gone wrong in the relationship and an anticipation that more still would go wrong. These narratives were characterised by constructions of victimhood, helplessness and inescapable character flaws. In ambiguous stories, Ayres (2000) describes a lack of coherence, many incomplete explanations, incongruous constructions and illogical rationales. For Ayres (2000), these stories are still being constructed. They are incoherent because they have not taken shape for the narrators yet; their shape is not yet recognisable. Ayres (2000) suggest that in looking for the form of the narratives of people caring for sick relatives we can see opportunities for reshaping narratives to include meanings that are sustainable and satisfying; opportunities for narrative intervention.

Aranda and Street (2001) conducted participatory narrative research, another member of the narrative family, with palliative care nurses with the aim of generating knowledge about the embodied knowledge and lived practice of nursing people who are terminally ill. They conducted individual narrative interviews with participants, asking them to relate a time when they had developed a friendship with a patient. Aranda and Street (2002) then gave the interview transcripts back to their participants before conducting narrative focus groups. Aranda and Street (2002) argue that this methodology allows for participants to reflect back on and develop their narratives, so that the research is witness to a process of a transforming narrative. Aranda and Street (2002) present interesting findings developed by their participants. In particular is the suggestion that people providing care may feel that they only qualify for support if they meet certain criteria; for example, a palliative care nurse must practice certain ethical boundaries and if he or she does not do that, his or her colleagues may show less sympathy and support.

We can transpose this possibility onto the people who are close to those diagnosed with mental illness and how we view them. If research is constantly looking for the most effective coping mechanisms and the personality or relationship qualities that are associated with a distressing caregiver experience, it is possible that we are communicating to this population that their experiences are only valuable to researchers if they are adaptive enough, positive enough or distressing enough.

Intimate Relationships including a Person with Mental Illness

Trump and Hugo's (2006) study of South African mental health patients found that 52% of their bipolar disorder sample was experiencing tension in their relationship with a partner or spouse because of their disorder. 57% of the participants were divorced or separated, and 26% of participants stated that they were divorced or separated because of the disorder (Trump & Hugo, 2006).

Horesh and Fennig (2000) compared couples who were not experiencing any significant distress with couples where one partner had been diagnosed with an affective disorder that was in remission. They argued that previous studies of how relationships were affected by the experience of bipolar disorder had studied the couples while the patient was experiencing acute symptoms of depression or mania. Horesh and Fennig (2000) argued that by studying such couples while the patient is in 'remission' they could control for the effect of a disordered state on the couples' reporting of the relationship. That is, they hypothesised that while the patient was in 'remission', the couple might function more like a 'well' couple. They found a negative association between being married to a person with bipolar disorder and positive perceptions of the relationship, even when the symptoms were not acute (Horesh & Fennig, 2000). They also found that the history of one or more suicide attempts, diagnosis, history of hospitalisation in the patient and employment in the partner were significant predictors of negative perceptions of the relationship. Duration of remission and age of onset of illness in the patient, and duration of marriage and demographic variables were not significant predictors (Horesh & Fennig, 2000).

This study provided useful quantitative data to show that even while in 'remission', a relationship involving a person with bipolar disorder is still more volatile than a couple not involving any observable distress. However, this study can be problematised in a number of

ways. Firstly, their hypothesis that while in remission couples with a person with bipolar disorder may resemble non-distressed relationships is reductionist. By hypothesising that if there are no symptoms there may be no distress in the relationship, one is reducing bipolar disorder to its acute symptoms with no acknowledgment of the on-going effects of past symptoms, sub-syndromal symptoms and side effects of medication. Furthermore, it is excluding the possibility that a major depressive episode or a manic episode might have lasting effects on a relationship. Secondly, Horesh and Fennig (2000) have isolated the symptoms of bipolar disorder as the independent variable without providing for the possibility that bipolar disorder is not just its symptoms (McWilliams, 2009). To think that symptoms cause distress, so no symptoms might mean no distress is a linear line of thinking that ignores the complexity of a life with bipolar disorder. Lastly, when Horesh and Fennig (2000) discussed their findings, they argued that couples' therapy should be included in treatment planning so that the patient would not be vulnerable to a "vicious cycle" (par. 17) of negative expectations from their partner exacerbating their symptoms which affirms negative expectations. Others (eg. Miklowitz, 2007) have commented on the self-fulfilling prophecy of family members' negative perceptions of a person diagnosed with a mental disorder. But to emphasise the importance of their research only in terms of the needs of the patient places undue responsibility on the partner for the course of the patient's symptoms, again reduces bipolar disorder as if absence of acute symptoms will mean absence of distress, and ignores the possible distress of the partner (Henderson & Forbat, 2002).

Rowe and Morris (2012) have made interesting observations concerning the associations between each partner's level of functioning and the functioning of the relationship. They also acknowledge the complexity of the phenomenon they have studied, stating that the cross-sectional design of the study provides a very limited view of the relationship (Rowe & Morris, 2012). However, the following quote can be viewed as a representation of most of the literature around bipolar disorder and intimate relationships.

> …These results support the need for further research on the predictors of partner mental health, including longitudinal studies that track the associations between symptoms, functioning, and relationship adjustment over time. Such work may have significant implications for interventions to prevent relapse in BPD [bipolar disorder] and improve relationship functioning, and thus, ultimately, quality of life for both partners. (Rowe & Morris, 2012, p. 335.)

Already a very under-developed area, the literature examined for this research assumes a view of bipolar disorder as an isolatable, abnormal phenomenon wreaking havoc on would-be healthy relationships. In the above quote, there is an assumption that preventing relapse in the patient will result in a 'healing' of the relationship, and that this movement towards better relationship functioning will yield better quality of life. Furthermore, in the above quote, there is no acknowledgment of the complexity of a relationship – that a relationship between two people, one having bipolar disorder, is more than just a mix of "symptoms, functioning and relationship adjustment over time" (Rowe and Morris, 2012, p. 335).

This study is then useful as a ground level scope of the social impacts of bipolar disorder, but it does not satisfactorily describe the complexity they have pointed to, making no mention of socio-cultural and political factors, individual perceptions of the relationship or a qualitative investigation into the 'functioning' of the relationship.

Checton, Greene, Magsamen-Conrad and Venetis (2012) focused on how the perception of illness uncertainty and illness intrusion affected communication in relationships where one person had a chronic health condition. Illness uncertainty – around the nature of the illness, an unknown future, perceived stigma, a lack of information and social support, conflicting diagnoses, or the development of new symptoms – was found to be positively associated with illness intrusion – the perception that the chronic health condition is negatively affecting daily activities, lifestyles and/ or interests. Illness uncertainty and illness intrusion were negatively associated with communication in the relationship (Checton et al., 2012). This study is valuable in its complex conceptualisation of how a relationship is affected by a chronic health condition. While they only focused on one particular interaction of factors they open spaces for possibilities of how relationships function and how partners in relationships may perceive their context uniquely. For example, the authors raised the possibility that relationships do not necessarily need to be characterised by absolute openness – they argue that it is natural to be discrete about some topics in a relationship. For Checton et al. (2012), this means that while there is a positive association between open communication and positivity around a chronic health condition, it does not mean that interventions should be aimed at indiscriminately facilitating open communication. For Checton et al. (2012) this is too simplistic an assumption. Instead, the authors recommend interventions that facilitate co-existence with illness uncertainty, managing a

chronic health condition so that it is incorporated into the relationship in a way that is sustainable and beneficial for that particular relationship (Checton et al., 2012).

In a more socio-politically oriented study, Simon and Barrett (2010) raise the assumption by social scientists that intimate relationships are more clearly associated with women's mental health. They argue that as gender roles have changed there has been an increase in recognition of the importance for intimate relationships for women and men (Simon & Barrett, 2010). They also argue that women are rendered more economically and financially dependent on relationships than men are, by political and economic forces (Simon & Barrett, 2010). Simon & Barrett (2010) go on to discuss the emotional benefits of intimate relationships (which they have found not to differ between men and women) and the effects of partner strain (which they have found to cause more depression in women and more substance abuse in men) (Simon & Barrett, 2010.)

While this study does not offer a qualitative investigation of relationships involving a person with bipolar disorder, it acknowledges socio-political forces, gives a more specific count of the complexity at stake, and makes a clearer argument for the benefits of intimate relationships for both the person with bipolar disorder and the partner.

Sheets and Miller (2010) sought to identify individual traits in the bipolar disorder patient and his or her family that might contribute to family dysfunction and strain. The authors argue that if these traits can be identified they can be targeted in family interventions (Sheets & Miller, 2010). This is an interesting study that looks at the influencing characteristics of individual units, but in this way the family system is overlooked, socio-cultural influences are ignored and individual characteristics are pathologised as being 'bad for bipolar disorder' or 'bad for family functioning'.

> It is likely that the patient depends considerably on his or her partner for support and consistency during mood episodes. If the partner's own maladaptive affective and behavioural patterns (Axis II pathology) compromise meeting these needs, the quality of the relationship, as assessed by the DAS [Dyadic Adjustment Scale], is likely to suffer (Sheets & Miller, 2010, pp. 376-377).

In acknowledging and exploring the family system, Stanton and Welsh (2012) provide useful recommendations for researching families and couples. They warn against reductionism and linearity, and suggest that a problem in a relationship must be conceptualised in terms of the

complex interaction of the origin, continuation and evolution of that problem. They argue that comprehending complexity, recognising reciprocity and accepting ambiguity are some of the lines of thinking that are conducive to understanding a family system (Stanton & Welsh, 2012).

Reid, Doell, Dalton and Ahmad (2008) present their systemic-constructivist couple therapy. This approach tries to understand the marital relationship as a unit that is affected by its culture and context. They argue that the four traditionally examined categories of variance in couple therapy – cognitions, behaviours, emotions and systemic parameters – need to be given equal attention in conceptualising the system, and that these categories need to be situated within a culturally and contextually sensitive understanding of the relationship (Reid et al., 2008). While systems theory is not a social constructivist perspective and is focused on intervention (Stanton & Welsh, 2012), the assumptions of this paradigm are useful to keep in mind for this research in order to comprehend the complexity of being in a relationship with someone with bipolar disorder.

In a more sociological direction, Santore (2008) outlines the social movements that may have contributed to differing conceptions of relationships. These include demographic shifts (the example given is of marriage and childbearing age) gender role ideologies, and social movements such as the emergence of identity and therapeutic culture (Santore, 2008). An important discussion is around the role of individualisation in relationships. The author uses literature to argue that the individual has been highlighted in the production of an intimate relationship. The individual is encouraged to pursue his or her rights to self-development, self-recognition, cultivation of personal identity, egalitarian partnership and deep emotional connection. Santore (2008) argues that this renders the relationship as a resource centre for the individual rather than some other intrinsically valuable thing.

Josselson (2013) raises interesting points in trying to understand relationships. Firstly, the triadic nature of relationships. The author argues that a relationship between two people is always performed, experienced and interpreted within a social context which must be treated as the "Third". The "Third" is also what forms an outside perspective of the relationship – the conceptualisation and expression of it are shaped by the context of the outside observer. Secondly, that:

> "…between two people, internal images and experiences mingle and are transformed and re-internalized in novel ways without any clearly identifiable sense of who has contributed which elements" (Josselson, 2013, p. 90).

That is, there is a "space between" each individual in the relationship that is often unnoticed when the relationship is analysed, where the intersubjectivity shared by the partners exists. The relationship meaning is co-created and shared by the partners in a way that, when treated as belonging separately to each individual, dissipates and is lost (Josselson, 2013). This means that we cannot hope to understand the shape, form and experience of the relationship by looking at one 'snapshot' of it (one of the partners describing and constructing the relationship in an interview context). Rather, we need to view the relationship as a dynamic, intersubjective phenomenon that has been locally constructed in a narrative account.

Conceptual Framework: A Social Constructionist, Narrative Approach

Qualitative research stands in opposition to the positivism and empiricism of quantitative research (Burr, 1996) and has been one of the forces in eroding the claims that traditional, empirical science make to what qualifies as 'knowledge' (Emerson & Frosh, 2009). Qualitative research has done so by denying that statistical representation of experience is objective and asserting that such representation is reductionist (Emerson & Frosh, 2009).

One such approach to qualitative research is social constructionism. Burr (1996) explains that social constructionism does not have one specific definition, but does have underlying assumptions that perspectives such as conversation analysis, discourse analysis, deconstruction, post-structuralism and narrative analysis have in common. Firstly, in social constructionism, taken for granted knowledge is regarded critically; it is not seen as objective. Social constructionism is opposed to positivism and empiricism, denying that we can simply observe the world around us to reveal its 'true' nature, or that what we perceive to exist, exists. This is an anti-realist stance that argues that what we know about the world is not a direct perception of a reality; our perception of reality is constructed. As such, the concept of 'truth' is problematised, and there is no attempt to define knowledge as 'objective fact'. In social constructionism it is argued that the categories that we use to order our knowledge of the world do not exist independently – they are arbitrary divides and groupings that are not necessarily 'real'. This is an anti-essentialist stance that assumes that there can be no finally determined nature to people and

the world. It denies that there is a 'true essence' or core content to humans and human life that can be discovered or defined.

Secondly, according to Burr (1996), social constructionism assumes that knowledge is historically and culturally specific. The categories and concepts that humans use in understanding their worlds are product of the time and space which they inhabit. As such, knowledge emerges and changes from its specific historical and cultural context. No knowledge is more 'right' or 'true' than any other knowledge, because all knowledge has been produced in contexts of complex social tapestries. Therefore, no one knowledge system should be privileged above another. This means that even knowledge generated from a social constructionist approach must always be regarded critically, because it too, has been constructed in a particular knowledge context. Social constructionists argue that because it is assumed that knowledge is never 'objective' and always a product of social context, sociology and psychology must give up on a search for the 'truth' about humans and the way they live together. Rather, the human sciences should attend to the ways in which history has produced certain knowledge systems and explore the ways in which social practices produce knowledge systems.

Thirdly, Burr (1996) describes knowledge as being sustained by social processes. In the specific times and places in which people live they construct knowledge together, communally and socially. In social interaction knowledge is created, developed, and shared. This makes language an important focus for social constructionism, because it is assumed that without language there can be no thought. While some traditional theorists regard language as an expression of thought – a more or less parallel revealing of what happens in our heads – social constructionism views language as the material of thought; a precondition for it.

Fourthly, knowledge and social action exist interdependently. As each thread of knowledge is constructed it invites, interpolates and constitutes social action so that we act in response to our knowledge. Some patterns of knowledge responses exclude and oppress other actions, and it is here that we can deconstruct knowledge responses to explore the possibilities for alternative, non-oppressive actions (Burr, 1996). Because language is regarded as a precondition for thought, language is conceived of as social action, rather than a passive transportation of thought (Burr, 1996).

Based on these four assumptions, Burr (1996) explains that social constructionism regards social phenomena as being created and sustained or changed through social practices. Social constructionism therefore turns its attention to these social processes, exploring interaction, language and the way in which knowledge is produced in social practices. Burr (1996) places social constructionism in a middle ground of traditional psychology's focus on the individual and traditional sociology's focus on social structures. Social constructionism holds both social structures and individual agency in mind to understand how individuals engage in, contribute to and resist social practices and knowledge systems.

Hook (2002) argues that the knowledge systems, or discourses, we use have consistently constructed difference by determining identity categories such as nationality, race, gender, religion. One of these identity categories is that of either being 'sane' or not. In line with a social constructionist perspective, Hook (2002) explains psychopathology as not existing independently of the human construction of it. It was not discovered, existing somewhere without human knowledge and outside of human thought. Psychopathology is a discourse that we use to define sanity, to explain what we think of as 'normal' psychology and what we reject as 'normal' psychology. Hook (2002) identifies the 'sane/insane' binary as being one of the fundamental political norms – that is, whether or not a person is sane is a central claim to power. Hook (2002) does not deny that there could be a biological basis to mental illness, but argues that as soon as we talk about mental illness, a social act, we construct this biological basis in ways that are historically and culturally specific. Even if there is a biological basis to mental illness that everyone can agree on, its existence can only be conceived of by discourses imbued with cultural, historical and political specifics.

One of the oppressive discourses around mental illness is that of the patient who presents to a psychiatrist with a problem, who is then passively diagnosed from the psychiatrist's expertise and prescribed a treatment plan that satisfies the psychiatrist's notion of what must be fixed and how (Fuller & Hook, 2002). We can transpose this discourse onto the 'caregiver' discourse currently being used in much of the literature on relatives of people with mental illness. Researchers diagnose 'caregivers' with 'caregiver burden', describe 'symptoms' of depression and anxiety, social isolation and stigma, and prescribe psycho-education. These people have been constructed as caregivers with obvious disregard of a cautious operational

definition. ‘Caregiving’ has been constructed as an active and one-way act towards a passive, disabled patient (Henderson & Forbat, 2002). ‘Caregivers’ are assigned the ‘personal tragedy narrative’ (Green, 2009), whereby they are viewed as victims of the destructive force that mental illness has been constructed as. When researchers explore the associative stigma felt by family members of people with mental illness they describe the feelings around being stigmatised and hypothesise about the possible implications, being complicit in treating stigmatisation of these people as understandable and natural because they are different (Green, 2009). Such treatment of stigma in the literature sustains the construction of stigmatisation as a natural response to ‘difference’, instead of attending to the institutions, discourses and social contexts that have constructed this ‘difference’ in the first place (Green, 2009).

Narrative inquiry is one of the social constructionist perspectives. In narrative inquiry attention is drawn to texts as ways of seeing which discourses a person draws on to structure their experiences (Emerson & Frosh, 2009). As a person makes meaning of his or her world they order their experiences temporally, including some events and excluding other events in a way that builds a story of what happened that progresses and aims to convey some of the meaning they have made (Burr, 1996). The bricks that a person uses to build this story are the discourses that bound their understanding of the world. As such, a person uses some discourses, challenges discourses, rejects discourses and contributes to discourses (Emerson & Frosh, 2009). Therefore, we can use narratives to gain a sense of how a person is making sense of their world, how they understand the event they are narrating. This is in opposition to other qualitative stances that assume that the content of a person’s research interview must be ‘true’ representation of their experiences, and that if one can see the same content in many people’s research interviews then it must be so for others like them (Burr, 1996; Emerson & Frosh, 2009). Rather, narrative inquiry focuses on the structures that can be seen in a person’s talk, to understand what tools a person is using to understand their experiences. At the same time, narrative research assumes the content of a research interview to be locally produced, dependent on many visible and invisible influencing factors, as well as on the particular interaction between the researcher and the participant. Narrative inquiry does not subject its participants to the ‘expert knowledge’ of the researcher but understands the authority of the research situation to be with the participant – the participant as narrator is knowledgeable about her or his own experiences (Emerson & Frosh, 2009). Individual narratives are viewed as intrinsically interesting and important, not as valuable

for the strength of the generalisability of research claims (Emerson & Frosh, 2009), but also valuable as suggesting possible realities for other people (Poindexter, 2002).

The strength of narrative inquiry lies in its ability to move from investigation to action (Emerson & Frosh, 2009). Where approaches like discourse analysis and conversation analysis have been criticised for being unable to account for the agency of people and therefore unable to provide opportunities for the social action, the narrative approach can provide both analysis and social action (Emerson & Frosh, 2009). While discourse analysis can comment on the underlying assumptions with which people understand their world, the narrative approach can explore these assumptions and then open spaces for human agency to reflect on, develop and resist the assumptions that are oppressive to them and those around them. The narrative approach is a tool for both the understanding of and facilitating alternative or replacement of oppressive canonical (widely shared and understood) narratives (Emerson & Frosh, 2009).

For this research then, the narrative approach lends assumptions of constructed, localised knowledge that is intrinsically important, of the narrator as more knowledgeable in the research situation, and of the ability to inform efforts to facilitate liberating and empowering narratives for other relatives of people with mental illness (Ayres, 2000).

Gaps in the literature

Even though there is a relatively large body of literature on the family members of people with mental illness, there are significant gaps in the literature. Firstly, most literature looks at more than one mental illness at a time, assuming that the experience of living with bipolar disorder, for example, is the same as living with schizophrenia. Furthermore, even though it is clear that bipolar and related disorders can present in vastly varying ways, there is no attention to the particulars of how family members perceive the symptoms. That is, there is no recognition that in such a diverse mental illness it may be the case that family members may be experiencing very different behaviours and mood states in the person diagnosed.

In the literature on family members of people with mental illness there is very little work that gives attention to how bipolar disorder exists in intimate relationships. While research has been conducted that identifies ways in which bipolar disorder can be detrimental to relationships, there is no research that tries to understand how two people incorporate and integrate bipolar

disorder into their lives. Bipolar disorder is treated as an isolatable phenomenon, with no recognition that it may not just be active manic or depressive states, or caregiving, that have an effect on the relationship.

Lastly, the few narrative studies that have explored the experiences of family members of people with mental illness have imposed a character of 'caregiver' on their participants. They have tried to understand the types of stories that are being told and what the nature of such types might imply about the 'caregiver experience' but have not tried to deconstruct the understandings that family members of people with mental illness have about their experiences.

Conclusion

While there is a relatively large amount of research on bipolar disorder and the 'caregivers' of people with bipolar disorder, it is clear that there are specific views from which this research is taking place. We can see that some research is now questioning the definition and conceptualisation of bipolar disorder, and that mainly pharmacological treatment of it is a complex and on-going process. However, research on the experience of bipolar disorder rarely takes the contestation of the characteristics of bipolar disorder into account, taking for granted the descriptions of it given by the DSM IV-TR or DSM 5. Furthermore, the socio-political context in which people are living with bipolar disorder is not given attention. When family members are given focus they are also given a responsibility for people diagnosed with bipolar disorder without a genuine interest in their experiences as important in and of themselves. In examining the family members of people with bipolar disorder there is a general theme that parallels the categorical, biomedically influenced conception of the disorder – that this pathology has created a new pathology of 'caregiver burden'. This 'diagnosis' is simplistic and itself centres around the mental illness – only acknowledging the burden of care when there might be a range of emotions and experiences involved when a person is close to someone with bipolar disorder.

The term 'caregiver' imposes a role that excludes the diversity of relationships between people who care for each other, the possible reciprocity in a caregiving relationship and emphasises the care aspect of a relationship at the expense of the other possible bonds between people. Specifically, intimate partnerships have not been given attention other than as a

conflation with any people close to people with bipolar disorder. Having identified the way 'caregivers' of people with mental illness have been positioned, and the lack of focussed attention to partners of people with bipolar disorder, the social constructionist approach and narrative method of inquiry will provide a perspective from which to challenge this master narrative.

Chapter 3: Method

This chapter will explain the methods of this research and the main concerns with which they were chosen. Based on the literature review, the complexity of bipolar disorder has been kept in mind and has been used as a resource rather than an obstacle. The methods for this research were chosen with the intention of gaining rich, diverse data that while not being generalisable or falsifiable, is interesting in terms of the insights it yields and has potential to inform future research.

Research Questions

In order to understand the experiences of partners of people with bipolar disorder, this research focuses on the following questions:

1. How have partners constructed the meanings of bipolar disorder in their narratives of their relationships?
2. How have partners constructed the effects of bipolar disorder in their lives and their relationship with the patient?
3. How do partners situate themselves and the patient within their narratives of the effect of bipolar disorder on their relationships?

These questions have focused this research on the ways in which partners of people with bipolar disorder make meaning from their experiences without the imposed role of 'caregiver', without a deterministic measuring of their experiences and without the aim of finding 'symptoms' of their experiences.

Research Approach

This research attends to its questions using an exploratory, co-constructive narrative approach.

Exploratory research. This research does not aim to test hypotheses, to be generalisable or to make any definitive claims (Patton, 2002). Rather, it looks at partners of people with bipolar disorder from a different theoretical stance and explores what can be seen. It is hoped that this research will contribute to future research as an exploration of the possibilities of how people experience being in a relationship with someone with bipolar disorder.

Co-constructive research. Holstein and Gubrium (2002) describe the active subject. The subject is not seen as a container of knowledge, phenomena or experience that can be tapped into or examined. Rather, participants are seen as active meaning-makers that are responding to an interactional situation (the interview). Therefore, the interviewees and the interviewer are seen to be constructing meaning together and in response to one another.

From this perspective, the interviewer is not seen as a contaminating force. In acknowledging the action of the interviewee, the action of the interviewer is seen as similarly interactional and further, unavoidable. Holstein and Gubrium (2002) and Speer (2002) argue that the interviewer cannot ever be removed from the interview situation, so instead of trying to control the ways in which the interviewer /researcher 'contaminates' the data we can shift our focus to how meaning is created by the interviewer and the interviewee in a specific interaction.

Co-constructive research is one of the underpinnings of the narrative approach. According to Schegloff (1997), narratives cannot be isolated as existing independently. They are interactionally and dynamically created. We cannot think of them as representing a person's whole life or their whole perspective, but as trying to achieve something in a particular time and space.

Narrative research. Andrews, et al. (2008) explain that the narrative method does not come with any general methodological rules. It is not an approach that dictates a certain structure, but rather a way of seeing the participants and the data. The authors assert that narrative enquiry examines "different and contradictory layers of meaning" (p. 2).

What seems more important than establishing structural guidelines is to understand the meaning of 'narrative' and what these 'layers of meaning' might be. The narrative approach assumes that there are "… individual, internal representations of phenomena – events, thoughts, feelings – to which narrative gives external expression" (p. 5).

This assumption is important in establishing what we are looking at. This approach distinguishes between ontology and epistemology (Carolan, 2005) and assumes that the ontology of the event is not directly knowable. Rather, we only have access to a person's narrative of an event, thought or feeling, and so to understand the possibilities of *what* happened, *how* the *what*

is being told must also be understood (Holstein & Gubrium, 2002). Here, the *what* is not conceived of as 'objective' or agreed upon by other people, the *what* is the nature – the events, thoughts, feelings – of the individual experience.

> "In everyday oral storytelling, a speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants the listeners to take away from the story. Events perceived by the speaker are selected, organized, connected and evaluated as meaningful for a particular audience." (Reissman, 2008, p. 3)

Here we start to see how the *how* is examined. The sequencing employed by the speaker, the consequences connected to story, and the purpose of the story are all unique features of each story. The speaker constructs the story from internal resources into a narrative that is expressed externally.

According to Andrews et al. (2008) we can look at many features of stories. We can look at how stories are structured, how they work to produce meaning, who produces what kinds of stories, how narratives are silenced, how they are accepted or rejected and what meaning is taken away from them and to what effect.

In wanting to pay attention to individualistic features of narratives and the social context shape of narratives, Andrews et al. (2008) suggest that analysis should maintain a humanist assumption of a singular, contained subject and concurrently an appreciation of the narrative as socially constructed, being constructed still and as variable and multiple.

An exploratory, co-constructive, narrative approach allows this research to understand the complex experiences of partners of people with bipolar disorder, and to understand whether partners construct the effects of bipolar disorder on their lives as similar to or differently to how the effects of bipolar disorder have been constructed in the majority of the literature.

Participants

This research used a mixed purposeful, non-probability sampling approach (Patton, 2002). Organisers of support groups and a manager at a step-down facility were asked to participate by sending the information for this research to their members (Appendix A), who were asked to contact me if they were interested in participating in my research. Four people from a support

group and one person associated with the step-down facility contacted me. All five of these people were eligible and all were recruited into the study.

Candidates were eligible for this study if they were adults who have been married to or in an intimate relationship with a person with bipolar disorder for five years or more from the time of diagnosis. This means candidates had to be twenty-three years or older to participate. Candidates could be in a relationship with someone with bipolar disorder at the time of recruitment into the study, or the relationship could have occurred in the past, provided that the relationship lasted for five years or more and occurred in the last ten years. This time frame was established as a way of including participants who have been experiencing the disorder for a significant amount of time – the assumption being that five years is a long enough time for the disorder to have had a noticeable effect on more than one domain of the partner's life, and the last ten years being an amount of time that still allows the candidate to have specific memories about the time in question. Two participants were in a relationship with people with bipolar disorder, one participant was in a long-distance relationship with his partner who had bipolar disorder, and two participants were separated from the patient at the time of data collection. Candidates had to be living in Johannesburg to allow for convenient contact.

Candidates were not excluded on the basis of gender, race or sexual orientation, as these were not influencing factors being examined. The socio-cultural background of the participants was taken into account as it pertained to their own narratives, and not how it compared to other participants. Candidates did not have to be South African citizens but they had to be comfortable with the interview being conducted in English.

This exclusion criterion was necessary because in acknowledging the complexity and importance of an accurate, socio-culturally sensitive translation (Temple & Young, 2004), this research recognised that it did not have adequate resources for such an endeavour. However, this exclusion criterion was irrelevant as all five participants were first-language English speakers. All five participants were white and middle-class. This aspect of the sample will be discussed in the *Strengths and Limitations* section in *Chapter 5: Conclusion*.

This research did not aim to be generalisable. Because of the time and resource limits of this research project only a small sample size was possible. At the same time, narrative inquiry

does not aim to find common themes or significantly recurring experiences in its analyses that can be mapped onto other populations (Riessman, 2005).

Because of the exploratory nature of this research, there is no particular socio-cultural focus except that of the South African context. While socio-cultural and political factors will be noted and examined in the participants' narratives, this research is not asking questions about how specific cultural groups experience this phenomenon, but rather how five individuals experience this phenomenon in the South African context and how their narratives can reveal the unique complexities of being in a relationship with someone with bipolar disorder.

Data Collection

A semi-structured interview approach was chosen. This maintained a focus on the research topic and questions that simultaneously allowed room for the participants' judgement of the topics that were important for them (De Fina, 2013). The semi-structured interview schedule (Appendix F) was based on the research questions and theoretical approach of this research.

This research project had time constraints that only allowed for ten hours of interview data to be analysed. Based on the exploratory aims of this research, it was reasoned that five participants each giving two interviews would allow for more complex and interesting data than ten participants each giving one interview. This is also more in line with a narrative approach – spending more time with fewer participants to unearth more narrative content (Riessman, 2008). Therefore, two interviews were conducted with each of the five participants.

The first interview was used to gain a sense of the history of the patient as it relates to the participant, a history of the relationship and the ways in which the participant feels bipolar disorder has affected their lives and their relationship with the patient.

The second interview served the purpose of enriching the data. The 'highlighted' aspects identified from the first interview were probed so as to gain a deeper understanding of them. The participants' reactions to the presentation of these highlighted aspects were carefully observed to identify whether a participant rejected those aspects as being unimportant, resisted them or accepted them. This is in line with a co-constructive approach – the researcher and the participants' input are viewed as being in response to one another (Holstein & Gubrium, 2002;

Schegloff, 1997). The two interviews' data were analysed alongside one another, taking care to examine differences and similarities across the two interviews. Interestingly, most of the central concepts the participants chose to bring to their narratives were consistent across the two interviews, but where the concepts were inconsistent it provided one source for analysing the "different and contradictory layers of meaning" (p. 2) discussed by Andrews, et al. (2008).

Riessman (2008) suggests that narrative interviews must encourage the "ubiquitous narrative impulse" (p. 26) by giving up the traditional authority given to the interviewer. The interview is re-conceptualised as a discursive event between two co-constructing individuals rather than a protocol where the interviewer guides the focus of the interview (Riessman, 2008). In narrative interviewing, questions are asked that encourage a representation of the sequence of the events, and the meanings that the participants have come to construct to make sense of those events without closing any possibilities for the topics, experiences or meanings that are important with the participants themselves (Riessman, 2008).

I conducted the interviews using Josselson's guidelines for narrative interviewing (R. Josselson, personal communication, 9 July, 2015). Josselson suggested that the interviewer begin by giving the participant a summary of their research aims and an invitation to explore this topic. By doing so, Josselson suggested that the participant is invited into the research arena on their own terms, and with no imposed structure on how they should deliver their narrative. The participant is encouraged to start where they feel the beginning is and to raise what they feel is most salient at that time. When needing to facilitate more narrative content from the participant, the interviewer can use techniques of silence, asking for clarification, reflecting and confronting. These techniques give the participant fuel for more narrative content without taking control of the focus of the interview. At the same time, the discursive acts of reflecting content and feelings, remaining silent, asking for clarification and confronting incongruences leave space for the participant to reject the interviewer's input or re-negotiate the meanings they have thus far expressed (R. Josselson, personal communication, 9 July, 2015).

Procedure

Once ethics clearance was granted, support groups for family members of people with bipolar disorder in Johannesburg were contacted and asked if they were willing to provide me with

access to their members (Appendix A and B). Only one facilitator of a support group returned contact within the necessary period, and e-mailed the participant information sheet (Appendix C) to her contact list. I attended her support group and explained my research to the members and answered their questions. Four people e-mailed me and expressed willingness to participate.

Gateway House (a residential home in Johannesburg for people with bipolar disorder and schizophrenia) was given the organisation participation information sheet (Appendix A and B) and asked if they were willing to give me access to any partners of people with bipolar disorder that they were in contact with. Gateway House agreed to participate and a psychiatric nurse who has maintained contact with the residents' families for a substantial period of time contacted several of the residents' partners to explain my research. Only one of those that she contacted expressed willingness to participate and I was given her contact details.

I made contact with each of the five participants and arranged a time and a place to conduct the first interview. I suggested to each participant that we meet at their homes if they felt most comfortable there, or at the Emthonjeni Centre at the University of the Witwatersrand if they preferred a more neutral location. Two participants invited me to their homes, two participants asked to meet at restaurants and one participant asked to meet at the Emthonjeni Centre.

Data was collected in two face-to-face audio-recorded interviews per participant. At the beginning of the first interviews I gave each participant another copy of my participant information sheet (Appendix C) and asked them if they had any questions about the procedure, anonymity or confidentiality. I then asked them to sign a form that corresponds to the participant information sheet (Appendix D) and a form that stated consent to audio record the interviews (Appendix E). This was taken as a formal record of their acknowledgment of their informed consent and consent to record the interviews. At the end of the first interviews I explained that I would take one to two weeks to process the first interview and then would contact the participant to arrange a time and place for our second interview.

The first interviews were listened to and reflected on, and images, themes and/or stories that seemed to be important in answering the research questions were identified. These important aspects were taken back to the participants in the second interview.

My transcription strategy did not involve capturing the pauses, breaths, intonations and suchlike as suggested by scholars like Jefferson (2004). Because my analysis conceptualisation did not involve such a close focus on interaction, I did not feel this was necessary. I did transcribe paralinguistics like stutters, 'hmmm's' and laughter according to Schegloff's (1997) argument that such vocal cues can provide meaning and contextual cues. Similarly, Schegloff (1997) argues that the clear conversational contraction of words such as 'trying to' as 'tryna' and 'want to' as 'wanna' do not have to be transcribed in the correct grammatical form. These are the words the participant has spoken. It is not necessary and even arguably disrespectful to impose a 'theoretical imperialism' (Schegloff, 1997, p. 167) on our participants when they have chosen to use less grammatically correct but probably more conversationally comfortable language. Of course, I cannot be sure that what I heard and how I expressed that in type is what the participants said (Jefferson, 2004), but I have made a concerted effort to deliver a conscientious written record of the interviews.

Transcription started while data collection was still taking place and continued after the data had been collected. Transcripts from the first and second interviews were examined alongside one another. The data was organised into those narratives that pertain to the research questions and those do not. This 'data gold-panning' process was reflected upon so as to allow for critique thereof.

The data was then analysed using a performative narrative approach with a specific focus on the participants' construction and positioning of 'characters' in their narratives (Bamberg, 1997). This approach will be elaborated on in the data analysis section of this paper. The reflexivity (described in the *Reflexivity* section of this chapter) carried out during the research process was referred to and integrated into the analysis and interpretation of data.

Data Analysis

After the first interview a naïve reading of the transcript highlighted salient themes, emotions and images. These highlighted aspects were reflected to the participant in their second interview. After the second interview both transcripts were read multiple times to gain familiarity with their content. I did not exclude any content, according to the suggestion that what was said by the narrator is relevant to them in some way (De Fina, 2013) and because everything said in a

narrative is important as contextual information (Riessman, 2005). However, I did draw attention to certain content that showed potential to answer the research questions.

Particular attention was paid to characters in the participants' narratives. Characters were identified and the narrator's positioning of and power given to these characters were explored according to Bamberg's (1997) model of three-level positioning analysis.

In Bamberg's (1997) first level of analysis we ask "How are the characters positioned in relation to one another within the reported events?" (p. 337). At this level the language used is examined to understand how the narrator achieved the placing of agency with the characters in their narratives. In what ways does the narrator give responsibility to certain characters and withhold it from others? How do characters interact with one another, and who is affected or even at the mercy of whose agency?

At the second level the question is "How does the speaker position him- or herself to the audience?" (Bamberg, 1997, p. 337). Because Bamberg argues that the audience will always have an effect on the form and shape of a narrative, we can try to understand how the narrator works to provide a particular characterisation of him- or herself to the audience. The narrator could construct an image of themselves as a repenting storyteller, a didactic presenter or as needing to vindicate themselves from blame.

At the third level we want to know "How do narrators position themselves to themselves?" (Bamberg, 1997, p. 337). At this point the narrator's language is explored for indications of truths that they hold about the event, their context and the greater social context. Beyond the local meaning of the narration, which assumptions does the narrator take for granted to be true, and which language devices can be shown to indicate these 'truths'? At this level Bamberg (1997) proposes that "the narrator transcends the question of 'How do I want to be understood by you, the audience?' and constructs a (local) answer to the question 'Who am I?'" (p. 337).

By analysing at these three levels Bamberg (1997) argues that we can understand how narrators make claims to identity and how they have inscribed the event with meaning. For Bamberg (1997), this method of analysis places at its centre the active construction process

achieved by the narrator. This method of analysis was chosen because, based on the argument made by reviewing the literature, that the research community has portrayed the partners of people with bipolar disorder as 'caregivers', we have assigned them a role, we have identified them as particular characters. This method of analysis has the potential to understand how partners of people with bipolar disorder want to be understood; whether the roles and identities they communicate are congruous with their characterisation in the 'caregiver' literature.

A 'character' was loosely defined as an influencing body. This might be a physical person such as a parent-in-law or a doctor, or it might be an abstract 'body' such as joblessness – an influencing 'character' that might be blamed, appraised or otherwise referred to (Bamberg, 1997).

Based on the medical model of bipolar disorder discussed in the literature review, the participants' narratives were explored for constructions of the disorder. Was the disorder constructed along the same lines as the medical model or is there evidence to suggest that the lived experience of it challenges this model? How, if it was, was the 'character' of bipolar disorder constructed?

The literature on the 'caregiver' experience was kept in mind when looking at whether the participants construct themselves as 'caregivers' of a partner with bipolar disorder, or whether they construct themselves in some other way – perhaps as victims, survivors or proxy sufferers of the disorder and being in a relationship with someone diagnosed with the disorder.

The relationship literature discussed was used as a reference to see how the participants construct the relationship and themselves in the relationship. Did the participant construct the relationship as intrinsically valuable (Santore, 2008) or was the relationship seen as a 'character' who influences their personal development?

At the same time, attention was given to the social context, Josselson's (2013) significant "Third" of the dyad. That is, elements of the narratives that describe or explain the social context that the participant is living in were examined to see how the "Third" might be influencing the experience and construction of the relationship and of the characters involved.

This method of analysis and the questions raised in this section provide a suitable way to answer the research questions in ways that represent the constructions that partners of people with bipolar disorder are making – of themselves, themselves in their relationship, of their partner and of bipolar disorder itself.

Reflexivity

Pillow (2003) argues that we can use reflexivity "…to be critically conscious through personal accounting of how the researcher's self-location (across for example, gender, race, class, sexuality, ethnicity, nationality), position and interests influence all stages of the research process." (p. 178)

Pillow suggests that we engage in 'uncomfortable reflexivity' (2003). This is a kind of reflexivity characterised by the researcher turning back on herself, her decisions related to the research and her interpretations of the research while maintaining that just because she has done so does not guarantee better decisions or better interpretations. It makes visible for the researcher and for readers how the research has been constructed.

> "A tracing of the problematics of reflexivity calls for a positioning of reflexivity not as clarity, honesty, or humility, but as practices of confounding disruptions – at times even a failure of our language and practices."(Pillow, 2003, p. 192)

In turning back on my emotional interest in this topic, I see that I feel passionate about the treatment of people with mental disorders and their family members. My uncle was badly affected by his relationship with a person with bipolar disorder – he has suffered extreme financial instability as a result of his divorce from his partner. He has also lost faith in the mental health support systems around him and in psychology in general. My uncle's experiences have left me with a feeling of resentment on his behalf, but not towards his ex-wife. Rather, I feel resentment towards the mental health support systems that should have provided him with information and appropriate psychological support. I also feel that his relationship with a person with bipolar disorder was not only destructive because of his ex-wife's condition. I know that the relationship had systemic difficulties. I feel that if these systemic difficulties were taken into account alongside her bipolar disorder, instead of isolating her bipolar disorder as the sole destructive force, their break-up might have been more amicable. This sympathy for my uncle's

experiences meant that when I was listening to my participants I often caught myself looking for signs of victimhood and dysfunction in the relationship.

For example, when I was interviewing Jake, I latched onto a perception his positioning of his wife as someone who has been dismissive of his provision of support towards her. I had posed this reflection to Jake earlier in the interview, but Jake misunderstood what I was trying to communicate at that time. I then tried twice more in the interview to ask the question, and only when I posed the question as a personal feeling did he respond directly to it. Jake answered in agreement, expressing that he does feel that his support for his wife has gone unnoticed by her. It is difficult for me to see whether Jake actually feels this or was responding to a leading question by his interviewer. I am more inclined to think that the feelings Jake expressed are genuine because of the way he brought up this issue in his first interview. He put on a nasal, mocking tone when playing the character of his wife berating his efforts to support her.

Parallel to this inclination to see victims in my participants, I often felt sympathy for them. After interviewing Ellen, I felt such pity for her situation that I immediately wanted to put her in contact with two of my other participants who I thought might be able to sympathise with and advise her. I wanted to rescue her. I felt similarly for Georgia. Georgia was very emotional during our interviews, and I felt a need to care for her. I walked her to her car, which I did not do for any of my other participants and made an extra effort to assist her in travelling to our next interview.

I also noticed that in some interviews I was making a concerted effort to look for signs of my participants rejecting the medical model of bipolar disorder. Throughout this research I have had a vague hypothesis that the lived experiences of bipolar disorder are very different to the way in which bipolar disorder is portrayed by texts like the DSM and by 'caregiver' literature. I want my hypothesis to be right because I have a perception that the field of psychology has not been as effective as it could be for family members of people with bipolar disorder. If we can change our view of mental disorders and their effect on communities, I hope that we, the psychology community can start getting it 'right'. My hope, of course depends on whether we have been 'getting it wrong' and what 'getting it right' would actually mean.

I am a white, female South African. I have been raised with relative privilege and while I make efforts to understand the lives of other populations I am often blind to the privileges of my own position. While gender was a subtle influencing factor in conducting my interviews, I believe that there was little discussion on race and class in the narratives given to me because I shared the race and class of my participants (Floyd & Arthur, 2012). This meant that I have not been able to examine the socio-political forces at work in the narratives of my participants as I had set out to do. I still believe that this research is valuable in the South African context because it sheds light on the way five individuals feel about the state of support for mental health in this country, but it cannot be valuable in unpacking the race, class and gender systems that affect this phenomenon. This issue will be discussed further in the *Directions for Future Research* section in *Chapter 5: Conclusions* of this report.

I hope that my 'uncomfortable reflexivity' (Pillow, 2003) and the reflections on my impressions of the participants (provided in the 'Analysis' for each participant) will allow for a critical engagement with my treatment and analysis of this topic.

Ethical concerns

I have no financial or material interests associated with this research. I do have an emotional interest in this research in that my uncle was in a relationship with a person with bipolar disorder. I have reflected on this emotional interest individually and with my supervisor in an effort to make clear to me what I might have wanted to gain from this research emotionally.

Informed consent was obtained through providing information to participants and asking for formal written consent to participate. Eligible candidates were given information about the research by their support group facilitator/ the manager of Gateway House, then in an information sheet (Appendix C) and they were invited to ask me and my supervisor any questions they had. They were then asked to sign an informed consent form (Appendix D) and consent to audio record the interviews (Appendix E).

There were no direct advantages or disadvantages to participating in this study. There were no foreseeable risks or harm associated with participating in this study. Because being in a

relationship with someone with bipolar disorder is a sensitive topic, it is possible that participants experienced some distress or heightened emotions as a result of being interviewed.

Free telephone counselling services were provided on the participants' information sheet and it was explained in the participant information sheet that I would assist them in contacting a counselling service or their support group facilitator if they experienced any distress as a result of their participation. Two participants became emotional during the interviews but it did not seem to be distress, and they seemed contained. All of the participants expressed some positive gain from participating, in the form of appreciation for being listened to or appreciation for attention to this topic.

In interviewing my participants I did not pressure them to answer questions. An effort was made to ask questions in a sensitive and open way. It is hoped that conscientious questioning allowed participants room to decide which topics they wanted to raise and which they would have preferred to avoid.

The voluntary nature of participation in this research was explained in the information sheets, consent forms (Appendices A-D) and again in person. The right to withdraw from the study at any time was also explained and would have been respected even if this research was to consequently lose data.

Confidentiality was and will be strictly adhered to. I will not share any information about my participants with anyone other than my supervisor. When I did discuss participants and their interviews with my supervisor, it was with the use of the pseudonyms assigned to the participants. Even though the participants' identities are known to me, I have used their pseudonyms when referring to them to my supervisor and in the research report I have produced. Participants have been referred to by their pseudonyms from transcription of data up to this final reporting of the research. No identifying information was included in any part of the research report. Therefore, their identities have been fully protected from others.

After audio recording interviews, I transferred the recordings from my recording device to my personal computer. The recordings were deleted from the device and kept in a password-

protected file on my password-protected personal computer. Data that explicitly referred to a participant's identity was deleted.

The participants' consent forms have been stored in my private, secure storage. I will keep these consent forms until this research report has been examined, after which I will destroy the documents.

All data, reflexivity in response to data and transcripts are kept in a password protected file on my personal computer – only accessible by me. The only person this information has been shared with is my supervisor. I will keep this data in its secure location on my personal computer after submission of this research in case I want to re-analyse the data for a different research project.

This research report is being submitted to the Faculty of Humanities at the University of the Witwatersrand for degree purposes. As such, it will be made available in the University Main Library and on the University's website. Therefore, anyone with access to the University's resources will have access to my research report.

Josselson (2013) proposes that alongside systematised guidelines for conducting ethical research, the research must approach his or her topic and participants with an ethical attitude. This attitude must encompass respect, sensitivity and tact when interacting with participants and what they provide for the research. The researcher must endeavour not only to fulfil the requirements of an ethics committee but must also create a safe and respectful relationship with his or her participants and must preserve their dignity (Josselson, 2013). I have tried to practice such an ethical attitude at all points of this study.

The uncomfortable reflexivity discussed earlier will also aid in developing responsible research (Chase, 2005; Atkinson & Delamont, 2006). In being able to critique how I have constructed this research, the representations of participants can be more transparent and therefore more able to create emergent, sensitive understandings of five people in a relationship with someone with bipolar disorder.

Conclusion

The methods chosen for the research were selected with the intention of producing responsible research based on the assumptions of social constructionism and the narrative approach. These methods allowed me to explore the experiences of partners of people with bipolar disorder in a respectful way that did not impose roles, definitions or expectations on them, but rather opened a space for them to give me a locally constructed narration of their experiences and perspectives.

Chapter 4: Presentation of findings

The findings from analysis are presented. As each participant has been analysed in their own case, each participant is presented separately. The narratives of each participant are presented in the three levels of Bamberg's (1997) positioning model. In the first level, the characters and their relational dynamics were explored to understand who the participant has made significant or important in their storying of their experiences. In the second level, the participant's relating to the audience – me, the interviewer – was investigated to gain an understanding of how the narrator positions the audience and what work they do to interpolate the audience. In the third level, the narratives are explored to understand what the participant takes to be true, what discourses and master narratives they use to make meaning of their experiences and as such how they are talking themselves into being (Bamberg, 1997)

For each participant a synopsis of their narrative is given, followed by my self-reflexive responses to them so as to allow for a critical reading in line with the co-constructive approach (Holstein & Gubrium, 2002; Pillow, 2003). A discussion of these findings follows in the next chapter.

Participant 1: Amanda

Amanda is an upper-middle class woman in her forties who is married to Ben. Amanda began her narratives of her experiences by constructing a scene with a background of her husband of nineteen and a half years Ben's family history. She explained that his sister had bipolar disorder and committed suicide and both his parents were alcoholic but only his mother was ever treated. Ben experienced what retrospectively seems to be a depressive episode seven years ago, but at the time Amanda thought this was a "mental breakdown".

A psychiatrist guessed that it could be bipolar disorder and prescribed anti-depressants. Two years ago, Ben stopped taking his medication. Last year, Ben went through what Amanda at the time thought was a mid-life crisis, but when he became incapacitated and was not responding to medication for a viral infection he was diagnosed with bipolar I disorder by the same psychiatrist. While in a state of mania Ben had an affair with the family's au pair and jeopardised the family's financial stability by spending excessive amounts of money. At the beginning of this

year Ben told Amanda about the affair and subsequently fell into a severe depression. Ben has been booked off work for six months, has been placed on a temporary disability grant and is being treated by a psychiatrist, an occupational therapist and counselling and support groups for the family. Amanda explained that things are starting to get "better now".

In Amanda's first interview she came across as energetic, pragmatic and relatively well-adapted while narrating her experiences. She used a lot of humour and performance in her narratives – for example she interrupted herself to engage with her pets in an amusing and entertaining way. I laughed many times during the interview, in response to Amanda's light, ironic and sometimes facetious portrayal of events. During this interview she often redirected her narratives of painful events towards a pragmatic contemplation of how to negotiate this change in the family's life now and in the future. In Amanda's second interview there was a more noticeable tone of sadness or melancholy. I enjoyed Amanda's company, her energy and her sense of humour. However, I noticed myself being irritated with her pattern of speech – her repeated use of phrases like "the biggest thing" and her incomplete sentences made it difficult for me to track her rhetorical movements sometimes. This could be because she was my first participant in the data collection process and because I was nervous I felt uncomfortable with the "roughness" of interviews conducted with real people – that is, the dogs barking, uncomfortable chairs and anxiety-provoking recording devices that are inevitable in some interview settings.

Positioning level 1: Characters. In Amanda's narrative she describes many characters and attributes interesting characteristics to each of them. Her children, the woman that Ben had an affair with, her friends and the mental health system are all positioned with different agency and responsibilities. Because of the focus of this research only the character of Ben will be analysed. Three themes emerge in Amanda's construction of her husband's character – the parent-child role, the attribution of agency and the distinction between Ben and bipolar disorder.

Throughout the interviews, Amanda narrates Ben as childlike and deserving of sympathy because of his attempts to make up for his past behaviour. She constantly moves between ascribing agency to Ben, attributing agency and responsibility to his disorder and making a distinction between him as a character and his disorder as a character. She maintains a parent-child relationship between her character and Ben's character, except when she is talking about

their relationship before Ben's manic episode and when talking about two recent events in which she describes feeling that he is once again her husband and partner.

When Amanda narrates the diagnosis process she doesn't give Ben's character much agency. She talks about "taking him to the doctor", him "being put on medication" and that she feels he's "still unable to go, okay I'm this, I'm an adult now, take ownership."

> Amanda: … he doesn't have access to our joint bank account. He has a bank account with a debit card on it, his salary gets sweeped- he doesn't get a salary, he gets a temporary disability grant [sic]. His- his gets sweeped into my account [sic]. I have access to his account. I can move money out and whatever. He can't move money in. I give him a daily allowance of like 250 bucks, just to cover basics. So it's a big deal for him, and he has to ask me for money. But he was spending so much, even now when he was better.

In this narrative we see that Amanda has cast herself in the role of having to take responsibility for Ben and deny him financial freedom, which she feels he might not be healthy enough to tolerate in a responsible way. This kind of situation parallels the way many parents give their children an allowance or restricted access to funds. She includes her recognition that he is uncomfortable with this arrangement, but narrates it as being necessary. In another case Amanda denies authority, casting it onto a medical professional.

> Amanda: Dr Smith said he couldn't take any medication, even Medlemon, and there's Flemeze, you know that cough mixture, and there's a whole lot of cough mixture and I said to him 'Have you been taking medication?' and he said 'Yes! I couldn't sleep!' I said 'But Dr Smith said-' so he attacked me and I was like 'I didn't make the rules, phone Dr Smith and yell at him.'

Here Ben seems to be positioned as a rebellious teenager, rebelling against the authority of the doctor. In this case Amanda's character resists the parent role, diverting his "attack" from herself to the original authority. This narrative also shows the discomfort that both Amanda and Ben feel around the parent-child role, which Amanda talks about several times in her interviews by saying things like "It's not nice for him and it's not nice for me." The parent-child roles persist throughout her narratives, but the quality of the "parent-child relationship" also changes to include a parental sympathy for a struggling child.

> Amanda: You know, he's try'na get through it and he's try'na say I'm sorry and he's try'na like re-live memories and try'na work out what happened when he - cos he just has big gaps in his memory, which I think must be really terrifying [sic].

In this quote it is almost as if Amanda wants to emphasise the effort Ben is putting into his recovery to engender sympathy for him – reminiscent of a parent asking for a child to be excused for making a mistake because the child is trying so hard now. Interestingly, the sympathy Amanda feels for Ben seems only to apply to him in his recovery. She talks about him going off his medication as if he was being careless or thoughtless:

Amanda: …about two years ago he decided to go off his medication because he'd been fine for five years as far as he's concerned.

She does not display sympathy towards 'bipolar', a character that she sometimes talks about as independent of Ben and sometimes as part of him. She defines bipolar disorder as "the third person in the relationship". She actively positions bipolar disorder as the character that had the affair, spent the money and behaved aggressively towards her. However, this distinction was not consistent in her narratives. She often moved between using the pronouns 'him' and 'it', indicating the differential assignment of responsibility to Ben and bipolar disorder respectively.

Amanda: … and it took a week for him to actually admit all the extent of it. So- and I think in that time I kind of was able to go 'this is not the person he is' so um it w- it's- so- it gave me kind of time to go 'right, this isn't, this is not him, it's the illness.'

Amanda: Last year was incredibly abusive…

Amanda: You can't just phone up any psychologist cos if they've got no knowledge of bipolar they can't- you know they go 'Yeah that's a very bad thing that he did.' Well actually, it had nothing to do with him, you know [sic].

Amanda also described finding it difficult to negotiate this distinction at different times.

Amanda: So even though he doesn't wanna be with her because he's come to his senses, you also wonder how much of it was… you know, whether- whether he actually does want, you understand what I'm saying [sic].

Amanda: So I'm thinking, for the rest of my life I'm gonna be going 'Are you like this because it's you?' Which is valid. Or 'are you like this because bipolar is kicking in?'[sic]

One interpretation of this difficulty distinguishing Ben from bipolar disorder is that Amanda wanted to isolate his behaviour as a "temporary character aberration" as she described seeing it, as opposed to how her daughter viewed it, as a "fundamental flaw which should not be tolerated" so that it could be medicated and their lives could progress as normal. It seems that she wanted to accept the theory of the "bipolar disorder [having] the affair" and Ben having "nothing to do with

[it]", so that her relationship with Ben might continue. However, she was struggling with the clarity of the distinction because she was not always certain from which position Ben was operating, and she felt she could not predict who she would be dealing with in the future, with Ben or with bipolar disorder,.

On a rational level she seemed to have accepted the distinction but on a deeper, more emotional level she still felt deeply hurt by his infidelity, mistrustful of him and uncertain about the status of their relationship. Significantly, in the above quote she does not even complete her sentence to give words to the possibility that Ben might have genuine feelings for the woman he had an affair with. She assumes that I have completed the sentence for her in my head (Poindexter, 2002), assumedly as:

Amanda: So even though he doesn't wanna be with her because he's come to his senses, you also wonder how much of it was [*him*] you know, whether- whether he actually does want [*her*].

Positioning level 2: Audience. Amanda positioned herself to the audience in a number of ways. She provided rationalisations of her mistrust of her husband and qualifications for not acting to treat his symptoms earlier. These points will be discussed in positioning level 3 when analysing how she wants to be understood in her narrative. At this level, her addressing the research situation, her use of humour and performance of skits and applauding the audience will be discussed.

At the beginning of her first interview, Amanda started by clarifying the research question and then asked me, "Should I start off by telling you… where it came- what happened and where it came from?" and then ended a number of her narratives with enquiries about whether she had answered my question and whether her narrative had given the right information. On the one hand, this reflected the interview situation as being one of pressure to give the 'correct' or the most appropriate answers. On the other hand, her concern for the interviewer might be interpreted as being an example of the responsibility she gave herself in order to be 'good'. Throughout Amanda's narratives she talked about being a "good" person and a "good" mother, and it is possible that she wanted to seek the approval of the audience for being a 'good' research participant (Potter & Hepburn, 2005).

Another interesting feature of her narratives, which might support the latter interpretation, was her working to minimise her experiences or reassure the interviewer.

> Amanda: You know you probably- because it's still quite a new and we've been through quite a lot of trauma you probably also getting a slightly more down view of it. Cos I think if you talk to me in a year's time I'll be like 'Okay, it's actually fine you know.'

Even though Amanda admitted that they had been through a traumatic experience, she made the assertion that this interview could be looking in on her experiences from a negative slant, and that after some time had passed she thought she would be "fine". This assertion could have served either to minimise her trauma, for herself or for my benefit, or to communicate to me that living with bipolar disorder was not as impossible or catastrophic as she felt she may have been framing it before. This could have been an effort to seek the approval of the audience by positioning herself as adaptive and able to withstand trauma. Either way, there was an appeal to the audience not to view her experience in a pessimistic light.

Amanda often used the expression "the biggest challenge" across a set of different topics. This could have been an idiosyncrasy of her speech, but it could also have been an attempt to "highlight" or bring attention to isolatable topics for the purposes of the research. If the latter was the case, her attempt to aid me in my research was another example of taking on the responsibility of being a 'good' research participant.

Amanda used a sense of irony and facetiousness throughout her narratives, which led to several instances of the interviewer laughing. As a matter of self-reflexivity, I was very quick to laugh and I often laugh when I am nervous, so Amanda's use of humour could have been more apparent to me because of my sensitivity to humorous situations or a response to my frequent laughing. In other words, Amanda could have been influenced to use more humour than usual because it felt good to keep telling jokes to someone who kept finding them funny. At the same time, Amanda could have been using humour as a defence mechanism, as a way of distancing and minimising her experiences.

Assuming that Amanda was using humour as a tool in her narratives, we can examine an example of her humorous skits.

Amanda: Um, and I think I'm a lot less um, rose-tinted about the future that um- like old age, you kind of- the next fifty years, I just have this thing of gonna be on a zimmer frame going *(puts on a voice mimicking an elderly woman)* "I won't take my medication!" and I'm like fff… *(Laughs).*

Amanda: Vanilla gets very upset if we arrive home and don't let him inside. He sits at the back door and like *(puts on a deep dull voice)* 'I'm here! Woof! Woof!'

Interviewer: *(Laughs)* Awwww.

….

Amanda: Oh my god. Anyway …. Yeah, so, a- a- I think he's in- he's in limbo with a lot more, because he's also in- in limbo, he's going back to work next month. And I think that must be really terrifying for him.

In the first narrative Amanda ends a serious and painful statement about not being as idealistic about the future, with the performance of a stereotype of a stubborn, incapacitated old woman. In the second narrative, Amanda has been talking about the deterioration of her daughters' and her husband's relationships, before performing a skit of her unnecessarily distressed dog. After completing this narrative, Amanda goes on to talk about how "terrifying" it must be for her husband to think about going back to work. This illustrates how swiftly she moved between humour and serious topics.

Assuming her use of humour was a tool in her narratives, Amanda could have been using humour to deflect attention (mine or her own) away from painful topics, or to lighten the mood when talking about painful things. Another interpretation is that Amanda could have been using these humorous situations, as well as narratives about her daughters and pets that seem untouched by her husband's bipolar disorder, to show me that bipolar disorder was not the centrally acting character or situation in her life.

An interesting thing that Amanda did at the end of her second interview was to express her admiration and pleasant surprise that the research was being conducted and in general the number of people who are interested in working with people with mental illness. In terms of the stage metaphor (Riessman, 2005) this is akin to a performer thanking or even applauding the audience. This point will be further elaborated on in the *Discussion* section of the next chapter.

Positioning level 3: Narrator. On the third level of analysis we can see how Amanda's language use pointed to the discourses she used to make sense of her life. Her language around mental illness and normality will be discussed. We can also see how she delivered a narration of survival.

Amanda often seemed to grapple with the word 'normal'. She aligned her husband's health before and emerging since the manic episode. This indicates that she held to be true a perspective of mental illness as 'abnormal'; that the mental illness could be isolated as abnormal among general normality. Alongside this, mental illness, or Ben's mania, was something that she positioned as being incongruous with their relationship.

Amanda: …it was going back to the behaviour of last year and the conversations and stuff like that and I was thinking 'Well maybe it's just- we can't be together anymore' because I'm thinking he's getting better.

So, for her, Ben's symptoms of mania were not compatible with their relationship. Furthermore, she described him as "starting to be the normal person that he was" as he responded to his medication. We can see that she was drawing on a discourse of 'normal' being good and in line with a happy family life, and 'abnormal' being bad and a hindrance to the continuation of their relationship (Parker et al., 1995). Similarly, she employed a discourse of being a 'good person' by staying in her marriage especially if Ben was ill.

Amanda assigns stigma to other people with bipolar disorder but then later acknowledges that she herself may not have trusted people not to react with stigmatisation towards her husband's diagnosis.

Amanda: But the other self-imposed thing was that you can't- y- you talk to a couple of friends and then depending on how they react I think it's- depends how you go forward, you know what I mean?

Amanda: So um, if- if- probably if we'd spoken to more people or been more open about it maybe I wouldn't have been quite so lonely.

Amanda: I- i- I have to tell you though, I do think that if I had told people i- i- t- it would've been fine. And I think it was just, I couldn't bring myself to tell people. For me it's quite a big thing that he had an affair, so although there's so many much worse things that happened...

At a few points in her narratives she asserted that people would have responded in an undesirable way to her telling them her husband's diagnosis, but later acknowledged the possibility that

people would have responded in a benign way. One interpretation is that telling other people about bipolar disorder would mean telling them about his infidelity, and it is this information that feels impossible to share.

Amanda: So having had a guy who- if you were to ask anybody on this planet, who knows Ben, and said 'Rate the possibility of Ben having an affair from one to ten' they would've said 'negative four-hundred-and-thirty-two', because he was just like- he's always been extremely clear that I'm like his person- that- i- it, you know, it would never have crossed his mind.

Looked at alongside her use of the normal/ abnormal discourse, we could interpret her equivocal treatment of stigma as being a reflection of her own stigma towards mental illness. Now that she had experienced it she could understand mental illness as not being an excuse to simply dismiss a person, but at the same time she still created a distinction between "normal bipolar people" and other people with the disorder, between people with mental illness who can be dismissed and people with mental illness who should not be dismissed.

Amanda: And I think it's quite a normal behaviour for bipolar people is that they don't have the same recognition or the same whatever for their medication that their partners do, because their partners have had to live through the crap that happens when you don't take your medication.

Amanda: …the first support group we wa- went to, literally it was us, and they bust in these people from the Edenvale equivalent of Tara. And we were like, 'we need to meet some normal people.'

Amanda: But maybe you- you can't be normal if you've got bipolar.

In the first narrative fragment she positioned her husband's medication non-compliance as being "normal for bipolar people", while in the second narrative she positioned the patients from the mental institution as not being "normal people". In the third extract Amanda actively excluded mental illness from normality.

To try to understand her stance towards mental illness and stigma, we can look at Amanda's language around Ben's manic episode and the work she did to construct her narrative as one of survival.

When Amanda talked about her husband's manic episode, she often used the word "destruction". She talked about the "destruction" of the close friendship between her daughter and the family's au pair, that her husband said a lot of "destructive" things when he was manic. Similarly she wondered:

Amanda: …how many people are walking around undiagnosed and creating havoc and, you know destroying relationships and financial stability and all of those good things.

Her use of the word "destruction" is indicative of how she experienced her husband's mental illness. She did not describe it as anything other than something that has broken or abolished the life she had before Ben's manic episode.

Amanda: You know your life savings are gone, your life plans turned upside down, the- the things that you thought were fundamental values are- don't actually exist because that person changes personality…

It does not follow that just because a person changes personality they necessarily become a destructive force, but for Amanda mania was more than an episode of illness or a "temporary character aberration" as she described it earlier in her first interview. Bipolar disorder being "an illness" or something temporary was contrasted starkly with bipolar disorder causing devastating, even irreversible damage to her life.

At many points in her interviews Amanda talked about "going forward" and managing things in the future. This suggests that she believed that there was a way forward from Ben's manic episode, that there was a future for her family. This seemed to contradict her repeated use of the word "destruction". The contradiction may be explained by her cautiousness when referring to the future, and her acknowledgement that they would have to learn to negotiate matters in a new way. At the end of her second interview this cautious acknowledgement of things having to change became optimistic when she said:

Amanda: It's like a fresh slate almost. And that's quite cool cos you don't often get that.

At this point, to use a metaphor, it was as if she was looking forward to the new growth made possible by a bush fire.

Amanda also included narratives about other people that seemed to be narratives of either success or failure. She talked about the German pilot who flew a commercial aeroplane into the Alps, a book about a person who was very negative about their diagnosis, their support group facilitator who had been diagnosed with bipolar disorder but had been stable for fourteen years, and a high profile bank executive who was open about his diagnosis. It seems that she sought out narratives of success and avoided or pathologised narratives of what she perceived as failure.

Amanda: So it's almost like trying to find examples of people who live successful lives with bipolar…

This came alongside her working to minimise her experiences and being optimistic about the possible advantages flowing from them for her family's situation.

Amanda: And that's what I've been tryin' to say to the kids is that, the fact that they've had to deal with all this stuff, is gonna make them the most amazing adults [sic].

Amanda: The biggest benefit out of all of this is that my 14-year-old and my relationship is just phenomenal… I have to tell you I'm like 'Yeah have an affair every year if that's what's gonna be the outcome' [sic]. You know, I mean not really but you know what I mean.

Amanda: And I think also, having had this whole thing there's certain things that Ben and I will be able to re-jig as well. You know going forward. Re-jig the way we do certain things because we can.

Overall, Amanda's narrative and her characters carry a theme of determination to survive. Even though she narrated some very painful events and recognised that this experience had been traumatic she repeatedly asserted that "going forward" was possible.

Participant 2: Carl

Carl is a man in his sixties who was in a long-term relationship with Dianne. He did not explain Dianne's diagnosis, but her having bipolar disorder seemed to be taken as assumed based on the nature of this research. His first interview started with his comments on the lack of knowledge about mental illness in society. His milieu provided an overarching theme for his narratives: the unjust way he felt Dianne, his partner, had been treated. Because Dianne's episodes were triggered by the stress of employment, she was living with and being supported by her mother. Carl explained that he was working towards being able to support her and "indulge her, gently". Even though they live in different provinces, Carl and Dianne still share a close and intimate long-distance relationship.

Carl came across as having a commanding and charismatic personality. He delivered his narratives slowly and clearly, in a way that made me feel like he was passing on an oral history to me. He seemed authoritative and experienced. I was nervous, because I was in a new place and only on my second interview, and there was at the same time something intimidating and anxiety provoking about him. I felt child-like around him, which may reflect the fatherly role he seemed to play with Dianne. Throughout his narratives he worked to provide evidence for his narratives, either with the use of details that I could relate to or recognise, or with physical

evidence (two ‘artefacts’, photographs and a video that was referred to several times but that I never saw).

Positioning level 1: Characters. Carl brought many characters into his interviews. Interestingly, Carl passed over a few of them quickly but most of his characters were clearly assigned to a ‘good’ or a ‘bad’ side. Carl began the first interview with his comments on the lack of knowledge within society, asserting the moral stance that Dianne’s parents should not have had children when they knew that there was a history of bipolar disorder in the family. In doing this, he positioned Dianne’s parents as villains – firstly for passing on genetic material that he argued shouldn’t be passed on and secondly in the way that they handled Dianne’s bipolar disorder.

Carl: … wh-what bothered me was the fact that- that her- notwithstanding the fact that her mother too is bipolar and as had been her father, that she still chose to have children herself. And that you know she had three children uh and Dianne happened to be the one who got, you know the short straw.

Carl: And um, her father should have recognised the fact that she should be kept in a nice little cottage- cos they have money, lots of money, lots.

Significantly, this comment implied that his partner should never have been born. It was clear from Carl’s narratives that he loved and felt affection for Dianne, so this implied thought seems to stem from Carl’s wish that Dianne had not suffered like she had, and not necessarily that her non-existence would have prevented his suffering.

Carl positioned Dianne’s father as being in denial about “his baby daughter’s” mental illness, not recognising the care that she needed, even though he had the resources to provide that care. In saying that Dianne’s father had “lots” of money, he could be have been reasoning that Dianne’s father had no excuse not to financially support her; that he should be judged more harshly because he had the means to provide material support. Carl even more clearly positioned Dianne’s mother as a villain or perpetrator. He assigned the blame for engendering bipolar disorder in Dianne directly to her mother, and put on a mocking voice when “doing” her character. He also interrupted her speech as if it could be easily dismissed.

Carl: *(Mocking mother voice)* 'Yeah but she's gotta learn- the value of responsibility and th-' [sic]
(Normal voice) 'She shouldn't be working, she shouldn't have to be working. You should be taking care of her, looking after her, and avoiding her being subjected to the type of situations, that cause her to b-be manic, which you people brought about by having her! How irresponsible was that?'

The two psychiatrists Carl brought into his narratives were also constructed as villains. He said that he did not like psychiatrists and had never found one he believed to be good for Dianne. He contradicted this later when he talked about one psychiatrist who talked with him and whom he imagined would take good care of Dianne. However, when he narrated the psychiatrists who prescribed medication to Dianne, he made it very clear that they were 'bad'. He described them as misogynistic and cruel. Similarly to when he was 'doing' the character of Dianne's mother, Carl used deep, forbidding voices to indicate the 'nastiness' of the psychiatrists.

Carl: I don't wanna make the sweeping statement but my experience with male psychiatrists as a result of this is that there is- misogyny rears its ugly head [sic]. Powerf- Men in powerful positions who will show women that they're the boss, they're in control. And it's like 'I'm going to teach you a lesson now.' We had- our- I'm talking about first-hand experience from three male psychiatrists.

Carl: We were waiting for him *(a psychiatrist)* to finish his rounds and- 'Oh yes and what have we got here?' When we were walking the- 'Oh no no, just uh get you to sign off an-' 'Oh really? Have you decided?' 'No no, you can s- you can see it's Dianne, this is-' 'Well will you allow me to decide upon that?' 'Ah yes, please- please do. Please- please do.' and then- I say yes, okay, half an hour later, he says 'Okay *(claps hands and rubs hands together)* she's ready to go and there's your prescriptions'.

Carl: ... He *(a psychiatrist)*'s of the old school who- who cannot relate to the fact that the patient has got the right to query, to question, to- and to say that- 'Is it possible that you could replace that there particular thing with something else because it causes me terrible dry mouth, slurry speech a- b- *(puts on deep, forbidding voice)* 'You will do as I prescribe.'

Carl positioned himself and Dianne as humble and unassuming non-provocateurs in both of these instances, perhaps working to show that the psychiatrists were 'bad' without being provoked. Furthermore, he narrated examples of the psychiatrists' behaviour that portray them as domineering and purposefully subjugating towards others.

Besides being a passive non-provocateur, Carl positioned himself as a suffering sinner, bearing the burden of his wrongdoings.

Carl: Please- please excuse and forgive me I eventually reached a stage where, having been deprived of sleep- now for her, that's- she can go a month without sleep. Being manic. As you well obviously- and uh, I- I was so frazzled, I was so… That eventually I picked up that laptop, and I ran at her, and I- I smashed it onto the ground, And I'll never look- I'll never forget that look of utter bewilderment on her face. Th- i- i- it- was, it was a look of utter… uh it was so sad.

Carl: … And we were driving down Jan Smuts Avenue and… it- it- it just got- it was just- it was just- uh and I slapped her… you know uh… God I- I- you know the thing is… um… you know you can steal from somebody and you can rectify the situation that it now no longer is an issue. There might be issues of trust or… You can't undo violence. Uh… because the slap or the murder or the assault uh… uh… is a- is- is- is- is- is a permanent thing, it can't ever be undone. And I live with those two issues… uh permanently. It can never be undone.

In these two narratives Carl's character is of a sinner who will confess and will bear the burden of condemnation. He accepts the burden of condemnation in never being able to forget Dianne's bewilderment, and the burden of never being able to undo his aggression. By explaining that it was Dianne's state of mania that drove him to violence, it is almost as if Carl was constructing a notion of bipolar disorder having turned him into a villain, a monster. These constructions were of 'temporary insanity'; he had 'caught' Dianne's mania himself and it made him act uncharacteristically.

Alternatively, Carl positioned himself as a "knight in shining armour".

Carl: I fetched Dianne off the bus I realised- she's in no position *(puts on mocking mother voic)* to go back to work now start looking for a job. I nursed her in bed for six months, that's how bad that depression had been… and how unbelievably over the top the medication had been. I can show you when I bring that camera with next time. Photographs of her in bed, you can see how well I took care of her. I was to bath her and dress her and do her make up every day.

Carl: And um, I was going through twice a day, every day, to Sterkfontein. And it- it- it almost ruined us because she was in the hands of black female um, professionals, you know nurses and um, and all these um patients, who on a daily basis were telling me, pointing towards her with th- *(draws finger across throat)* they gonna kill her, 'There's our shopping list,' okay [sic]. And uh, I kept it up for about two or three weeks, two trips a day with this shopping list of food and cosmetics and toiletries, and then th- uh- eventually I r- I arrived there one day and I- I literally kicked the door down. Um… and I said to them 'I'm coming back this afternoon with a shotgun, I'm coming to kill you all.' Cos I wasn't sleeping, I- th- I was- I w- was vicariously living Dianne's experience, where they would one day put her in the one ward that's got only ice cold water in the plumbing and then the next day into a ward where there's only boiling hot water, no cold water. This is the staff and the- you know the patients who are part of the running of the- of the- of the ward, you know the… and then her sister-in-law turned up there one day and the- and then we visited her privately, and- and then she showed us the marks on her body of the assaults, and the bruises, and- an- and she wasn't in a manic state, she was *(acts drowsy and incapacitated)* in a very weepy state and- incapable of taking care of herself and… being abused you know. And- and then I made it my life's ambition to find a way to get her out there.'

Even though Carl here provides another instance of being driven to violence because of the distress of Dianne's state, as the saviour he is self-sacrificing and determined to do what is necessary to protect and care for his partner. Dianne is, in these narratives, positioned as a damsel in distress, in need of "saving" from 'bad' people. Throughout Carl's narratives her character is a victim. Her character is helpless, innocent and child-like. Carl described her as "the poor girl", and used a soft and sympathetic tone when speaking about her.

Carl: I got there the next day and *(the woman in charge of the hospital)* said 'You can fetch Dianne and you can take her. She's free to go.' Oh God the poor girl. She was in no situa- no position to go. She was no longer *(acts drowsy and incapacitated)* she was alive and alert and… but… still in the grips of mania… restless, want to get up, want to walk, want to- not feeling very well and uncomfortable an- out of sorts.

Carl: I heard they were back and so I was coming to- to see- to come and see Dianne, and shame, as I was driving along the lane that goes on the- on the side of the- within the- the complex, she was standing on the veranda looking out for me. And- i- in the darkness I saw her because she felt uncomfortable b- d- be- because Tommy was causing a fuss by the fact that she was drooling, you know?

Looking at Carl's characters, we can see a clear distinction between the characters who are assigned responsibility and those who were narrated as passive, at the mercy of the other characters. Dianne's parents and the psychiatrists are assigned power, responsibility and agency. Carl works to show that these characters have consciously done the wrong thing as in the case of Dianne's mother having children even though she was aware of a family history of mental illness, or the case of the psychiatrists "subjecting" Dianne to medication that she didn't need.

Interestingly, Dianne was only ever assigned agency when Carl talked about how he suspected that Dianne had recently managed to divert herself from a manic episode. In the narrative, when Dianne experienced severe symptoms of bipolar disorder, the fault lay with the people or situations surrounding her, as if they were responsible for her symptoms or 'gave' her bipolar disorder. On the other hand, when Dianne's symptoms were diminishing she was given the agency of maintaining her health.

On the other hand, Carl's character was constructed as a rational, logical person who understood and accepted punishment for his mistakes and would do what was necessary to defend his wronged partner. He assigned himself responsibility for Dianne, who was constructed

as the victim of unjust and cruel treatment. His responsibility for Dianne was explained by his unwavering loyalty, which will be discussed in positioning level 3.

Positioning level 2: Audience. Carl worked hard to make sure the audience understood how his narrative was contextualised. He often checked with me to see if I could relate to what he was talking about and referring to. In the second interview Carl spent thirty-nine lines or almost five minutes taking the audience on a visualised trip to the house where he and Dianne lived and ran a business together, when it was not immediately clear why it was important to know where the house was. That is, the point of Carl's story did not depend on the exact physical location of that house.

Carl's hard work had to be in the service of some other goal. One interpretation is that he wanted to give the audience as much information as possible, to paint as detailed a picture as possible. It is possible that Carl was trying to sketch the financial context and scene; a wealthy suburb containing vast houses. When taking into account how Carl provided 'artefacts' to enrich his stories, it is also possible that Carl was working to provide evidence to his audience. In his second interview he said:

Interviewer: Well, th- it- it seems like there was a real sense of anger towards the- the healthcare system.

Carl: I don't know if it's justified. It's- it's- this is why I wanted you to see that video, to show you how um… how regressive her state was.

In doing this, Carl was not only providing the audience with the authority to justify or approve his anger, but he was also appealing to the audience as judge – I, the interviewer, (having studied psychology) might be able to provide an independent opinion as to how unnecessary it was for the psychiatrist to prescribe such powerful medication. He did this in a similar way in his first interview when he said:

Carl: Please- please excuse and forgive me…

With this plea he put the audience in the position of being able to forgive or excuse him; he gave the audience the power to pass moral judgement. However, he later contradicted this appeal after he had described the situation that led to him slapping Dianne:

Carl: Uh whether I can be excused or understood or acknowledged or- is neither here nor- nor there, they- you know they happened.

At this point then, the power previously given to the audience to excuse or forgive Carl for slapping Dianne is taken away; the audience's moral judgement is made irrelevant by Carl claiming the burden of "living with" what he did. This appeal for and then dismissal of vindication could be interpreted as a sense of shame that was so deep that Carl felt that he could not be given vindication and deserve a life of having to "live with" slapping Dianne. On the other hand, it could also be interpreted as excluding the possibility of anyone else being able to sympathise or empathise with him for the state he was in when he slapped Dianne. In saying that being "excused or understood or acknowledged" is "neither here nor there" Carl could have been applying the logic that understanding the reason that he slapped her did not undo the action of the slap, so forgiveness was inconsequential.

Positioning level 3: Narrator. It seems that Carl wanted to be understood as an authority on several topics. He worked to show his understanding about morality in society, mental illness and the mental health system – usually backed up with an argument of logic.

Carl: Uh I'm a philosophy uh graduate, so you know I look at things in that completely- from a- uh uh completely l-logical based point of view.

Carl began his narratives with a commentary about the lack of knowledge in society about mental illness. He phrased it as "illogical", the way in which mentally ill people are treated. Throughout his two interviews Carl also gave his comments on other sociological topics such as patriotism and the nature of commitment. One of the topics that he often returned to is the morality of having children when the family has a history of bipolar disorder. Carl argued that Dianne's parents were conscious of the ways in which bipolar disorder can affect a person's life, and that having children was "irresponsible". By delivering his judgement of Dianne's parents, he takes a strong stance on the subject – one that seems to be grounded in logic and not emotion. To express the view that your partner's parents should not have procreated, for the reason that your partner has suffered too much, is a strong display of ethical reasoning. Carl seems to want to be understood as an ethically minded person, one who is committed to ethical practice.

Another topic under which Carl worked to be understood as an authority is mental illness. Carl explained, in both interviews, how he had experienced "paler shades" of mental illness. He narrated being clinically depressed and feeling hypomanic. He talked specifically about understanding the feeling of not being in control of your emotions, and also not choosing to

behave in the ways associated with mental illness. He was careful to qualify his understanding of the experience of mental illness, saying that he can "relate… from that point of view", but adding that he did not know exactly what it was like. He connected with this framing later, when he said that he felt empathy for Dianne and not sympathy. He rejected my interpretation of sympathy; insisted it was empathy.

Interviewer: So um, one thing I wanted to ask you is that, when I was listening to our first interview again, I- I got a real sense of um, sympathy and sadness, and also anger. Um- sympathy for- for Dianne and- and sadness about her condition but also-

Carl: Empathy, yes, yes, yes, yes! Deep. Yes…

In Carl's narration of the 'knight in shining armour, when he successfully got Dianne out of a mental institution after weeks of a distressing stay there, he seemed to have 'armed' himself with knowledge of policy.

Carl: …And the mental health r- legislation to get someone out of a healthcare institution after a member of family has signed you in, is the most convoluted and complex and in- have you checked it out?

Interviewer: No.

Carl: You haven't? Oh God. I eventually ended up becoming a healthcare um… administration legislation expert…

Carl: And then I made it my life's ambition to find a way to get her out there. Which is where I then at night used to sit and study and- and- you know what it's like doing assignments, the collecting the all the various bits and pieces and then putting it all together. And then I sent a copy to the- to the um… um, the woman in charge of the hospital, um, and I said to her 'I wanna see you tomorrow and I want you to have read this, to know what's waiting for you in court.' [sic]

In this narration, again, Carl wants to be understood as an authority on the legislation around mental health institutions, and as a person who is determined to work until he has mastered a knowledge of legislation enough to 'win' Dianne's freedom; to 'battle it out' in court. The knight in shining armour is thus armed with knowledge. This narrative has a distinct air of chivalric literature.

Taking into account Carl's concern for morality and ethics, and his many narratives of Dianne as a very special person who needs attention and care, it seems that an overarching theme in Carl's stories was the unjust treatment of Dianne. Carl felt that Dianne's parents, the mental system and he himself had been unable to give her what she needed. He thought that Dianne's

parents should have given more thought to her birth, and should have provided her with the special care she needed instead of expecting her to lead the typical life of a mentally healthy person. When Carl talked about the mental system it was almost always in negative terms, positioning it as underdeveloped and unethical. He felt that Dianne's experiences had revealed a fundamental characteristic of society, that there is a lack of knowledge and logic when it comes to the treatment of mentally ill people. At the same time Carl mentioned, but did not spend much time talking about, his role in Dianne's mental illness. He alluded to the notion that his exciting lifestyle contributed to her episodes of mania and had he known this he would have been "gentler" with her. He also alluded to a plan to have a life with Dianne where he could care and provide for her in a way that was calm and isolated, but where she still had the things that made her happy. Carl talked about "indulging her gently", buying an isolated farm but also giving her a newer version of the car she loved so much before.

Carl never positioned himself as a victim. It is clear throughout his narratives that he saw Dianne as the victim. When he did talk about his own distress, it was almost as if these experiences came second to Dianne's experiences or came about as a result of Dianne's experiences. He talked about not sleeping because he was too busy taking care of her and being vicariously traumatised by her stay in a mental institution. It is possible then that for Carl the most distressing part of having a partner with bipolar disorder was to watch her go through it. He talked about how now that he was not living with Dianne anymore, he had time for himself. That he felt relief when he put her on a bus to go live with her mother. Carl still wanted to have Dianne in his life, but it is possible that for him being with and taking care of her was a painful and distressing matter.

When I asked Carl how their relationship had progressed over time he responded that over time his loyalty to Dianne had deepened. He asserted that he had always and would always feel deeply loyal to her. He provided two narratives on the topic – one of how his father was unyieldingly and even inexplicably loyal to his mother, and another narrative of Dianne's very capable and stern grandmother asking Carl to promise to always take care of Dianne. He made a joke of never being released from this promise, and then in a more serious tone asked rhetorically how he could possibly undo such a commitment. He explained his loyalty as part of his upbringing, inscribed in his make-up, and as a clear and simple resolution. At the same time,

what Carl understood to be loyalty was vague. He had resolved to stay loyal to her but was not clear about what this loyalty might entail. He alluded to playing a providing and protective role but maintained that if she developed a relationship with another man he would not be perturbed. He said that he and Dianne would always have a strong and special relationship, but at this point it seems uncertain what kind of a relationship this might be. One explanation for this apathy towards Dianne's dating life is Carl's paternal role in their relationship. As a father might feel about his daughter, he seemed to think that their relationship was the most important one, and any other male relationship might be temporary or less meaningful. Then he could safely disregard any other relationship she had and trust that their relationship would remain consistent.

Participant 3: Ellen

Ellen is a high-profile executive in her forties who has been in a long-term relationship with Fred for nine years. Ellen began her narrative by giving a history of how she and Fred realised that he was suffering from bipolar disorder. When they moved in together she started to feel that his reactions to apparently small problems were out of proportion. He was then diagnosed with rapid cycling bipolar II disorder. He had often threatened suicide and had mostly been non-compliant with pharmacological treatment and psychotherapy. Two months ago, Ellen asked Fred to move out, but at the time of the first interview they were still very close and involved in each other's lives. At the time of the second interview, Ellen was adamant that the relationship had come to an end, even though she felt that Fred was pursuing her obsessively.

I experienced Ellen as friendly and relaxed when the first interview started, but as the interview progressed I noticed that not a lot of emotion was shown in her speech. She would make sarcastic or ironic comments and smile or laugh, but even when she was talking about what could be very painful events her tone and facial expression were neutral. I struggled to give accurate reflections, especially in the second interview, because I struggled to read her emotions. There were stark differences between the first and second interviews both in terms of content and the tone of her narratives. In her first interview I assumed she wasn't talking about herself, not admitting her feelings and talking more about Fred than about herself. This might not necessarily be true but could instead be my own imposition of a victim role on her. In the second interview Ellen seemed resistant. The main theme of her second interview was her feeling of having had

enough of Fred and bipolar disorder after breaking up with him, so it is possible that this feeling was generalised to participation in research on bipolar disorder. Alternatively, what I took to be resistance could have been other things like tiredness, frustration, or uneasiness with my interpretation of what she had said in the first interview.

Positioning level 1: Characters. Ellen provided inconsistent positionings of her characters, both within the first interview and between the first and second interviews. Her positioning of Fred was particularly inconsistent, and her positioning of her own character was more subtly varied across her narratives. Interestingly, her narration of the mental health system was clear in the first interview, and almost absent from the second interview. The possible reasons for these inconsistencies will be discussed as this analysis progresses.

In her first interview, Ellen moved between constructing Fred's character as that of a victim and as a perpetrator.

Ellen: …but I see him as a complete victim. Someone who's got this dreadful disease, that he didn't ask for and he doesn't know how to deal with.

This construction is accompanied by a lot of sympathy:

Ellen: But he sits- he's unhappy and I find that almost worse. When he fights with me because then I get aggressive back and I say 'Back off' then I'm actually fine, but when I see him sobbing, and desperate and lonely- because he shuts himself off from the rest of the world. He doesn't talk to anyone, he doesn't tell them.

Ellen: But then he tells me I don't understand. Maybe he's right, I don't. I don't know what it's like to wake up every morning and have to fight off thoughts of suicide and demons in your head and voices and- I don't know. Um, and you know, be fighting tears every minute of every day because you hate yourself so much an I- no I don't know… he sees it as all- consuming. There's not a thought that he can have that doesn't start and stop with how to get around this disease.

By looking at the words she uses to describe his experiences, it seems clear that Ellen felt a lot of sympathy for Fred. Watching Fred experience bipolar disorder was distressing for her, and seems to have led to a sense of loyalty towards and responsibility for him. By labelling him as a victim of bipolar disorder, it seems that Ellen felt that Fred was unfairly suffering and deserved to be helped and cared for. However, Ellen also showed an opposing characterisation of Fred as a perpetrator, that he was devious in his self-destructive behaviour and that he had not taken full responsibility for his treatment.

Ellen: I co- I started to see eventually when he was never on his drugs and he'd lie to me and I could see straightaway I could see he's lying. So he played around with his drugs. He is a- he's a medical practitioner, so he knows better than everyone else about all the drugs and what to do and what not to do, so you know he's very clever in that way.

Ellen: Um, and yeah it was all the lies that go with it, you know, 'Yes I'm in therapy' but he wasn't, and 'No I'm not going drinking' but he is.

She described this as a "Jekyll and Hyde" scenario. She seemed to be referring directly to the sudden and drastic change that could happen in Fred's and her personas, but the image of a deformed, uncontrollable monster who consumed the good Dr Jekyll might be important in her experiences of bipolar disorder.

One interpretation of this inconsistent portrayal of Fred links to Ellen's repeated grappling with the thought of leaving Fred. She had broken away from him, but they still seemed to lead very integrated lives. If Ellen was determined to leave Fred but felt too responsible for and loyal to him to act, then each of her opposing characterisations of Fred would serve to rationalise her opposing feelings on the topic. That is, if Ellen felt too guilty or afraid to leave Fred, then a victim character would support that notion. On the other hand, her determination to leave Fred might be supported by her interpretation of him as a perpetrator, responsible for his own destructive behaviour and not proactive enough in his treatment. This interpretation of her inconsistent portrayals of Fred is supported by the characterisations in the second interview. At the time of the second interview Ellen had completely broken up with Fred, was adamant that she would not go back to him, and seemed angry with him. Fred's victim character was given a lot less space in her narratives, and she spent most of the second interview positioning his character as a provocateur. In her second interview, she positioned herself as the victim.

In terms of the agency that she ascribed to Fred, Ellen also vacillated between presenting Fred as an acting agent, responsible for his own actions, and lacking agency, being subjected to cruel situations. However, Ellen spent significantly more time depicting Fred as relatively powerless, even in her second interview. In the following extract Fred is positioned as being the victim of a late diagnosis; the late diagnosis having caused difficulty for Fred.

Ellen: I think he was thirty-seven at the time, um and I think that's made it quite hard for him because that late acceptance in life has been, you know, he's even more resistant then to acceptance, less compliant with anything. And then also unpacking now thirty-seven years of everything he's ever done wrong an- so that's been quite hard.

It is possible that at the time of the first interview, when Ellen was still negotiating her plan to leave Fred, she still felt the pull of the need to save a victim. At the time of the second interview, even though her concept of Fred as a victim had not changed, this concept was less relevant to her; it was even unhelpful to her. That is, at the time of the second interview Ellen had stopped seeing Fred as a victim that she could be responsible for without sacrificing herself. She could not subject herself to the relationship anymore, and so could not simultaneously spend time thinking about Fred's victimhood. Returning to her metaphor of Fred being Jekyll and Hyde, it is possible that she now saw more of Fred's "Mr Hyde" than his "Dr Jekyll".

Ellen: But still, I mean I wouldn't wish it on anyone. But the thing is I can't focus on that cos then I feel sorry for him again and then I think shame, it's not his fault [sic]. So yes, I do, I think it's a dreadful disease, I wouldn't wish it on my worst enemy but I'm just not prepared to look at him as a victim of it, because then it just- it makes it harder for me to stand up for myself.

Even though the main character in her narratives was Fred, Ellen also characterised the mental health system, the bipolar community and Fred's parents. Fred's parents were constructed as uncaring, oblivious to his mental health difficulties and irresponsible.

From the way that she spoke about Fred's parents it seems clear that she thought they were to blame for the extent of Fred's suffering. In the first place, she believed that they were irresponsible in 'handing off' their parenthood to a boarding school, which she hypothesised had contributed to Fred's emotional problems. In the second place, Fred's parents had not been active in his treatment, and seemed to deny his experiences. Thirdly, Ellen believed that the lack of support from Fred's parents had exacerbated his feelings of self-hatred and shame. When speaking about the effects on herself, Ellen seemed to feel resentful towards Fred's parents for not supporting him because the burden fell solely on her. She raised the point that she was not related to Fred, possibly reasoning that his parents should take more responsibility because of their relation to him. She talked about this in her first and second interviews.

Ellen: When he was hospitalised in April they were actually here – cos they live in Botswana – they were actually here. They showed no interest whatsoever, they didn't wanna go to the therapy … but- I think that's been part of it for him because he's lived with the shame, and not even his family was interested [sic].

Ellen: So I felt the pressure being the only one who knew, the only one who understood, the only one who was involved.

Ellen: But you know he doesn't wanna talk to them about it now [sic]. But yeah no, I think the reason why it gets to me is that they actually related to him and I'm not, and they just not shouldering any of the responsibility. They haven't asked to see his doctors, they don't go with him to see his therapist.

It is possible that Ellen felt that she had been unfairly indicted into the role of taking care of Fred, and felt resentment towards his parents was based on wanting to resist responsibility for Fred.

Ellen positioned the medical community as an authority in her first interview. She used characters from the medical field as qualifiers for some of her statements, as if what she was saying had to be objectively true if it was also said by a medical practitioner. For example, she used the medical community to validate her understanding of the situation.

Ellen: And so I've done this because first of all I need the break, but secondly he also needs to- he needs to focus on getting his head straight. He really has to. And it's- I- I can- I know it's not gonna happen with me and his doctors even agree [sic]. His doctors said he- he needs to go on this new journey on his own.

Interestingly, Ellen did this kind of positioning many times in her first interview but not at all in her second interview. Because we know that at the time of the second interview Ellen was in the process of cutting bipolar disorder out of her life, it is possible that the medical practitioners were being cut out of her life as part of that process. It could also be that because at the time of the second interview Ellen was so determined to leave Fred, she no longer needed the validation of medical professionals; her own determination was enough for her at this point.

Positioning level 2: Audience. As previously discussed, Ellen narrated differently in her first and second interviews, and she positioned herself to her audience differently too. In her first interview Ellen worked to explain her actions to the audience, was distracted from the audience and tested the audience. In her second interview Ellen was more resistant, contradicting and interrupting the interviewer.

At two different times in the first interview Ellen 'tested' the audience. Both questions seem to test knowledge of psychology, perhaps meant to assess the 'psychology-know-how' of a psychology researcher. The questions could also be meant to show me that Ellen herself has experience of the psychology world, positioning herself as a psychology expert.

Ellen: D'you know Prof Rita Tom?

Interviewer: No.

Ellen: Don't you? She's the head of Donald Gordon Psychiatry centre and she also lectures at Wits so I thought you would've been-

Interviewer: Okay, alright, she might be lecturing a different-

Ellen: Mmmm.

Ellen: Um, the Unquiet Mind, I'm sure you've read that. I wouldn't say-

Interviewer: No, no.

Ellen: Haven't you? It's one of the classics.

Another interpretation, keeping in mind Ellen's characterisation of mental health professionals as authority figures, is that Ellen was simultaneously checking whether I as a 'psychology advocate' could be characterised as an authority, and showing that she could 'keep up' with such an authority or even be more knowledgeable than such an authority. This interpretation would be based on an assumption that Ellen sees a psychology master's student as being of the same character as the mental health professionals she speaks about.

In her second interview, this narrative tactic (if it was the same tactic) changed considerably. She engaged in interviewing the interviewer – asking the interviewer questions. At the time I felt that I needed to answer her questions, perhaps being too anxious to override her. I did feel distinctly that she was taking control of the interview situation.

Interviewer: …um, o- one of the things that I found in the literature is that they- they treat bipolar as this isolatable thing, you know, that comes into a life and destroys a life and then as soon as you take the bipolar out then everything is fine. And that's really not the sense that I'm getting. You can't isolate it and-

Ellen: Oh really? What a- what is the sense that you getting?

Interviewer: Well just that's so much more um, it's- it's entangled in people's lives in such a more complex way, um, that you can't really just you know, say 'Medicine', done.

Ellen: Yeah, absolutely, absolutely. Yeah we complex beings so- *(phone rings)* let me just put this on silent.

Interviewer: Um, is there- is there anything else you wanna add? Is there anything else you wanna talk about? [sic]

Ellen: I don't think so. Are your other people also still in the relationships or have some of them also broken up?

Interviewer: Some of them have broken up.

Ellen: So you looking at both. Recently like- or long long long ago?

Interviewer: Um, I think one was um, maybe two, three years ago.

Ellen: Okay, so it's quite in the past then.

Interviewer: Yeah.

Ellen: Yeah. No I was just wondering if everyone is still current or if that affects the data collection but it doesn't really…

Interviewer: No, no. Yeah because that's not a variable that I'm looking at. Um, because I mean also the- the thing that I'm finding is that these relationships are so complex, they're not good or bad, absent or present, they're you know, a lot- a lot more more complex than that.

Ellen: And have you got any- any case studies where it's working well? Where people are managing?

Interviewer: Yeah, yeah.

Ellen: Oh well that's good, I'm very pleased to hear that. I really am. Because I do believe it's possible, I really do. I think it has to be possible. It's what I try and tell Fred all the time, but how to make it possible I don't know. *(Laughs)* But I'm glad to hear that.

Interviewer: Cos also I mean it- it would be nice to conduct research on the successful couples and how- how they've made it work.

Ellen: Yes, completely. And I think that would inspire lots of other people. Cos I mean I wouldn't even know of anyone that I could go talk to and say 'How did you guys get it right?' No idea. So, yeah. It would be nice to- *(both laugh)*.

Interviewer: Yeah. Yeah but I mean this is just a- such a rich topic, there are sooo many things here.

Ellen: It's huge, yeah. Your PhD's waiting. *(Laughs)*

Interviewer: It is, yeah *(laughs)*.

Ellen: Yeah exactly. Have you got any other questions for me?

Interviewer: No, no. Um, I- like- uh- when you talk you- you- you give a lot of information, um, so yeah, even if we haven't spent a lot of time talking there's been a lot coming out.

In both these instances one gets the impression that Ellen is asking a specific question: "What do you know about making relationships with someone with bipolar disorder work?" She seems to want to gain information about the possibility of such a relationship succeeding. This could be because she does actually want to be in a relationship with Fred but just cannot find a way to

tolerate the relationship at this stage. If this is the case, Ellen interviewing the interviewer could just be her taking the opportunity to ask someone who is studying the topic of being in a relationship with someone with bipolar disorder about the possibility of it. This could also be linked to how she talks about breaking up with Fred in the first interview – it is an extension of her tension around leaving him. It could be that Ellen indirectly wants to find out if other people have ended their relationship, which would vindicate her. If other people have also ended their relationship with a person with bipolar disorder it means it is something about bipolar disorder that makes these relationships impossible rather than something about Ellen's own character. On the other hand, these two instances could also be Ellen's work to take control of this research situation, to express to the interviewer that she too can get information after giving so much information. As related to her characterisation of mental health professionals and the argument made about the authority in this relationship, Ellen could be working against this 'authority'.

The other interesting thing Ellen did with her audience in the second interview was to mount a form of resistance. In her first interview she resisted some reflections that I made, but that was not the general tone of her interview. In the second interview she spent much more time resisting the interviewer.

Interviewer: Yeah. Um and last time you spoke about um, feeling doubtful as to whether leaving him was the right thing to do, so this must be-

Ellen: I think I was doubtful that I'd actually get it right. But there's no question in my mind it's the right thing to do- and it's just getting more clear every single day.

Interviewer: Um because you were talking about how there was um… th- there had been growth in the relationship and now there was regression. Now you guys were growing in a…

Ellen: I don't know that growth's the right term, I think maybe that stopped a very long time ago.

Interviewer: Um. Okay, and then um, can you tell me a little bit more about his family being denial and why that was so difficult for you?

Ellen: Well I don't- I think before you gotta be in denial you gotta know there was a problem and I think they just didn't even know there was a problem.

In the first extract Ellen interrupted the interviewer to assert a different understanding of her doubt around the break up. In the second extract she contradicted the interviewer's use of the term "growth", even though this was the term she used in her first interview. In the third extract she did the same with the term "denial". By resisting the interviewer's conceptions of her

experiences it is possible that she was trying to gain control of the research situation. This could be an indication that she was trying to exert control over the bipolar disorder situation more generally. By resisting the interviewer's interpretations, she could have been trying to re-interpret the situation herself, thereby gaining control in the form of a different understanding of the situation – one where she was powerful in contrast to a situation where she was powerless.

Interviewer: *(When talking about support structures available for the family members of people with bipolar disorder)* And what about for you?

Ellen: Um see I'm not interested anymore *(laughs)*. No I'm really not, no I'm really not.

This assertion by Ellen is much clearer and more straightforward than anything she expressed in her first interview about support structures. It seems that she had given up on being supported by mental health structures to such a degree that she was not even willing to elaborate on what she needed at that moment. After saying this, she went on to talk about family members supporting a person with mental illness in general, but avoided personalising this talk. This disinterest supports the argument that she was resisting bipolar disorder in general. She was not interested in engaging in the topic anymore, not even to attend to or elaborate on her own support needs.

Positioning level 3: Narrator. Ellen spent a lot of time in the first interview explaining her break-up with Fred. She reasoned that doctors had encouraged the break-up, the break-up was the best thing for him and that she could not sustain the relationship anymore. It is possible that she worked so hard to explain her decision because she wanted to make sure her break-up was being understood in the way she wanted it to be. The break-up being the "best thing" for both herself and Fred would mean that she was not guilty of abandoning him, something she seemed to be concerned about. It seems that Ellen wanted to be understood as doing the most mutually beneficial thing in breaking up with Fred, that the break-up was 'right'.

Ellen: But I also think I- I'm too much of a trigger for him, I'm just- I've realised that now, I'm way too much of a trigger. If I'm on the phone he needs to know who it is, if I'm working late- he's not jealous, but he's very insecure. And so I- he's- all his focus is on me and my behaviour…. And so instead of him just focusing on his own mental health he's become focused on me. And so I've done this because first of all I need the break, but secondly he also needs to- he needs to focus on getting his head straight. He really has to. And it's- I- I can- I know it's not gonna happen with me and his doctors even agree [sic]. His doctors said he- he needs to go on this new journey on his own.

Ellen informed me that she had broken up with Fred, which she said had to be "important for [this] research" and augmented this information with the reasons she had broken up with him. In this extract the reasons she provided were that her presence was catalytic to his emotional upheavals, that he was unable to focus on himself when she was present in his life, and that she needed respite from the relationship. She supported these reasons with what she saw as agreement from his doctors, as previously discussed.

Besides admitting that she needed a break from the relationship, Ellen didn't spend much time describing her emotional experiences. It seems that she wanted to be understood as a resilient sufferer. She did describe her negative and painful experiences, but these were almost always accompanied by laughter, an expression of dry irony or a deflection to someone else. These actions gave the impression that she was coping well with these experiences or that she was even relatively unaffected by them.

Ellen: Uh I mean I've had lots of stressed-induced illnesses, I've had shingles and I'm far too young to have shingles *(laughs)*… And I probably drink far too much wine, now I'm an alcoholic *(laughs)*. Thank God I'm not, but it probably is too much *(laughs)*.

Ellen: So the night I came home with all the suicide notes all over the house, I actually folded them all up and went to bed. And it was one of the hardest things I've done. But I just thought, you know what, 'If you gonna do it you gonna do it.' [sic] Um, but he didn't, so… Um, but, anyway. Eventually you stop doing it, you've done it enough, you stop doing it and you know what *(laughs)* they generally don't kill themselves.

In these two extracts she was distanced from the risk of Fred's death – she treated it almost as if a child-like Fred had thrown a tantrum, so she, like a resigned and exhausted mother, cleaned up the mess and ignored his unacceptable behaviour. When she did talk about a possible emotional reaction to conflict between her and Fred she did so with another reference to Jekyll and Hyde.

Ellen: So I- I struggle, but now I'd say- it's probably not a good thing but I've mastered completely the art of living a Jekyll and Hyde life… I've had to master that. I haven't had a choice. I cannot be crying in the bathrooms.

Ellen had spoken about Fred's Dr Jekyll and Mr Hyde before, but now shifted the comparison to herself. This reference also alluded to the possibility that she was currently occupying a Dr Jekyll state. If her emotionality in the face of tension between her and Fred was her Mr Hyde, and her business-like, professional persona was her Dr Jekyll, then the business-like persona she was occupying in the interview also had to be her Dr Jekyll. The implication then is that her Dr Jekyll

was not necessarily her true self, or that her emotional life in response to Fred was a monster to her.

It became more difficult to understand how Ellen wanted to be understood in her second interview. If she was working to disentangle herself from Fred in the most benign way possible in her first interview, it's possible that in her second interview she wanted to show that she had freed herself from him. She spoke about Fred pursuing her "relentlessly" and "obsessively", but she made it clear that she did not want to engage with his behaviours anymore. Even so, she was still concerned about his emotional ability to separate himself from people. We saw a glimpse of the concern she felt for Fred, at her expense, that was shown in the first interview, followed by a return to the determination of the second interview.

> Ellen: Yeah, so- I mean he's just not- he's not able to create that separation at all. Which worries me for his sake, but it just makes it very clear for me that I'm not prepared to have someone like that in my life.

> Ellen: …he's really not handling the break-up well, but he's conflated everything in his life in it now. So his job and his life and where he lives and even stay in this country or go overseas is all part of that whole thing… And I just- that's not a reason for me to stay in a relationship. So if anything it's made it very very clear to me that it- that you know it's not how I would stay in a relationship...

As discussed previously, she then worked to be understood as having given up acquiring support for her experiences in general. It seems as if she as a narrator wanted to be understood as having tried, having been proactive, trying to find the most beneficial solution, and then giving up, distancing herself from that world and wanting to be free of the responsibilities involved with being in a relationship with Fred. In the first interview Ellen wanted to be understood as a resilient sufferer. In the second interview this still seemed true, as Ellen continued to avoid explanations of her own feelings and experiences. In the second interview, however, there is also a sense of Ellen transferring Fred's victimhood to herself. Whereas Fred was not given a lot of agency in his victimhood, it seems that Ellen was a victim determined to escape, even that she was already in the process of escaping.

Participant 4: Georgia

Georgia is a middle-class woman in her 50s who has been married to Harry for thirty years. They are in the process of getting divorced. Ten years ago Harry's brother died, which triggered

emotional distress for Harry. He became depressed, was withdrawn, obsessively focused on work and experienced mood changes. Harry and Georgia's relationship suffered because Georgia felt that he was not participating in her life anymore and didn't engage with her. Four years ago Harry was diagnosed with bipolar II disorder. Harry attempted suicide several times and was periodically non-compliant with his medication. At the same time Georgia was diagnosed with diabetes. The stress of caring for Harry was a danger to her health and it was decided that Harry should move into a psychiatric residence. Harry has been living there for two years and Harry and Georgia have separated, but they still communicate and see each other.

In Georgia's interviews she seemed enthusiastic and emotional. She cried in both interviews, but remained calm enough to eloquently explain her experiences. She came across as somewhat helpless, but friendly and warm. I felt empathy for Georgia; I felt with her in her emotionality and wanted to comfort her. I resisted this urge but Georgia's interviews did feel like counselling sessions. While I do not think this is problematic, especially with the consideration that narrative interviews can be inherently therapeutic (Ayres, 2000; Poindexter, 2002), it is possible that I was more sensitive to Georgia's experiences than to those of the other participants.

After her first interview Georgia sent me an e-mail, which ended with, "I hope this helps you a bit more as I was really tearful and overwhelmed on Wednesday." According to the narrative framework, the content of the participant's narrative should be guided by him or her (De Fina, 2013; Riessman, 1993). In keeping with the narrative perspective, Georgia's e-mail will be included in the analysis because it is clear that she had extended her narrative in it. Most of the e-mail reiterated or reformulated what she spoke about in the first interview, and so does not create the problem of this participant getting more interview data than the others, which is in any case not problematic for research that does not intend to generalise its findings. Above all Georgia's e-mail provides an interesting issue for positioning level 2 – communication with the audience.

Positioning level 1: Characters. Georgia's narratives included few characters – most of her narratives only involved herself, Harry and sometimes Harry's mother. She mentioned her son, her dog, two clients, mental health professionals and the community of the mentally ill, but

she did not spend time narrating their characters. This small 'cast of actors' was an important quality of Georgia's narrations because it demonstrated how lonely these experiences have been for her. She expressed on more than one occasion how lonely she had been for the last ten years, saying that this period was the loneliest of her life. Specifically, when I asked her about loneliness, Georgia responded in terms of Harry's character.

Interviewer: Um. So… I was- I was wondering if this is has been a very lonely road for you. Which you've experienced as a lonely road.

Georgia: Yes. Very. And… but it's… uhuhuh, it's getting better now… But you've- spot on with that. *(Crying)* It was the loneliest ten years of my life. Because Harry wasn't with me in this. He was in his own… And it's still lonely Mia. It's still lonely. Because when I'm with him I feel alone.

In this positioning, it is Harry's absence that Georgia narrated as causing her loneliness. She had previously mentioned not reaching out to other people for support during these experiences, but she did not relate that isolation to her loneliness. For her, Harry's absence was the most salient, not the absence of other support structures.

Georgia spent most of her time talking about Harry and how she had perceived his behaviour. Furthermore, she mostly narrated his behaviour since she started noticing his symptoms and his present behaviour, but she seemed unable or unwilling to talk about Harry before his behaviour became problematic for their relationship. She talked about Harry "always" being a withdrawn, moody and self-centred man, but perhaps was unable to narrate the good parts of their relationship, or the character that she fell in love with.

Georgia: He was a quiet man- as I said, he was a quiet man. He lived in his own world. And I'd learnt how to live around that world with him. I would watch his mood, I knew how he got, he just was- and he- all he wanted was me in his world and that was it, then he was comfortable and happy. And you learn to adapt to that. But it means that you don't live.

Another interpretation of Georgia's narration of Harry's character revolves around her use of metaphors of life and death. Harry was described as ghost-like, "lost" and a "flat-line". Georgia also described herself as "not living" while she was still living with and caring for Harry, whereas now she is "living again".

Georgia: And… he changed after the first set of shock treatment so he's not the same person. And… so he has no dreams, he has no motivation he- he just exists, he's a flat-line.

Georgia: To watch a person like that- it's just- it is a death, so it's like I have mourned him for years and years and he's still very much alive.

For Georgia, Harry was dead or occupying a death-like state. It seems that Harry's bipolar disorder and specifically his electroconvulsive therapy had "killed" him. He was now living as a shadow of his former self. This concept extended into Georgia's choice of tenses when speaking about her feelings for Harry.

Georgia: …because I loved him. I do love him.

Georgia: … he was… he's very important to me Mia, he really is.

Georgia's ascription of agency to Harry parallels the ghost-like quality given to his character. She often talked about taking care of him, protecting him, and seemingly making decisions for him, further developing the passivity of his character. Even though she talked about Harry being controlling and obsessive, she still gave her general impression of him as being a character with insubstantial power and agency. When she did give Harry agency it is on the topic of his medication non-compliance or his suicide attempts.

Georgia: So we managed to keep him in his job for a further year.

Georgia: …he then decided he was doing well and he went off his on- anti-depressant on his own and things just took a turn for the worse from that.

Georgia: … and then he decided to take all his pills.

This agency was given with the implication that when he was active he made ill-informed and self-destructive decisions.

Positioning level 2: Audience. The narrative tools that Georgia used to position herself to the audience also created an intimate relationship between her and her audience. She often used my name, she became emotional, she appealed to the audience for information and she worked to attend to her audience's needs.

Georgia used my name at many different points in both her interviews. She sometimes used my name when saying something particularly emotional or important to her, but this pattern did not seem to be consistent.

Georgia: You don't have a relationship Mia. You… you don't have a normal relationship, you don't function as a normal couple.

Georgia: Um, and… it's- that's- it's- so I've reached acceptance Mia, you do- in the r- you- uh- he- well he accepted I've got a- that it's over no um… I know the relationship's over and it's never gonna be what it was [sic].

Georgia: I trust the doctors Mia, it's not that I don't, and I trust the psychiatrists, they deal with him.

In the first two extracts it is easy to see that these two topics were very important to Georgia. The fundamental existence of her relationship or the 'normality' of her relationship with Harry, and the acceptance that she had achieved are understandably emotional issues. In the third extract it was less clear why her trust of the psychiatrists was an important issue for her. Trust of psychiatrists could be a dominant topic in many people's lives, but at least in these narratives Georgia spent substantially more time talking about the state of her relationship and the acceptance she had gained than how she felt about mental health professionals. It is possible that she used the interviewer's name when she particularly wanted to be understood. The only other time Georgia wanted to speak about mental health professionals was when I reflected on being angry with Harry's psychiatrists.

Georgia: … I don't think I was frustrated with the medical side because I understand that- the difficulty they have… I'm frustrated- I am frustrated with him, I mean I'm angry with him… But please Mia not at the medical field. They did everything that they could.

It could be that Georgia was appealing especially to her audience by using the audience's name because at that moment she was feeling misunderstood and wanted to work harder to be understood. If this is the case, then Georgia wanted me to understand that she blamed Harry more than the psychiatrists who treated him, that she felt a greater anger towards Harry for his part in the events. By saying "they did everything they could", she could have been trying to explain that she acknowledged the psychiatrists' good intentions and efforts, while she did not feel that Harry had made the same kind of effort in his treatment. A few lines later, Georgia admitted that she did feel frustrated with the medical community, explaining that the inconsistency in diagnosing Harry and the apparent inefficiency of his treatment was difficult for her. However, she still made it clear that she understood the limitations of their power in a situation like this, and again indicted Harry, saying "I really believe he could've fought harder for himself." For Georgia, Harry had more agency and responsibility in this situation than his treatment did.

Interestingly, she used my name eight times in the first interview and eighteen times in the second interview. If this narrative characteristic is indeed indicative of the intimacy of the relationship between the narrator and the audience, then it makes sense that the narrator would feel a more developed relationship in the second interview.

Georgia's emotionality in the interviews was intense. She cried many times and described her experiences emotively. These emotional expressions gave the interviewer a sense of honesty – she was showing what she was talking about. At the same time, her emotional expressions gave me the impression that she was very present and very committed to her research participation. That is, because she was showing her emotions so openly, it seemed that she was willing to be completely honest and unrestrained in what she gave her audience. This was especially appealing because instead of just describing her experiences, she was also performing the emotions of her experiences.

The e-mail Georgia sent after her first interview seemed to be an attempt to do even more work for her audience. The e-mail brought the narratives she gave in the first interview into a more coherent whole, even though I didn't experience her interview narratives as incoherent in any way. She positioned herself as a provider for the audience, giving a story and giving a satisfying story. It seems as though she assumed that what she had said in her interview was not satisfying enough, and wanted to compensate for this perceived lack. In this way Georgia simultaneously positioned herself in a helping role and as a 'good participant'.

Georgia: *(At the end of her e-mail)* I hope this helps as I was really tearful and overwhelmed on Wednesday.

Georgia: *(At the beginning of second interview)* I hope that- that's why I sent the- the e-mail- that helped you. Just giving you more information. Cos I kinda felt like I'd started in the middle [sic].

In her e-mail she reiterated or reformulated what she spoke about in her first interview, but she formed her narrative more linearly. She started the narrative with a synopsis of their time together, described Harry's character and behaviour, described her response to Harry's behaviours and then explained her perspective of the present situation. This e-mail thus supplies a more logical, comfortable narrative. Georgia's concern for providing for the audience and being a 'good participant' was also echoed in her first interview when she said:

Georgia: So, our whole normal life that we kind of had before just disappeared. And you become strangers. So I don't know if this is helping you Mia.

In her second interview Georgia also appealed to her audience for information.

Georgia: So I'm kinda thinking, are there different types of bipolar? [sic] Are- do they- what is it?

Georgia: So I don't know, is it genetic? That would help us, because I have a son. And it worries my son.

These appeals for information about the nature of bipolar disorder were not persistent in the sense that they came across as rhetorical questions. Even though there was a distinctive feeling that she wanted an answer, she did not insist on an answer. It is possible that, in line with her providing for the audience, she was now asking for something in return. These questions do not come across as trying to gain control in the interview situation; she was not interviewing the interviewer. It seems as though she wanted the audience to address some of her concerns. In asking these questions she was also positioning me as expert, able to give her information that she did not have.

Positioning level 3: Narrator. Georgia appealed to discourses of 'normality' in her narratives. However, where others might use the discourse of 'normality' to describe a sense of how things 'should be', or the typical way to do things, Georgia seemed to be talking more about functionality.

Georgia: You don't have a relationship Mia. You… you don't have a normal relationship, you don't function as a normal couple.

Georgia: They tired, they can't sleep, they stressed, [laughs] they have- it's always their troubles and their problems. And that's the biggest concern, the biggest issues in that's why don't have a- a normal relationship. It just becomes all about them.

Georgia: And I know that in his- that he loves me and he cares but he can't care to the point that- what I would need in a normal relationship.

It seems that for Georgia, 'normality' in a relationship has more to do with the ability of the couple to care for each other, to be interested in each other – to participate in each other's lives equally, rather than what she has experienced with Harry. With Harry she felt that the relationship was one-sided, which for her characterises an abnormal relationship. This one-sided relationship could be more like a parent-child relationship to Georgia than an intimate adult relationship. Georgia also talked about normality in terms of lifestyle.

Georgia: And, I've always loved my husband unconditionally. I just can't live with him. Be- because we can't function together. But he is his illness and that's the difficulty, and he behaves in a way that society doesn't necessarily accept, if you can't, you know live normally.

Georgia: …so I've struggled watching other bipolar people live… s- kind of normal lives… Because I have another client now I mean she's also a bipolar person. But she's working. And she's married and she's living a really kind of… what I would term a normal life. And I don't see that with Harry.

Georgia: But at the same time now I'm learning that it's okay for me to live in my uh what I would- normal way of living, that it's okay.

When Georgia was talking about "living normally" or "behaving in a way that society accepts", it seems that she was referring to how Harry would behave in public – specifically getting into others' personal space and becoming emotionally overwhelmed in public spaces – which she felt was the cause of their increasing isolation from other people. Georgia said in her first interview that if other people didn't understand or accept her husband then she wouldn't want to have those people in her life, so it seems that Georgia would have rather given up her social life than expose Harry to the difficulties of being in society. This, as well as the 'abnormality' of their relationship itself, is what was 'abnormal' about the life they lived together – their inability to interact easily and regularly with other people.

Following from Georgia's conception of a 'normal' life and relationship was the way she wanted her role in Harry's life to be understood. For Georgia the 'normality' of a relationship was parallel to what she wanted from a relationship – mutual interest in each other's lives. When she and Harry were living together she said that she was playing the role of a caregiver, nurse and mother; something she did not want and did not see as 'normal'.

Georgia: Oh God I was m- you right. Nurse, mother. And all I wanted to be was actually a wife, and a partner. And- and that- that disappeared. And I don't want to be the caregiver now. I don't wanna be the- his mother, I want to be a partner, a wife [sic]. And we can't have that.

Georgia: Yes, I want him to be part of my life and to- and when we went for um, the therapy together, um, in the early stages when it started. I mean, gosh, the- the therapist tried to help us and she'd say to him, 'Harry listen to Georgia and you gotta work with her, and this is what she needs.' [sic] And it just- we just couldn't get past that point. He could never see that there were two of us, it was- that- his condition became our life.

Georgia: Um, and that too, I mean, you'd come- you- you just- as a- as a partner you gotta be prepared to just do everything [sic]. It's a relationship where it's all give and you get very little in return.

Georgia's distinction between 'normality' and 'abnormality, as well as the roles she was playing in the relationship which she did not want are then used to explain why she couldn't stay in the relationship:

Georgia: …so your relationship becomes a very strange one, with the condition. So you very right there, you end up being the nurse, the caregiver, um, you worry for- you actually take over that- you… you live for them. And you become non-existent, you- you almost lose your own identity in all of this.

Georgia: …from the partner's side, everybody tells you to hang in there and be patient and look after them and you should be there for them. And you can't. You get to the point after being there for years and years and years that you just… it drains you, you give up. Because you stop living. So I stopped living. And he just carries on.

Georgia wants to be understood as not having received what she needed from a husband and wife partnership; that her relationship with someone with bipolar disorder meant that what she understood as the husband and wife roles were not and were never going to be possible. They were subsumed by a caregiver role. Her understanding of the roles and normality of the kind of relationship she wanted in her life fitted with her use of life and death metaphors. The way that the relationship was functioning when she and Harry were living together was "not living", whereas she was again "living" after she and Harry had separated.

Georgia: So yeah it's worse than death Mia. Cos death you can come to terms with that you never gonna see them again [sic]. Where with this you just watch the… the process of them disappearing.

Georgia: Then I thought I was being selfish. And then I got guilty that I was living. That was the other- I felt bad that I was living and laughing and enjoying life, and then I wouldn't share things with him that were happy things because he would not show any joy around that and then I felt bad.

Georgia: …so it was r- only afterwards that when he started going to (step-down facility) that I realised I was just on this train, that I wasn't living. Absolutely. I was living this crazy life.

As previously discussed, Georgia compared Harry's existence to a "flat-line", she spoke about "mourning" him, and she spoke about living with Harry as "not living". In her second interview Georgia referred to herself as a widow nine times. In these extracts we can see that for Georgia, Harry's bipolar disorder was a death. In one way it was a death for Harry, who she described as "lost" and "gone". In another sense it was a death for her – she described "not living" while she was living with and caring for Harry. Importantly, Georgia said several times in her interviews that she had started to "live again". For her, "living again" meant interacting with other people, working, and enjoying herself. Moving Harry into a step-down facility allowed her to focus on

her own life, instead of what she termed "living for Harry", with his bipolar disorder being the centre of their existence.

In terms of Georgia's metaphor, her guilt around being happy and "living" is a kind of survivor's guilt. She felt guilty showing happiness, enjoyment and "signs of life" in front of Harry, when he was not capable of sharing those emotions with her. Georgia said her guilt was passing as she moved towards acceptance of Harry's "death" and acknowledgement that she had done everything in her power to help or "save" him.

Based on this line of thinking, it is possible that Georgia wanted to be understood as having suffered through a life-threatening ordeal – one that claimed her husband, but one that she herself had ultimately survived and was recovering from.

Participant 5: Jake

Jake is a man close to retirement age who has been married to his wife, Kathy, for close to thirty years. Jake began his narrative with a history of the relationship. He explained that when he met his wife he found her to be energetic and outgoing, but also knew that she sometimes became very sad. When they had children Jake found that Kathy was unable to participate in the household activities as much as she needed to. She was eventually diagnosed with rapid cycling bipolar II disorder. Jake went on to explain that the medication stabilisation process had been long and frustrating until they came across one psychiatrist who has been able to provide Kathy with effective medication. This medication has been important for Jake but has also come with its own set of difficulties in the form of its side effects. Jake also brought into his narratives his wife's trouble with an "OCD mentality" before giving a condensed history of his wife's life, seemingly trying to show how her disorder had "developed". He ended his first narrative by explaining that he would have married his wife whatever the circumstances, and that he was relieved that her case was not as "bad" as the cases he heard about from the support group his wife was involved in.

I found Jake to be very interesting and his narratives absorbing, even though I sometimes could not follow exactly what he was saying. This was because the location of our interviews was in a distracting place and Jake has an accent that I'm not accustomed to. Even though I

enjoyed listening to Jake, I sometimes found him to be patronising. I felt vaguely irritated by his attempts to teach me things, especially 'life lessons' that didn't necessarily apply to me. However, I found it easy to dismiss these feelings and focus more on Jake's narratives. It was also difficult for me to give reflections on what Jake was saying – I struggled to grasp the deeper meaning of some of his narratives until I transcribed and analysed what he was saying. During the interviews we sometimes misunderstood each other. Jake didn't bring a lot of emotion into his narratives, which made it difficult for me to give reflections during the interviews. However, upon analysis I understood much more of what Jake was trying to communicate.

Positioning level 1: Characters. Jake spent most of his narratives developing his own and his wife's characters. He also spoke about a psychiatrist, a psychologist, his children and both his and his wife's family, but these characters only play 'cameo' roles in his narratives.

Jake characterised his wife as a "vivacious, outgoing" woman who is smart and capable. He alternated between qualities that made her an impressive-sounding woman, and the symptoms that made up her bipolar disorder and her obsessive compulsive traits.

> Jake: But on the other hand, she's one hell of a smart cookie. My wife is one sharp cookie. And she had an ability to hold knowledge, really very very long. So it might be part of the OCD kind of reinforcing the knowledge she's learns and so on, so that when she speaks about something you know- don't- don't argue with her, she knows what she's talking about.

Jake also expressed that she had been on a "tough road". He explained that members of her family exhibited characteristics of bipolar disorder, and that she had suffered extensive losses in her family. He then went on to explain that many of Kathy's friends have left South Africa, and made a connection between her history of loss and her mental disorder.

> Jake: So… about the time she got to thirty- no at twenty-two her father died, twenty-two- yeah, twenty-two, um, lemme just work this one out, she was… thirty-six when her brother died [sic]. And her only sibling. And her mother died four years later, um, forty. By the time my wife reached forty years old she- her entire family was gone. Now, one of the underlying factors of the whole thing is loss.

When Jake started to position himself to Kathy, he often spoke about how Kathy would be dismissive and critical of his efforts to understand and support her. In this way he positioned her as a hen-pecking wife, and himself as the hen-pecked husband. This positioning seems to only

occur in terms of Jake's understanding and support of Kathy's bipolar disorder and not in other areas of his narratives.

Jake: So, on that level, I try be somewhat of a supportive spouse but, oh my wife would turn and klap me from here to hell and say 'You didn't, don't-' blah blah blah [sic].

Jake: I'm glad in a way my wife is not here, because she's t- she- she'd be throwing me down the staircase a few times for not understanding everything that goes on in her head.

Jake: And um, this is really a challenge because one has to sort of say 'Stick to the decision, we're gonna go forward.' [sic] 'But but but but-' I say 'No no we going forward like this.'

Jake: And the kids- as- so- as long as they know Daddy was in charge of the finances, everything was going right and I planned it and I organised everything.

Jake developed his own character as "the engineer", based on his occupation. 'The engineer' was logical, pragmatic, and emotionally neutral, and extended from being his profession to his personality and perceptions of life. He used the characteristics of 'the engineer' to explain both how he was able to manage his wife's symptoms and why it was that he found it difficult to support her emotionally.

Jake: I'm always just quote and unquote, the same engineer. Sometimes I blow my top but it's not common. Okay. And I can get really cross, okay. But generally I'm pretty pssht straightforward [sic]. I mean I'm fine with- incredible stress can come on me, not just within the house, but in the office, or with my clients.

Jake: I was maturing- quote unquote- maturing into the engineer, who looks at numbers and things, and not worrying about feelings, not worrying about emotional aspects. And so that makes it much harder for me as an engineer to try to kind of come to grips with emotional turmoil my wife was going through.

Furthermore, 'the engineer' was used to explain why he did not feel that he had grounds to challenge Kathy on her criticism of his support for her.

Jake: So, she'll crit- she'll say I- I- I've not been very supportive. Uh I- I- I find it challen- I couldn't- I couldn't gainsay her, I couldn't argue with her because I'm just the engineer. Just the engineer.

Jake: So one of the problems that we face- well I face, is that as an engineer I need to have facts in front of me, so I can argue… So yes, my wife would say 'You're not supporting me' and I'd say 'yup, I haven't.' And I agree with her because if I attempt to gainsay her, to get the upper hand of it, on one hand I feel like I'm not sure I've got enough facts to justify my intent- my defence.

Kathy and 'the engineer' were positioned in a complex way. It was not a simple matter of one character having more agency than the other or that one character was sympathised with more

than the other. In matters of emotion Kathy was positioned as the authority. Jake explained how he did not understand the emotional lives of people well. He acknowledged that Kathy understood much more how emotions work and argued that her frustration with his lack of emotional sensitivity was justified. On the other hand, when it came to Kathy's lack of pragmatism, Jake positioned himself, or 'the engineer' as the authority and expressed difficulty in understanding, and even frustration with, her procrastination and inefficiency.

Jake: Cos I find myself out of my depth in that particular topic, dealing with depression and I say, so what do you wanna do about it? And my using the word do- do- D-O- use that word 'do', it forces her- and she says 'I don't wanna do anything I just wanna feel.' Sometimes the engineer wants to do, to fix that and solve problems, and try to make everything better for everyone… And I'll say 'Well let's see what we can do about this thing' whereas again it's not doing, it's feeling. And say well 'We can only feel this for about a few minutes, what do you wanna do after that?' You doing something just feeling. [sic]

Jake: …it's a funny thing that's been lately- has been driving me mad … um my wife is the only one who says 'Doublecheck something.' I said 'Wait a minute, either you check or you don't check. What's this double check?' …like that cellphone's on the table. 'Make sure it's on the table.' 'Yes honey.' 'Will you doub- double check that it's on the table?' And then you gotta go ballistic and you say 'It is on the table.' So that kinda happens. That can happen. [sic]

These positionings of Jake's and his wife's characters are indicative of the way he presented their relationship. Jake narrated their relationship as one of equality – of equal effort, equal guilt and equal agency. That is, throughout his narratives Jake described challenges for both himself and his wife, as well as each of their strengths. As previously discussed, Jake struggled with emotional understanding and Kathy struggled with pragmatism. Jake provided stability to his wife's actions and the relationship with his logical and efficient problem-solving skills and Kathy enriched Jake with her emotionality, energy and intelligence.

In terms of Kathy's bipolar disorder, Jake gave her the agency. He positioned her as more knowledgeable about her disorder, more affected by her disorder and responsible for her treatment. Jake explained that there was no "caregiver-patient mentality", and expressed his belief that such a mentality would be counter to a successful partnership.

Jake: More partnership yeah. Yeah the partnership issue- it works out very- I don't remind her to take her medication, I expect her to take care of her own medication. It is- that's what makes the relationship to my mind work. It's not a case of where I have to nurse and make sure she does X-Y-Z-. Cos otherwise it isn't an- a- a relationship of equality.

Kathy's bipolar disorder and obsessive compulsive traits were never presented as characters, or individually influencing forces, but as characteristics of her personality. Jake often spoke about bipolar disorder being "part of the package".

Jake: She's- she's had a tough road. She's had a tough road. But, I'll take that package. I'll take that package. That's what I married, I'll take the whole lot. Hook, line and sinker, the whole lot. I wouldn't change her for anything. Yup.

As such, her symptoms were spoken about as complications to their relationship in much the same way as particular personality characteristics, belonging to both Jake and Kathy, were spoken about as complications to their relationship. These complications were never presented as impossible or intolerable, but just as elements requiring negotiation and management.

Positioning level 2: Characters. Jake positioned himself towards his audience in a distinctly professor-student role. He did this by delivering his opinions of matters as factual statements, by providing illustrations for the points he was making much like a teacher would do, and by sometimes being patronising towards the interviewer. He was never patronising in an offensive way, but it came across to me that he was trying to teach me things that he assumed I needed to be taught.

Jake acknowledged that he played this role in his work environment.

Jake: In the engineering world there are people who are talkers. Then there are people who are doers. I am in my job, I am the professor. I'm not the only professor, but I am the prof- a professor in terms of I can take calculations out of these books here and whatever, and I would give you an analysis and I would say exactly what is important to say, exactly how to work with the important- and that's to be included. And I'd say either you'll work or you'll fail.

Jake's explanation of his professional role transfers very well onto how he answered some of my questions. For many, if not all of my questions it seemed that he gathered a lot of information he had gained through study and experience, gave his audience a summary and an analysis, and then pointed out to the audience what was important to pay attention to.

Jake: And so, at the end of it all, um, her- sense of her gyroscope- that's a word I wanted to stress is the gyroscope was… is really important. You've gotta have a sense of- look at what you're doing. You wanna do a Masters and you wanna understand a certain aspect of psychology, clinical psychology. Okay fine. You have a gyroscope that says "I'm going to achieve that certain thing." Alright. Well, I also have one- everyone has a gyroscope. But the challenge is the gyroscope doesn't like too many changes. It- unless you are really one very solid individual inside your

head, you are not wanting to look forward to change, radical change. I.e., leaving the country. [sic]

In this instance, Jake identified the concept of stability as one of the most important aspects of the success of his and his wife's relationship. He analysed his relationship and the way that people respond to their environments and applied the analogy of a gyroscope (an analogy very fitting from 'the engineer') and went on to explain this concept to his audience. Interestingly, he did not present this analogy as his own way of understanding other people, but as if it were a well-accepted piece of psychological theory. After saying the above, he went on to give an illustration – that when his son moved to America to study he developed a 'gyroscope' for his son. He prepared his son for the move by giving 'practice rounds' of living by and providing for himself. So, for Jake, the 'gyroscope' was a person's sense of boundaries and coping mechanisms – the things that people and relationships need to remain 'stable'. By delivering this analogy as a teachable concept, a piece of theory, he became a professor delivering a lecture to his audience.

He also took on a research supervisor role towards me, knowing that I am a master's student. He made suggestions for topics I could or should attend to, and said repeatedly that I had a tough job ahead of me.

Jake: She tells me about people- y- it would be- if you haven't been to her support group it might be worthwhile just to take a look at it-

Interviewer: I have.

Jake: You've been there. Yeah.

Jake: If in your write-ups you wanna stress the idea for the- the um other person not the bipolar one to learn the Rogerian- Carl Rogers- approach, actually learning how to draw out that person and get them to talk, that has been very very very important for us. [sic]

Jake: It- it's very… you got a tough- you got tough nut here. You got a tough nut, because it doesn't manifest itself as a clear, the guy's got a broken leg. Doesn't work like that.

Jake: You have a tough job. And try to get across to the people who are gonna read your research, or when you publish it or get it out on the net, to try to identify symptoms or signposts that people who are all high and mighty, those psychiatrists- I mean they charge an arm and a leg and they don't give you very much in return… [sic]

It is difficult to make an interpretation of Jake's assertion that the topic of this research was a difficult one, because the interview ended at this point and he did not raise that viewpoint again.

It is possible that in expressing to me, his audience, that my undertaking was going to be difficult that he was once again establishing himself as an authority. As a 'professor' on the topic of partners of people with bipolar disorder he positioned himself as one who had the authority to teach the subject. In telling me about the level of difficulty of this topic he was positioning himself as a person who could judge that level of difficulty. He was not expressing that these experiences had been difficult for him, but that as someone with experience and knowledge on the subject he could say with certainty that it would be difficult for me to research.

Positioning level 3: Narrator. In examining the things that Jake held to be true and how he wanted to be understood we can look at the discourses Jake used to make sense of events in his life. In line with the character of 'the engineer' Jake applied a rigid, methodical understanding of gender, relationships, and mental illness.

Jake: Even when she was- well depressed as she said. I didn't see it particularly out of the ordinary because, look, with men you expect kind of a constant c- um, constant [keel] for their life. They're pretty energetic, not upset pretty […]. Woman have menstruation and you're never quite too sure how PMS has come along that affect upward and downward- my sister had the same thing… That's why […] and you'll find amongst your own friends as well, your female friends, that the PMS can become a problem you know up and down, you don't know what's flying- they're hormonal changes. So a- as a man I reckon that's okay, women have their own sort of cycle.

Jake: S- the other day we were talking- my wife and I were talking about it and had she continued with that medication, I probably wouldn't have children. For that I would be very cross. My children are healthy and normal. Healthy and normal thank you. And they don't demonstrate and they've never demonstrated any of the aberrations that my wife has come across.

Jake: Cos I think by the time my second child was born I said "There's- there's just no way we're gonna split up this thing, this relationship." I wouldn't even have thought about it. Cos I've got my wife, two kids, and I- we- we're gonna make this marriage work. Would you say you know- if you knew about the bipolar would you have chucked it out? No, I wouldn't have. But I- I, me- don't operate that way. Others may do so. And your other people, your other narratives may come across like that, you don't know. [sic]

In the first extract, Jake used a discourse of pre-menstrual syndrome (PMS) being a reliable explanation for mood changes in woman. He explained that when he first started noticing his wife's emotional difficulties he didn't think it was anything other than PMS. For him, emotional "upheavals" in a woman could be explained by the general characteristics of women. It was Kathy's insistence that her experiences could not be characterised as PMS and her diagnosis of bipolar disorder that made Jake think otherwise.

In the second extract Jake used a discourse of the lack of diagnosed mental disorder being equal to health and normalcy. He also used the word "aberration" to talk about either his wife or possibly the people in her support group. Interestingly, every other time Jake used the word "normal" in his interviews he qualified it with "so-called", "quote-unquote" or some such relativising term, demonstrating that he was aware of the vague meaning of the word. However, when talking about the development of his children he lapses into a binaried discourse about people being 'normal' and 'abnormal', in which his children are 'normal' in contrast to his wife.

In the third extract, Jake made use of a discourse of the necessity of a marriage staying intact because of the presence of children in a family. For Jake, because they had children, there was now "no way" that he would allow the marriage to break up. This is interesting because throughout his interviews Jake never expressed feeling such unhappiness in the relationship that not being together might be a relief. He even acknowledged that this might not be true for all people. It is almost as if Jake appealed to this discourse because it was available, not necessarily because the discourse might explain his staying in the relationship, or to pass judgement on those who may have ended a relationship.

Jake's use of these discourses suggests that he had schemata that he used to make sense of the world; women are more emotionally unsteady than men, normality implies the absence of ill-health, and his commitment to his marriage is absolute. These schemata are in line with the methodical, logical 'engineer' that he presents in his narratives. They could possibly be an intellectual mode of coping for Jake, because as he often said in his interviews he was much more comfortable with logical, categorical perspectives than with emotional, interpretive perspectives.

Jake: For me as an engineer yes, I'm an academic and look at the problem and one plus one equals two, it has to equal two.

'The engineer' is also an analyst, a professor and an authority on the topic of bipolar disorder. Jake establishes himself as a 'veteran' of living with bipolar disorder, as if he wants to be understood as someone who has lived through and survived this phenomenon. It is possible that in his interviews he came across as didactic and analytic because he wanted to communicate to me that he knew more than I do; he had gained the knowledge and experience of this matter by living through it.

Conclusion

This chapter presented the findings of the interviews conducted with five participants. Each participant provided interesting, rich and complex data and it is acknowledged that this research project could only analyse parts of these abundant narratives. The participants raised positive and negative aspects of bipolar disorder being present in their lives; exhibited different positionings of bipolar disorder as an active agent in their lives, constructed many different relational positions between them and the patient, displayed varied emotions, issues around stigma and the treatment of mental illness, constructed their role in the situation in different ways and expressed their experience of the effects of bipolar disorder on their lives and relationships in many different ways. They constructed characters who were victims, villains, antagonists, sufferers, nurses, authorities, professors and various other roles. They positioned their audience as an expert, an onlooker of a comedic performance, a judge, an evaluator, a force to be resisted and a student. They appealed to discourses of normality, morality, ethics, monogamy, responsibility, commitment and gender. These interviews yielded abundant data which could not all be attended to. A focused discussion of these findings follows in *Chapter 5*.

Chapter 5: Discussion and Conclusions

This chapter provides an overview and discussion of the findings of this research in response to the research questions and the literature reviewed. The overview of the findings will explore the characters, roles and positionings constructed by the participants and the discourses and social constructions appealed to by the participants. Even though this research has not aimed to be generalisable or to find common themes in the data, some salient topics common to the participants will be raised. The discussion will respond to the literature reviewed for this study and argue that there are many possibilities of meaning construction in the experiences of partners of people with bipolar disorder, and will discuss the term "caregiver". The strengths and limitations of this research will be discussed with a view to highlighting the value of the findings and a critical engagement with what was not possible for this research. Implications for future research will then be discussed to suggest the ways in which progression can be made from these findings. This chapter will end with the conclusion of this report, gathering the context, existing literature, methodological concerns, findings and implications of this research to a close.

Overview of Findings

Bamberg's (1997) model has been useful in deconstructing the narratives of the participants. It has allowed a view of how they present the different people involved in their lives with bipolar disorder and how they understand the roles and influences of those people. It has allowed insight into how they want to be understood by the people who will listen to them. It has allowed a critical perspective of what discourses they appeal to in order to structure their understandings and experiences.

The characters involved and constructed in these narratives were diverse, but some character constructions were common amongst the participants. For Amanda, Carl, Ellen, and Georgia a parent-child dynamic surfaced between them and the patient. This seemed to develop from the participants' perceived need to police their medication compliance and to ensure the safety of the patient. For Amanda this dynamic was particularly salient in terms of the family's finances; because her husband had exploited the family finances during his manic episode she felt too afraid to allow him access to their joint bank account. She identified this as an uncomfortable issue for both her and her husband.

For Carl the parent-child dynamic seemed to revolve around his partner's low tolerance for stressful situations which he felt should have been attended to much earlier. He gave himself the responsibility of rescuing her in several situations and aimed to be able to provide materially for her and indulge her in a limited way so that she could be safe, relaxed and comfortable. This seems like the role of a father.

For Ellen the parent-child dynamic felt necessary because she constructed her partner as a person who could not take care of himself. As such she constructed her role as being a butler, a nurse, a mother and an emotional manager. She simultaneously constructed the role as necessary and as unnecessary – it seemed necessary for Fred to have such support but she seemed to be resisting the necessity of her having to fulfil this role.

For Georgia, Harry's non-compliance with his medication, his rigidity in demanding particular routines and his suicidality led to her to taking on the responsibility of parenting him. She expressed not wanting this role, but instead, like Amanda, a relationship characterised by equality and reciprocal care and attention. Like Ellen, Georgia experienced her partner's needs as overwhelming and left the relationship because she could not tolerate living with him anymore. Georgia expressed often that she still loved her partner very much, and Ellen implied that had it not been for her partner's resistance of treatment she would want to be with him.

When it came to the nature of Jake's dynamic he seemed clear that his relationship with his wife was one of equality. During his interview he spoke about the challenges for both of them in the relationship and asserted that he did not police his wife's treatment. He was supportive of the process and the on-going treatment plan, but he did not take responsibility for managing his wife's treatment plan for her.

What was made clear was that each relationship had an intricate and multiply-experienced past, present and future. Amanda, Carl and Jake seemed determined for their relationships to progress. Amanda displayed some apprehension when talking about the future because for her Ben was still an ambiguous entity. She made a clear distinction between her husband when he was in the grips of mania and depression and her husband when he was asymptomatic. It is possible that she wanted to be married to her husband but not to her manic or depressed husband, and was still negotiating this meaning. It is clear from these interviews that

for each participant the matter of the relationship was complex, varied and situated in its history. For none of the participants did it come down to a matter of caregiving, symptoms or burden.

Some of the participants constructed clear villains in their narratives. For Amanda the entity to blame for the perceived destruction of her family life was her husband when he was manic. For Carl the medical professionals who he felt had treated Dianne unethically and even cruelly, as well as Dianne's parents were to blame for creating and maintaining Dianne's illness. Ellen seemed to blame bipolar disorder in general. She acknowledged the efforts of mental health professionals, she felt sympathy for her partner's suffering and even expressed understanding towards Fred's parents, to whom she assigned some blame. However, it seems that Ellen came to understand bipolar disorder as an encompassing, impossible obstacle to her and her partner's happiness. She expressed resentment towards her partner for not committing to treatment but it seems that Ellen's main enemy was bipolar disorder itself. This also seems to be the case for Georgia. Georgia expressed anger towards Harry's mother and towards Harry himself for not fighting his illness with more commitment. However, in Georgia's narratives bipolar disorder and the treatment of it "killed" her husband and came close to "killing" her. Jake expressed a critical attitude towards some medical professionals, but otherwise did not include constructions of villains or perpetrators in his narratives. Perhaps because Jake presented his relationship and his wife's bipolar disorder as well-managed he did not need a villain in his narrative.

Agency was assigned in various ways for the participants. In the cases of Amanda, Ellen and Georgia agency was assigned inconsistently to their partners in that, for example, their partners were given responsibility for going off their medication, but were not assigned responsibility for going onto their medication. Amanda, Ellen and Georgia claimed agency in initiating treatment processes but relinquished this agency when their partners defaulted in the treatment process. Carl assigned Dianne very little agency throughout the narratives of triggers, symptom onset, needing to rescue her and nurse her recovery after episodes. The only time Carl assigned agency was when he hypothesised that for the first time she could be curbing the onset of mania. It is possible that these inconsistent constructions could be the effect of the tension between the practicalities of the 'sick role' and the emotional response to being close to someone with such a debilitating disorder. When Amanda, Ellen, Georgia and Carl were in close range of

the effects of bipolar disorder, particularly the paralysing depression, there was no choice but to claim agency and take care of their debilitated partners. However, when their partners were well but not committing to treatment or avoiding the onset of symptoms the distinction between the person and the disorder seemed clearer.

The participants positioned me, their audience in a number of interesting ways. Amanda worked to entertain me, possibly as a way of communicating her resilience. Carl positioned me as having the authority to judge his actions and worked to give evidence for his narratives. Ellen at times wanted control of the interview situation or seemed resistant to it and tested my level of expertise in psychology. Georgia worked to create an intimate connection and appealed to my knowledge of psychology similarly to Ellen. Jake took on the role of a professor and research supervisor, 'teaching' me about marriage, relationships, gender dynamics and theory useful to the study of bipolar disorder. In this work he established himself as a scholar or veteran of being in a relationship with someone with bipolar disorder.

Amanda, Carl, Georgia and Jake all seemed to take on the role of 'the good participant'. In this position they checked if they had answered my questions, highlighted aspects which might be important to research and provided information to contextualise other information, possibly in an effort to be as helpful as possible to my research. It is possible that these participants were responding to my age by wanting to 'make things easier' for me – a kind of adult reflex to guide or assist children. It is also possible that being part of a research project, especially one in which they had such a great stake, was an exciting endeavour, and as such these participants wanted to demonstrate cooperation and productive participation. This notion is compatible with the consideration of how each participant expressed admiration or gratitude about this research being conducted – applauding their audience for listening to them. If this is the case, this is testament to the need for further research on this topic. Such appreciation for this research by its participants implies that these participants want attention to and focus on their unmet needs.

The most interesting discourses that the participants appealed to were the concepts of normality and abnormality. Amanda and Georgia seemed to grapple with the concept of normality. Amanda, similarly to Jake, seemed determined that her partner, when asymptomatic,

was ‘normal’. Like Jake she understood there to be people with mental illness who are ‘normal’ and people with mental illness who are ‘abnormal’. Unlike Jake, who saw his wife as being more ‘normal’ than some other cases of people with bipolar disorder, Amanda seemed to still be negotiating the particular meaning of ‘normality’ and ‘normal living’ when it came to her husband before his manic episode and since his debilitation. Jake was careful to qualify his use of the word ‘normal’ at times, but at other times used this discourse with specific reference to his family.

Georgia also grappled with the discourse around ‘normality’, and it was argued that for her this was more a construction of social and occupational functioning than societal expectations of appropriate behaviour. It seemed that Georgia was struggling to make sense of her husband’s functionality in their relationship and family life, appealing to a discourse of ‘normality’ as a way of reasoning that living with bipolar disorder in a way that includes successful relationships was possible. Ellen proposed that her partner’s suicidality should never be considered ‘normal’, possibly as a way of releasing herself from the responsibility of having to tolerate it. Carl seemed unconcerned by discourses of ‘normality’ and ‘abnormality’. He asserted a critical stance towards society’s treatment of mental illness, naming it ‘illogical’ and possibly alluding to a more anti-psychiatry perspective of mental illness being one of the possibilities of human experience and not as a deviation from what human experience should be (Parker et al., 1995).

The discourse of a ‘caregiver’ was only ever used by Georgia and Jake. Georgia spoke about being Harry’s caregiver when he was living with her and needed assistance because Georgia said that she didn’t want to be his caregiver or his nurse or his mother, that she wanted to be his wife and his partner. For her the two roles were incompatible. Her ‘caregiver’ role was one of the things that caused her so much stress that she could not live with Harry anymore. Similarly, Amanda narrated only recently feeling once again that she and Ben were in a marriage partnership. Jake only made reference to a ‘caregiver’ role when talking about what he was not to his wife. That is, when explaining that he expected his wife to manage her bipolar disorder on her own, that he was there to support her when she was ill but he wanted a relationship of equality, he said that he was not her caregiver. Carl, Ellen and Amanda made reference to providing care for their partners but never constructed it as a distinct role. Carl often constructed

scenes of his having to nurse Dianne while she was depressed or manage her when she was manic. These constructions involved such concern and commitment that to characterise him as just a 'caregiver' seems to negate the loving relationship from which this provision of care became possible. Ellen described managing Fred's house for him, but never used the word 'care'. Amanda similarly described having to do things for Ben but this construction seemed more like a supportive role than a caregiving role. There was resistance to the term 'caregiver' by all the participants either by the absence of its use or in Georgia's case the usage of it followed by a resistance to the implied role. Importantly, even though the extant literature has identified a population as 'caregivers' and researched their associated distress, for every one of these participants the caregiving role was not what caused them distress and for Georgia it was certainly not the only thing that caused her distress.

Both Ellen and Georgia made reference to the contagious nature of bipolar disorder discussed by Jeglic et al. (2005). The image of a contagion is a useful one for imagining the feeling of a mentally ill partner's distress being passed on and being felt as one's own distress, but this discourse also aligns bipolar disorder with bio-medical diseases, implying the malicious spread of a virus. Ellen and Georgia both contextualised the use of this image with narrations of feeling sympathy, sadness, fear, anger and frustration in response to living with a person with the disorder. When they used the image of bipolar disorder being contagious it was a narrative tool to communicate the depth of their involvement with their partner with bipolar disorder, but when this discourse is engaged with in literature it is much less useful. The description of bipolar disorder as contagious to 'caregivers' denies human responsiveness to a loved one's circumstances. Georgia and Ellen did not 'catch' bipolar disorder because bipolar disorder is a dangerous communicable virus but because the experience of witnessing the suffering of their partner, being involved with frustrating treatment plans, having to provide care without their own needs being met and the emotional 'labour' (Henderson & Forbat, 2002) involved was distressing in itself; distressing enough to produce emotional pain that mirrored the symptoms of bipolar disorder.

It is clear that four of the participants have at some stage during their relationship with a person with bipolar disorder experienced distress. Amanda expressed that bipolar disorder devastated her relationship, her family life and her material security. Carl narrated Dianne's

manic and depressive episodes as if they were traumas. Ellen's partner's suicidality and emotional turbulence left her exhausted and unable to continue her relationship. Georgia constructed her current state as one of mourning and grief for the disappearance of her husband's personality. These experiences confirm and add to the literature establishing the negative effect on family members of people with mental illness. The participants also narrated positive experiences in line with 'caregiver' literature. However, what was also made clear by analysing the narratives of the participants of this research is that the distress experienced because of being in a relationship with bipolar disorder had developed from a complex set of circumstances. Distress was as a result of complex perspectives, histories and dynamics between the patient and his or her partner. While quantitative and deterministic qualitative studies have been valuable for developing a sense of the scope and salience of being distressed by being close to someone who is mentally ill, the extant literature has not been able to offer a consideration of the complexity with which this phenomenon is experienced. In these narratives the effects of bipolar disorder situated within a multiple-experienced relationship becomes much more complex, intricate and variable.

Discussion

There are several points with which the findings of this research can respond to the literature. The literature reviewed, suggesting that bipolar disorder might present in a more complex way to that described by the DSM 5 (APA, 2013), was helpful. Even though reviewing the DSM 5's description of bipolar and related disorders was useful for developing an image of the symptoms that partners might be responding to, the findings of this research can also refer to Bauer et al.'s (2005) and Bower's (2000) suggestion that the symptoms of bipolar disorder do not present as discrete 'poles'. For Georgia and Ellen, there was not a distinct period wherein their diagnosed partner displayed no symptoms. They were consistently experiencing difficulties with their diagnosed partner's depression and anxiety. Georgia and Ellen's experiences also reflect Mazza et al.'s (2011) argument that inter-episode periods should not be considered as 'symptom-free' periods; that there are challenges in between discrete mood episodes.

It is also clear that the findings challenge the suggestion that high EE causes a higher probability of 'relapse' for the person with bipolar disorder (eg. Miklowitz, 2007). This is not to

say that this conception is incorrect, but that it positions the partners of people with mental illness as 'behaving badly'; as if there is something about them that makes it more difficult for people with bipolar disorder to remain stable. None of the participants positioned themselves as characterising high EE, but they did try to communicate that responding to bipolar disorder is painful, complex and dynamic. As such, even if the participants do display behaviour that could be defined as high EE, such as being critical of the patient's behaviour, it is not because of fundamental flaws in their characters but because of the nature of living with bipolar disorder. We should not criticise the ways in which partners of people with bipolar disorder respond to their mentally ill partners. We should rather take into consideration that displaying high EE behaviour is in all probability a function of their difficulty in responding to bipolar disorder.

Further, in considering Pollio et al.,'s (2006) suggestion to implement one-day psycho-education workshops, we can extrapolate that such an intervention would attend to only one of the needs of the partners of people with bipolar disorder. Amanda, Ellen and Georgia all expressed a need for more information, but it was clear that this need existed alongside other needs of understanding their partner's unique behaviours and ways of coping with life, needing attention to their own pain and distress at living with a person with bipolar disorder and, needing support in negotiating the particular difficulties of their relationships. Ellen and Georgia specifically seemed to be trying to negotiate their leaving their partners, which a psycho-education workshop would assumedly not been able to support. While it must be considered that interventions may be more successful if they focus on specific elements, psycho-education workshops will still place the emphasis on the patient's experiences, with little or no attention to the partner's experiences. This argument is in agreement that support for the family members must attend to the family members' experiences as intrinsically important, not just as another means to support the patient (Henderson & Forbat, 2000; Lavis et al. 2015).

The participants did not raise stigma as a particularly salient issue. Neither Carl nor Jake raised stigma at all. This could be because Jake's wife was an active bipolar disorder outreach spokesperson, and Carl's philosophical take on mental illness made him dismissive of the construction of bipolar disorder as stigmatisable. For Amanda, Ellen and Georgia there was an element of stigma in their narratives. Amanda spoke about not being able to tell people in her community because she anticipated stigma against her husband (Quinn & Chaudoir, 2009).

Similarly, Georgia reported ‘not caring what others think’, but found it difficult to be in public with her husband. Ellen also displayed anticipated stigma in confirming at the beginning of her interviews that both her and her partner’s identities would remain confidential, with a specific implication that their association with bipolar disorder would be problematic for their professional identities. These findings then suggest Goffman’s (1963) concept of internalised stigma, because Amanda, Georgia and Ellen responded to anticipated stigma by concealing the ‘mark’ of their partner’s bipolar disorder (Goffman, 1963; Quinn & Chaudoir, 2009) suggesting that even though they have a loved one with bipolar disorder they still ‘know’ the discourse of mental illness being a discrediting characteristic (Goffman, 1963; Green, 2009; Link et al., 1989).

These findings support Henderson and Forbat’s (2000) argument that ‘caregiver’ literature has assumed a one-directional caregiving dyad, has positioned caregiving as the identifiable feature of relationships, and has assumed an independence/ dependence boundary. The findings showed that for these five people, caregiving was not one-directional, if caregiving was present at all. Furthermore, none of the participants identified themselves as caregivers or as caregiving being the part of the relationship that was challenging for them. The participants also narrated their partners with bipolar disorder as being dependent in some ways and independent in others. Therefore, these findings show how the ‘caregiver’ positioning imposed on family members of people with mental illness is simplistic, reductionist and often incorrect.

Oshodi et al.’s (2002) and Östman and Kjellin’s (2002) finding that some family members of people with mental illness reported wishing that their partner were dead was reflected in Carl’s and Georgia’s narratives. It must be taken seriously that this feeling is an indication of the pain that may be felt by people who have bipolar disorder, and the pain of watching someone live with bipolar disorder. However, Oshodi et al. (2002) and Östman and Kjellin (2002) did not discuss the implications or context of such a wish. This is likely to be because their studies were not designed to consider context, but only to describe the commonalities amongst a number of people related to someone with bipolar disorder.

These findings challenge perceptions of ways in which ‘caregiver burden’ might be relieved. Jeglic et al., (2005) suggested that the ‘contagion effect’ of bipolar disorder is mediated

by the ‘caregiver’s’ perception of the negative and positive behaviour of the person with bipolar disorder. As discussed earlier, bipolar disorder was not ‘transferred’ to any of the participants, but their distress at interacting with their partner resulted in responses that mirrored the symptoms of bipolar disorder. Similarly, for Jeglic et al. (2005) to suggest that the more ‘caregivers’ perceive their partner’s behaviour to be ‘negative’ the more likely they are to ‘catch’ bipolar disorder, medicalises an arguably natural response to volatility. That is, it seems understandable that the more a person experiences difficulties and distress in their bipolar disorder, the more likely their partner is to experience difficulty and distress in response to that. Jeglic et al., (2005) conceptualise this phenomenon in terms of contagions, positive and negative behaviours and an implication that ‘caregivers’ need only to change their perceptions to develop stronger ‘immunity’ against bipolar disorder. For these participants, their responses to their partners’ ‘negative behaviours’ stemmed from pain at witnessing their partner’s suffering, a history of the relationship and frustration with the course of the disorder. Research that conceives ‘caregiver burden’ in terms of perception (Jeglic et al., 2005), rumination versus perceived mastery (Perlick et al., 2012), individual traits associated with ‘caregiver burden’ (Sheets & Miller) or the ‘caregiver’s’ appraisal of their role places responsibility and pressure on family members of people with mental illness to be more ‘adaptive’. It also ignores the complex and intersubjective nature of emotional experience in an intimate partnership between two people, as was demonstrated in these participants’ narratives.

The findings also challenge conceptions of relationship functioning being simply associated with the presence of symptoms (Horesh & Fennig, 2000; Rowe & Morris, 2012). Such research seems to suggest that once bipolar disorder has been ‘removed’ from the relationship or the condition has been stabilised, the relationship will have a better chance at ‘better functionality’. Firstly, from the social constructionist perspective we can be critical of how Horesh and Fennig (2000) and Rowe and Morris (2012) construct a ‘well-functioning’ couple. More importantly however, the findings suggest that the ways in which bipolar disorder has affected these relationships is not isolatable or even easily definable. These relationships have been influenced depending on the history of the relationship and the specific meanings the participants have made of bipolar disorder in their lives. It is clear that for these participants, bipolar disorder has been woven into their lives and cannot be extracted in any simple way.

Overall, the findings of this research support studies that have pointed to the multiple permutations of the 'caregiving role' and the diverse ways in which bipolar disorder could be experienced in intimate relationships. The findings challenge simplistic, linear conceptions of 'caregiver burden' being related to perceptions and easily controllable traits in the 'caregivers'. The findings challenge the notion of the 'caregiver role' being an accurate positioning of the family members, and dispute claims that bipolar disorder influences relationships in categorisable, easily definable ways.

Strengths and Limitations

The strengths and limitations of this research must be considered to emphasise its value with an acknowledgement of what it has not been able to attend to.

While this research set out to deconstruct the unique ways in which experiencing a relationship a person with bipolar disorder might occur in South Africa, it has not been able to offer an analysis that unearths the many ways in which culture, society, politics and the economy shape the South African experience. Especially because my sample only consisted of white, middle-class people I can only offer the possibilities for this population. I am an insider; a white, middle-class citizen and as such cannot provide a critical deconstruction of the political and socio-economic context in which I, like my participants am living (Atkinson and Delamont, 2006).

The sample I collected was a matter of convenience. The support groups for bipolar disorder which I contacted early on in the data collection process which would have provided access to black participants were not responsive and I did not persist in trying to involve them because of time constraints in initiating the data collection process. Furthermore, the density of the data from my participants yielded so much to discuss that I did not feel capable of critically turning back on the social and political structures influencing my participants' experiences below the surface. I do not offer these reasons as good excuses, but merely as logistical reasons for the neglect of an important aspect of such research.

Atkinson and Delamont (2006) point out that the insider status of the researcher and matters of convenience are often the reasons for the privileging of white, middle class narratives.

This is a fundamental flaw in many research efforts – that because of constraints of time, space and insider status the narratives of low socio-economic status and black individuals are often neglected (Atkinson & Delamont, 2006). With this criticism in mind, it is suggested that future research of this type prioritise the involvement of black and low socio-economic status individuals to gain a broadening of our knowledge about the experience of mental illness in South Africa.

As a matter of self-reflexivity I often found it difficult to stay loyal to Josselson's (2015, personal communication) guidelines for conducting interviews. Especially when I found the interview situation anxiety-provoking I regressed to asking questions that may have imposed meaning or direction on my participants. I have tried to understand at which points in the interview I felt I needed to take control so that this weakness in my interviewing skills can be explored in terms of the co-constructed discursive event conceptualised by the narrative method of inquiry. However, a limitation of this research is that the data collection was not a rigorous and loyal practice of the narrative approach.

While the narrative approach and this research specifically does not aim to be generalisable (Emerson & Frosh, 2009), the ability of this research to directly impact communities experiencing bipolar disorder is low. It can only comment on the constructions of bipolar disorder in the existing literature and point to the complexity of the experiences of five people who locally constructed their meanings.

At the same time, the ability of this research exists to argue that social constructionist and specifically narrative approaches to research of this kind are possible and necessary and useful. The exploratory nature of this research means that it is not conclusive or generalisable, but it is useful as a way of identifying something important that has been missed by previous research

This research is valuable in its ability to show the many possibilities for the experience of being in a relationship with bipolar disorder. It has supported the arguments made by Henderson and Forbat (2002), who suggested that firstly, relational dynamics have been ignored in 'caregiver' literature and secondly that the construction of a 'caregiver' is reductionist.

Furthermore, the narrative approach is valuable in its ability to give attention to stories with the assumption that narratives can be altered (Aranda & Street, 2001; Ayres, 2002). The narrative approach offers a theoretical paradigm and a therapeutic perspective at the same time so that research and intervention can be closely associated (Stern, et al. (1999).

Directions for Future Research

In general it is clear that much more research needs to be done on the experiences of the people close to those who have been diagnosed with a mental illness. Even though there is a substantial body of research that examines the 'caregivers' of people with mental illness, it has been argued by reviewing the literature that our knowledge is based on a reductionist account of caring for people with mental illness. This construction of people who give care to people with mental illness reduces the possibilities of such experiences to an imposed role of caregiving, ignores the multiplicity in which relationships between people can exist and neglects the intrinsic experience of witnessing and being affected by mental illness (Henderson & Forbat, 2000).

It is suggested that the continuation of research into the lived community experiences of people with mental illness should include social constructionist and specifically narrative approaches to the topic. This research has shown the value of the narrative approach; it is powerful as way of returning to a focus on the emotional, contextually situated and dynamic nature of human experience in contrast to the cold structure of positivist paradigms. Alongside research on interventions based on psycho-education, narrative therapy interventions must be given attention as a way of practicing with the insight gained through a narrative perspective, and researching what effect such practice might have (Emerson & Frosh, 2009; Stern, et al., 1999).

The body of research on family members of people with mental illness does not include enough knowledge about the South African context. With our immense diversity it is imperative to explore the multiple ways in which communities might construct and experience mental illness. A social constructionist perspective will again be useful in this endeavour as a way of understanding the discourses used to construct mental illness across different cultures and socio-economic statuses in South Africa. The institutions and discourses which inform our understanding of experiences in a country with such varied possibilities for lived experiences

must be interrogated to find master narratives that are oppressive or limiting, even if unintended as such (Poindexter, 2002).

Finally, it is suggested that the term ‘caregiver’ be used more carefully in research so as to include only the thing to which it refers and to open possibilities for multiple ways of experiencing mental illness. That is, the term ‘caregiver’ must be carefully re-constructed and operationalised to refer to people who self-identify as caregivers and not to a conglomeration of different possible relational dynamics that include a caring aspect to various degrees and in various contexts. This re-thinking of the ways in which we position those who we research would be part of a larger project of developing more responsible, compassionate research (Poindexter, 2002).

Conclusion

This research report presented an introduction which suggested that the topic of how people experience a relationship with a person with mental illness is an important, underdeveloped area which must be turned back on and interrogated to identify mis-constructions and gaps in our knowledge. In the literature review research and theory were explored to gather a context in which this research might exist, and showed that existing literature has treated people in relationships with people diagnosed with mental illness as homogenous ‘caregivers’ rather than abundantly varying people in varying relationships and with different experiences. Specifically, it was argued that partners of people with bipolar disorder have not received enough research attention with the acknowledgment that the experience of bipolar disorder within an intimate relationship might carry different meanings to a father, mother, sibling or other relationship involving a person with another mental disorder. The method used for this research was then described and explained to report the assumptions, perspectives and procedures with which this research was carried out. The methods chapter showed that this research was conducted with an exploratory, co-constructive narrative approach with a view to producing responsible research that did not impose theoretical concepts on its participants and embraced the complexity of their experiences. The findings were presented, which showed the richness and diversity of the data that was gained for this research. This chapter presented an overview of the findings and a discussion which argued that there are many possible constructions and meanings to be found in

the experiences of partners of people with bipolar disorder. It was discussed that these data show that the topic of the people related to those who have been diagnosed with mental illness has been treated simplistically and even inaccurately. The strengths and limitations were discussed, and suggestions for future research were made.

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Appendices

Appendix A: Information Sheet for Bipolar Disorder Support Groups

PSYCHOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4541 • Fax: 011 717 4559 • E-mail: psych.SHCD@wits.ac.za

Good day,

My name is Mia Pienaar. I am currently a Psychology Research Masters student at the University of the Witwatersrand. To fulfil the requirements of my degree, I am researching the experiences of partners of people with bipolar disorder in South Africa. The aim of this research is to understand the multi-dimensional experiences of those people who are in or who have been in an intimate relationship with a person who has been diagnosed with bipolar disorder, by analysing the narratives of interview participants.

In order to do this I would like to interview approximately 5 people. I would like to use your organisation to identify potential candidates. I would like to attend a support group meeting and then approach such individuals via a working member of your organisation – someone who has already established rapport with the members of the support group. As such, your organisation's participation in my research will mean allowing me to attend one or more support groups and for me to approach members of your support group. Alternatively, you may wish to email potential participants with the information about this research.

Candidates will be eligible if they have been in an intimate relationship with a person diagnosed with bipolar disorder for five years or longer, if they are 23 years or older, and if they feel comfortable being interviewed in English. The relationship does not have to be current but should have occurred in the last ten years.

Once a working member of your organisation has liaised with potential participants who are interested in being a part of this research, I will ask for their contact details and contact them one week later. I will explain the nature of the research, what is involved in participation and their rights as a participant. If they agree to participate, I will arrange the first of two interviews with them at a time and place that is convenient to them. The second interview will be arranged at the end of the first interview. To allow for transcription and analysis of data, the interviews will be audio recorded with the permission of the participant. The results of this research will be presented in the form of a research report. Upon request, the participants and your organisation will be given access to a summary of my results.

Please note that due to the use of face-to-face interviews with me, anonymity is not granted. However, anonymity will be guaranteed in the report of the research as no identifying details of the participants will be used in writing up this research. Therefore, only I will know the identity of the participants and this information will be carefully guarded. Furthermore, the information given to me in the interviews will be kept strictly confidential. The participants will be asked for permission to record the interview. The transcripts of the recordings will be kept in a secure and private location. I will need to share some information about the interviews with my supervisor to assist me in the research procedure. However, the participants' identities will also be anonymous to my supervisor, and she will also keep interview content strictly confidential.

It is acknowledged that bipolar disorder is a sensitive topic and the participant will be at liberty to answer only those questions she or he feels comfortable with, and may stop the interviews or withdraw from the research at any time. I will provide the participants with telephone support resources which they can use if they feel distressed in any way by their participation. I will also suggest that if participants feel distressed as a result of the interviews they may contact their support group facilitator to be debriefed.

Participation is entirely voluntary and there will be no negative consequences should your organisation choose not to participate.

If you have any further enquiries, please do not hesitate to contact me or my supervisor, Prof. Tanya Graham.

If you would like to participate, please complete the attached consent form.

Kind regards,

Mia Pienaar

Masters student in Psychology

Department of Psychology, University of the Witwatersrand

Mia Pienaar

Tel: 072 115 5685

Email: miapienaar@gmail.com

Prof. Tanya Graham

Tel: (011) 717-8330

Email: tanya.graham@wits.ac.za

Appendix B: Consent Form for Bipolar Disorder Support Groups

PSYCHOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4541 • Fax: 011 717 4559 • E-mail: psych.SHCD@wits.ac.za

Consent form to participate in research project conducted by Mia Pienaar

Please complete this form if you are willing to participate.

I have read the information letter and understand both the nature and the purpose of this research.

I _____ hereby grant permission for Mia Pienaar to attend a support group meeting and approach potential candidates for her research through a working member of the support group.

Signature:_____ Date:_____

Appendix C: Participant Information Sheet

PSYCHOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4541 • Fax: 011 717 4559 • E-mail: psych.SHCD@wits.ac.za

Good day,

My name is Mia Pienaar. I am a Psychology Research Masters student at the University of the Witwatersrand. In order to fulfil the requirements of my degree, I am conducting research on the narratives of partners of people with bipolar disorder. Specifically, I would like to know how such individuals feel bipolar disorder has affected their life and how their relationship has been affected by the disorder. I hope that this information will help to inform support systems for families of people with bipolar disorder. In order to achieve this, I would like to conduct two interviews with partners of people with bipolar disorder. I would like to invite you to participate in this research project.

Participation in this research will require that you are 23 years or older, that you have been in a relationship with a person diagnosed with bipolar disorder for 5 years or longer (which may be a current relationship or one that occurred in the last 10 years) and that you feel comfortable being interviewed in English.

Participation in this research will entail being interviewed by me on two separate occasions. The interviews will be conducted at a time and in a quiet, private place that is convenient to you. Both interviews will be approximately 40 minutes to one hour long. With your permission, the interviews will be audio recorded to allow for transcription and data analysis.

Because this research uses face-to-face interviews, anonymity cannot be granted. I will know your identity. However, you will be referred to by a pseudonym in all parts of the research, so that your identity will not be known to any other person. Direct quotes from interviews may be used in the results report, but will be stripped of any potentially identifying information. Furthermore, the information you give me in the interviews will be kept strictly confidential. The interview recordings will be kept in a private, secure location that will not be accessible to any person other than myself. I will need to share some information with my supervisor to assist me in the research procedure, but your identity will be anonymous to her, and she will also keep interview content strictly confidential.

Participation is completely voluntary and you will not be disadvantaged in any way if you choose not to participate. Your decision to participate will not influence your access to this organisation.

Because this is a sensitive topic, you will not have to answer any questions that you feel uncomfortable with or don't want to answer, and you have the right to withdraw from this research at any time before the research is submitted for examination. In the case that you

experience any distress or heightened emotions because of your participation in this research, contact details for relevant and free counselling services have been provided on this form. You may also want to contact your support group facilitator to be debriefed.

This study has been given clearance by the Human Research Ethics Committee at the University of the Witwatersrand, which means that an ethics committee has given approval for the research to be carried out. The results of this research will be written up in the form of a research report, which will be submitted to the Department of Psychology at the University of the Witwatersrand. If you would like, you will be given access to a summary of the results.

If you would like to participate in this research please complete the interview consent form, attached. I will contact you telephonically to address any questions you have and to organise the first interview. Alternatively, you may contact me or my supervisor, Prof. Tanya Graham, if you have any questions or concerns.

Kind regards,

Mia Pienaar

Masters student in Psychology

Department of Psychology, University of the Witwatersrand

Tel: 072 115 5685

Email: miapienaar@gmail.com

Prof. Tanya Graham

Tel: 011 717 8330

Email: Tanya.graham@wits.ac.za

Free counselling services:

Lifeline: 0861 322 322

South African Depression and Anxiety Group (SADAG): 011 262 6396

South African Bipolar and Schizophrenia Association (SABDA): 011 463 9901

Appendix D: Consent Form for Participants

PSYCHOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4541 • Fax: 011 717 4559 • E-mail: psych.SHCD@wits.ac.za

Consent to participate in research conducted by Mia Pienaar

I _____ have read the information sheet and understand the nature of this research. I hereby voluntarily consent to being interviewed by Mia Pienaar for her Masters research report on the partners of people with bipolar disorder.

I understand that:

- Participation in this research is completely voluntary.
- There are no direct advantages or disadvantages to participating in this research.
- I may refuse to answer questions I would prefer not to.
- I may withdraw from the study at any time before it is submitted for examination.
- Confidentiality will be guaranteed.
- Direct quotes from interviews that do not identify me in any way may be used in the research report.
- I will receive a summary of the results if requested.
- The researcher will assist me in contacting the relevant counselling services should I feel distressed as a result of my participation.

Signature: _____ Date: _____

Appendix E: Consent Form to Record Interviews

PSYCHOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4541 • Fax: 011 717 4559 • E-mail: psych.SHCD@wits.ac.za

Consent for audio recording of interviews

I _____ hereby voluntarily consent to my interviews with Mia Pienaar for her research on the partners of people with bipolar disorder to be audio recorded and transcribed.

I understand that:

- The audio recordings will only be heard by the researcher and her research supervisor, and will only be processed by the researcher.
- No identifying information will be used in the transcripts of the audio recordings.
- All audio recordings and transcripts will be kept in a secure, private location which only the researcher will have access to.

Signature: _____ Date:_____

Appendix F: Semi-structured interview schedule

Interview 1

1. Please tell me a bit about your relationship with (the patient).
2. When did you first notice (the patient's) symptoms?
3. What has been your role in the course and treatment of (the patient's) disorder?
4. In what ways have you noticed the effects of (the patient's) disorder on your relationship?
5. In what ways have you noticed the effects of (the patient's) disorder on your life?
6. Who or what has influenced the way you have experienced being in a relationship with (the patient)?
7. How has your experience of being in a relationship with (the patient) changed over time?

Interview 2: Probes

- In our first interview you said "…". Can you tell me more about that?
- Can you give me an example of when you felt…?
- Can you give me an example of an event/ occasion when…?
- From what you said in our first interview, it seems to me that… Would you agree?
- From our first interview, I understood that… Would you like to add anything?