Understanding the diagnostic process of Bipolar Disorder:

A qualitative study of patients in Cape Town, South Africa

Claire Battiston - Weggelaar

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Supervisor: Dr. Sally Swartz

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DECLARATION

I declare that this thesis, entitled *Understanding the diagnostic process of Bipolar Disorder: A qualitative study of patients in Cape Town, South Africa*, is my own work, and that it has not been submitted for any degree or examination to any other university. Each significant contribution to, and quotation in this thesis from the work, or works, of other people has been attributed, cited and referenced accordingly.

Signature: Signed by candidate Date:____________________

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ABSTRACT

Bipolar Disorder (BD) is a complex psychiatric disorder posing many diagnostic challenges. Recent international research has highlighted a concerning rise in the number of patients diagnosed worldwide with BD each year. Although many studies have been conducted over the past two decades that aimed to assist in reducing misdiagnosis rates of BD, few have focussed on this topic from the perspective of those suffering with the disorder. Furthermore, no African or South African research could be found on this topic, which supports the need to investigate this phenomenon more in-depth from a South African perspective.

The aim of this study was to deepen the current understanding of the diagnostic process of BD in a sample of South African patients. This was achieved by exploring the diagnostic journeys of 12 participants diagnosed with BD through semi-structured, qualitative interviews. A grounded theory of diagnostic patterns and the factors that might mitigate and complicate this process was then formed.

The results highlight the unique and often contradictory experiences of each participant, which calls into question the attempt to simplify the diagnostic process of BD. In this sample of 12 BD patients, no two diagnostic experiences were the same. Factors that were found to influence this process include: (1) the DMI pattern (Depression-Mania-Interval) where a manic episode naturally follows a depressive episode, which occurs first and is often diagnosed and treated as unipolar depression; (2) the ever-broadening definition and revised DSM-5 diagnostic criteria for BD, culminating in the highly controversial concept of a bipolar spectrum; (3) the diagnostic interview and the need for clinicians to carefully consider all differentials, as well as the patient's ability or willingness to convey important information, before making a diagnosis; (4) the role of primary care physicians (GPs), who are often the first port of call for patients seeking help for their symptoms; (4) the collection of collateral information from people close to the patient and the opaque consequences thereof; (5) implicit expectations of patients from treating clinicians and how this informs help-seeking behaviour.

Although common trends in diagnostic processes could be identified that echo what existing literature has already found, there were just as many unique outcomes, ambiguities and contradictions evident in these results. Thus, future research would do well to focus on this instead to obtain new and unique insights that could assist in better understanding, diagnosing and treating BD in generations to come.

TABLE OF CONTENTS

APPENDICES

LIST OF TABLES

CHAPTER ONE: INTRODUCTION

"When a trout rising to a fly gets hooked on a line and finds himself unable to swim about freely, he begins a fight which results in struggles and splashes and sometimes an escape. Often, of course, the situation is too tough for him.

In the same way, the human being struggles with his environment and with the hooks that catch him. Sometimes, he masters his difficulties; sometimes, they are too much for him. His struggles are all that the world sees and it usually misunderstands them. It is hard for a free fish to understand what is happening to a hooked one"[1]

Bipolar Disorder (BD) is a lifelong mood disorder characterized by recurrent manic or hypomanic episodes and depressive episodes (Oyffe, Shwizer & Stolovy, 2014). It is a multifactorial disorder that is associated with cognitive and social impairments, as well as proneness to a range of comorbid physical and psychological conditions, including substance abuse and anxiety disorders (Oyffe et. al., 2014). Recent research investigating the prevalence of BD has highlighted a concerning rise in the number of patients diagnosed worldwide with BD each year. However, these prevalence rates vary greatly from study to study, casting a spotlight on the diagnosis of this disorder and the high rate of misdiagnosis that appears to now be taking place (Dunner, 2003; Singh & Rajput, 2006; Oyffe et. al., 2014).

Although many studies have been conducted and reports written over the past two decades with the aim of reducing the misdiagnosis of BD and highlighting the potential stumbling blocks surrounding this process, there is a dearth of research that explores this topic from the perspective of those suffering with the disorder. When patients' perspectives were included in these studies, it was predominantly to explore statistics surrounding misdiagnosis and issues of stigma (Michalak, Yatham, Maxwell, & Lam, 2007; Michalak, Livingston, Hole, Suto, Hale, & Haddock, 2011; Link, Struening, Rahav, Phelan & Nuttbrock, 1997).

Thus, there is a growing need to understand the referral and diagnostic patterns leading to BD diagnoses or misdiagnoses, and to the factors contributing to the apparent challenge of diagnosing BD accurately and early in the course of the disorder (Daigneault, Duclos, Saury,

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[1] Excerpted from page 3 of *The Human Mind* by Karl A. Menninger.

Paquet, Dumont & Beaulieu, 2015). For these reasons, this study was designed to fill this gap in the literature by looking to understand this phenomenon from the unique perspectives of individuals who have been diagnosed, and are living with, BD.

Aim of the present study:

This study aims to deepen the current understanding of the diagnostic process of Bipolar Disorder (BD). This will be achieved by exploring the diagnostic journeys of participants diagnosed with BD, from their own point of view, in order to develop a grounded theory of diagnostic patterns and the factors that might mitigate or complicate this process.

Outline of this thesis:

Chapter two will review the literature on Bipolar Disorder (BD), with particular attention being paid to the history and evolution of the disorder, the current understanding of the different subtypes, and the reasons why our contemporary diagnostic system is the topic of much debate and controversy. Chapter three will describe the methodological approach employed in this study, followed by a detailed description and discussion of the research findings in chapter four. Finally, chapter five will provide a summary of the main findings of this study, a discussion of the limitations, and will conclude with recommendations for future research.

CHAPTER TWO: A REVIEW OF THE LITERATURE ON THE DIAGNOSIS OF BIPOLAR DISORDER

This chapter aims to introduce the reader to Bipolar Disorder (BD) and the complexities surrounding the trajectory, diagnosis, and treatment thereof. Firstly, I begin by discussing the evolution of the disorder from first inception in the late 1800s to today's current understanding. The latter description then leads to the latest definition of BD as published in the Diagnostic and Statistical Manual of Mental Disorders, Version Five (DSM-V), and will define and explain the different types of BD. Thereafter, I will present a summary of both international and local literature on what is arguably one of the most debated topics in contemporary psychology and psychiatry – the diagnosis of BD.

Introduction to Bipolar Disorder

In 1854, Jules Baillarger and Jean-Pierre Falret independently presented descriptions of what is now known as BD to the Académie de Médicine in Paris. Baillarger called the illness *folie à double forme* ('dual-form insanity') whereas Falret named it *folie circulaire* ('circular insanity') (Burton, 2012). Falret observed that the disorder clustered in families, and correctly postulated that it had a strong genetic basis (Singh & Rajput, 2006).

In the late 1800s and early 1900s the renowned German psychiatrist, Emil Kraepelin, studied the natural course of the untreated disorder and found it to be punctuated by relatively symptom-free intervals (Burton, 2012). On this basis, he distinguished the disorder from *démence précoce* (schizophrenia) and coined the term 'manic–depressive psychosis' in 1855 to describe it. Kraepelin emphasized that, in contrast to *démence précoce*, manic–depressive psychosis had an episodic course and a less malignant outcome (Burton, 2012; Philipps & Kupfer, 2013).

Controversy surrounding the diagnosis of BD became apparent in the 1950s when the United States Government refused to recognize 'manic depression', as it was then called, as a legitimate illness for medical insurance purposes, despite it being widely accepted in the psychiatric world for approximately 50 years already (Singh & Rajput, 2006). It was only in the late 1970s that this changed and the National Association of Mental Health (NAMI) was subsequently formed (Singh & Rajput, 2006).

One year after the formation of NAMI, the American Psychiatric Association (APA) released the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III). In this edition, the term Manic Depressive Disorder was replaced with Bipolar Disorder. From this point onwards, the boundaries of BD have steadily shifted outwards. In the DSM-III published in 1980, BD was classified into three distinct categories, namely Depressive Type, Manic Type, or Circular Type (APA, 1980). In the revised version published in 1987, the DSM-III-R added subtypes to the original three categories. These subtypes were heralded as a major improvement to the understanding of BD, which was the result of a surge in research studies on mood disorders at this time. The new subtype classifications were Bipolar Disorder-Mixed, Bipolar Disorder-Manic, Bipolar Disorder-Depressed, Bipolar Disorder-Not Otherwise Specified (NOS), and Cyclothymia (APA, 1987).

In the DSM-IV (1994) and the revised DSM-IV-TR (2000), the definition again evolved from a "monolithic disorder with a single set of criteria, to a more nuanced subtype system", where Bipolar I, Bipolar II, Cyclothymia, Rapid Cycling Bipolar, and Bipolar Disorder-Not Otherwise Specified (NOS) were individually recognized and diagnosed as separate forms of BD (Singh & Rajput, 2006: p.58).

In the current edition of the DSM, version five (2013), *Bipolar and Related Disorders* and *Depressive Disorders* have been separated into two new and distinct classification categories in an attempt to separate and define mood disorders, including BD, even better (APA, 2013). Furthermore, Bipolar Disorder-Not Other Specified (NOS) has now been deleted and replaced by Other Specified Bipolar and Related Disorders, with its own set of diagnostic criteria (APA, 2013). Furthermore, three more categories of diagnosis have been added too, namely, Substance/Medication Induced Bipolar and Related Disorder, Bipolar Disorder due to Another Medical Condition, and Unspecified Bipolar and Related Disorder (APA, 2013).

These various changes in the understanding and operationalization of BD have been criticized by many in the field. From an historical perspective, the clinical profession has often expanded psychiatric definitions in an attempt to concretize abstract constructs, and then later retreated from this diagnostic expansion as negative results, such as over-diagnosis, become apparent (Kuiper, Cullan & Malhi, 2012). Evidence of this can be seen in the evolution of disorders such as schizophrenia, depression, anxiety disorders, attention-deficit disorder, borderline personality disorder, and impulse control disorders (Kuiper et. al., 2012; Goldberg, 2010). According to many authors on this topic, the current expansive form of bipolarity is "charting an uncomfortably similar course" (Kuiper, Cullan & Malhi, 2012: p.1025; Baldessarini, 2000; Paris, 2005; Smith & Ghaemi, 2010, Goldberg, 2010). These authors, and many others who hold the same concerns, fear that BD may be a “diagnosis in crisis”, emphasising an urgent need to “correct course” rather than accelerate further into unknown territory that will place both disciplines of psychology and psychiatry in turmoil as a result of its over-inclusivity (Kuiper et. al., 2012: p.1025).

Bipolar subtypes according to the DSM-V

According to the DSM-V, BD is an affective disorder in which patients experience episodes of elevated or irritable mood, known as mania or hypomania, as well as episodes of depression (APA, 2013). What follows next is a basic outline of each bipolar subtype as described by the DSM-V. A full list of the diagnostic criteria per subtype can be found in *Appendix A*.

Bipolar I

The bipolar 1 disorder criteria represent the modern understanding of the classic manic-depressive disorder. The only pre-requisite for a diagnosis hereof is that the individual meets the diagnostic criteria for a fully syndromal manic episode. In contrast to earlier understandings on the disorder, neither psychosis nor the lifetime experience of a major depressive episode is now a requirement for a diagnosis of Bipolar 1. However, the vast majority of individuals whose symptoms meet the criteria for a manic episode also experience major depressive episodes during the course of their lives (APA, 2013).

Bipolar II

Bipolar II disorder requires the lifetime experience of at least one episode of major depression and at least one hypomanic episode. It is no longer thought to be a ‘milder’ version of BD, largely because of the amount of time individuals with this condition spend in depression and because the instability of mood experienced by individuals with bipolar II is typically accompanied by serious impairment in functioning across several domains, including work and social spheres (APA, 2013).

Cyclothymic Disorder

Cyclothymic disorder is diagnosed in adults who experience at least 2 years (for children, one full year) of both hypomanic and depressive periods without ever fulfilling the criteria for an episode of mania, hypomania, or major depression (APA, 2013).

Substance / Medication Induced Bipolar and Related Disorder

Bipolar and Related Disorder due to Another Medical Condition

These two new categories of BD were created in recognition of the fact that a large number of substances of abuse, some prescribed medications, and several medical conditions can be associated with manic-like phenomena. Thus, these two new categories now provide clinicians with a more accurate way of diagnosing an individual who shows signs of manic-like symptoms but also presents with co-morbidities that may be triggering a bipolar episode, or be caused by a bipolar episode (APA, 2013).

Other Specified Bipolar and Related Disorder

This category was created for those individuals (including children and adolescents) who experience bipolar-like phenomena but do not meet the full diagnostic criteria for bipolar I, bipolar II, or cyclothymic disorder. There symptoms are therefore sub-syndromal but show signs of a possible bipolar diagnosis (APA, 2013).

Literature Review

Bipolar Disorder (BD) is a complex psychiatric disorder posing many diagnostic and therapeutic challenges (Nivoli, Colom, Murru, Pacchiarotti, Castro-Loli, Gonzalez-Pinto, Fountoulakis & Vieta, 2011). It is ranked as one of the top 10 causes of disability internationally by the World Health Organisation (WHO) and is seen as both chronic and debilitating with a high personal and societal toll (Singh & Rajput, 2006; Keck, Kessler & Ross, 2008). Risk of suicide is believed to be as much as 20 times higher than that of the general population, which translates into a significantly high risk of mortality (Keck et al., 2008). Furthermore, relapse rates are reported to be as high as 90%, with a progressive deterioration in functioning that very rarely matches symptom improvement rates (Keck et. al., 2008).

Decreased ability to function optimally also impacts negatively on overall quality of life in several domains including interpersonal relationships and occupational ability. This poses a substantial economic burden on the state as a result of lost productivity and high costs of healthcare resources (Dunner, 2003; Singh & Rajput, 2006; Keck et. al., 2008). Several studies have shown that individuals diagnosed with BD utilize health care services more frequently and have higher direct medical costs than those with other mood disorders, including unipolar depression (Matza, Rajagopalan, Thompson & de Lissovoy, 2005; Kleinman, Lowin, Flood, Gandhi, Edgell & Rivicki, 2003; Dean, Gerner & Gerner, 2004; Dunner, 2003). A recent South African study by Norman et. al. (2006) revised the burden of disease estimates published in 2000 and found that neuropsychiatric disorders were the third highest cause of non-fatal disability in the country. The neuropsychiatric disorders that rank in the top 20 causes for "disability-adjusted life years" in South Africa are unipolar depression, substance abuse disorders, bipolar disorder, schizophrenia, obsessive-compulsive disorder and panic disorder (Norman, Bradshaw, Schneider, Pieterse & Groenewald, 2006: p.19).

Prevalence rates worldwide vary greatly from study to study, with some findings reporting figures as low as 0.5% and others estimating much higher figures of around 6% (Dunner, 2003; Bruchmuller & Meyer, 2009; Singh & Rajput, 2006). Unfortunately, prevalence rates of psychiatric disorders (in general) and BD (specifically) in South Africa are not yet known (Wright, Niehaus, Koen, Drogemoller & Warnich, 2011). This is largely the result of the many different ethnic groups that make up the population and the way in which the country is still racially / ethnically divided according to socio-economic class (Wright et. al., 2011). South Africa has a population of approximately 52 million inhabitants, of which 79% are classified as black, from African descent; 9% are Caucasian, mostly from European descent; 9% are coloured and have a mixed ancestry; and 3% are Indian or Asian, from eastern descent (Wright et. al. 2011). According to Seedat et. al. (2008), the majority of South Africans suffering from psychiatric disorders do not get treatment, primarily because access to treatment is not readily available to them (Seedat, Stein, Herman, Kessler, Sonneger, Heeringer, Williams & Williams, 2008). This makes collection of data regarding psychiatric illness a difficult task, one which has not yet been accomplished at a national level.

Having said this however, evidence from the South African Stress and Health Study conducted in 2010 suggests that prevalence rates of BD in South Africa are not very different from non-African populations (Stein, Seedat, Herman, Moolman, Heeringa, Kessler, & Williams, 2008). As mentioned already, these rates vary greatly from one research study to the next. This variance is commonly cited as the result of high misdiagnosis rates, for which there are many different reasons and contributing factors (Oyffe et. al., 2014; Dunner, 2003; Bruchmuller & Meyer, 2009).

Firstly, BD patients often experience depressive episodes before experiencing their first manic or hypomanic episode (Wolkenstein, Bruchmuller, Schmid & Meyer, 2011; Faravelli, Amadei, Scarpato & Faravelli, 2009). There are three major difficulties faced by clinicians as a result of this. Firstly, patients are far more inclined to seek help during a depressive phase than during a manic / hypomanic phase. According to Faravelli et. al. (2009), approximately 50% of patients have the so-called DMI pattern (Depression-Mania-Interval) where the manic episode naturally follows the depressive one, which usually occurs first. Secondly, the Diagnostic and Statistical Manual of Mental Disorders (DSM) requires at least some evidence of a manic episode before a diagnosis of BD can be made (Bowden, 2001; Faravelli et. al., 2009). Thirdly, the diagnostic criteria for bipolar depression and unipolar depression are exactly the same (APA, 2013). Thus, the resulting difficulty is the frequent misdiagnosis of bipolar depression as unipolar depression, which can have negative ramifications for patients (Singh & Rajput, 2006; Bowden, 2005). An incorrect diagnosis of unipolar depression carries the risk of treatment with anti-depressants (particularly in the western world where anti-depressants are considered the first line of treatment for depression) which can result in an induced manic episode or rapid cycling if patients are, in fact, bipolar (Singh & Rajput, 2006).

The use of anti-depressant medication in BD is controversial and there are as many different findings and conclusions of their efficacy in bipolar patients as there are studies. Fountoulakis and colleagues (2005) reviewed 27 guidelines for treatment of BD and concluded that recommendations for bipolar depression were scant, at very best, as most guidelines focussed on the treatment of mania instead of depression. Almost every guideline, however, recommended the use of anti-depressants only in combination with an anti-manic agent (Fountoulakis, Vieta, Sanchez-Moreno, Kaprinis, Goikolea & Kaprinis, 2005). In sharp contrast to this, at the other end of the recommendation spectrum, are the results of the systematic review of randomized control trials of antidepressant use for treatment of bipolar depression, conducted by Gijsman and colleagues in 2004. Their research reviewed the results of 12 randomized control trials and found that antidepressants are effective in the short-term treatment of bipolar depression, even for those who are not taking anti-manic medication simultaneously. Their review also concluded that the trial data did not find "manic switching to be a common early complication in treatment with antidepressants" (Gijsman, Geddes, Rendell, Nolen & Goodwin, 2004: p.1537).

Thus, findings vary greatly regarding clinical impact of antidepressant usage among patients with BD and there is little consensus regarding the use of this class of medication in this population of patients. However, what is commonly agreed upon across the profession (and is also recommended by the APA in their Bipolar Disorder treatment guideline) is that using antidepressants in isolation without mood stabilizers of some sort is dangerous, primarily because of the high risk of manic switching or cycle acceleration (Nivoli et. al., 2011; Bowden, 2005; Singh et. al., 2006; APA, 2013). Again, what is agreed upon is that an incorrect diagnosis and subsequent incorrect prescription of medication can be counter-productive and can actually worsen the long-term course of illness (Bowden, 2001). Furthermore, if a manic episode is induced, it can be potentially life-threatening (Dunner, 2003; Katzow, Hsu & Ghaemi, 2003). For this reason, recommendations tend to err on the side of caution rather, despite several researchers claiming that there is no risk.

The next major factor that contributes to the difficult diagnostic process of BD is related to the overlap in symptoms between the different subtypes of BD and other psychiatric illnesses. Bipolar type 2, for example, is particularly difficult to distinguish from unipolar depression because of frequent depressive episodes and the absence of fully syndromal mania in this type of BD (Faravelli et. al., 2009; Phillips & Kupfer, 2013). Depressive episodes are typical in BD and their prevalence is higher than manic or hypomanic episodes (Phillips & Kupfer, 2013).

Linked to this is a recent body of literature that points out how mixed mood episodes, which are characterized by both depressive and manic or hypomanic symptoms, or a rapid alternation of the three symptoms types (rapid cycling), are being increasingly recognised as more common in people with BD than was previously thought (Marneros, 2001). These episodes might also obscure the detection of mania or hypomania, in view of the reporting bias towards depressive symptoms in people with BD seeking treatment, making early and accurate detection of BD more difficult (Phillips & Knupfer, 2013).

There is therefore a large overlap in phenomenology of disorders such as bipolar II, cyclothymia, unipolar depression, and even some personality disorders, such as Borderline Personality Disorder (BPD) (Henry, Mitropoulou, New, Koenigsberg, Silverman & Siever, 2001). Paris, Gunderson & Weinberg (2007) report that this overlap in phenomenology has lead to a confusing suggestion of a 'bipolar spectrum' that includes cases of unipolar depression, anxiety disorders, substance abuse disorders, eating disorders, as well as BPD. This has been the subject of much controversy in the field of psychology for two decades already as many view this shift away from a focus on polarity of mood states as increasing the chances of misdiagnosis as it becomes too over-inclusive.

Kuiper et. al. (2012) also discuss the problems associated with such a broad spectrum diagnosis. They point out that this expanded view of bipolarity has been suggested as a component of almost every disorder recognised in modern psychology and psychiatry, including psychosis, anxiety disorders, personality disorders, attention-deficit-hyperactive-disorder (ADHD), eating disorders, substance abuse disorders, autistic spectrum disorders, somatization, dissociation, conversion disorder, and dementia. In such expansive forms, bipolarity is suggested to be present in approximately 25% of the general population (Kuiper et. al., 2012). Moreover, as the phenomenological boundaries of BD are expanded outwards to include brief and less severe mood swings, the diagnostic field steadily shifts away from episodic mood elevation to affective instability, which is interestingly the key diagnostic feature for the diagnosis of BPD (Kuiper et. al. 2012).

Distinguishing between BPD and BD can be especially difficult as the two have many similar symptoms and often co-occur. This is a contested issue in the profession, with some arguing that BPD should be placed on the bipolar spectrum and not as a separate diagnostic category because of its shared symptomology with bipolar II, rapid cycling bipolar, and cyclothymia (Magill, 2004; Ghaemi, Dalley, Catania & Barroilhet, 2014; Akiskal, 2004; Mackinnon & Pies, 2006). Others however, vehemently justify the necessity of having two distinct diagnostic categories, arguing that although there is a shared set of symptoms, BPD and BD have different aetiologies, phenomenologies, family histories, biological data, outcomes, and responses to medication (Paris & Black, 2015; Barroilhet, Vohringer & Ghaemi, 2013; Paris et. al., 2007; Ghaemi, Galley, Catania & Barroilet, 2013).

Furthermore, Barroilhet and colleagues (2013) make the assertion that distinguishing between two seemingly similar conditions should take place via careful consideration of their *differences* and not their *similarities*, which they point out as a common mistake made by clinicians that complicates the diagnosis of both conditions. In agreement with this, Ghaemi et. al. (2013) assert that many psychiatric disorders have similar symptoms (such as insomnia in schizophrenia and anxiety disorders). However, the similarities between BPD and BD (such as mood lability and impulsivity), should be seen as peripheral and secondary features as opposed to core features (Ghaemi et. al., 2013). This perspective on the BD / BPD debate brings into focus Katzow, Hsu and Ghaemi's (2003) reasoning *for* the adoption of a bipolar spectrum (although their version of this spectrum does not include BPD as others would have it), in sharp contrast to the backlash against its formation by the APA. More specifically, Katzow and colleagues (2003) see this evolution of "classical" BD into a bipolar spectrum in a more positive light, stressing that the introduction of a spectrum "shifts the emphasis in diagnosis from polarity … towards other diagnostic validators" such as course, family history, and response to antidepressant medication, which may assist in identifying significant differences in psychiatric disorders that have similar symptomology, such as BPD and BD, thereby aiding clinicians in more accurately diagnosing BD (Katzow et. al., 2003: p.436).

Over the past 20 years there has also been an increasing awareness of the high prevalence of dual-diagnosis and comorbid disorders typically co-occurring with BD, another factor that is seen to complicate the diagnosis thereof. BD is linked to a myriad of other medical and psychiatric conditions, which means that its public health impact goes far beyond discrete episodes of depression, mania or hypermania (Manning, 2015). BD has been described as a "multisystem condition" complicated by a multitude of comorbid conditions (Manning, 2015: p.S.10). Unfortunately however, the vast majority of these comorbidities may go undiagnosed and therefore untreated in everyday practice, which can have negative ramifications for patients.

A systemic review of literature from 1959 to 2007 conducted in 2009 by Roshanaei-Moghaddam & Katon found that, compared with age- and sex-matched controls in the general population, patients with BD have a decreased life expectancy because of co-morbid chronic medical conditions, the disordered physiological conditions associated with BD, as well as lifestyle. Latest studies reveal that approximately 60% of BD patients suffer from co-morbid disorders that complicate not only the diagnostic process, but also treatment (Magalhaes, Kapczinski, Nierenberg, Deckersbach, Weisinger, Dodd & Berk, 2012). Of these patients, one or more comorbid medical conditions were found in 82% of this population (Manning, 2015). Obesity (often as result of medication induced metabolic syndrome), hypertension, thyroid disease, diabetes, kidney disease and migraine headaches are just some of the many illnesses typically associated with patients suffering from BD (Manning, 2015; Burgess, 2006). In another study, comorbid psychiatric diagnoses were found in 57% of bipolar patients, the most common being anxiety and substance use disorders (Bauer, Altshuler, Evans, Beresford, Williford & Hauger, 2005).

In particular, substance use disorders are "overrepresented in patients with Bipolar and bipolar spectrum disorders" (Levin & Hennessey, 2004: p. 738). Numerous studies have reported high rates of alcohol related disorders in bipolar patients (Brown, Suppes, Adinoff & Thomas, 2001). Furthermore, in a recent review of 14 studies conducted with bipolar patients in both inpatient and outpatient psychiatric settings, Brown et. al. (2001) reported that the lifetime rate of drug abuse for bipolar sufferers ranged from 14% to 65% compared with rates of 6% to 12% in the general population. Similarly, Cassidy, Ahearn and Carroll (2001) found that nearly 60% of their sample of patients hospitalized for manic or mixed episodes had a lifetime substance use disorder (Levin & Hennessey, 2004). However, these prevalence rates of BD and comorbid substance use disorders have been largely presented without addressing the underlying difficulty in diagnosing BD in substance abusing patients (Levin & Hennessey, 2004). It is therefore possible that some of the latest elevated rates of bipolar type 1, and particularly bipolar spectrum disorders such as cyclothymia, might be a result of this.

The most recent development in research on the topic of misdiagnosis of BD clouds the picture even further by suggesting that years of under-diagnosis has now evolved into a period of over-diagnosis of the disorder. According to Goldberg (2010), the surge that took place in publications, academic journals, newsletters, advertisements, and continuing medical education around the late 1990s that attempted to raise awareness about the under-diagnosis of BD and overtreatment of potential BD patients with antidepressants (so, misdiagnosis of bipolar depression as unipolar depression), has now resulted in a "modern-day epidemic of Bipolar Disorder" that saw a "doubling of adult…diagnoses and a … 40-fold rise in paediatric diagnoses" between 1994 and 2003 (Goldberg, 2010: p.539).

Over the past 15 years in particular, the general public seems to have become captivated with the self-description of 'bipolarity', which can likely be attributed, at least in part, to the United States Food and Drug Administration's (FDA) relaxation of broadcasting restrictions in 1997, resulting in advertising of prescription medication directly to the public (Yutzy, Woofter, Abbott, Melhem & Parish, 2012). This has resulted in what is known as direct-to-customer advertising (DTCA), which is increasingly available via the internet beyond the countries where it is legal (Unites States of America and New Zealand) (Raven & Parry, 2012).

A growing body of research on this topic has emerged with expressed concern for the ramifications of this phenomenon. Specifically, the pharmaceutical industry has been criticized for spending billions on marketing campaigns and DTCA, creating a mentality of "a pill for every ill", which reaches millions of people around the world via the internet (Raven & Parry, 2012: p. 513). Furthermore, pharmaceutical industries reportedly hold disease awareness campaigns and include "symptom checklists" that are seen to over-simplify complex psychiatric diagnostic processes while simultaneously promoting the phenomenon on self-diagnosis (Raven & Parry, 2012: p. 513). Pharmaceutical company websites commonly provide checklists for people to take to their clinicians to discuss, thereby creating greater sway in the minds of both patients and clinicians (Lupton & Jutel, 2015). Thus, the primary concerns with this promotion of self-diagnosis-by-checklist are that it allows more people to self-identify as having a disorder, and that it may also be an important mechanism by which broadened diagnostic criteria for psychiatric disorders (such as BD) increase the pool of "potential customers" for those disorders (Raven & Parry, 2012: p. 513).

Consequently, this increased awareness in both the clinical and public domains can be seen as another possible influence over the tendency to diagnose, and potentially over-diagnose, BD (Zimmerman, Ruggero, Chelminscki, & Young, 2008). Several research authors, and even the APA via the DSM-V, warn against what is known as "cookbook" diagnoses or mentalities which oversimplify diagnostic procedures without careful consideration of clinical significance (APA, 2013; Raven & Parry, 2012; Boyce, 2006; Eisenberg, 1986; Lipowski, 1989).

As recognised by Hutto (2001) and Bowden (2001) in their respective letters to the editor of *Psychiatric Services*, errors in diagnoses can occur when DSM criteria are applied too strictly (often resulting in under-diagnosis), or too loosely (resulting in over-diagnosis). Most clinicians easily recognise typical, fully-manifest mania, but variants of this (such as hypomania, for example) are more questionable and therefore more difficult to identify (Hutto, 2001). Given the overlapping symptoms of many psychiatric disorders, each criterion for mania has its own differential diagnosis (Hutto, 2001). For example, grandiosity also characterizes narcissistic personality disorder. Thus, a loose application of DSM criteria could certainly increase the number of people diagnosed with BD, leading to unnecessary false positives (Hutto, 2001).

Bowden (2001) describes how attempts to establish a history of mania or hypomania on the basis of a patient's reports can lead to missing the diagnosis, but as Hutto (2001) points out, it can also lead to over-diagnosis. In their reports, patients often minimise substance abuse during episodes of mania, or they may state that they abuse substances only when they are manic (Hutto, 2001). Furthermore, they may also misunderstand what the clinician is looking for. For example, simple inquiry into whether the patient's thoughts ever 'race' can result in a range of replies, depending on the patient's understanding of the concept. If this is not clearly explained to patients, misdiagnosis may occur.

Moreover, the overlap in symptoms of BPD and BD have also been attributed to the over-diagnosis of BD. The recent trend in treatment of BPD with atypical antipsychotic medication (originally approved for treatment of psychosis and related disorders, specifically BD and schizophrenia) further confounds this phenomenon. Recent research has shown that anti-psychotics have become the top selling drug class in North America, rating the industry at $14.6 billion dollars in 2008 (Yutzy et. al., 2012). Although these drugs do appear to reduce mood lability and impulsivity, regardless of diagnosis, to infer that a specific illness is present (such as BD) simply because a particular medication has helped, would be regarded as "faulty logic" (Hutto, 2001: p. 687). This is criticized, however, as being another common reason why prevalence rates of BD have increased so rapidly of late.

It is evident, therefore, that the topic of misdiagnosis of BD is not new to academic literature or public forums, and has, in fact, been a hot topic in circulation for several decades already. A review of this subject in academic journals results in an abundance of research articles, clinical guidelines, consensus statements, and expert opinions, some dating as far back as the 1970's, all with the similar aim of raising awareness, pointing out diagnostic difficulties, and highlighting strategies to reduce misdiagnosis and increase the likelihood of BD being picked up by clinicians as early on as possible in order to decrease unnecessary suffering (Nivoli et. al., 2011; Matza et al., 2005; Phillips & Kupfer, 2013; Bongards, Zaman & Agius, 2013; Faravelli et. al., 2009; Bruchmuller, 2009).

A brief review of the literature available to the general public via the internet, which is often a patient's first port of call when querying a possible diagnosis or forming a hypothesis about presenting problems, brings up a plethora of websites dedicated to explaining the phenomenology of BD as well as the similarities and differences between BD and other disorders carrying similar symptoms, with the implicit aim being that of psycho-education in order to accurately diagnose and treat BD. Examples of some popular international websites and blogs dedicated to assisting sufferers of BD with their questions and frustrations (or those who suspect they may have BD but have not yet been formally diagnosed) are *Bipolar Burble* (www.natashatracy.com), *Bipolar Beat* (www.blogs.psychcentral.com/bipolar) , and *Bipolar Hope* (www.bphope.com).

Despite there being a sharp focus on this issue for several decades already however, with an amplitude of literature available to both clinicians and the general public regarding this difficult diagnostic process and complex condition, misdiagnosis still appears to be very common in everyday clinical practice. The latest studies on this topic reveal that misdiagnosis rates are as high as 30% for under-diagnosis of true cases, and 40% for over-diagnosis (cases that should have been diagnosed as some other illness or disorder) (Goldberg, 2010). In a sample of 85 mood disorder patients, Ghaemi et. al. (2000) found that 37% had previously been diagnosed with unipolar depression, a quarter of whom had been evaluated at least three times before being correctly diagnosed with BD. Based on a National Depressive and Manic Depressive Association survey, Hirschfeld et. al. (2003) reported that 69% of participants with BD were misdiagnosed, most typically with unipolar depression (60%). In a follow-up study, Hirschfeld et. al. (2005) reported that 21.3% of adults from an outpatient family medicine clinic had been prescribed an antidepressant for depression, but screened positive for BD. Das et. al. (2005) reported that 112 (9.8%) of 1157 patients seeking treatment at a general medicine clinic serving a low income population in New York, USA, screened positive for BD. Furthermore, of these 112 patients, 81 (72,3%) sought professional help for their symptoms, but only 9 (8.4%) reported receiving a diagnosis of BD and only 7 (6.5%) had been placed on mood stabilizing medication (Das et. al., 2005).

Thus, despite the abundance of literature available on this topic with in-depth caveats and recommendations, guidelines and prescriptions, misdiagnosis seems to have merely morphed in presentation as opposed to dissipating in prevalence. Focussing on under-diagnosis seems to have resulted, whether directly or indirectly, in over-compensation of some sort, not least because of the many complicating factors contributing to the very challenging diagnostic process, as well as the potential influence that patients themselves have over the diagnosis, as mentioned above.

Motivation for this study

It is clear from the literature available on the difficulties diagnosing Bipolar Disorder (BD) that delayed treatment, as a result of inaccurate diagnosis or other contributing and complicating factors, leads to prolonged suffering and an increased risk of hospitilization, suicide attempts, mortality rates, psychosocial impairment, unemployment rates, and treatment complications (Singh & Rajput, 2006; Keck et. al., 2008). It is concerning to find that significant delays, ranging from six to 10 years or longer, have been reported to be the norm before BD is correctly diagnosed and appropriately treated (Ghaemi, Sachs, Chiou, Pandurangi & Goodwin, 1999; Ghaemi, Booiman & Goodwin, 2000; Suppes, Leverich, Keck, Nolen, Denicoff, Altshuler, McElroy, Rush, Kupka, Frye, Bickel & Post, 2001; Birnhaum, Shi, Dial, Oster, Greenberg, Mallett, 2003; Wang, Berglund, Olfson, Pincus, Wells & Kessler, 2005) . It goes without saying then, that increased diligence in diagnosis can only have a positive influence (Bowden, 2003; Daigneault et. al., 2015). Thus, if early detection and accurate diagnosis is of paramount importance in successfully treating and managing BD, and a host of literature is available to clinicians in addition to the revised DSM-V recommendations to assist in mitigating the complexities influencing the diagnostic process, why is BD still so difficult to diagnose?

Assuming that the APA has done its best to take into account all of these aforementioned contributing factors, and that despite criticism from a branch within the profession, the revision in diagnostic criteria and subtypes in the recently released DSM-V is evidence thereof, the question then remains: what *else* is at play that hasn’t been adequately addressed or acknowledged yet? With misdiagnosis rates still so high, it appears that other factors may be contributing to this phenomenon. Perhaps a place of departure in attempting to answer this question would be the guidelines for responsible clinical practice that highlight the point that individual factors and contexts, such as varying symptoms, gender, culture, social class, substance usage / abuse, age, mental status, level of education, and socio-economic conditions, all affect the diagnostic interview between clinician and patient and therefore the diagnosis decided upon by the clinician, too (APA, 2013).

Thus, perhaps the difficulty in accurately and timeously diagnosing BD can be attributed, at least in part, to the great variance in personal attributes of each patient and the subsequent difficulties faced by clinicians needing to take all of these influential intra- and interpersonal differences into account when deciding upon diagnoses. With this in mind, a recent article by Harris (2011) comes to the fore in which he quotes a psychiatrist who reported feeling compelled to make diagnoses within the first consultation session with his clients. Although no other research could be found with similar findings, this is a proverbial ‘red flag’ to bear in mind when investigating diagnostic practices, particularly in light of the aforementioned individual variance in personal factors that need to be taken into account during the diagnostic interview.

For these above-mentioned reasons, it is timely to investigate the diagnostic process of BD further, as experienced by patients who have been diagnosed with the disorder, the assumptions here being that: (1) There might be variability in the diagnostic procedure experienced by patients, and that (2) Patients’ accounts of their own personal diagnostic journeys will be a new and unique way of establishing any variance, or potential “gaps” in the diagnostic procedure that they experienced, through a systematic data analysis process. The first assumption is a result of the extensive literature published on the difficulties faced by clinicians when diagnosing BD, coupled with the recommendation made in several review articles regarding the need for supplementing information to be provided by a potential bipolar patient’s family, colleagues, or other people who are familiar with the patient’s daily routine, moods, and struggles, so as to ensure that the diagnosing clinician does not miss any vital information that was not provided by the patient him/herself (Nivoli et al., 2011; Bowden, 2001; Dunner, 2003; Singh & Rajput, 2006; Faravelli et. al., 2009; Bruchmeller & Meyer, 2009).

The second reason for this assumption is based on my own personal experience of working in a clinical setting where psychiatric diagnoses are made on a daily basis and discussions about negative consequences faced by patients as a result of under-recognized or missed symptoms, is a common occurrence.

Furthermore, variability in diagnostic procedures that may lead to the above-mentioned diagnostic “gaps” could be related to the clinician making the diagnosis. However, it could also be the result of complex and inter-related personal factors, such as gender, educational level, family relationships and access to mental health resources that played a part in diagnoses. This study therefore analyses personal factors that played a part in the diagnostic journeys of a population of patients diagnosed with BD.

The rationale in choosing to interview patients as opposed to clinicians for this study is that the patients will be able to provide first-hand accounts of their own diagnostic journeys, giving valuable insight into the process as a whole, as well as their own feelings about the process, both currently and retrospectively, which can then be used to deepen existing knowledge available on this intricate diagnostic process. Moreover, when analysing the plethora of existing literature on this subject it became apparent that patients’ perspectives of the difficulties in diagnosing BD have been under-researched, with the vast majority of data being collected from clinicians making the diagnoses, or academic professionals. In studies where patients *were* interviewed, the data collection process was mainly quantitative in design, with self-report questionnaires being the main tool of assessment used to gather information, which was then analysed statistically. In the few qualitative studies that were found relating to the diagnosis of BD, the focus was on stigma surrounding diagnosis (Michalak, Yatham, Maxwell, & Lam, 2007; Michalak, Livingston, Hole, Suto, Hale, & Haddock, 2011; Link, Struening, Rahav, Phelan & Nuttbrock, 1997; Bjorklund, 1998).

During the literature review process, no African or South African studies on this topic were found either, which further supports the need to assess this phenomenon more in-depth, from a South African perspective.

CHAPTER THREE: METHODOLOGY

Introduction

This research study aims to deepen the current understanding on the diagnostic process of Bipolar Disorder (BD), and in doing so, to establish the factors that influence this process. This chapter begins by outlining the epistemological paradigm and theoretical framework within which this research is located. Next, I explain the qualitative research design and why this was chosen as best suited for this study, followed by detailed information about the sample, inclusion and exclusion criteria, and the data collection and analysis process (including the grounded theory approach utilized for analysis of data). Ethical considerations are then discussed, and the chapter is concluded with a discussion on power, reflexivity and validity.

Epistemological Paradigm and Theoretical Framework

Researchers always bring their own worldviews, paradigms, or sets of beliefs to a research project and these inform both the conduct and writing of a qualitative study (Creswell, 2007). Furthermore, in many approaches to qualitative research, researchers use interpretive or theoretical frameworks to further shape the study (Creswell, 2007). Robust research requires making these paradigms and frameworks explicit and also awareness of the influence they will inadvertently have over the inquiry (Creswell, 2007). Although these elements often overlap and reinforce each other, for the purpose of this study they will be discussed separately in order to make my own worldview and role as a researcher clear.

According to Guba (1990), a paradigm or worldview can be defined as a “basic set of beliefs that guide action” (Guba, 1990, cited in Creswell, 2007: p. 19). In this study, I adopted a social constructivist worldview which posits that individuals seek meaning and understanding of the world in which they live and work. Thus, I believe that people develop subjective meanings of their experiences which are varied and multiple. As a result, I looked for these variations and any resulting complexities rather than narrowing the meaning of each participant’s view into just a few categories or ideas. The goal then was to rely on the participants’ subjective views of their diagnostic processes and to generate a theory of meaning from these accounts (Creswell, 2007).

In terms of practice, the research questions were broad and general so that participants could construct their own individual accounts of their diagnostic journeys. I also focussed on processes of interaction among individuals (such as the participants and their clinicians, or participants and their families) as well as specific contexts in which these participants lived, so as to understand the historical and cultural settings that may have played a part in their construction of meaning. Furthermore, I recognized that my own background will have shaped my interpretations and thus positioned myself in the research to acknowledge how my interpretations flow from my own personal, cultural and historical experiences (Creswell, 2007). This will be explained in more detail in the section entitled *Power, Reflexivity and Validity.* According to Creswell (2007), the constructivist worldview often manifests in grounded theory research approaches, which is the approach adopted for this study. Thus, my theoretical orientation is grounded in the perspectives or views of the study participants.

As mentioned above, the constructivist paradigm calls for the researcher to make sense of, or interpret, the meanings others have about the world. In order to do this, I had an "interpretive lens" or theoretical framework (Creswell, 2007: p.24). These interpretive positions assisted me in gaining perspective on all aspects of the research project. In this study, I adopted a post-modernist theoretical perspective, which can be considered a family of theories or perspectives rather than one theory alone (Creswell, 2007).

One premise of post-modernism is that knowledge claims must be set within the multiple perspectives of class, race, gender, and other group affiliations (Creswell, 2007). These "conditions" are seen as formative and they show themselves in the presence of hierarchies, power and control by individuals in these hierarchies (Creswell, 2007: p.25). Some examples of these conditions include bringing to light concealed hierarchies, dominations, oppositions, inconsistencies and contradictions (Boland, 1995; Clarke, 2005; Creswell, 2007). For this reason, a research approach that is able to draw attention to narrative inconsistencies, gaps and contradictions, is well positioned to build from data to theory without getting hijacked by already existing hierarchies or power and knowledge. It is therefore fitting that a grounded theory research approach be used in this study. The focus of this study will thus be on the patterns that emerge between the responses of the participants as well as individual storying of experiences.

Research Design

Qualitative Research

For the qualitative researcher, human experience and the meanings attributed to that experience are critically important when generating knowledge about a particular person, situation, or phenomenon (de la Harpe, 2010). Qualitative research is interested in how people experience certain life events and what they do in order to cope with pain, personal struggle, and social inequalities (Willig, 2001). Like social constructivism, qualitative research acknowledges that there are multiple realities, and that a person's interpretation of their experience is largely dependent on their social context (de la Harpe, 2010). Thus, there are multiple meanings, experiences, opinions, subjectivities, and perspectives to be explored and challenged.

The techniques used in qualitative research are flexible enough to accommodate new or unanticipated categories of meaning and experience that may come up during the research process (Willig, 2001). The research questions are open-ended and permitted to change along the way. Furthermore, the research questions act as a guide that will point the researcher in a direction without predicting what will be found (Willig, 2001). For an exploratory study such as this, this type of design is favourable because of its open, flexible and inductive approach (Babbie & Mouton, 2004). Furthermore, this exploratory outlook allowed me an opportunity to look for new insights into the phenomenon of bipolar diagnoses, as experienced by a sample of participants from Cape Town, South Africa (Babbie & Mouton, 2004).

From both a social constructivist paradigm and a post-modernist theoretical framework, the subjectivity and context of people who have been diagnosed with BD is very important when building knowledge about diagnostic journeys. Therefore, a qualitative methodology is appropriate for this project as it emphasises both subjectivity and the context within which people are embedded. In order to analyse and understand the diagnostic experiences of people diagnosed with BD, I needed a method of accessing patients' diagnostic histories and their feelings around this process. Qualitative research provided a method to attain those accounts via semi-structured interviews. Moreover, using qualitative research rooted in a post-modernist lens of interpretation, I was able to reflect on my own subjective contribution to the research, which is a fundamental part of this framework of inquiry.

Research Aim and Questions

This study aimed to better understand the diagnostic process of Bipolar Disorder (BD) by examining the diagnostic journeys of participants diagnosed with BD in order to develop a grounded theory of some of its patterns. This theory is based upon research guided by three primary research questions:

1. What did the diagnostic journey look like for each participant in this study, from their own, unique perspective?
2. Are there any factors that complicated or assisted the diagnostic process for these participants?
3. Do the emerging patterns suggest any opportunities to improve the current diagnostic system, as experienced by these participants?

For the purpose of this study, grounded theory can be defined as a "qualitative research design in which the inquirer generates a general explanation (a theory) of a process, an action, or an interaction shaped by the views of a number of participants" (Creswell, 2007: p.63). Thus, the intent of grounded theory is to move beyond description and to generate or discover a theory (Creswell, 2007). However, theory-development does not come "off the shelf", but is rather "grounded" in the data from the field, collected from participants who have already experienced the process or action being studied (Creswell, 2007: p.63).

Sample

12 Participants were recruited by me from three out-patient and community-based support groups for people living with BD. These support groups take place in Cape Town, South Africa and thus all 12 participants were from this area, too. According to recommendations made by Babbie and Mouton (2004) and Terre Blanche, Durrheim and Desmond (2006), 12 participants are sufficient for in-depth, individual interviews for the exploration of case studies such as these (Babbie & Mouton, 2004; Terre Blanche et. al., 2006).

I considered various sampling options when designing this study. Random purposive sampling, criterion sampling and theoretical sampling strategies were all studied and then carefully considered. In the end, a combination of theoretical sampling and purposive sampling was used. Purposive sampling is an informant selection technique that is widely used in qualitative research (Creswell, 2007). It is the deliberate choice of an informant based on the qualities they possesses (Bernhard, 2002). Simply put, the researcher decides what needs to be known and sets out to find informants who can and are willing to provide this information through their knowledge or experience. Purposive sampling is especially typical of this key informant technique where individuals are solicited to act as guides to a culture or phenomenon (Bernhard, 2002). According to Babbie and Mouton (2004), sampling in studies where qualitative methods are used is almost always purposive. In this case, there were specific inclusion and exclusion criteria for this sample population, which critically informed the research study and the sampling strategy employed.

Theoretical sampling can be defined as the process of data collection for generating theory whereby the researcher jointly collects, codes and analyses the data and decides what data to collect next and where to find it in order to develop the theory as it emerges (Babbie & Mouton, 2004). Strauss and Corbin (1998) further explain this process as beginning with the study of a homogenous sample group of individuals and then, after initially developing a theory, studying a heterogeneous sample group in order to confirm or disconfirm the theory (Creswell, 2007).

Although a grounded theory approach was employed for this research project (which is typically espoused with a theoretical sampling strategy), the systematic, analytic procedures associated with the literature of Strauss and Corbin (1998) were not followed. Instead, the constructivist approach of Charmaz (2005) was adopted, which advocates that the grounded theory approach lies squarely within the interpretive approach to qualitative research, thereby allowing it flexible guidelines (Charmaz, 2005). Furthermore, Charmaz places more emphasis on the views, values, beliefs, feelings, assumptions, and ideologies of individuals than on the methods of research, although she does describe the practices of “gathering rich data, coding the data, memoing, and using theoretical sampling” in a flexible manner (Charmaz, 2006, cited in Creswell, 2007: p. 66). Thus, although theoretical sampling was used in this specific research project, a secondary heterogeneous sample group was not recruited after the theory was developed. After thoughtful consideration, it was not thought necessary to confirm or disconfirm the theory that developed from this study through a secondary sample, because of the small scope of this project.

Recruitment of participants took place at three support groups, held at three different private psychiatric clinics in Cape Town, South Africa. One of these support groups was in the West Coast area (Table View), one was in the Southern Suburbs (Kenilworth), and one in the Northern Suburbs (Goodwood). All three clinics are private clinics with almost identical facilities, admission criteria, operating procedures, payment requirements (either via private medical insurance or cash paid upfront) and treatment programmes, which resulted in a fairly homogenous group of participants. The support groups run from these clinics are voluntary, free of charge, and open to anyone to attend, including patients and family or support members of people living with BD. Most patients attending these support groups were referred by private psychiatrists and other treatment specialists practicing at these clinics, for continued support after completion of the in-patient programme. Thus, these support groups can be seen as 'out-patient' groups because those in attendance are not in acute psychiatric care at the time (which was an ethical consideration taken into account and will be discussed in more detail later).

Access to these groups was negotiated and agreed to in writing by the relevant directors of the clinics and/or their designated authorities. Moreover, permission was granted by the relevant group leaders to attend their support group sessions and explain the purpose of this study, with the aim of recruiting volunteer participants, after ethical approval was presented to these leaders. Three support group sessions were then attended, one at each of the participating clinics, in order to introduce myself, explain the nature of this study, and ask for volunteers who would like to find out more about participation. These volunteers then gave their contact details to me and I followed up with each of them individually to discuss the study in more detail and assess their appropriateness for participation based on the below inclusion and exclusion criteria.

Inclusion criteria were as follows:

1. Participants must have been diagnosed with BD (any of the Bipolar Spectrum disorders according to the DSM-V) by a healthcare professional (i.e. not self-diagnosis). The participants' current diagnosis did not have to be BD - this may have changed along their diagnostic journey - but there needed to have been an official bipolar diagnosis and subsequent bipolar treatment at some point in time.

2. Participants must have been diagnosed with BD at least one year prior to the interview taking place (i.e. diagnosis cannot have taken place recently). There needed to be a reasonable amount of time in between diagnosis and the interview in order to allow the participant to reflect back on their diagnostic journey. This criterion also served to protect participants who were emotionally vulnerable as a result of a recent BD

diagnosis (which, according to the literature, often occurs during or just after a manic or depressive episode).

3. Participants had to be 18 years or older and had to be able to:
    a. Understand the rationale of the study and what would be required of them
    b. Give their own consent to participate in the study and sign their own consent forms
    c. Be proficient in English, which is the language in which the interviews took place

4. Participants had to volunteer willingly and could not be coerced to partake in this study or feel that continued access to their respective support groups was in any way contingent on participation in this study.

Exclusion criteria were as follows:

1. Participants being treated as in-patients at any psychiatric clinic or hospital were not eligible for participation in this study. The aim here was to avoid any possibility of taking advantage of emotionally vulnerable patients. This will be discussed further in the ethics section of this chapter.

2. Participants with any pre-existing relationship with me, that could result in a conflict of interest or call into question issues of confidentiality, trust, or power, would not be permitted to take part in the study.

The first 12 participants who volunteered to take part in this study and who met all of the inclusion criteria and none of the exclusion criteria were then interviewed by myself using semi-structured, in-depth interviews. Participants were asked to identify standardized demographic information about themselves at the start of the interviews (which included age, race, gender, religion, and place of residence). This was noted because differences in individual identity and context may have had an influence on the participants' recollection of their diagnostic journeys, as well as their current feelings about events that occurred during their journeys and their BD diagnoses. Although this sample is a small one, emerging patterns provide some important context to the findings:

Age and years since BD diagnosis: Participants ranged in age from 20 to 55 years old (with a mean age of 32.3 years). According to the literature on this topic, BD is seen as a chronic psychiatric disorder with strong genetic links in its aetiology. Thus, onset of symptoms can occur at any age, even in childhood, although diagnosis does not often occur immediately after onset and there is typically a long delay between onset of symptoms and BD diagnosis (Oyffe et. al., 2014; Keck et. al., 2008; Bruchmuller & Meyer, 2008). The DSM-V does not stipulate a minimum age for diagnosis of BD, which is a controversial topic in itself. For the purpose of this research study however, only adult volunteers were permitted to take part. Thus, the broad age range of these study participants is consistent with the literature that explicates how BD can manifest at any age.

The approximate average amount of time between age of onset of symptoms (which was difficult to recall or pinpoint by some participants and is therefore only a rough estimation), and their BD diagnoses, was approximately 19.75 years. However, the average time between first contact with a medical professional about these symptoms and their BD diagnoses, was much less, at 5.5 years. These two findings are valuable not only when taking into account the years that these participants have lived with the disorder, but also the years with which they have lived with their BD diagnoses, which adds valuable context to this data and will be discussed in more detail in the results section.

Gender: Nine of the participants were female and three were male. During my visits to the various support groups, it was noted that the majority of attendees were females. Thus, it was not surprising that the proportion of female to male participants for this study was also skewed in the same way. Interestingly, research indicates that the prevalence of BD is almost equal when comparing the gender ratio of this disorder (Diflorio & Jones, 2010). This could therefore indicate an important social influence at play when it comes to help-seeking behaviour among bipolar patients – one that is perhaps more accepting towards female help-seeking behaviour and disclosure of psychiatric illnesses than their male counterparts.

Race: Eight of the participants identified themselves as [2] white, three self-identified as coloured, and one self-identified as black. This over-representation of white participants was not surprising given the settings and context in which recruitment of participants took place.

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[2] The terms used here are used to refer to people who were, under the apartheid government, identified as 'white', 'coloured' or 'black'. The researcher's use of these terms is not intended to indicate an agreement or endorsement of the use of these terms. However, although originally used as apartheid racial designation, most South Africans still use these terms to classify themselves racially.

Specifically, participants were recruited from support groups run from private psychiatric clinics, where most of the participants had previously been treated as in-patients. This meant that they were able to afford private medical insurance, or to pay in cash upfront for their treatment. According to a survey conducted by Statistics South Africa in 2011, only 27.9% of the South African population were able to afford private medical treatment when needed (Statistics South Africa, 2013). Furthermore, there were particularly wide disparities between the black and white population groups. Approximately 88% of the white population group in South Africa utilized private health care services when needed as opposed to only 17.2% of the black population group (Statistics South Africa, 2013). Thus, this over-representation of white participants in this study highlights the socio-economic factors that inadvertently affected the sampling, and therefore also the results of this research project.

Data Collection

Data collection took place via semi-structured, individual, in-depth interviews with the research participants. This type of interview allowed data to be gathered within the qualitative research approach that would assist in achieving the aims of this study, while simultaneously remaining flexible to allow the participants to speak for themselves and to answer questions freely by giving their own descriptions of their journeys through mental illness in their own ways, and in their own words (Babbie & Mouton, 2004).

The interviews took place at one of three possible locations: either my office at the clinic located in Table View, or at consultation rooms that are available for professional use via a booking system at both clinics in Kenilworth and Goodwood. Both the latter clinics were visited before setting up the interviews with participants in order to negotiate available times to make use of the consultation rooms with the relevant authorities at the clinics, and to investigate their suitability for the interviews. All three of these venues were enclosed, private office spaces conducive for private interviewing. Interviews were scheduled with the participants telephonically at times most convenient for them, which included after-hours and weekend time slots for those who were not available during working hours. Each participant could choose from the three possible locations, depending on which venue was most suitable for them to attend the interview. Five participants were interviewed at the Table View clinic, four at the Kenilworth clinic, and three at the Goodwood clinic.

Each interview began with personal introductions and explaining of the purpose of the interview. The participants already had a good idea of the purpose of the study by this stage as it was be explained to them during the recruitment process at the various support groups, and again telephonically during follow-ups with them to determine that they met all of the inclusion criteria. This reduced the time needed for explanations and increased time available for the interview itself. Following this introduction, a consent form was handed to the participant to sign, which was explained in detail, verbally, and included information about the purpose of the interview, the recording of the interview, the storage of the data collected, confirmation of anonymity and confidentiality, possible risks and benefits, and the right of the participant to pull out of the study at any point in time. A copy of the consent form is attached as *Appendix C*.

Once consent was obtained and the participant signalled their readiness to begin, the interview commenced. Each interview was recorded with a mobile phone, making use of an application called *Express Pocket Dictate* specifically designed for recording of interviews. This allowed for the interviews to be directly uploaded from the mobile device to my personal computer for safe keeping immediately after each interview. The audio file on the mobile was then immediately deleted. This process was also explained to the participants for their consent before beginning the interviews. A dictaphone was also utilized as a back-up recording device.

A semi-structured interview schedule was utilized during the interviews and served as a guideline rather than a strict set of prompts needing to be followed during the interviews. A copy of the interview schedule is attached as *Appendix B*. This schedule covered the broad areas of interest that needed to be discussed during the interviews, as well as a few specific questions to be asked in order to meet the aims of this study. This flexibility allowed further questions to be added at a later stage as the grounded theory began to develop. More specifically, the data analysis process began after the first interview already, thereby forming an adaptable theory from the ground up. Questions were then added to the interview schedule in order to confirm or disconfirm the central categories of the theory as they emerged. To ensure that all participants were asked the same questions and given the same opportunity to respond to everything, follow-up discussions were required with some of the first participants interviewed, which took place telephonically, to ask any additional questions that arose after their interviews were completed.

In order to assist participants to recall important life events and experiences, each person was asked to create a timeline, using different coloured pens and stationary made available to them, during the interview process. Participants were given free rein to be as creative as they wanted to be, with the only request being that they decide which experiences they'd like to write on their timelines (or have written by me on their behalf if they didn't want to write themselves) in order to create a visual flowchart of their individual diagnostic journeys. Participants were asked to start their timelines off with the first time they recall feeling like something was 'wrong', and then to punctuate the timeline from that time onwards with significant life events, including their BD diagnoses, up to the day of their interviews.

At the end of every interview, a few minutes were set aside to answer any questions from the participants. It appeared that many of the participants saw me as an 'expert' on the topic of BD and thus took this opportunity to ask me questions about the disorder that they were still not clear about, which was noted as relevant additional data to be taken into account during the analysis process. These questions ranged from very general and vague (such as , "What is bipolar actually?") to more specific questions about their medication and the need to take medication for the rest of their lives. In the former case, I felt confident that it was within my scope of practice to answer these more general questions about BD. However, with questions relating to individual prognosis and/or medication, referrals were made to their respective psychiatrists who would be better qualified to answer these questions.

Data Analysis

Given the qualitative nature of this study and the theoretical framework within which it is rooted, grounded theory was used as the means of data analysis.

Grounded theory is a qualitative research design in which the researcher generates a general explanation of a process, action or interaction shaped by views of participants (Creswell, 2007). Participants in this type of study have all experienced the process or action in question, and the development of the theory might thus help explain practice or provide a framework for further research (Creswell, 2007).

This research study follows the guidelines of Kathy Charmaz who broke away from the prescriptive, highly-structured teachings of Glaser and Strauss who first developed the grounded theory approach in 1967 (Creswell, 2007). Charmaz advocated for a constructivist grounded theory that was emancipated from the traditional positivist underpinnings of Glaser and Corbin.

Instead of embracing the study of a single process or core category as in Strauss and Corbin's approach, Charmaz's perspective emphasizes diverse local worlds, multiple realities, and the complexities of these different worlds, views and actions (Creswell, 2007). Thus, constructivist grounded theory is appropriate for this research study because more emphasis is placed on the views, values, opinions, beliefs and experiences of participants themselves than on the methods of research. Having said this however, Charmaz does delineate specific guidelines for grounded theory analysis, which I followed in the analysis of data for this study.

Firstly, interview recordings were transcribed verbatim after completion of all 12 participant interviews. Secondly, all of the transcripts were coded using the computer programme *AtlasTi (version 7)* which is designed specifically for the analysis of qualitative data. Coding took place in three phases in order to follow the process suggested by Charmaz (2006). The first step in coding the data was *Initial Coding*, which involved naming each line or segment of data in order to "mine" this raw data for analytic ideas to pursue in further data collection and analysis (Charmaz, 2006: p. 46). During this first step, the aim is to remain open to all possible theoretical directions indicated by the interpretations of the data (Charmaz, 2006). During this phase, 212 initial codes were developed by segments of data, using *in vivo* codes where appropriate, and using gerunds (as opposed to nouns) in order to gain a stronger sense of action and sequence (Charmaz, 2006).

The second phase of coding is called *Focussed Coding* and is more directive, selective and conceptual that *Initial Coding*. Here, I began to synthesize and explain larger segments of data. According to Charmaz (2006), this process entails sifting through the initial set of codes created to identify the most significant and/or frequent codes (Charmaz, 2006). As part of this non-linear process, I found that statements from some participants made explicit what was implicit in earlier statements, which prompted me to study earlier data afresh. Thus, topics that may have been initially glossed over were returned to for further interpretation and theory development at this stage. According to Charmaz (2006), by comparing data to data, codes become more focussed. By then comparing data to these codes, it helps to refine them even further (Charmaz, 2006).

The third and final phase of coding was originally coined by Strauss and Corbin but has been advocated by Charmaz for use in her approach to analysis, too. *Axial Coding* "relate[s] categories to subcategories, specifie[s] the properties and dimensions of a category, and reassembles data [that was] fractured during initial coding to give coherence to the emerging analysis" (Charmaz, 2006: p. 60). Thus, subcategories of the main categories of data were developed and the links between them were specified as more information about the experiences of the participants was uncovered. These emergent categories, subcategories and links reflect how I made sense of the data.

The third step in the data analysis process is referred to by Charmaz (2006) as *Memoing*, which is seen as the "pivotal intermediate step between data collection and writing drafts of papers…that prompts [the researcher] to analyse the data and codes early in the research process" (Charmaz, 2006: p. 72). Consistent with the flexibility of this approach, memoing was conducted during the second and third stages of the coding process already. This assisted in capturing the comparisons and connections that were being made during the coding process, and also directed and focused any further data collection that was needed. *AtlasTi* was utilized for this memoing process, which allowed me to link my memos to certain segments of text and therefore certain codes, too. In this programme, memos can also be linked to other memos in order to form a graphic representation of commentary or thoughts that support each other across participants, which is called a *Network View*. Below is an example of one such memo.

MEMO: Unable to give a straight answer (1 Quotation) (Super, 2015-09-10 20:27:21)
P 6: Transcription Participant # 6.docx:
(235:239)
No codes
Linked memo: Difficulty concentrating
Type: Commentary

Similar to quite a few other participants, she really struggles to focus her attention to the question being asked. She doesn't finish her sentences (possibly racing thoughts?) and digresses immensely, to the point where I realised that I was feeling quite frustrated and bored, but obviously couldn't show it. The interview took much longer than expected because of this. I wonder how her doctors / psychiatrist / psychologist treat her if she is like this constantly and how this may impact the quality of the relationship and treatment she receives? Remember to explore this further with other participants too.

Theoretical sampling is the final step in the data analysis process, which is accompanied by *saturation* and then *sorting.* Theoretical sampling occurs at this point in the study for the first time and is different to the initial purposive sampling. The purpose of theoretical sampling here is to obtain data that will assist to explain in more detail the categories of information I had already developed (Charmaz, 2006). Thus, when the categories are "full", they reflect qualities of the participants' experiences and provide a useful means of understanding them (Charmaz, 2006: p. 100).

In this study, this final process of analysis was conducted by going back to the participants and asking follow-up questions, where necessary, to create fuller categories of data and fit the emergent theory with the data (Charmaz, 2006). This was achieved by telephonic follow-up with participants who had not all been asked the same questions (because of new categories of information and emergent ideas that became apparent as more and more interviews were conducted). This process continued until category saturation was achieved, that is, "when gathering fresh data no longer sparks new theoretical insights nor reveals new properties of the core theoretical categories" (Charmaz, 2006: p.113).

Finally, the data was sorted, which, in terms of grounded theory, occurs through theoretical integration of the categories of data created. Thus, sorting is the final step in the data analysis process and prompted a comparison of categories at an abstract level. At this point in time, I also diagrammed my memos and axial codes in *AtlasTi* using the *Newtork View* option, which further facilitated the sorting process until clear core and sub-categories were evident which was representative of the theory developed.

Ethical Considerations

Informed consent was obtained from all participants before interviewing commenced. The consent forms contained detailed information about the purpose of this study as well as the recording of the interview, the storage of the data collected, confirmation of anonymity and confidentiality, possible risks and benefits, and the right of the participant to pull out of the study at any point in time.

Participants were informed that all disclosures made by them will be kept strictly confidential between the participant and I, and that only I will have access to the data after the interview has ended. To ensure anonymity and protect the identities of the participants, they were each given a code number at the beginning of their interviews, and their personal names or identifying data were not used in any way during the research project that could breach this anonymity and confidentiality. Furthermore, data from the interviews were stored on my private laptop, in a password protected file that only I had access to. The data will be stored for a period of five years after completion of the interviews, after which it will be destroyed. However, voice recordings from the interviews were deleted immediately from my mobile phone after it was uploaded to my personal computer. Once transcribed, the voice recordings were deleted all together.

Participants were informed that they have the right to change their minds about their participation in the study, at any stage of the process, and that if they choose to withdraw from the study there will be no negative repercussions for them. I also discussed the minimal, yet possible risk of talking about painful memories regarding their diagnostic journey through mental illness, while I was explaining the consent form to them (before beginning any interviews). The participants were thus informed that they may stop the interview process at any stage if they feel that it is too painful or distressful to discuss any of these memories.

Finally, as part of the exclusion criteria, I stipulated in the research design phase already that participants who were admitted as in-patients at a psychiatric facility or hospital at the time of recruitment for this study, were *not* eligible to partake. This is based on the experience I have and subsequent assumption I made that admission to a psychiatric facility as an in-patient usually only takes place when a bipolar patient is emotionally unstable and in need of round-the-clock medical and psychological intervention and containment. Thus, interviewing patients during this treatment period could be seen as taking advantage of them while they are emotionally vulnerable, and was therefore not permitted as part of the recruitment eligibility criteria, for the protection and best interests of the patient.

A section entitled *Distress* was also added to the consent form that each participant was required to read and sign before commencement of any interviews. If either the participant or the researcher felt that the participant was becoming too distressed or too emotional during an interview, it was stipulated in this section that I would stop the interview immediately and assist the participant to make contact with the person they have chosen as their emergency contact person (this was asked of them at the beginning of the interview and they were required to provide the name and contact number of someone that I could contact in an emergency situation). It was explicitly stated that I would stay with the participant until their chosen emergency person arrived to assist them. If need be, I would take the participant to their chosen emergency person, if they were unable to come to the participant or needed urgent medical intervention.

Fortunately, however, the above-mentioned *Distress* clause did not need to be actioned during any of the interviews. Although some participants were emotional during certain parts of their interviews, this did not escalate to an emergency situation that needed intervention in any of the cases.

Finally, ethical approval for this study was granted by the Psychology Department

Research Ethics Committee at the University of Cape Town before commencement of any data collection.

Power, Reflexivity and Validity

Qualitative research, particularly when rooted within the social constructivist paradigm, requires a focus on issues of power and dominance. Furthermore, it requires the researcher to be aware of how power is reproduced or challenged during the research process (Parker, 2004). Those conducting research are often seen as well- educated, authoritative, omniscient experts on the subject of the study. These assumptions can influence what is shared by participants and therefore also the end result of the data analysis process. Thus, it is always important to bear in mind that the researcher's interpretation of the data is only one interpretation and that there may be several other equally valid interpretations thereof. As Creswell (2007) asserts, how we write is a reflection of our own interpretation based on the cultural, social, gender, class, and personal politics that we bring to research.

By employing a qualitative approach to this research study, I aimed to empower a group of people that might otherwise be seen as fairly disempowered by virtue of the traditional expert-amateur hierarchy set up in the clinical / psychiatric world (where clinicians are seen as 'experts' and patients are seen as 'amateurs' needing the help of these 'experts'). By doing this, I could be seen as challenging the traditional power dynamic of this context, in that the participants were seen as experts on the topic of BD and I saw myself as the amateur requiring their assistance to better understand the intricacies of this disorder and its trajectory.

Reflexivity is the process through which a researcher acknowledges his/her role in the research being conducted, as well as his/her personal reasons for doing the research (de la Harpe, 2010). I was therefore required to acknowledge my own subjectivity and the impossibility of being 'objective' or 'neutral' towards the research (Willig, 2001). My aim was therefore not to interfere or control the research, but rather to acknowledge the impact I might make on the process. In this case, it is particularly important to note that I was placed in a position of power by virtue of my status as a clinical psychology masters student (thus, by my affiliation to the 'expert' world of psychology) and also by many of the participants themselves who were aware of this socially constructed hierarchy and were willing to oblige to this dynamic. This was evident in the way some participants addressed me as "doctor" (which I am not), in the way they asked for my opinion on their prognosis or medical prescriptions, and even in the way some participants appeared to be looking for my approval by reiterating their compliance with instructions given to them by their treating clinicians, or by using complex medical / psychiatric terminological (such as "dissociative episode" or, when describing their medication, "I use Adco-Merterin as my antidepressant, which is a tri-cyclic medication, not an SSRI").

Thus, some participants positioned me as being different to them (in the examples mentioned above, this difference represented a sense of being 'better' or 'more powerful' than them), and some saw me as being similar to them (for example, one participant asked if I knew anyone with BD personally, and when I told them I do, their whole demeanour changed instantaneously). This participant made remarks like, "…so you know what it's like then to live with it, how hard it is, you understand". This indicated a sense of identification with me that I believe enhanced the interview process.

There were other ways, too, in which I was similar and different from the participants. I am a 30 year old white female, with several years' experience as a counsellor and psychometrist. I therefore have a tertiary level education, which is a privileged position to be in in South Africa, where the majority of the population cannot afford this.

Interviewing male participants as a female, especially a young female (all of the male participants were older than me), may have resulted in a different gender dynamic than if they had been interviewed by a male researcher. My age might also have influenced the power dynamic, as well as the amount of trust participants had in my ability. Speaking English as my first language, and therefore conducting the interviews in English too, may have influenced how the participants saw me and their ability to connect, trust and be completely open with me, especially for those who did not speak English as their home language.

On the other hand, all the participants knew I was a student at the University of Cape Town and they knew what I was studying, too. This may have instilled a sense of confidence in some participants, especially for those who asked me a bit about my background and thereby found out about my experience as a counsellor (which includes working with BD sufferers previously).

The influence of my experience on my data analysis was something I had to constantly be aware of and this was discussed at length with my supervisor throughout the research process in order to increase the validity of this study and follow best practice guidelines of qualitative research (Willig, 2001). Furthermore, my readings on qualitative research assisted me in realising that *I am* the research instrument in my study and that in order to minimise bias I needed to put myself "in a frame of mind appropriate to the naturalistic paradigm", rather than being detached in an attempt to be "objective" and mitigate this bias (Gavin, 2011, p. 246).

CHAPTER FOUR: RESEARCH FINDINGS AND DISCUSSION

Introduction

In attempting to assimilate, make sense of, and form a grounded theory from the information received from participants in this study, one thing unequivocally stood out throughout the analysis process, namely, just how different and complex each person's diagnostic journey has been. For this reason, it was often difficult to find trends or common threads amongst these cases, except perhaps for the pattern of difference.

What follows next is a description and discussion of the findings, which is split into three sections. These sections and the categories therein emerged from the coding process described in the methodology section above. Part one aims to draw the reader's attention to the complexity of these participants' histories and diagnostic journeys, while part two will discuss the factors that have arisen from these participants' accounts of their diagnostic journeys that can be seen to mitigate or complicate the diagnostic process. This section concludes in part three with a discussion of the 'outlying' results, which aims to highlight the many differences, contradictions and ambiguities in these findings.

Reflections on the interview process

Before introducing the results of the interviews with these participants, it is fitting to foreground this section with some personal observations and feelings that arose during the data collection process.

Firstly, the average time spent with each participant was far more than initially anticipated, which was a maximum of one hour with each person. Where the situation allowed for it, the interview continued well past the one hour mark, with the average being approximately 90 minutes, and some continuing even longer where this was possible. This is excluding the follow-up discussions that took place telephonically at a later stage with many of the participants, too. Even with such generous amounts of time spent with the participants, I often felt that time was rushed and that there was so much more to their stories that could be added to their timelines given the chance.

Thus, the complexity of these participants' experiences was pervasive throughout the interview process. This complexity manifested in many different ways. In some cases, participants struggled to piece together coherent memories. In these cases, the use of the diagnostic timeline (as an aid to remember and place life events in chronological order) was very useful. In other cases, journeys were punctuated with so many significant events or experiences that the time spent together during the interview seemed to only scratch the surface of some very complex life stories. In other instances, participants became very emotional when recalling difficult memories of past experiences, some successfully struggling to hold back their tears, and others not. This was another unexpected benefit of utilizing a written timeline during the interviews, as it often became a way for participants struggling with emotions to regain focus by writing on the timeline and continuing with the next significant event.

My personal experience was very different with each participant. Some participants were easy to talk to and seemed very comfortable during their interviews. Others were much more guarded and it was more difficult to elicit deep, reflective answers. In these cases, constant prompting was needed, which often felt arduous and frustrating. Some participants were tired during their interviews and yawned right through, which made me feel like I needed to rush to complete things with them, or that they were not particularly vested in the process. On the other hand, some participants were energetic and appeared to be really interested in this topic of research and how they could play a part in it. This affected the tempo and nature of the conversation. Some participants appeared to be overly medicated (one in particular was making repetitive involuntary movements by opening and closing her mouth when she was not talking) or suffering from side effects of medication (like drowsiness when interviews were held in the morning), which was both concerning and distracting.

Two participants in particular seemed to be going through depressive episodes at the time of their interviews, as demonstrated by their lethargic body language, slow speech, difficulty recalling events and experiences, tiredness, tearfulness, and overall low affect. Two other participants were the opposite and appeared to be manifesting symptoms of mania. These participants were extremely entertaining and our discussions with punctuated with constant laughter on both parts. Having said this however, these interviews were not easy at all. These participants needed constant assistance with writing on their timelines, and I had to constantly bring their attention back to the topic at hand. In some instances, it was difficult for me to even follow what was being said, which, although comical at times, was also frustrating and tiring.

Thus, the interview process was a journey in itself, one which allowed me a brief glimpse into the world of constant highs and lows, turmoil and muddle, laughter and sadness - all characteristic of this convoluted disorder, and all of which left me feeling completely exhausted at the end (which was, of course, just the beginning of a new process).

Part 1: The diagnostic journeys of participants

a. Work history

Of the 12 study participants, the majority were either working or studying at the time of their interviews, which is relevant considering the potentially crippling consequences of unmanaged BD - inability to work and earn a living being just one of them. Only four participants were not working or studying and had been placed on disability leave. When the reasons for this leave were discussed with them, all four participants cited reasons that could be seen as related to their BD diagnoses, either directly or indirectly. Two participants had been involved in accidents at work because of carelessness, impulsive decision making, aggressive behaviour or being under the influence of alcohol while on duty, while the other two were placed on leave because of poor work performance, constant absenteeism and ultimately an inability to perform their duties any longer as their respective jobs required of them.

Although the number of participants not working or studying is fairly low as a percentage of the total number of participants, the concerning aspect here was the age of these four participants: two were only 27 years old, the third was 31years old, and the oldest of this group was just 55 years old (See *Table 1*, Participants 7, 8, 10, and 12). Furthermore, when looking at other relevant demographic information of these four participants, the reason for concern becomes more apparent: all four participants completed their formal academic schooling up to grade 12 and two have tertiary qualifications - one participant (age 27) has a Bachelor of Commerce degree and was previously working for a multi-national investments firm before being placed on disability leave indefinitely; the second participant (age 55) has three university degrees in Law, Theology and Forensic Auditing and has not been able to work since 1992 (when he would have been only 41 years old).

Furthermore, a retrospective look at the employment histories of all 12 participants revealed a very complicated clinical picture. Some participants had been able to hold down jobs for long periods of time, despite having gone through various manic or depressive episodes. Some were not able to do this though, as mentioned earlier. Participant 11 identified a period of great instability in his diagnostic timeline where he left several jobs impulsively, resigning “on the spot” because he felt he deserved better, or that he could do better if he worked for himself. Unfortunately, he realised every time that his “creative schemes” were not going to get him where he imagined he would be after resigning to start his own business, and was forced to go back “cap in hand” or look for new employment and start from scratch all over again, time after time:

> *Or I'd think, "You know what, I'm better than this” (laughs). And then I would, then I would get up and I'd just leave. "I'm not coming back. You phone me once you've discovered I'm better than this place". But I think they don't, they don't do that (laughs). And then I was home for like a year, just over a year, and then I started all from the bottom again, at some other… It was a very humbling experience…Cause you have, like, (sighs)...a good job, with all those things, then all of a sudden you just get a ... (sighs)...I don't know, you just get up and leave. Just like that. People look at you so (pulls face with big eyes)… so you've got to start all from the bottom again.*
>
> *Participant 11*

Some participants mentioned walking out of jobs, or leaving their studies, because they felt too stressed or pressurized. Some did not do this despite feeling stressed. This leads to another question: what makes this different from one patient to the next? One possible answer to this question might be found in the link between these participants’ descriptions of their work or student lives with an overall sense of purpose in life. When they spoke about their work or student lives, it became clear that many had found a constructive way of mitigating their symptoms to a large degree by focussing their energy and efforts on their work. Not only did this help to quell the inner turmoil taking place in their minds, but it also provided a greater sense of belonging and purpose:

> *Interviewer: So in terms of your anxiety, I would imagine that you were quite distant from people as well? Social settings were not appealing to you, I would imagine?*
>
> *Participant: Ja, right, absolutely! But I was at college and I got, I went to college every day, and I had my assignments to write, and that was my focus. Just get the assignments done and hand it in on time. That was my purpose.*
>
> *Participant 4*

While some participants found it more difficult to function during manic episodes as a result of their racing thoughts, impulsivity, tendency to get bored very quickly and easily, and attentional difficulties, others found it much more difficult during depressive episodes. However, many of them recalled how their work actually kept them going during these trying times:

> *Again, I found it difficult to interact with people, I found it difficult to be in social situations, I found it difficult to just…(sighs)…function (starts to get tears in her eyes). It was a struggle, but, it was a reason to keep going (wipes away tears).*
>
> *Participant 3*

A few other participants mentioned that, contrary to what might be expected, university was a good time in their lives as it kept their minds occupied:

> *Interviewer: So what happened after university?*
>
> *Participant: Oh that's when I lost the plot! After university (laughs). 'Cause I didn't have anything to do, I mean, I started working but then I now had money and my mind wasn't occupied, you see? So I think that's where things went wrong for me…'Cause I had all this free time and with my money I could buy cars, I could get myself into debt, all these things. But that doesn't happen when I'm studying for some reason. That's why I said I wanted to start studying again, you see?*
>
> *Participant 11*

In most of the literature published on this topic, patients with BD are cautioned against taking on anything that could cause stress in their lives, which in many cases includes possible work-related stress, as this has been strongly associated with worsening of symptoms in BD patients (Post & Leverich, 2006). However, these findings indicate that this is not always the case, and that working or studying can possibly mitigate some of the symptoms of BD (such as racing thoughts, increased anxiety levels and symptoms associated with a depressive episode) by providing a sense of purpose which might otherwise be lacking. Thus, these results highlight just how diverse the work trajectories of these participants were and how differently they dealt with work-related stress, for example.

Table 1: Participant Demographic Information (Participants 1 to 6)

	P.01	**P.02**	**P.03**	**P.04**	**P.05**	**P.06**
Current age	33yrs	42yrs	20yrs	28yrs	26yrs	33yrs
Gender	Female	Female	Female	Female	Female	Female
Race	White	White	White	White	White	White
Current work / study situation	Childrens' youth pastor at church	Sales consultant at car company	Studying drama; working part-time as promoter	Aftercare supervisor at a preschool (recently dismissed from teaching role because of incapacity / poor work performance)	Part-time work at university in Information Dept; Volunteers at two NPOs	Working part-time in restaurant, looking for ful-time employment
Highest level of education	Bachelor of Theology Degree	Management Diploma & Paramedics Diploma	Matric (currently studying Performing Arts)	Post-graduate Certificate in Education	Honours In Social Anthropology	Honours In Politics (currently completing Masters)
Current relationship status / maritial status	Single	Single	Single	Single	Engaged	Single
Position in family	Eldest of 2 by 5 yrs (younger half brother)	Third of 4 girls (current ages 46,44,42 & 40)	Eldest of 2 girls (younger sister 17yrs)	Second of 2 (older brother 29yrs)	Eldest of 3 (sister 14mo younger; brother 4yrs younger)	Eldest of 2 (brother is 23yrs)
Type of Bipolar	Bipolar 2 (although mentions "cycling" regularly)	Bipolar 1	Doesn't know (and never asked)	Bipolar 2	Bipolar 2	Bipolar 2

Table 1 continued: (Participants 7 to 12)

	P.07	**P.08**	**P.09**	**P.10**	**P.11**	**P.12**
Current age	31yrs	27yrs	27yrs	55yrs	39yrs	27yrs
Gender	Male	Female	Female	Male	Male	Female
Race	Coloured	Coloured	White	White	Coloured	Black
Current work / study situation	Senior technical operator (currently on Temp. Disability leave indefinitely for Injury On Duty)	Not currently working - gets disability grant.	Teaches English online to foreigners part-time	Unemployed, living in homeless shelter. Hasn't worked since 1992.	Sales and Marketing Manager at meat manufacturing company	Customer Service Dept. at investments company (currently on Temp. Disability leave indefinitely)
Highest level of education	Dropped out in grade 11, completed grade 12 part-time later on while working	Matric (home schooled from grade 9 for religious reasons, finished at age 21)	Matric (incomplete teaching degree)	Masters degree (LLM) LLB; Forensic Auditing degree; Bachelor of Theology degree	B.Com & incomplete LLB (currently studying part-time to complete LLB)	B.Com Economics
Current relationship status / maritial status	Single	Single	Single	Divorced twice, currently single	Married (3yrs)	Single
Position in family	4th of 6 (3 brothers, 2 sisters)	Eldest of 2 (brother is 24yrs)	Eldest of 4 (twin brothers 24yrs, sister 21yrs)	Eldest of 3 (younger brother & sister - brother deceased)	Eldest of 3 (younger sister & brother)	Youngest of 6 (3 older brothers - 1 adopted, 1 deceased, 2 sisters)
Type of Bipolar	Bipolar 2	Bipolar 1	Bipolar 2	Not mentioned (still refers to Manic Depression)	Bipolar 2	Bipolar 1

b. Relationships

The results of this section speak strongly to the feelings of loneliness, social isolation, and also the interpersonal difficulties often experienced by people living with BD (Jaeger and Vieta, 2007; Murray and Lopez, 1996). As Table 1 demonstrates, the majority of participants in this study were single. More specifically, 9 of the 12 participants had never been married and were not in a romantic relationship with anyone at the time of their interviews. One participant had been married twice before, was divorced twice, and was also not in a romantic relationship at the time of the interview. Thus, in total, 10 participants were single.

This is a notably high number considering that this was a group of adult participants, all over the age of 18 (the youngest being 20 years old). Only one participant was engaged to be married and one had been married for three years already. According to the literature on this topic, people with BD have few social interactions and smaller social networks than healthy comparison subjects (Bauwens, Pardoen, Staner, Dramaix & Mendlewicz, 1998; Depp, Mausbach, Harrey, Bowie, Wolyniec, Thirnquist, Luke, McGrath, Pulver & Patterson, 2010). Furthermore, people with BD are less likely to get married, or sustain romantic relationships, than the average population (Judd & Akiskal, 2003; Depp et. al., 2010).

Unfortunately, due to time constraints in the interviews with these participants, the topic of interpersonal difficulty was not focussed on. Although relationship status was gathered as part of the demographic questions asked to participants, it was not elaborated on or explored in more depth for the purpose of this thesis. However, it does appear at surface level that this sample of BD patients is not very different from the reported norm with regards to interpersonal and relationship difficulties. Thus, this is something that should be explored in further research on this topic.

c. Diagnostic delay

Diagnostic delay (sometimes also called treatment delay) refers to the time period between initial onset of symptoms and the actual diagnosis of BD and subsequent treatment with mood stabilizers (Oyffe et. al., 2014). Research is divided primarily into two bodies of literature that report very different statistics regarding the prevalence of BD. One body suggests that approximately 0.5 to 2% of the general population have BD, while the other body believes this number to be much higher, between 5 and 7% (Fajutrau, Locklear, Priaulx & Heyes, 2009; Pini, de Queirez, Pagnin, Pezawas, Angst, Cassano & Wittchen, 2005; Dunner, 2003; Bruchmuller & Meyer, 2009; Singh & Rajput, 2006). This major disparity is commonly cited as being the result of high rates of misdiagnosis of BD and subsequent treatment delays, which range on average between six to 10 years, or even longer, for most patients (Oyffe et. al., 2014; Ghaemi et. al., 1999; Ghaemi et. al., 2000; Suppes et. al., 2001; Birnhaum et. al., 2003; Wang et. al., 2005).

In this study, diagnostic delay varied greatly from participant to participant, the shortest delay being three years and the longest being 47 years. It is important to note here however, that these results more accurately depicted two different concepts. The first concept is the same as the above-mentioned diagnostic or treatment delay. The second concept to emerge was the delay between the time participants first sought help from medical professionals / clinicians for their symptoms, and their eventual BD diagnosis. A distinction between these two concepts renders very different findings when considering diagnostic delays and is something that is not typically distinguished between in other research on this topic. *Table 2* below provides a summary of the diagnostic delays for these participants, and also distinguishes between the traditional understanding thereof and the second concept uncovered in this study. Those who indicated that they sought help immediately after the onset of their symptoms will only have one time period indicated for them in the table below.

Table 2: Diagnostic delays

	P.01	**P.02**	**P.03**	**P.04**	**P.05**	**P.06**
Time btwn 1st recollection of problem & BD diagnosis	3.5 / 4 yrs	36yrs (although first sought help from GP +-3yrs ago, so more accurately 3yrs)	3 years	24yrs (although first sought help from GP 5yrs ago, so more accurately 5yrs)	7 years	17yrs (although long period with no symtoms in adolecence - 9yrs since first sought help from psychologist)
	P.07	**P.08**	**P.09**	**P.10**	**P.11**	**P.12**
Time btwn 1st recollection of problem & BD diagnosis	23yrs (although 1st saw psychologist 3yrs ago & was diagnosed 3 months later with BD. So more accurately 3 months)	5 years	20yrs (although 1st saw psychologist 13 years ago, so more accurately 14yrs)	47yrs (was diagnosed with manic-depression at age 5, but was only treated with medication at age 51 for the 1st time)	Approximately 39yrs. (Although 1st got help at age 32, diagnosed with BD at 36, so 4yrs of treatment before BD diagnosis)	12 years

Many participants stated insightfully that they would not have been able to identify their BD symptoms at the time of onset, and that the knowledge they have acquired since then has enabled them to look back, in retrospect, and identify these symptoms.

> *Well it's an interesting question because, um, it's got two aspects to it. There's, there's the time when I definitely remembered, that I remember that, um, in a context that, there's definitely something wrong, but there's also, with this whole journey, as such, times before then where I realised, if I look back on it that things weren't quite right. So, um, the typical sort of story of someone who receives a diagnosis and then looks back and says "Oh" and they can pin point that and that and that.*
>
> *Participant 5*

This supports most other research findings investigating the reasons for diagnostic delays, specifically that patients do not often view their behaviour as problematic at the time of onset or manifestation, especially manic or hypomanic symptoms (Bowden, 2001; Singh & Rajput, 2006; Keck et. al., 2008; Bruchmuller & Meyer, 2008; Oyffe et. al., 2014).

Therefore, some participants were able to identify in retrospect specific instances where they were experiencing symptoms of BD, and interestingly, others were not able to do this, even in retrospect after years of living with their BD diagnoses. Those participants who could not pinpoint when they first starting thinking or feeling like something was ‘wrong’ all had a similar reason for this difficulty: they described themselves as feeling ‘normal’ most of their lives, up until a major crisis, crash, or episode happened which prompted or forced them to seek professional help. Thus, some participants were able to recall specifically when their symptoms first started to manifest as a function of their psychoeducation and knowledge acquired over time, while others struggled with this as they did not feel that their behaviour was symptomatic, per se, but rather a part of their personalities and characters. For example:

> *Interviewer: ... can [you] remember when you first felt or you first thought that something wasn't right. That something was wrong?*
>
> *Participant: Okay that's a tough one because for me I was always right (laughs). So, you know for me you don't think of yourself as ... (silence)... you know? I feel normal. You feel fantastic most of the time.*
>
> *Interviewer: So at what point in time did you start to think, “This isn’t normal” then?*

> *Participant: People would tell me that some of the stuff you did just doesn't make sense. But you don't see it as not making sense 'cause everybody else is talking, you know? I feel normal, this is just me, what are you talking about?*
>
> *Participant 12*

Thus, even in hindsight, some participants struggled to identify their symptoms (which were seen by others as problematic) with a mental illness or disorder, because they themselves were still not convinced that these "symptoms" were "problems". This may, in part, be related to their feelings about mental illness and specifically BD, which will be discussed at a later stage in more detail. It may also be related to the type of symptoms experienced more regularly. As mentioned already, it is likely that manic symptoms (and especially hypomanic symptoms) are less likely to be seen as problematic than depressive symptoms (Bowden, 2001; Singh & Rajput, 2006; Keck et. al., 2008; Bruchmuller & Meyer, 2008).

One other interesting detail to emerge from the analysis of this specific topic was that very often, those who struggled to pinpoint when their problems began were most often those who had been diagnosed with Bipolar 1, whereas those who were more easily able to connect the dots in hindsight were diagnosed with Bipolar 2. In turning to the literature related to this finding, many authors state that patients who suffer from Bipolar 2 (and therefore hypomania) are inclined to spend more time in depressive episodes than in hypomanic ones (Benazzi, 2008; Katzow et. al., 2003; Bowden, 2003). Also, hypomanic symptoms are not punctuated with the extreme highs and energy levels of full blown mania. Thus, it is not surprising that those suffering from Bipolar 2 could recall their symptoms and past episodes more readily than those who suffer from Bipolar I.

Furthermore, many participants mentioned that in the time preceding their BD diagnoses, they were not often able to identify their symptoms themselves, but others close to them, such as family members, could. When asked what was said to them by these people, most admitted that they didn't say anything to them directly, but rather spoke amongst themselves about what they perceived to be problematic behaviour. The exception here was when the participants were still in childhood and their parents took them to doctors, psychiatrists or psychologists because they could clearly see that their child was struggling. However, as adults, the consensus seemed to be that family, friends and colleagues who noticed problematic behaviour tended to keep it to themselves. When the participants were asked how they came to know about this, they said that when they shared their BD diagnoses with these people later on after being diagnosed, there was very little shock, confusion or questioning that took place, which prompted a discussion between the parties about this.

> *Participant: Um, but uh, one of the things I was quite surprised about was my sisters saying that they knew there was two of me… For a very long time. And that I actually felt a bit upset about that cause I felt, "Why didn't somebody say something or do something". You know? Because I didn't realise it.*
>
> *Interviewer: And did you ask them that?*
>
> *Participant: Ja I did…they [said they] just accepted that that was me.*
>
> *Participant 2*

d. Hospitalization for mental illness

This component of the interview was designed to ascertain the severity of each participant's diagnostic journey, as indicated by their need for hospitalization (which includes treatment in private psychiatric clinics, too). It also aimed to ascertain, from the participants' perspectives, whether admission was the result of BD directly or indirectly, or something else (related or unrelated). Previous research has indicated that the risk of suicide for BD sufferers is as much as 20 times higher than that of the general population, which translates into a significantly high risk of mortality (Keck et al., 2008). Furthermore, relapse rates are reported to be as high as 90%, impacting negatively on patients' lives and often requiring hospitalization for acute treatment (Matza et. al., 2005).

Taking this into account, it was no surprise that the results of this study indicated almost this entire sample as having needed hospitalization at some point in time as a consequence of their BD. A total of 11 out of the 12 participants were admitted to hospitals or clinics for a time period that ranged between two weeks and four months. Furthermore, 10 of these 11 participants needed frequent admission during periods when their BD was not well managed or a change in medication was required. Admission was often the result of undiagnosed BD (many of the participants were first diagnosed with BD while in hospital) or relapses culminating from stopping or inaccurate usage of psychiatric medication (which includes suicide attempts), according to their own accounts.

Some participants needed regular admission, as much as two or three times per year for several years in a row, which is certainly a concerning finding. When questioned in more detail about the events leading up to these admissions (and inadvertently the reasons why such frequent admission was necessary) it became clear that suicidal ideation or actual attempts were common occurrences for these participants. This was the result of several factors including manic, depressive, and psychotic episodes. Moreover, managing these episodes optimally seems to have been a very difficult task for the treating clinicians in these cases. Often, participants complained about feeling like ‘guinea pigs’ as their doctor(s) chopped and changed their medication in attempts to find the right dosage and prescription for them. As a result, participants frequently gave up, either on their medication and its ability to help them, or on their doctor’s ability to help them:

> *Um…and there’s times when I feel like I can just stop taking, something, one of the things, cause I feel like, “I don’t need this”. And then in two weeks’ time I feel like, “Okay, wait a minute, you do need this”. And then I take it. So I’m not, I’m not going to lie and say I take it religiously…it’s a bit of a…a hop and a skip thing, you know?*
>
> *Participant 2*

> *My, my mom has always been, totally, just, “this medication's not, not right”. 'Cause it's just been building, building, building... I mean I was on, the most I was on was about 10 anti-depressants at a time, and it's just not... (shakes head)... It wasn't working, it's still not, to this day. I mean, we don't quite know what's happening and my doctors, I'd see the looks on their faces, they're confused, (laughs), it scares me that, you know, the professionals are still, kind of, figuring me out.*
>
> *Participant 3*

Side effects were also frequently cited as the reason for stopping medication, which inevitably led to an episode, as mentioned above.

Lastly, three of the participants had been hospitalized as a direct result of damage caused by self-harming behaviours (all three cases were females who had cut themselves with blades and needed stitches and/or emergency surgery). It is important to note that more participants admitted to self-harm behaviours, but only three actually needed to be hospitalized. This most likely complicated the clinical picture further for the professionals treating these participants. Given the prominence of dual diagnosis in the literature, only one participant admitted to having a dual diagnosis of BD and Borderline Personality Disorder (BPD). The presence of co-morbidities and/or symptoms of BPD (as a co-morbid disorder to BD or on their own) have been known to cause particular diagnostic difficulties for clinicians (Paris et. al., 2007; Kuiper et. al., 2013). Specifically, the overlap in symptoms such as impulsivity, aggression, and emotional lability can cause diagnostic confusion if they are not understood contextually and a thorough diagnostic history is not taken (Henry et. al., 2001).Furthermore, the literature on the prevalence of misdiagnosis of BD proposes that BPD is often misdiagnosed as BD because of these overlapping symptoms (Henry et. al., 2001; Paris et. al., 2007; Benazzi, 2008; Ruggero, 2009; Barroilhet et. al., 2013; Ghaemi et. al., 2014; Paris & Black, 2015). Thus, it is possible that more participants in this study meet the criteria for BPD, although this is purely speculation and is not possible to know for sure without interviewing their treating clinicians, too.

e. Diagnoses before Bipolar Disorder

The findings of this section will echo what the literature and previous research studies have found regarding common reasons for misdiagnosis of BD. This is both reassuring and worrying simultaneously: reassuring because previous research findings have been confirmed once again, which should make solving these issues easier, and worrying because, despite the fact that this knowledge has been available and addressed internationally in clinical circles for years already, very little seems to have changed, or at least not in this context of this population.

Consistent with the literature on the misdiagnosis of BD, nine of the 12 participants in this study were diagnosed with some form of unipolar depression before being diagnosed with BD. A plethora of studies have been conducted on this topic, all with similar findings that approximately 60% of BD sufferers are first diagnosed with unipolar depression (Ghaemi et. al., 2000; Hirschfeld et. al., 2003 & 2005). Furthermore, these diagnoses were followed by prescriptions of anti-depressant medication in all nine instances, which is known to be associated with high risks of manic switching, or worsening of symptoms, in bipolar patients (Singh & Rajput, 2006; Bowden, 2005; Chun & Dunner, 2004). As expected, the participants in this study also reported similar experiences when taking this medication: either no effect at all, in which case most participants said they went back to their treating clinician to complain about the medication not helping; worsening of symptoms, particularly suicidal ideation; and in a few cases, increased or induced manic symptoms:

> *He put me on um, SSRI's which I took for a while and that but uh, there was a lot of times when I just, I didn't remember things. I'd do things and I'd have no recollection…I know that when I did start with the medication that he gave me I just started sort of acting in a bizarre way. And um, I'd do things and I'd like sleep walk, I'd open a bottle of wine I'd have 2 glasses of wine and I'd go back to bed and I'd wake up in the morning with the front door open and I'd think, "Well who was here?" And there'd be nobody that was here, it was just me. And I had no recollection of things like that. Um…[so] I did phone the GP. And I said that I had, um, amnesia and stuff like that, I can't remember things. And then he said, "Okay, increase your dosage", which I did. Um…and then it just, I just got worse… I started becoming a bit, out of control.*
>
> *Participant 2*

> *And I kept telling the doctor, "I'm depressed, I'm depressed, I'm depressed" ... but he didn't listen to me when I kept saying, "I'm depressed" and I got so depressed that literally I didn't want to live anymore. I was, I was, and a lot of my manic episodes there was one specific manic episode that I spent obsessing about this cause I wanted to sue him for 50 million cause he ruined my life, you know? So ja, I jumped off the bridge… I broke, I burst two vertebrae in my back so I had a back operation. I was in the hospital for 4 months.*
>
> *Participant 8*

Secondly, these participants received a myriad of other diagnoses too before they were diagnosed with BD. Two participants were diagnosed with anxiety disorders occurring co-morbidly with their depression, which is not an uncommon clinical presentation (Matza et. al., 2005; Manning, 2015). As a result, they were given anti-anxiety medication together with anti-depressants. Other diagnoses that occurred before BD include Post Traumatic Stress Disorder, Attention Deficit Disorder, and Schizophrenia.

Interestingly, only one of the participants mentioned BPD as a diagnosis that was considered (and in her case, accepted as a dual diagnosis with BD). This may be because it wasn't actually considered as an option by the clinicians treating these participants, or because the participants didn’t want to mention this in their interviews because of the stigma so often attached to personality disorders in general and BPD specifically (Corrigan, 2004; Aviram, Brodsky & Stanley, 2006). However, this is purely speculation and without having interviewed the clinicians too, it is impossible to say for sure.

Nevertheless, this was an interesting occurrence because many of the participants mentioned experiencing symptoms or problems that would have fulfilled, at least in part if not entirely, a diagnosis of BPD too (such as impulsive self-harming behaviours when emotionally distressed, as well as mood swings that occur several times daily). An example of this can be seen in Participant 9’s account of her manic episodes, a necessary prerequisite and distinct differentiator between BD and personality disorders:

> *I think, um, just like I said, it's not a really dangerous time for me. It's more of a...I get super focussed, super energized. But it has to be done now, it has to be done my way. And it can't be any other way cause any other way is wrong and it has to be my way. And uh... Ja. It's usually just a couple of hours…[and then] I go back to being numb and neutral. And sometimes, small bouts of depression here and there… My mom says my mood would fluctuate but mainly during the day. It wasn't like an extended period of so many months I'm happy, so many days I'm happy, so many...it was more a case of so many hours and then it would go down and then it would be up and then I would, apparently, be all bouncy again, and then it would go down again.*
>
> *Participant 9*

This same participant also had frequent suicide attempts by cutting herself in various places on her body, and has been hospitalized every year since early adolescence up until last year as a result. She has seen a plethora of psychologists and psychiatrists over the years and had been diagnosed with unipolar depression, anxiety, and even Schizophrenia before receiving her bipolar diagnosis. Thus, it was interesting to hear that this participant’s psychiatrist decided on a diagnosis of BD as opposed to BPD, especially considering that this diagnosis was made in her first consultation with him (see *Appendices E and F).* This begs the question, what *else* did he/she see that this participant did not, or still to this day cannot see (as per her account of her diagnostic journey, which seems to be more inclined to a BPD diagnosis than BD)? Or, conversely, are we seeing something different to what he/she saw in his first consultation with her, perhaps because of the comprehensive timeline developed together during the interview?

Table 3: Diagnoses received before Bipolar Disorder

	P.01	**P.02**	**P.03**	**P.04**	**P.05**	**P.06**
Diagnoses before Bipolar Disorder	MDD (by GP) ; MDD & GAD (by Psychiatrist). Both prescribed SSRIs. Psychiatrist changed SSRI & gave higher dosage. Prescribed anxeity meds too.	Depression (GP). Prescribed SSRI. Doubled prescription when it wasn't working. Eventually referred her to psychiatrist when he saw cuts on her neck.	MDD (Psychiatrist). Prescribed several SSRIs in search of the "right one".	Depression (Psychologist and GP and psychiatrist, both the latter prescribed SSRI's), PTSD, ADD (Neuropsychologist), Social Phobia. Prescribed SSRIs and anxiety meds.	Depression (GP's x2 - once in school, once years later in university). Both prescribed SSRIs to "help her through this tough time".	Depression (GP, several psychologists and psychiatrist). Prescribed SSRIs by GP and different one later by psychiatrist.
	P.07	**P.08**	**P.09**	**P.10**	**P.11**	**P.12**
Diagnoses before Bipolar Disorder	PTSD (psychologist) but suspected possible Bipolar Disorder & referred him immedicately to psychiatrist.	None mentioned	Depression & anxiety (several psychologists); Schizophrenia (psychologists & psychiatrists at Valkenberg). First given SSRI, then later changed to atypical antipsychotic, which she said "did nothing".	None mentioned.	Depression (Psychologist at FAMSA)	Depression (GP's x2, once in adolescence and once in early twenties). Both prescribed SSRIs.

f. Help seeking behaviour

One of the core codes that emerged from the analysis of the timelines constructed with these participants during their interviews was that of help-seeking behaviour. With this in mind, a closer look at which clinicians these participants decided to seek help from first when they decided to seek assistance for their difficulties was necessary. The findings show that these participants sought help from either their local GPs, psychologists, or psychiatrists first. Specific experiences for each participant are summarized in *Table 4* below, where it will show that the majority of participants visited their GP first (six participants in total), followed by five who chose to go straight to a psychologist, and only one who saw a psychiatrist first (which was the result of a psychotic break that landed him in hospital. Thus, this was not really his choice).

Table 4: Help-seeking behaviour

	P.01	**P.02**	**P.03**	**P.04**	**P.05**	**P.06**
First professional consulted and outcome thereof	GP diagnosed Depression & presecribed SSRI	GP diagnosed Depression & prescibed SSRI	Psychologist. Didn't diagnose anything but referred her to psychiatrist after a few sessions.	GP , who referred to psychologist immediately - no medication given.	GP, did blood tests and physical checkup, found nothing. Prescribed SSRI and recommended psychologist, but didn't give official diagnosis.	Psychologist. No diagnosis. A few therapy sessions.
	P.07	**P.08**	**P.09**	**P.10**	**P.11**	**P.12**
First professional consulted and outcome thereof	Psychologist on duty in hospital when he was admitted for accident at work (asked to come by plastic surgeon). Suspcted either PTSD or Bipolar, referred to psychiatrist.	GP - gave her injection to "relax her" (calm her down probably). Had bad side effects, mom took her to clinic where psychiatrist saw her.	Psychologist at age 11 . She refused to talk to psychologist, therapy didn't last very long. Teacher thought she was depressed but psychologist thought she was just anti-social & uncommunicative.	Psychologist at age 5 at WITS (where his mom worked). Diagnosed with manic-depression.	Psychiatrists at Groote Schuur hospital for psychotic break. No diagnosis. No medication given when he was discharged 2 weeks later. Prompted him to seek help privately from psychologist.	GP at age 16 - diagnosed depression and presecribed SSRI.

It is important to note here that the majority of the participants in this study chose to seek help from their local GPs first. This means that GPs continue to serve a very important role in treating mental illness within South African communities, particularly middle to low income earning ones where the average person does not have private medical insurance and cannot afford to go straight to private psychological or psychiatric care facilities. Having said this however, when comparing the diagnostic timelines of participants who first sought help from their GPs versus those who first visited psychologists, there did not appear to be a clear advantage in terms of shorter diagnostic times for those who visited psychologists first. This was contrary to what I expected to find, partly because of the literature published on the increased risk of BD being missed by doctors who are not properly (or specifically) trained to investigate symptoms of depression further when diagnosing this in patients (Keck et. al., 2008; Mitchell et. al., 2010; Daigneault et. al., 2014).

These responses spoke very strongly to the general sense of unhappiness with medical treatment received by the participants. However, this was once again not unique to the participants who chose GPs as their first port of call for psychiatric intervention. Rather, this was a common complaint across the board, and will be discussed in more detail later.

> *I think, I have a personal opinion about this. I know other people might not agree, but I believe that people shouldn't go to a doctor. A GP shouldn't be the one handing*

> *out anti-depressants. That they should know better, to send someone like that to a psychiatrist. Umm...ja.*

Participant 1

> *Ja. I felt particularly angry, but only later, with the 2007 situation, I was given antidepressants by the GP. I don't know, like, I just felt like this was the biggest, this was really key. And it was a, and I don't know why, I don't know if it was, like my behaviour was so strange. I was cutting, and I had a G, this GP I'd been seeing for, like a good year and a half, because I was sick frequently. He knew me, and I just felt like I was another sort of, like there was not enough concentration on what was going on? I don't know.*

Participant 6

Furthermore, the outcome of these participants' first consultations yielded interesting information about the clinicians treating mental illness on a daily basis, as well as the process typically followed by them. In the majority of cases where participants chose to visit their GP first, a diagnosis of depression was made and prescription of anti-depressant medication was given. In these cases, none of the GPs made referrals for further psychiatric evaluation or psychological support. Thus, their depressive symptoms were treated in a purely medical manner, which does seem to be a cause for concern given the psychological nature of mental illness (including mood disorders such as depression), and once again, the potential for misdiagnosis because of lack of differentiation between symptoms of unipolar and bipolar depression (Bowden 2001 & 2005; Singh & Rajput, 2006; Hantouche & Akiskal, 2005).

Two GPs did not make a diagnosis: one of them gave the patient an injection to help "calm her down", but no further referrals were made after this. This participant then experienced bad side effects and was taken by her concerned mother to a clinic where she was seen by a psychiatrist for the first time:

> *…and some [3]IDIOT doctor that my mom took me to, took me to BEFORE she took me to a psychiatrist, he gave me an injection that's supposed to calm me, but I think it was Valium now that I'm thinking back, because, when I was admitted to [4]De Tijger*

---

[3] The bold words in this quotation indicate emphasis as spoken by the participant.

[4] De Tijger is a private psychiatric clinic in Cape Town.

> *the nurses were very upset cause my eyes were going like this (demonstrates eyes rolling back in her head).*

Participant 8

Only one GP out of six made a referral to a psychologist immediately without prescribing any medication. In this case, the participant did not have a long-standing relationship with the doctor which could be seen to aid the diagnostic process. She booked an appointment to see a GP because of trouble she'd been having with mouth sores that weren't recovering naturally. Furthermore, she had also lost a lot of weight, and lost her appetite too. After discussing her concerns with the GP, the participant divulged a recent armed robbery incident that she'd been involved in where she was attacked at knife point by a group of men. The GP subsequently referred her to a psychologist:

> *And she said that actually, she didn't think that there was anything physically wrong. Had anything stressful happened to me recently? And I said, "Well actually, there was this thing with these guys and some knives, and whatever." And she said, she referred me to the clinical psychologist.*

Participant 4

Of the five participants who consulted a psychologist first, only one made a diagnosis, which was Manic Depression (this was in the 1960's when the participant was five years old). This participant continued to see this psychologist for therapy for several years until the psychologist moved away and he didn't see anyone else after that. He described his relationship with this psychologist and the subsequent treatment that he received from him as helping him immensely through his childhood and teenage years:

> *I would go see him and we used to look at a lot of pictures, do a lot of fun things, talk a lot, and it was a real release. So the psychotherapy was an absolute total release for me.*

Participant 10

The other four psychologists didn't make any diagnoses, even after seeing the participants for several sessions. However, two of these psychologists did recommend that the participant see a psychiatrist and referred them to possible options. This likely means that they judged the participants' symptoms to be serious enough to warrant further investigation and/or medical intervention too. Although this certainly demonstrates responsible clinical practice in acting in the best interests of the patient, it is interesting that, according to the participants, none of these psychologists made a diagnosis themselves. This appears to be seen as the role of psychiatrists. Although there is evidence that shows that different theoretical orientations of psychologists can influence the diagnostic and treatment process of the clients they see, the above-mentioned finding is interesting because, according to the Health Professions Council of South Africa (HPCSA), it is within the scope of practice of clinical psychologists to identify, diagnose, and apply interventions to people with psychological and psychiatric conditions (HPCSA, 1998; Meyer et. al., 2004).

In analysing these participants' help seeking behaviours further, the reasons given by the participants for seeking help in the first place were also focussed on, which included why they saw who they saw. These results yielded very interesting information about help-seeking patterns of behaviour that could be helpful for clinicians to be aware of in the future.

Firstly, eight out of the 12 participants sought help because significant others, family members or friends had recognised symptoms displayed by them that were cause for concern, and subsequently recommended that they seek professional help. Thus, the majority of participants either chose to discuss the problems they were facing with someone close to them first before seeing a professional, or vice versa in that others close to the participants confronted them, or took action, regarding their concerns. In seven out of the eight cases, concerned parents took the participants for help, most often because they were still minors at that stage (which speaks to the age of onset of symptoms, which was in childhood already for almost all the participants).

Of the above-mentioned eight participants, four went to see GPs first (three were taken by their parents because they were still minors and one took herself as an adult after discussing her symptoms with two different friends who both recognised signs of depression and convinced her to see her doctor). Furthermore, three participants went to see psychologists first (all three were taken by their parents) and one saw a team of psychiatrists at a public hospital when he was taken there by his concerned family during his first psychotic episode.

Thus, it is clear from these findings that family members, and significant others including friends, played a vital role in the start of the diagnostic and treatment processes for these participants. This emphasizes the valuable information that clinicians could have access to as collateral information during the diagnostic process in order to add to the information received from the patient and form a richer, more comprehensive understanding of the clinical picture (Bowden, 2001; Matza et. al., 2005; Mitchell et. al., 2010). It should also be emphasized, however, that collateral information *could* be helpful to this process, but it could also end up being a double-edged sword as outsiders unintentionally mislead the clinician, making an already complex process even more complicated.

The second important finding with regards to patterns of help-seeking behaviour was that three participants sought help first for physical problems they were experiencing. More specifically, the first participant went to see her GP because she thought she had a bladder infection. After doing the necessary tests, the doctor concluded that there was nothing wrong with her physically and subsequently starting asking her questions about her mental health (which resulted in him diagnosing her with depression and prescribing anti-depressant medication). The second participant presented at her GP with mouth sores that wouldn't heal on their own. After doing a physical examination, the doctor started probing about other possible reasons why she might have developed these sores, and subsequently uncovered a great deal of trauma she had recently experienced. The GP then immediately made a referral to a psychologist. The third participant was taken by her mother to the local GP when she was 14 years old because she had been complaining of constant muscle aches and pains. In this case too, the doctor ran a battery of tests and when the results showed no signs of medical abnormalities, he prescribed anti-depressants (without making any diagnosis according to the participant).

Only one participant took herself to see a psychologist because of stress and pressure in her Honours year at university. She saw this psychologist until the end of the academic year, but no diagnosis was made. A few years later she was taken to the local GP by her boyfriend because she had cut her wrists badly when he had tried breaking up with her and consequently needed stitches. The doctor diagnosed her with depression and prescribed anti-depressant medication. She had no further follows-ups with this doctor and was not referred for further psychiatric or psychological intervention.

Finally, one participant was sent to the psychologist on duty at the hospital where he was admitted after a serious accident at work. The plastic surgeon who conducted his surgery requested that he be seen by a psychologist, which was then arranged by the hospital. The psychologist told the participant that he suspected possible PTSD, as a result of previous trauma he'd suffered in childhood when he lost his eye, and also the accident at work (which nearly saw him lose his arm, too). However, he told the participant that he suspected possible BD too, and wanted a psychiatrist to evaluate him immediately. The psychiatrist on duty at the hospital then diagnosed him with BD 2. The participant continued to see both the psychologist and psychiatrist after he was discharged from the hospital.

These trends in diagnostic patterns among professionals treating psychiatric patients would be very interesting to investigate further in a future study, to assess how these different groups of clinicians go about their diagnostic process.

g. Feelings around diagnosis

As was expected, the results from this section varied greatly from person to person depending on their individual contexts and journeys up until the point of BD diagnosis and also thereafter. However, there were many similarities that the participants experienced, too.

Firstly, the most typical answer to this question was one that revealed denial as the initial reaction to being diagnosed with BD. There were several reasons for and subsequent consequences of this initial hesitance. First and foremost, many participants mentioned that they doubted this diagnosis because they still felt “normal”, and having a serious condition like BD would then mean that they would not be “normal”. Two participants in particular struggled with their doctors’ explanation for their decision to diagnose BD because they thought the problematic symptoms, as seen by others, were just part of their personalities. For one participant, her family also struggled to accept the diagnosis for the same reason:

> *Ja, and seeing all these doctors and then you have to take all these pills (pulls face and shakes head). Ja, so I mean it was very difficult to accept. After 31 years to be told now, "You've got this"... It’s just who I was. It’s me, (says name).*
>
> *Participant 11*

Thus, receiving this kind of diagnosis caused some participants to question themselves and essentially, what they believed to be true about themselves, thereby causing an identity crisis of sorts, which resulted in the initial reaction of denial.

Denial was also apparent in the way some participants dismissed their diagnoses as a mistake, or a common trend on the incline:

> *Um, I felt like it was a big mistake. Ja. I felt like maybe the doctor is wrong. Ja. Just, because, you know, pretty much a lot of people are diagnosed with Bipolar and it's not Bipolar. Everybody's got Bipolar these days, you know? So, ja, when I was diagnosed with it I was like, "Ja right". You're just one of the statistics. Really, it's not really the truth.*
>
> *Participant 2*

As a result of this scepticism, some participants mentioned going home and doing research themselves, most often on the internet, in an attempt to disprove the diagnosis, or to understand the diagnosis better. In their minds, there were other good reasons why they were feeling the way they were feeling, or acting the way they had been, such as stress, other people's treatment of them, or even other "lesser" mental illnesses such as depression or anxiety. This revealed a sort of hierarchy of mental illnesses with the stigma surrounding each one steadily increasing the higher up the hierarchy they were perceived to be (and BD was quite obviously near the top of this hierarchy):

> *So I went to see him and the very first thing he said to me was, "You're not schizophrenic" and I said, "Thank God!" (laughs). Um, and that's then, when he said that he thinks I'm Bipolar… So, uh, based on what I understood with Bipolar, the whole up and down thing, it made perfect sense.*
>
> *Participant 9*

The second quotation above not only demonstrates this hierarchy of mental illness mentioned earlier, but also indicates another emotion commonly experienced by participants upon diagnosis of BD, namely relief. In this case, the participant was much more open to accepting the BD diagnosis because she was relieved that it wasn't Schizophrenia. Many other participants also expressed a sense of relief when they were diagnosed because they felt like there was finally a valid explanation for their behaviour and experiences. They were relieved that it wasn't "just them" and some even felt relieved that they could finally give their loved ones and friends some reassurance that there was a medical explanation for their behaviour, which meant that it could be treated and that things would therefore start to improve:

> *Umm, at first when I got the official diagnosis it freaked me out because of the label of Bipolar and what that meant. You know, like it was, I was a bit nervous, worried.*

> *But at the same time I wanted the label so I could address it and move forward with my life. So it was a very bitter sweet feeling.*
>
> *Participant 1*

Other typical emotions experienced include sadness, especially when thinking about what this would mean for them and their futures, as well as anger, particularly for those who had been through a long or difficult diagnostic process up until that point. Thus, they then felt angry that BD hadn't been picked up sooner and that they had to lose so much and struggle for so long before it was eventually identified (which included taking unnecessary medication, too).

Fear was a prominent emotion experienced by the majority of participants, too. This had to do with being given such a "big, bad label", what this would mean for them, and also how other people would treat them if they found out, especially at work:

> *It is very, like for me is, that is my biggest thing, is how do you, how do you go into the world once you've been diagnosed? And, what do you do? Like I said, who do you tell, who don't you tell? And ultimately for me, the other thing is that I feel like there's needs to be, something needs to be addressed in general around mental health and the workplace, because I think it's a problem.*
>
> *Participant 6*

> *Um, I just, I dealt with a lot of things on my own and I internalized a lot of things. Um…I just, I just never told my family because if I did tell them, what were they going to do? Put me away somewhere? You know? I didn't want to be labelled, as mad. So I, I just kept it to myself.*
>
> *Participant 2*

Eight out of the 12 participants admitted to feeling anxious when they received their BD diagnosis, which often became worse when participants thought about how other people would treat them or what they would say once they found out. This frequently resulted in social withdrawal and anxiety whenever conversations arose about stressful situations and how other people handle stress, because they knew this was something that they had often struggled with and thus became anxious to talk about this with others"

> *When I heard that I was devastated. I was thinking, "Why me Lord, why?! All this, why is all this stuff happen to me?!" In a short period, it's like a lot is just dump on me and, I didn't know how to come out of it, how to, to to to, deal with all this stuff. So it was quite hectic. And also, I was trying to be strong, but it didn't happen. I was, must tell, I was broken. Broken down, like a old car I was just standing there, on the road, nobody cares, and stuff. I was beginning to, to distract me from people. Don't be in people's conversations, and stuff… or if I heard people talk about stress and stuff, then I, I dragging away, because I don't want to hear that words because, the doctors, and the people is telling me this, and, it's like "No man! I was a person, and why this, all this things, just, go mad?"*
>
> *Participant 7*

Part 2: Mitigating and complicating factors of diagnosis

a. Participants were often unable to recognise symptoms of BD within themselves, even when being probed by their psychiatrist / psychologist / medical doctor during a diagnostic interview or history-taking session. It was clear that symptoms of depression were much easier for participants to identify as problematic in their lives than symptoms of mania or hypomania, which supports most other research studies on this topic (Bowden, 2001; Dunner, 2003; Singh & Rajput, 2006; Matza et. al., 2005; Mitchell et. al., 2010). Indeed, nine of the 12 participants were diagnosed with depression before being diagnosed with BD. Seven of these nine participants were diagnosed with depression by more than one clinician.

> *Ja because I started, I started staying out late nights, and not sleeping and waking up at 5 o' clock in the morning expecting the rest of the family to wake up at 5 o' clock, (laughs) putting music on, waking up at 2 o' clock in the morning to dry the dishes that I forgot to dry, (laughs) you know stupid things like that. Cause at the time I was doing, cause I, I, I, according to me I had come out of depression, so I was happy. But I didn't know I was manic cause I didn't know what manic was, so I came out of the depression and I was just happy.*
>
> *Participant 8*

Thus, accurate diagnosis by clinicians often calls for insight that isn't necessarily fair to expect from patients and could lead to valuable missed information if clinicians do not take this into account and find ways of compensating for this possibility when interviewing patients, especially those who present with depressive symptoms. This finding echoes what several others researchers have found in their studies too and is therefore not a new insight into this phenomenon (Bowden, 2001; Dunner, 2003; Singh & Rajput, 2006; Faravelli et. al. 2009; Bruchmuller & Meyer, 2009). According to Singh & Rajput (2006), hypomanic episodes are milder in presentation and can occur without major impairment to social or occupational functioning, which is why they are often under-reported by patients. Additionally, the increased energy and heightened activity levels often experienced by patients during manic episodes may not be considered negative events by the patients who experience them (Oyffe et. al., 2014). In structured hospital or professional office settings, a patient's behaviour may be more organised than in the course of the patient's usual daily activities (Bowden, 2001). Considering the fact that a BD diagnosis cannot be made without evidence of at least some sort of manic symptomology, these results highlight the increased likelihood of misdiagnosis if patients alone are relied upon for diagnostically relevant information.

This calls to mind the recommendation made by several authors regarding the need for supplemental information to be provided by a patient's family, colleagues, or significant others who are familiar with the patient's daily routine, moods, and struggles, when they present with symptoms of depression or when the clinician suspects that there may be more to the clinical picture than what is being presented by the patient alone (Bowden, 2001 & 2003; Ramsley, 2006; Singh & Rajput, 2006; Mitchell et. al., 2010).

b. Many participants admitted to feeling reluctant to discuss their symptoms or problems honestly with their treating clinicians. This was because participants often felt guilty or embarrassed about their behaviour and feared judgement or possible negative repercussions if they divulged the full extent of what was happening (especially during manic episodes). When asked whether she had told her new psychiatrist about everything that had been happening in her life that caused her to seek help in the first place, this participant's response was:

> *Well I never, whatever she asked I, I disclosed. I mean I never went into [5]DETAIL about things. So it was very quick, very quick. "Let me get the analysis done and jot everything down" and so forth. It was very quick. Um, and I was just sitting there, because, ja. I don't know. I think there was a part of me that wanted help. Definitely. But…(doesn't finish her sentence).*
>
> *Participant 2*

Further discussion about this with this participant revealed that she was not going to bring things up on her own because she had not yet established a relationship with her new psychiatrist and feared being "told off" in the same way that her family often did when she acted "out of the ordinary". Thus, she would answer questions asked of her honestly, however, if something wasn't specifically asked about, she wouldn't bring it up, even if she knew it might be significant.

c. Financial constraints and not having private medical insurance was often cited as the reason why participants delayed seeking help. In some cases, even for those who did have private medical insurance or were supported financially by family members, the cost of continuous visits to the psychiatrist and psychologist, as well as the cost of the medication they needed monthly, exhausted their financial resources very quickly, leaving them out of pocket. As a result of this, participants often mentioned feeling rushed in their sessions, particularly with psychiatrists. This was not necessarily a result of anything said or done by the psychiatrists, but rather, in most cases, the result of participants "watching the clock" in an attempt to share as much information as they could in as short a time as possible (usually half an hour) so as not to incur any additional or unexpected consultation fees. According to Dr. Stephen S. Sharfstein, a former president of the APA, "brief consultations have become common in psychiatry…It's a practice very reminiscent of primary care" (Harris, 2011: health page).

> *Participant: You know for me, being in a clinic, that whole idea, like, under concentrated supervision, I got so much more out of it than just going to one therapy session every now and then. And also, you know, when I saw the psychiatrist I wasn't in a rush to get out.*

---

[5] Capital letters indicate the participant's own emphasis.

> *Interviewer: You mean when you saw her as an in-patient in the clinic?*
>
> *Participant: Ja. As opposed to when I saw her privately at her offices. Before then. Because of the cost of it. So I didn't want to just get in there and say, "Ok, just give me some more meds, let's go, goodbye". I was really committed to getting to the bottom of everything once and for all.*
>
> *Interviewer: So finances were actually a really big constraint for you and played a very big part in this whole journey for you?*
>
> *Participant: Ja, I'm starting to think that it might have been different for the psychiatrist if...you know... (goes quiet)*
>
> *Interviewer: If she had had more time with you, you mean when you saw her privately and she diagnosed you with, um, GAD and MDD?*
>
> *Participant: Ah huh. Ja. Which is why I then said, "Okay, I realise I need to see someone else to spend that time with me that I need, that doesn't cost as much as she does". And then she recommended the psychologist I'm now seeing who gives me a discounted rate because I'm paying cash.*
>
> *Participant 1*

> *And then, something that was really hectic for me was going to see my psychologist, and I know I only have an hour, this precious hour. And, I'm fortunate to have that hour, people don't have an hour, but I got neurotic about it, I was like "I only have this much time", the same with [says name of psychiatrist], "I only have this much time. I have to get as much out of this as I can. And, um, this is like a golden spot of time." And, I would be hard on myself, 'cause that was the problem after. "You didn't ask this, you forgot to ask this, you didn't do this, you didn't say that, now you won't know this". So it added to the whole, stress thing.*
>
> *Participant 5*

Furthermore, financial constraints tended to result in participants only seeking professional help as a last resort, when things become really unbearable, which exacerbates the problem even further because by this stage, acute psychiatric treatment is often needed, which once again requires financial reserves of some sort. One session with a psychiatrist or psychologist is often not enough to make an accurate diagnosis, or for adequate treatment (Harris, 2011). However, participants who couldn't afford to keep returning were then forced to either stop the process, or divulge what they thought to be the most important or relevant issues needing attention, often resulting in a great deal not being said.

Moreover, this process could also be seen to set patients up for failure in the way that it relies on them personally judging what the most pressing issues are that need treatment. Research has shown that for most bipolar sufferers, judgement can be impaired during manic or depressive episodes, as can memory (Bowden 2001; Singh & Rajput, 2006). Thus, a latent expectation of patients to accurately recall information, present it in a logical manner that aids a speedy diagnostic process, or decide what exactly is or is not relevant during diagnostic interviews, will likely increase the chances of an inaccurate diagnosis and subsequent treatment.

Interestingly, only four of the 12 participants had accessed state treatment from state hospitals when they could no longer afford private care. It is likely this is affected by stigma and social perceptions of poor delivery of care associated with state hospitals, which private clinics have worked hard at changing. One patient discharged herself after 24 hours because she was unsatisfied with being made to wait for a hospital bed, being asked to move beds twice, and the overall treatment received by staff. When this was discussed with her, this participant vehemently stated that she would "never" make use of state institutions again:

> *I would rather die than go back there! I will never go back. And they say (names the hospital) is the best one in Cape Town. Ha! I can't imagine how bad the others must be then. I will find the money somewhere, but I'll never go back to that rubbish.*
>
> *Participant 2*

d. The majority of participants in this study mentioned feeling frustrated with the medication given to them by their doctors, which was very costly and often didn't work as they expected it to:

> *Ok, so firstly she changed my anti-depressant immediately. Umm, money was a huge issue for me so she couldn't really put me onto the anti-depressants that I should have been on. Ja, money was a huge thing. So I then went onto Cilift, which I felt didn't work*

> *either. Umm, it did help for a bit ok, and so did the Rivitrol, which she gave me for the anxiety. That did help. But, umm, ja (shakes her head as if indicating "no"). It was very frustrating cause I felt like things would work initially, then after a while, just nothing. And I was having to ask my dad to help me out financially, cause this stuff is SO expensive if you don't have medical aid. And after a while he started getting annoyed too, with all these bills I was sending him.*
>
> *Participant 1*

This finding also foregrounded a somewhat implicit, unspoken need that may exist between patients and their doctors / psychiatrists, to prescribe, or be prescribed with, "something" right from the first consultation.

> *Participant: So every 6 months I needed a repeat prescription, so I'd go to my GP…He would say, "Do you still want the meds?" and I'd say, "yes please", and then we would go (laughs).*
>
> *Interviewer: And when you saw the psychiatrist?*
>
> *Participant: Um, like I said, the first time she just changed my anti-depressant and gave me the Rivitrol for my anxiety too.*
>
> *Participant 1*

This calls into question the job function of clinicians who prescribe psychiatric medication, the expectations of patients when visiting and paying for psychiatric intervention, as well as the interpretation of clinicians of what they perceive their roles to be. This was not examined in this study however, but future research would do well to study this in more depth because of its possible link to frustration of psychiatric clients, who then become more symptomatic and less likely to comply with treatment long term. While several studies have examined the factors causing treatment non-adherence (including medication non-adherence) in BD patients, there is a gap in the literature around the issue of being treated as a medical "guinea pig" (Colom & Vieta, 2002; Goodwin & Jamison, 1990; Sajatovic, Davies & Hrouda, 2004).

As mentioned in part 1 above, only one participant out of six that first sought help from a GP was *not* given any medication and was referred instead to a psychologist for further clinical investigation. All of the participants, except for the one mentioned above, who first sought help from a GP or a psychiatrist (six participants out of 12), were given medication. Furthermore, none of the five GPs who treated these participants identified possible bipolar symptoms and therefore prescribed anti-depressant medication, which is known to have possible adverse effects on patients with BD if not used in conjunction with a mood stabilizer (Ghaemi et. al., 2000; Bowden, 2005; Ramsley, 2007).

Thus, this practice could not only be medically dangerous, but also sets up an unrealistic expectation by the patient, who then becomes frustrated when their symptoms do not improve or become worse. This could then decrease the likelihood of compliance with medical prescriptions in the future while simultaneously undermining the credibility of the profession, too. Thus, there is a need for research that investigates the link between incorrect medication prescription, or prescription of medication that does not improve a BD patient's symptoms, and future help-seeking behaviour of those patients, which will inadvertently affect their diagnostic journeys.

e. Many participants mentioned, at some point during their diagnostic processes, having had at least one bad relationship with the professional treating them. Sometimes this was due to personality clashes, sometimes it was because of uncomfortable feelings triggered in the participants by the clinician, and at other times it was because of perceived unprofessional treatment. What stood out as common thread amongst these narratives, however, was that when there was no relationship yet established between the participant and the clinician, there was consequently very little trust. Without trust, most participants were hesitant to discuss personal information about themselves. From a clinician's perspective, this may hamper the diagnostic process and draw it out over a longer period of time, which may further affect the process negatively if financial constraints exist or there is an expectation from patients of immediate diagnosis or treatment, as mentioned above. Participant 5 describes how this affected not only her relationship with her first psychologist, but quite possibly also the diagnosis she received because of her reluctance to discuss her background:

> *I don't think it [the relationship] lasted very long. And I was frustrated, I really was frustrated because she tried to spend a lot of time on my family history and everything and I just, you know as a patient I just wanted the, the answer like, "What do I do to stop*

> *feeling stressed?". I didn't want to go into anything more. I mean, I don't know this person from a bar of soap! I know it's their job but I mean, you know?*
>
> *Participant 5*

Trust lies at the foundation of almost all theories of interpersonal relationships, including the therapeutic dyad (Bowlby, 1969; Erikson, 1963; Homes & Rempel, 1989; Simpson, 2007). This begs the question whether psychiatric patients can realistically be expected to trust their clinician from the first time they see them? It also highlights, once again, the implicit expectation of receiving a diagnosis and/or subsequent treatment, in whichever form offered by each clinician. Moreover, if trust is something that takes time to develop, as might be expected, then the likelihood of clinicians receiving forthright information from patients that paints a full clinical picture for diagnostic purposes right from the first consultation session, might be slim. This is also further complicated by the fact that patients do not always have insight into their thoughts, behaviour, and emotions, or that they are selective with the information that they choose to share, as mentioned above (Bowden, 2002; Hirschfield et. al., 2013; Culpepper, 2015).

f. Four participants in this study had utilized both public and private mental health facilities and treatment centres over the course of their diagnostic journeys. Although they were not asked to compare their experiences in these two different settings, what did emerge from their descriptions of treatment received in both sectors was another possible underlying factor that could affect the diagnosis of BD. More specifically, it became evident that GPs, psychologists and psychiatrists working in private practice often work in isolation and are therefore not part of a multidisciplinary team, as is usually the case in public facilities and hospitals in South Africa. A multidisciplinary team typically consists of a diverse group of healthcare professionals, such as GPs, nurses, social workers, occupational therapists, physiotherapists, psychologists or counsellors, psychiatrists, neurologists, and other medical specialists (Codispoti, Douglas, McCallister & Zuniqa, 2004). Jefferies and Chan (2004) describe multidisciplinary team work as "the main mechanism to ensure truly holistic care for patients and a seamless service for patients throughout their disease trajectory and across the boundaries of primary, secondary and tertiary care". In healthcare setting where this approach is used, the patient is seen to be the centre of the team. When properly implemented, Codispoti et. al. (2004) report that this team approach can have better diagnostic and treatment outcomes than individual patient care for chronic medical conditions such as diabetes. Given that BD is also a chronic, lifelong disorder, a multidisciplinary approach to diagnosis thereof may also have similar positives outcomes.

Thus, as reported by participants in this study, diagnoses are often based on one clinician's judgement, at one point in time (sometimes in the first session with a client), and on information given to them by the patients themselves without collateral information from other key role players in their lives, as has been recommended by several authors on this topic (Bowden, 2002; Singh & Rajput, 2006; Matza et. al., 2005; Faravelli et. al., 2009). This could potentially result in misdiagnosis, or missed diagnosis, particularly when dealing with mental illnesses as convoluted as BD.

g. As alluded to above, the need to actively seek collateral information from family members, friends, colleagues, or significant others in the patient's life, appears to be of importance when attempting to diagnose mental illnesses that share so many common symptoms and therefore complicate the diagnostic process. In this study, six of the participants indicated that key role players in their lives had been directly involved in their diagnostic process by communicating with their clinicians or joining them in their individual sessions. This likely means that the clinicians who treated the other six participants throughout the course of their diagnostic journeys had not asked to speak to anyone else for collateral information (according to the participants' knowledge).

When comparing the participants who did versus those who didn't have family or friends as part of their diagnostic process, the results show a trend towards longer diagnostic time periods for those who didn't have others involved in their diagnosis. However, this was not always the case as there were instances where participants did have others involved and it still took long for BD to be identified as a possible diagnosis. For example, participant 9 (see Table 5 below) had always had her mother actively involved in trying to get her the help she needed from a young age already (she saw her first psychologist at age 14). However, it took this participant 14 years from the time she saw her first psychologist to her eventual BD diagnosis, despite having her mother constantly talking to the clinicians treating her. Thus, receipt of collateral information may be a double edged sword in reality: helpful in some cases, but as seen in this case, not necessarily helpful in others. In fact, it is possible that collateral information may actually aggravate the diagnostic process as opposed to mitigate it.

Table 5: Comparison of diagnostic time periods with collateral information received from others

	P.01	**P.02**	**P.03**	**P.04**	**P.05**	**P.06**	**P.07**	**P.08**	**P.09**	**P.10**	**P.11**	**P.12**
Did professionals ever consult with family / colleagues / friends before making diagnosis?	No	No	Yes	Yes	No	No	Yes	Yes	Yes	No	Yes	No
Time between 1st recollection of problem & Bipolar diagnosis	3.5 / 4 years	36 years (although first sought help from GP +-3 years ago, so more accurately 3yrs)	3 years	24 years (although first sought help from GP 5 years ago, so more accurately 5 years)	7 years	17years (although 9 years since first sought help from psychologist)	23 years (although 1st saw psychologist after accident at work at age 28, was diagnosed 3 months later with Bipolar.	5 years	20 years (although 1st saw psychologist at age 11, so actually more like 14 years)	47yrs (was diagnosed with manic-sepression at age 5, but was only treated with medication at age 51 for the 1st time).	39 years, (although 1st got help at age 32, diagnosed with Bipolar at 36, so more accurately 4 years)	12 years

In participant 9’s case, her mother felt frustrated with so many different doctors giving different diagnoses and her daughter not seeming to improve with the various medications she had been given. She had a history of self-harm and suicide attempts that started in her early teenage years already, which resulted in many hospitalizations. When asked about her manic episodes, participant 9 described them as follows:

> *I think, um, just, like I said, it's not a really dangerous time for me. It's more of a...I get super focussed, super energized. But it has to be done now, it has to be done my way. And it can't be any other way cause any other way is wrong and it has to be my way. And uh... Ja. It's usually just a couple of hours.*
>
> *Participant 9*

This participant’s mother indirectly confirmed her daughter’s version of events, including her daily ‘ups and downs’ and mood swings, in a letter she wrote to me and gave to her daughter to hand to me during our interview for this study. A copy of this letter is attached as *Appendix F* at the end of this thesis.

To continue with this case illustration, participant 9’s mother did some internet research and started reading up on BD because of her aforementioned frustration. She suggested this as a possible diagnosis to the psychiatrist at the time, who dismissed it by (allegedly) explaining to her that he was leaning more towards a diagnosis of a personality disorder. Because of unforeseen circumstances, participant 9 ended up having to see a new psychiatrist. Her mother shared her opinion with this new psychiatrist too. Participant 9's diagnosis was changed in her first consultation with the new psychiatrist to Bipolar 2.

Although it is impossible to speculate why her psychiatrist decided on this diagnosis without having spoken to him/her, this case illustrates the aforementioned point that collateral information shared with clinicians *may* impact the diagnostic process in both positive and negatives ways, thus highlighting the double-edged sword binary. Furthermore, it also illustrates how internet 'surfing' as a means of investigating medical / psychiatric problems in search of, essentially, a differential diagnosis, can play a part in influencing the diagnostic process too (Robertson et. al., 2014). This is something that has not yet been well-researched and there is a gap in the literature on this point that still needs to be filled in order to better understand this relationship and the possible complications hereof.

h. It became clear as this study progressed that many participants did not have a good understanding of their diagnoses and it thus raised concerns regarding how well it had been explained to them. With reference to part 1 above, initial feelings such as denial, shock, confusion and sadness, a tendency to dissociate during emotionally stressful times, and struggling to concentrate and pay attention as a result of manic or depressive symptoms, could all contribute to missing important information during a psychiatric diagnosis. This could then ultimately result in a lack of understanding later on, once initial feelings have subsided or symptoms have improved. Demographic characteristics of both the patient and the clinician could also contribute to a lack of understanding, such as first language and level of education (Proudfoot et. al., 2009). Ultimately, a lack of understanding on the patient's part could have negative ramifications for them that include medication cession or non-compliance, worsening of symptoms, and 'shopping around' for a different diagnosis that makes more sense or is more acceptable, thereby aggravating the management of their disorder and prolonging successful treatment (Proudfoot et. al., 2009; Goicoechea, 2002).

> *And I was a guy that wasn't, um, like in, taking pills and stuff a lot. So for me, the taking, like in 6, 7 pills in the morning, 2 in the afternoon, like 5 to 8 the, pills at night, it was hectic for me. There was times that I, I didn't do it, because I was just thinking "No man! I can't drink this pills! I'm not mad man! Nothing is wrong with*

> *me! But why are they giving me this, so lot of medicine?" So... Let me say that, let me say it for you like this. This is also for me, it's like I'm seeing somebody* [6]*new, so, maybe you can give me perspective, because I was seeing [says name of therapist], now I'm seeing you, and I didn't saw you, in clinic we only do such things, but now I seeing you like, in, in this,*[7] *uh, now you begin and to analyse it and so maybe next time you can say me, okay what is what. It's almost for me like, I took it as a second opinion…'cause I still don't actually understand what this thing really is, you know?*
>
> *Participant 7*

In this case, participant 7 was asking me for a "second opinion" on his diagnosis, based on the information he had shared with me in the interview and the diagnostic timeline we had constructed together. At the end of this quote, he admits to still not understanding what BD really is, more than three years after being diagnosed and treated.

Part 3: Diversity and Difference, Contradictions and Ambiguity

While the majority of the findings discussed above attempt to piece together what emerged as main codes during the grounded theory analysis process, there were still findings that appeared to be relevant to understanding the diagnostic process of BD better, but that fell 'through' the coding revision process. This occurred because these parts of some participants' narratives contradicted what the majority were saying, were ambiguous and therefore not obviously contributing to anything, or diverged from the 'norm in some way. Thus, although these 'outlying' findings are difficult to link to previous research on this topic and are not typical findings in this study, they represent the very nature of BD perhaps even better than any other findings. These outliers demonstrate the uniqueness of the participants' journeys with BD, which is in itself a convoluted illness with a complex and non-linear trajectory that has escaped in-depth understanding for decades already. Future research should therefore focus on outliers such as these in an attempt to better understand this complicated disorder and how best to go about identifying it as early on as possible.

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[6] The participant was referring to me, as the interviewer, as "somebody new"

[7] The participant is referring to the interview here

a. While most participants stated at the end of their interviews that in retrospect, they can see opportunities in their individual journeys for things to have been done differently (by themselves, by treating clinicians, by family members, or a combination thereof). Many participants felt strongly that had these things been done differently, their diagnosis may not have taken as long as it did, and a great deal of suffering may have been prevented. For example, five participants were of the opinion that going straight to a psychiatrist as opposed to a GP when seeking help initially, would have had a positive impact of their trajectory. Of course, there is no way to know whether this would actually have been the case in reality – as the saying goes, “hindsight is always 20/20 vision”. However, what this does illuminate is the ability of most participants to look back and assess their diagnostic histories critically, albeit some more than others, and highlight potential gaps in the system that could be evaluated in more depth in future research.

In stark contrast to this however, two participants had very different responses to the majority. One participant was not able at all to look back over his timeline critically and assess potential opportunities or gaps. In fact, this participant struggled to create a coherent timeline all together. He was constantly confused, which manifested in both his questions and his answers. I subsequently found myself feeling increasingly frustrated as the interview progressed and at one point thought, “No wonder it took him almost 50 years to be properly diagnosed and treated”. This was not a typical experience for me during the interview process.

For example, this is an extract from our conversation about his thoughts around the reasons for his delayed diagnosis:

> *Interviewer: I'm wondering, you know, you were diagnosed when you were 5 years old actually with Manic Depression, but yet you've only, um, you were only medicated much later on when you were 50-odd. What was your attitude towards medication?*
>
> *Participant: When I first got it?*
>
> *Interviewer: No, in-between when you were first diagnosed and when you were treated MUCH later on.*
>
> *Participant: When I first got it, oh, in-between?*

> *Interviewer: So before you were given medication around age 50?*
>
> *Participant: Oh, there's no ways I would have taken it! (laughs)*
>
> *Interviewer: (laughs) There's no ways you would've taken it?*
>
> *Participant: I would never ever. No. But had they told me it was for Manic Depression I would have taken it.*
>
> *Interviewer: Okay...*
>
> *Participant: No I would have taken it. Had they told me in-between that it was for the illness that I was diagnosed with originally, I would have taken it. I'd have no problem taking it.*
>
> *Interviewer: So what did you have a problem with then?*
>
> *Participant: Sorry?*
>
> *Interviewer: What did you have a problem with? Or what was the problem in-between?*
>
> *Participant: (Hesitates)*
>
> *Interviewer: 'Cause you first said, "There's no ways I would have taken it". That was your first response.*
>
> *Participant: No no no no no, I was just too lazy to take medication.*
>
> *Interviewer: Okay, okay. So you wouldn't have taken it on your own, but if you had known just how much it could have helped you and that it was for this original illness that you had been diagnosed with, then… (participant interrupts)*
>
> *Participant: The only things I suffered from between then and now, and 51, were things like a cold.*
>
> *Participant 10*

The second participant with a different response to the majority on this topic stated that she believes that nothing could have been done differently that might have made her diagnostic journey smoother and that, "we all did the best with what we had at the time" (Participant 4).

Thus, in her opinion, all the role players in her diagnostic journey (including herself) did the best they could given the circumstances and the multiple factors at play in this process at any specific point in time. Attempting to simplify this process by searching for diagnostic “gaps” or missed opportunities would therefore not necessarily be beneficial in understanding this process better.

b. Three participants first sought help from medical professionals for physical symptoms. After medical examinations revealed no physical ailments, clinicians then cast their nets wider to possible psychological disturbances in search of a diagnosis. In all three cases, this resulted in a diagnosis of depression, which is known to typically be the first diagnosis received by patients suffering from BD (Bowden, 2001 & 2005; Singh & Rajput, 2006; Wolkenstein et. al., 2009; Philipps & Kupfer, 2013). Thus, as well as depression being a possible ‘red flag’ for BD, physical complaints rendering no physical diagnosis should also be considered as such.
c. BD is commonly associated with decreased level of functioning (interpersonal, occupational, cognitive, emotional, etc.), as is depression (Dunner, 2003; Singh & Rajput, 2006; Keck et. al., 2008). In fact, this forms part of the diagnostic criteria for Major Depressive Disorder (MDD) in the DSM-V (see *Appendix 1*). While this was noticeably the case with most participants in this study, there were, however, a few who demonstrated extreme resilience in their given circumstances. Thus, when they presented for first treatment (most often during depressive episodes) they were still able to function at work, home, and interpersonally (although not to the same level as usual), at least by their own accounts. Thus, if decreased level of functioning is focussed on when considering a BD diagnosis, then not only could MDD be misdiagnosed as a ‘lesser’ form of depression, but this could then also affect the likelihood of BD being considered as a possible diagnosis down the line.

d. Three female participants mentioned being treated for endometriosis. Although there is no direct link in the literature between endometriosis and mood disorders (generally) or BD (specifically), this was something that these participants felt “wreaked havoc” on their moods until it was diagnosed and treated properly. One of these participants even had to undergo a hysterectomy in her early thirties because of complications caused by her endometriosis. Both of the other participants had undergone surgery, too, although not as extreme. This is something that should therefore be researched further given the mood component of BD.

e. The majority of participants (10 out of 12) disclosed the difficulties they experienced in childhood and adolescence already, that manifested in various ways and in different contexts. For example, several participants admitted to having had turbulent upbringings and unstable home environments. Others discussed interpersonal difficulties with parents, siblings, and school friends that affected them from an early age. However, two participants had completely different experiences to this norm. In these two cases, both participants reported having always had good relationships with family, having enjoyed long-term romantic relationships with few unusual difficulties, and having no particularly bad or traumatic childhood memories ("I was a very happy child. I really can't complain about my childhood or teenage years at all" – Participant 11). These two participants also reported performing well academically at school and later at university, too. Interestingly, they were the only two participants in this population were in relationships at the time of their interviews: one was married and one was engaged to be married. This stood out in stark contrast to the other 10 participants' life stories.

f. The majority of the participants presented for their interviews well-groomed and neatly dressed. However, one participant arrived in her pyjama pants and slippers, two others smelled slightly of alcohol (although these two were neatly dressed and were able to express themselves coherently), and two were extremely overweight. Co-morbid disorders such as alcohol abuse or eating disorders are not uncommon amongst BD sufferers, although none of these aforementioned participants mentioned being diagnosed with such (Brown et. al., 2001; Levin & Hennessey, 2004; Magelhaes et. al., 2012; Manning, 2015). In fact, those who did mention having struggled with alcohol / food / drug abuse in the past did not present as being extremely overweight, underweight, or smelling of alcohol. The opposite was thus the case (although it is also possible that obesity could be medically induced as a result of metabolic syndrome often caused by certain atypical antipsychotic and mood stabilizing medications) (Burgess, 2006).

g. Two participants stood out from the group for showing what could be interpreted as inappropriate or incongruent affect. Whereas the majority lowered their voices and their gaze when recalling traumatic experiences, pausing frequently while talking and, in some cases, struggling to hold back their tears, the aforementioned two participants showed emotions opposite to what was expected most of the time. For example, Participant 8 burst out laughing when she spoke about jumping off a bridge in an attempt to commit suicide, which resulted in a four month hospital stay from her multiple serious injuries. Participant 11, too, laughed while describing his experience of being “like an animal locked up in a cage” when he was admitted to hospital during his first psychotic episode, which lasted three weeks. Although this nonchalance and light-heartedness could certainly be associated with protective internal factors, it might still be beneficial to ‘red flag’ as a factor that could possibly affect the diagnostic journeys of some patients.

CHAPTER FIVE: CONCLUSION

Summary of findings and recommendations for future research

It is evident from these research findings that BD is a complex and contradictory disorder, as unique as the individuals who suffer from it. More than a century after it was first identified and studied, there is still little consensus among medical professionals regarding the definition of this disorder (Kuiper et. al., 2012). Indeed, one of the biggest controversies in contemporary psychiatry surrounds the ever-broadening boundaries of BD that has resulted in the notion of a bipolar spectrum (Akiskal, 2004; Magill 2004; MacKinnon & Pies, 2006; Gunderson et. al., 2006; Paris et. al., 2007; Kuiper, 2012). The consequence hereof is the steady inclusion of more and more phenomenology under the umbrella of 'soft bipolarity' (Kuiper et. al., 2012).

Under this broad umbrella, bipolarity has been suggested as a component of almost every psychological disorder recognized, from psychosis to personality disorder, anxiety, ADHD, eating disorders, substance use, autistic spectrum disorder, somatisation, dissociation, conversion disorder, and dementia (Kuiper et. al., 2012; Akiskal et. al., 2000; Zdanowicz and Myslinski, 2010; Lunde et al., 2009; Levin & Hennessey, 2004; Ragunath et al., 2011; Ng et. al., 2008). In such expansive forms, research indicates that approximately 25% of the population could be diagnosed with a 'bipolar spectrum disorder', which is certainly cause for concern given that estimates of true bipolarity internationally range from only 0.5% to 2.5% (Kuiper et. al., 2012; Angst, 2003; Merikangas et. al., 2011; Moreno et. al., 2007).

As we expand the boundaries of BD to include briefer or less severe mood swings (see *Appendix A*), the diagnostic field steadily shifts away from episodic mood elevation towards affective instability, which is in itself interesting insofar as this is currently a DSM-V criterion for BPD (Goldberg et. al., 2008; Kuiper et. al., 2012; Manning, 2015). The boundary between BD and BPD is yet another blurred one resulting from the introduction of this bipolar spectrum, and has been the subject of much blame for the last research findings that indicate a trend towards over-diagnosis of BD (Manning, 2015; Paris et. al., 2006; Barroilhet et. al., 2013; Benazzi, 2008). Indeed, in this study too, there were participants who had more a BPD 'feel' than that of BD.

This expansion of the definition of BD is just one of the reasons why diagnosis of this disorder appears to be so complex. As evidenced by the life stories and diagnostic journeys of the participants in this study, each BD sufferer has had a unique experience that makes simplification of the diagnostic process for more accurate identification, a difficult task for clinicians. This supports the findings of other researchers who report significant heterogeneity between patients of BD, such that they report widely different symptoms. This makes accurate diagnosis that much more difficult (Singh & Rajput, 2006; Bowden, 2001; Zimmerman, 2010).

There are several other reasons too that arose from the results of this study for the difficult task of diagnosing BD. Some of these reasons relate to the disorder itself, and some to the system that participants found themselves in.

The DMI (depression-mania-interval) pattern reportedly experienced by approximately 50% of BD patients was found to be true among this population of participants too (Faravelli et. al., 2009). This is where the manic episode naturally follows the depressive one, which usually occurs first. In fact, the majority of participants in this study (nine out of the 12) were diagnosed with depression before being diagnosed with BD. Seven of these nine participants were diagnosed with depression by more than one clinician. Because there is no differentiation between unipolar depression and bipolar depression in the DSM-V, and some form of mania is required before a diagnosis of BD can be considered, the likelihood of a delayed diagnosis is high (Bowden, 2001 & 2005; Singh & Rajput, 2006; Faravelli et. al., 2009; Daigneault et. al., 2014).

Furthermore, the risks of treating bipolar disorder (or bipolar depression) with antidepressant monotherapy are reportedly very high, which is why it is important that clinicians, and especially primary care practitioners (who, as evidenced in this study, are often the first port of call when patients seek help for problematic symptoms) be educated about how to screen for and treat BD (Keck et. al., 2008; Culpepper, 2014). Although BD may be mistaken for other typical co-morbid psychiatric disorders (such as anxiety, substance abuse, or ADHD), the consequences are generally less harmful than for those misdiagnosed with unipolar depression (and subsequently treated with antidepressants) (Bowden, 2001). Most treatments for other disorders do not worsen BD (Bowden 2001).

Thus, this study has highlighted the important role that primary care physicians (GPs) continue to play in the diagnosis of mental disorders, including BD, in South Africa. In agreement with this, Mitchell et. al. (2010) report that primary care practitioners are well positioned to coordinate patient care and play an important role in the identification of BD and the monitoring of manic and depressive episodes (including manic switching as a result of medication). Culpepper (2014) also asserts that primary care physicians serve key roles in first contact and ongoing care for patients with BD.

Linked closely to this topic is the issue that was highlighted by the participants in this study regarding network of services. More specifically, it is common practice for clinicians working in public health institutes in South Africa to work in collaboration as a multidisciplinary team when treating patients. However, in private practice, clinicians tend to work more independently and, according to the accounts of many of these participants, this often results in a lack of continuity in treatment when patients change from one clinician to another. As clinicians were not included in this study, it would be beneficial for future research to focus on this topic from the clinician's perspective in order to better understand how diagnosis and treatment takes place from one clinician to another, and also how much contact clinicians have with each other when deciding on a diagnosis and appropriate treatment method. In the words of Robert W. Bjorklund, a clinician with the Washington State Mental Illness Research and Training Institute who was written extensively about his struggles with BD and his misdiagnosis with schizophrenia, "I urge frontline mental health professionals to not accept or pass along a diagnosis without at least questioning why past treatment plans have not worked for some individuals" (Bjorklund, 1998: 655). This questioning can take place in the treatment room, as part of the diagnostic interview, or outside of this space, by contacting clinicians who previously treated and/or diagnosed patients.

The issue of obtaining collateral information from family, friends, colleagues, or other key role players in patients' lives, is something that has been written about extensively in the literature. In fact, of all the articles reviewed in preparation for this study, every author that has written about utilizing collateral information has recommended this to supplement the diagnostic interview and assist with providing information possibly not provided by patients themselves (Bowden, 2001; Matza et. al., 2005; Singh & Rajput, 2006; Mitchell et. a., 2010; Manning, 2015). However, the results of this study were not as conclusive on this topic. Although half of the participants in this study did have significant others provide their insight and opinions to the treating clinicians, and there was a trend towards shorter diagnostic delays among these six participants, there were participants who had extremely long diagnostic delays despite of this. Furthermore, there were also participants who did not have any outsiders involved in their diagnostic interviews who experienced relatively short diagnostic journeys. In at least one case, it was evident that the participant's mother could quite possibly have a played crucial role in her diagnosis of BD, despite showing all the signs of BPD and having being told by a previous psychiatrist that he does not believe she has BD.

Thus, this study has brought to the fore the point that collateral information *might* aid the diagnostic process, but might also hinder it as outsiders (consciously or unconsciously) complicate the process with their subjective views and opinions. This is therefore, a very double edged sword that clinicians should utilize with caution when they feel it may be beneficial.

There was an implicit expectation that became evident from the accounts of these participants' experiences with clinicians treating them along their diagnostic journeys. Specifically, there seemed to be a need for clinicians to prescribe 'something' to alleviate their suffering or pain, whether psychological or physical, right from the first consultation. This is dangerous for several reasons, not only medically because of the high risk of manic switching associated with antidepressants prescription for patients who appear to have unipolar depression but may actually be bipolar, but also because it can set up an (often unrealistic) expectation of being 'cured' once medication is taken. In reality, research shows that the first medication prescribed to patients with BD is usually not one that is associated with positive long term outcomes (Gijsman et. al., 2004; Chun & Dunner, 2004; Nivoli et. al. 2010). This is again a consequence of the many factors at play that affect the initial diagnostic interview (Nivoli et. al., 2010).

Thus, as reported by the majority of patients in this study and is echoed throughout the literature, frustration with medication not working as expected, or when symptoms don't improve as expected by patients, is a common occurrence and also a high risk (Nivoli et. al., 2010; Bowden, 2001; Oyffe et. al., 2014; Keck et. al., 2008). Complaints about being treated as medical 'guinea pigs' could possibly be mitigated by more careful and structured screening before medication is prescribed. Furthermore, the need for regular patient follow-up when psychiatric medication is prescribed has been recommended by several authors as a means to monitor treatment reactions more closely (Bruchmuller & Meyer, 2010; Matza et. al., 2005; Mitchell et. al., 2010; Bongards et. al., 2013). The results of this particular study have also highlighted the need for clinicians to be cautious with the way in which they frame, or explain, what medication can and can't do for the patient. Two participants in this study mentioned that, when prescribed antidepressants by their GPs, it was explained to them that this medication would “help [them] through this hard time” (Participants 4 and 5). This could be interpreted by the patient (as it was in these two cases) that the hardship would be short-lived and that symptoms would improve with medication. Unfortunately, this was not the case for either of these two, who went on to become distrustful of later clinicians and sceptical of any medication’s ability to help alleviate symptoms.

Because of the emotional factors commonly at play during these types of interviews (such as anxiousness, fear, embarrassment and guilt, as expressed by the participants in this study), the importance of asking the right questions in a way that elicits honest answers from patients while simultaneously exploring all possible diagnostic avenues and building trust, has been illuminated. As stated by Participant 2, “What she asked, I answered honestly”. Based on the information she disclosed in her interview, this above response implied that she did not provide her psychiatrist with information that was not asked of her, even if she thought it may be relevant. It is a clinical take on the “don’t ask, don’t tell” mentality.

This echoes what the literature recommends regarding the need for more structured, systematic diagnostic assessments which will generally identify evidence of some BD symptoms and could then be the start of a further, more extensive investigation. While there are a number of clinician administered and self-report assessment tools that can be used to supplement the diagnostic interview and assist in screening for symptoms of BD fairly quickly, these have been predominantly developed for use in research contexts (Mitchell et. al., 2010). In general, they are not widely used in clinical settings – neither psychiatric nor general practice (Mitchell et. al., 2010; Baldassano, 2005; Picardi, 2009).

Evidence of this could be seen in this study, too, as only two of the 12 participants were asked at any point in time in their diagnostic histories to complete assessment instruments or questionnaires. One of the more widely used screening tools is the Mood Disorder Questionnaire (MDQ), which screens for a lifetime history of mania and hypomania (Mitchell et. al., 2010). Furthermore, the result of a recent study conducted by Yu Ting Wang (2008), reports that patients who score higher than 2 points in the first section of the MDQ and have been diagnosed with depression, should be followed up more closely for a possible BD diagnosis. Thus, routinely utilizing questionnaires such as this when conducting a diagnostic interview with a patient who displays symptoms of depression, or other disorders commonly co-occurring with BD, may assist an accurate diagnosis. This particular questionnaire takes approximately two minutes to complete and would therefore not necessarily require an increase in time needed for diagnostic interviews, which would have financial implications for patients.

Lastly, as mentioned at the beginning of this chapter, BD is both a complex and contradictory disorder with a myriad of factors affecting its diagnostic likelihood. This complexity has been discussed at length already, some of which echoes other findings on this topic, and some of which is new and therefore contributes novel findings to the body of literature that already exists. However, the contradictory nature of BD is something that has not yet been reported on and appears to be important in helping to address the difficulty faced by clinicians diagnosing this disorder. More specifically, the majority of existing literature provides best practice guidelines to increase the likelihood of early detection and accurate treatment of BD. However, this literature focusses on common trends in diagnostic and treatment patterns, as well as typical ways in which the disorder itself manifests.

What this study has found, however, is that within a sample population of 12 participants, all diagnosed with BD, no two diagnostic journeys were the same. While there were certainly common trends that echo what existing literature has been pointing out for decades already, there were just as many unique outcomes, ambiguities, and contradictions to the ‘norm’. It is therefore plausible, under the new broad umbrella of the bipolar spectrum, that there is so much variance in the way BD manifests and is experienced by patients, that any attempt to focus purely on commonalities for simplification of diagnostic processes will continue to perpetuate the cycle of misdiagnosis that this disorder has been trapped in for decades. For this reason, my final recommendation is for future research to focus on these contradictions, ambiguities and ‘outliers’, as therein may lie new and unique insights that could assist in better understanding, diagnosing and treating BD in generations to come.

Limitations

This study is the first to offer an insight into the intricacies of BD and its trajectory as experienced by a sample of South African patients. To date, very little is known about this disorder in the African and South African contexts. As such, it serves as a stepping stone towards a more nuanced understanding of BD and the systems that patients find themselves in that affect their diagnostic journeys and the diagnosis of BD overall in a South African context. It does not purport to be a conclusive effort, but should rather be seen as a tool advancing a more robust dialogue on a topic that is in dire need of further attention.

Furthermore, this study was limited to the experiences of patients who have been diagnosed with BD. It is acknowledged that this is only one of the puzzle pieces of a complex clinical disorder. Thus, in order to paint a clearer picture of the diagnostic process and enhance further understanding of the factors that shape and influence this process, clinicians should ideally be interviewed too.

Lastly, the use of semi-structured interviews, while useful in this study in the way it assisted me to stay focussed on the research questions during the participant interviews, could however be seen as a limitation. Indeed, a less structured approach to interviewing might yield very different results. Moreover, the data from this study is susceptible to a different type of analysis, such as discourse analysis, for example, that would pay closer attention to the language used by BD patients and how they construct meaning through the use of language.

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APPENDIX A

Diagnostic Criteria for Bipolar Disorder(s)

DSM-V: page 123 - 155

Manic Episode

A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy, lasting at least 1 week and present most of the day, nearly every day (or any duration if hospitalization is necessary).

B. During the period of mood disturbance and increased energy or activity, three (or more) of the following symptoms (four if the mood is only irritable) are present to a significant degree and represent a noticeable change from usual behaviour:

1. Inflated self-esteem or grandiosity.

2. Decreased need for sleep (e.g., feels rested after only 3 hours of sleep).

3. More talkative than usual or pressure to keep talking.

4. Flight of ideas or subjective experience that thoughts are racing.

5. Distractibility (i.e. attention too easily drawn to unimportant or irrelevant external stimuli), as reported or observed.

6. Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation (i.e., purposeless non-goal-directed activity).

7. Excessive involvement in activities that have a high potential for painful consequences (e.g. engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments).

C. The mood disturbance is sufficiently severe to cause marked impairment in social or occupational functioning or to necessitate hospitalization to prevent harm to self or others, or there are psychotic features.

D. The episode is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication, other treatment) or to another medical condition.

Note: A full manic episode that emerges during antidepressant treatment (e.g., medication, electroconvulsive therapy) but persists at a fully syndromal level beyond the physiological effect of that treatment is sufficient evidence for a manic episode and, therefore, a bipolar I diagnosis.

Note: Criteria A-D constitute a manic episode. At least one lifetime manic episode is required for the diagnosis of bipolar I disorder.

Hypomanic Episode

A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased activity or energy, lasting at least 4 consecutive days and present most of the day, nearly every day.

B. During the period of mood disturbance and increased energy and activity, three (or more) of the following symptoms (four if the mood is only irritable) have persisted, represent a noticeable change from usual behaviour, and have been present to a significant degree:

1. Inflated self-esteem or grandiosity.

2. Decreased need for sleep (e.g., feels rested after only 3 hours of sleep).

3. More talkative than usual or pressure to keep talking.

4. Flight of ideas or subjective experience that thoughts are racing.

5. Distractibility (i.e. attention too easily drawn to unimportant or irrelevant external stimuli), as reported or observed.

6. Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation.

7. Excessive involvement in activities that have a high potential for painful consequences (e.g. engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments).

C. The episode is associated with an unequivocal change in functioning that is uncharacteristic of the individual when not symptomatic.

D. The disturbance in mood and the change in functioning are observable by others.

E. The episode is not severe enough to cause marked impairment in social or occupational functioning or to necessitate hospitalization. If there are psychotic features, the episode is, by definition, manic.

F. The episode is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication, other treatment).

Note: A full hypomanic episode that emerges during antidepressant treatment (e.g., medication, electroconvulsive therapy) but persists at a fully syndromal level beyond the physiological effect of that treatment is sufficient evidence for a hypomanic episode diagnosis. However, caution is indicated so that one or two symptoms (particularly increased irritability, edginess, or agitation following antidepressant use) are not taken as sufficient for diagnosis of a hypomanic episode, nor necessarily indicative of a bipolar diathesis.

Criteria A-F constitute a hypomanic episode. Hypomanic episodes are common in bipolar I disorder but are not required for the diagnosis of bipolar I disorder.

Major Depressive Episode

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

Note: Do not include symptoms that are clearly attributable to another medical condition.

1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g. feels sad, empty, or hopeless) or observation made by others (e.g. appears tearful).

Note: In children and adolescents, can be irritable mood.

2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation).

3. Significant weight loss when not dieting or weight gain (e.g., a change of more than

5% of body weight in a month), or decrease or increase in appetite nearly every day.

Note: In children, consider failure to make expected weight gain.

4. Insomnia or hypersomnia nearly every day.

5. Psychomotor agitation or retardation nearly every day (observable by others; not merely subjective feelings of restlessness or being slowed down).

6. Fatigue or loss of energy nearly every day.

7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).

8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).

9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. The episode is not attributable to the physiological effects of a substance or another medical condition.

Note: Criteria A-C constitute a major depressive episode. Major depressive episodes are common in bipolar I disorder but are not required for the diagnosis of bipolar I disorder.

Bipolar I Disorder

A. Criteria have been met for at least one manic episode (Criteria A-D under "Manic Episode" above).

B. The occurrence of the manic and major depressive episode(s) is not better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified or unspecified schizophrenia spectrum and other psychotic disorder.

Bipolar II Disorder

A. Criteria have been met for at least one hypomanic episode (Criteria A-F under "Hypomanic Episode" above) and at least one major depressive episode (Criteria A-C under "Major Depressive Episode" above).

B. There has never been a manic episode.

C. The occurrence of the hypomanic episode(s) and major depressive episode(s) is not better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified or unspecified schizophrenia spectrum and ther psychotic disorder.

D. The symptoms of depression or the unpredictability caused by frequent alternation between periods of depression and hypomania causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Cyclothmic Disorder:

A. For at least 2 years (at least 1 year in children and adolescents) there have been numerous periods with hypomanic symptoms that do not meet criteria for a hypomanic episode and numerous periods with depressive symptoms that do not meet criteria for a major depressive episode.

B. During the above 2-year period (1 year in children and adolescents), the hypomanic and depressive periods have been present for at least half the time and the individual has not been without the symptoms for more than 2 months at a time.

C. Criteria for a major depressive, manic, or hypomanic episode have never been met.

D. The symptoms in Criterion A are not better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified or unspecified schizophrenia spectrum and other psychotic disorder.

E. The symptoms are not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition (e.g., hyperthyroidism).

F. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Substance / Medication-Induced Bipolar and Related Disorder:

A. A prominent and persistent disturbance in mood that predominates in the clinical picture and is characterized by elevated, expansive, or irritable mood, with or without depressed mood, or markedly diminished interest or pleasure in all, or almost all, activities.

B. There is evidence from the history, physical examination, or laboratory findings of both

(1) and (2):

1. The symptoms in Criterion A developed during or soon after substance intoxication or withdrawal or after exposure to a medication.

2. The involved substance/medication is capable of producing the symptoms in Criterion A.

C. The disturbance is not better explained by a bipolar or related disorder that is not substance/ medication-induced. Such evidence of an independent bipolar or related disorder could include the following:

The symptoms precede the onset of the substance/medication use; the symptoms persist for a substantial period of time (e.g., about 1 month) after the cessation of acute withdrawal or severe intoxication; or there is other evidence suggesting the existence of an independent non-substance/medication-induced bipolar and related disorder (e.g., a history of recurrent non-substance/medication-related episodes).

D. The disturbance does not occur exclusively during the course of a delirium.

E. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

With onset during intoxication: If the criteria are met for intoxication with the substance and the symptoms develop during intoxication.

With onset during withdrawal: If criteria are met for withdrawal from the substance and the symptoms develop during, or shortly after, withdrawal.

Bipolar and Related Disorder due to Another Medical Condition:

A. A prominent and persistent period of abnormally elevated, expansive, or irritable mood and abnormally increased activity or energy that predominates in the clinical picture.

B. There is evidence from the history, physical examination, or laboratory findings that the disturbance is the direct pathophysiological consequence of another medical condition.

C. The disturbance is not better explained by another mental disorder.

D. The disturbance does not occur exclusively during the course of delirium.

E. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning, or necessitates hospitalization to prevent hard to self or others, or there are psychotic features.

Other Specified Bipolar and Related Disorder:

This category applies to presentations in which symptoms characteristic of a bipolar and related disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning, predominate but do not meet the full criteria for any of the disorders in the bipolar and related disorders diagnostic class. The other specified bipolar and related disorder category is used in situations in which the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for any specific bipolar and related disorder. This is done by recording “other specified bipolar and related disorder” followed by the specific reason (e.g., “short duration cyclothymia”).

Examples of presentations that can be specified using the "other specified" designation include the following:

1. **Short duration hypomanic episodes (2-3 days) and major depressive episodes:** A lifetime history of one or more major depressive episodes in individuals whose presentation has never met full criteria for a manic or hypomanic episode but who have experienced two or more episodes of short duration hypomania that meets the full symptomatic criteria for a hypomanic episode but that only last for 2-3 days. The episodes of hypomanic symptoms do not overlap in time with the major depressive episodes, so the disturbance does not meet criteria for major depressive episode, with mixed features.
2. **Hypomanic episodes with insufficient symptoms and major depressive episodes:** A lifetime history of one or more major depressive episodes in individuals whose presentation has never met full criteria for a manic or hypomanic episode but who have experienced one or more episodes of hypomania that do not meet full symptomatic criteria (i.e. at least 4 consecutive days of elevated mood and 1 or 2 of the other symptoms of a hypomanic episode, or irritable mood and 2 or 3 of the other symptoms of a hypomanic episode). The episodes of hypomanic symptoms do no overlap in time with the major depressive episodes, so the disturbance does not meet the criteria for major depressive episode, with mixed features.
3. **Hypomanic episode without prior major depressive episode:** One or more hypomanic episodes in an individual whose presentation has never met full criteria for a major depressive episode or a manic episode. If this occurs in an individual with an established diagnosis of persistent depressive disorder (dysthymia), both diagnoses can be concurrently applied during the periods when the full criteria for a hypomanic episode are met.
4. **Short-duration cyclothymia (less than 24 months):** Multiple episodes of hypomanic symptoms that do not meet criteria for a hypomanic episode and multiple episodes of depressive symptoms that do not meet criteria for a major depressive episode that persist over a period of less than 24 months (less than 12 months for children or adolescents). In an individual whose presentation has never met full criteria for a major depressive, manic, or hypomanic episode and does not meet criteria for any psychotic disorder. During the course of the disorder, the hypomanic or depressive symptoms are present for more days than not, the individual has not

been without symptoms for more than 2 months at a time, and the symptoms cause clinically significant distress or impairment.

Unspecified Bipolar and Related Disorder:

This category applies to presentations in which symptoms characteristic of a bipolar and related disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the bipolar and related disorders diagnostic class. The unspecified bipolar and related disorder category is used in situations in which the clinician chooses *not* to specify the reason that the criteria are not met for a specific bipolar and related disorder, and includes presentations in which there is insufficient information to make a more specific diagnosis (e.g. in emergency room settings).

APPENDIX B

Interview Schedule (Bipolar Diagnosis Study):

1. **Introduction:** welcome respondent and thank them for their willingness to participate in the study.
    - Gather relevant background information from the respondent
        - **Prompts:** age; work; living situation; relationship status, religion / culture, family, children, support network, access to medical resources; psychologists / psychiatrists, emergency contact person; current diagnosis; first diagnosis; length of time diagnosed with BD.
    - **Opening question:** *When do you remember first feeling like something was wrong?*

2. **Diagnostic journey: (Create visual timeline with participant)**
    - **Prompt:** *When did you first get help for the problem(s) you were experiencing?*
        - Why then? What happened? What were repercussions? Did diagnosis change? Who changed it? When? Agree or disagree?
        - Continue same process through all changes / new diagnoses to current diagnosis and situation in 2015.

3. **Perception of missed opportunities?**
    - **Prompt:** *Do you think that, looking back now in retrospect, there were any opportunities for things to have been done differently?*
        - By whom? Why? What part did they have to play in any misdiagnosis / changed diagnosis that may have taken place? How long have they felt this way? Have they ever told this to anybody else? Contextual factors?

4. **Opportunities to improve diagnostic system:**
    - **Prompt:** *As you look back now over your journey through mental illness over the past …. years, can you think of anything that could have been done better, that would have resulted in less suffering for you?*

- **Prompt:** *If you were a psychiatrist or a doctor, what would you do differently to what you've experienced with your Bipolar Diagnosis?*
    - Why? What effect would this have?

Appendix C

Informed consent form for participation in a research study

University of Cape Town

Researcher: Claire Battiston-Weggelaar

Topic: Understanding the diagnostic process of Bipolar Disorder from the patient's perspective

Reference Number: ___________________________

Dear Patient

You are invited to take part in a research study that will be conducted by Claire Battiston in partial fulfilment of her Masters' degree in Clinical Psychology at the University of Cape Town (UCT).

Study Purpose:

The purpose of this research study is to better understand the diagnostic process experienced by people who have been diagnosed with Bipolar Disorder (any type of Bipolar Disorder). The researcher believes, through her own personal experiences, that patients have valuable insight regarding this diagnostic process that could assist medical professionals and clinicians in preventing misdiagnosis, or "missed opportunities", to diagnose Bipolar Disorder accurately in the future. This is why you have been asked to take part in the study.

Study Procedures - What will I be asked to do?

- If you agree to participate in this study, you will be asked to take part in an individual interview that will last approximately 60 minutes. If the researcher has any follow up questions afterwards, she may contact you about arranging a second meeting at a later stage.

- The interview will take place at the place where you are now. You will not be required to travel anywhere else.
- The interview will contain several questions about your journey with Bipolar Disorder. For example, the researcher is particularly interested in things such as:
    - What prompted you to seek professional help in the first place?
    - Who was the first professional person that helped you? (A psychologist; psychiatrist; medical doctor)
    - What was the very first diagnosis that you received, and how did you feel about this?
    - Did your diagnosis change at all along the way? If so, what did it change to, who changed it, and why?
    - Did you agree with any changes made to your diagnosis? Why so, why not?
    - Looking back now, do you think there might have been a better way of doing things?
- Your name will not appear on any record. This will be kept strictly confidential at all times before, during, and after the interview process. Only the place of interview will be noted. You will receive a number to identify your interview.
- With your permission, the researcher would like to record the interview so that she can later transcribe and analyse it. The interview will be recorded with an application on the researcher's iPhone called *Pocket Dictate Scribe*. The researcher will upload the interview from her cell phone to her personal computer for safe keeping, immediately after the interview ends. The audio file on her cell phone will then be deleted immediately. All information that you disclose during your interview will be kept strictly confidential and nobody other than the researcher and her thesis supervisor will have access to the interview data.

Possible risks or inconveniences:

Some of the questions that you are asked during the interview may make you aware of some difficult feelings you may have about your diagnostic journey and/or your Bipolar diagnosis. If at any stage you feel uncomfortable or too emotional to continue the interview, please tell the researcher so that she can stop the interview. In the unlikely case of this happening, the researcher will assist you to make contact with a person of your choice who could help you resolve any difficult emotions you may be experiencing (you will be asked at the beginning of your interview to give the name and contact number of someone you trust that you or the researcher could contact in case of an emergency).

Further than that, the time it takes to complete the interview (approximately 1 hour) may be an inconvenience.

Possible benefits:

There are no direct benefits to you if you choose to participate in this study, but we hope that information gained through your and other similar peoples' experiences will help us to answer some important questions about the diagnostic process of Bipolar Disorder and how this could be made better in the future. Also, it is possible that you will learn new insights into your own past experiences which you might fight enlightening and rewarding.

Alternatives:

Participation in this study is completely voluntary and you have only two options: to participate, or not to participate. If you choose rather not to participate, there will be no negative consequences at all for you. Furthermore, you have the right to pull out of the study at a later stage down the line if you change your mind. If you decide not to participate any more, you will still be able to attend the Bipolar Support Group where you met the researcher. No matter what happens with this study, you will always be allowed to continue participating in the Bipolar Support Groups as long as you want to.

Payment:

You will not be paid for participating in this study. It is a voluntary study and if you choose to participate, you will have to incur your own travel costs in order to get to the interview. The researcher will arrange a place for the interview that is most suitable for you, but will not be able to pay for your transport, or pay you for your time, unfortunately.

Voluntary Participation:

If you choose to participate in this study, it is completely voluntary. You are free to refuse to answer any question. You decision regarding participation in this study will not affect your access to the Bipolar Support Group. As mentioned above, you are free to change your mind about participation at any time without it having any negative consequences.

Distress:

If you decide to participate in this study, the researcher will ask you questions about your experiences of Bipolar Disorder in the interview. During the interview, if you feel that you are becoming too distressed or too emotional to continue with the interview, please tell the researcher immediately. The researcher will then stop with the interview and will help you to make contact with the person you choose as your emergency contact person (this will be asked of you at the beginning of the interview, and you will be required to provide the name and contact number of someone that the researcher can contact in an emergency situation). The researcher will stay with you until your chosen emergency person can come and assist you. If need be, the researcher will take you to your chosen emergency person, if they are unable to come to you.

Confidentiality:

Information about you from this study will be kept anonymous. You will be given a reference number right from the start, which the researcher will use to identify you throughout the study. All personal information that you disclose during this study will be kept strictly confidential and will not be shared with anyone else except for the researcher’s supervisor, who is bound by a strict ethical code of conduct and may not disclose any confidential information contained in this study to anyone else. The supervisor is a senior staff member in the Psychology Department at UCT with many years of experience on this type of research.

The interviews with the researcher will be recorded using the researcher’s iPhone, which has a programme called *Pocket Dictate Scribe* loaded on it, for the purpose of recording interviews. As soon as your interview is finished, the researcher will upload the recording from her phone to her private computer, and the recording will be deleted from her phone immediately. All recordings and study data will be kept in a password protected file on the researcher’s computer that nobody else will have access to. All of the voice recordings will be deleted immediately after it has been transcribed by the researcher. The final research thesis that will be written from the results of this study will NOT contain any personal or identifying information about you or anyone that you talk about in your interview. The same applies to any later reports or publications that may make use of the results of this study.

Questions:

Any study-related questions, problems, or emergencies, should be directed to the following researchers:

Mrs. Claire Battiston (researcher)	-	072 355 8460
Dr. Sally Swartz (supervisor)	-	021 650 3902

If you have any concerns about the way the study was conducted, or your rights as a participant, please feel free to contact the Department of Psychology at UCT on 021-650 3435.

Participant's Informed Consent:

I have had all of the information contained in this form explained to me, and I understand this explanation. My questions about this study have been answered. I hereby voluntarily consent to participate in this research study.

____

Name and Surname of Participant

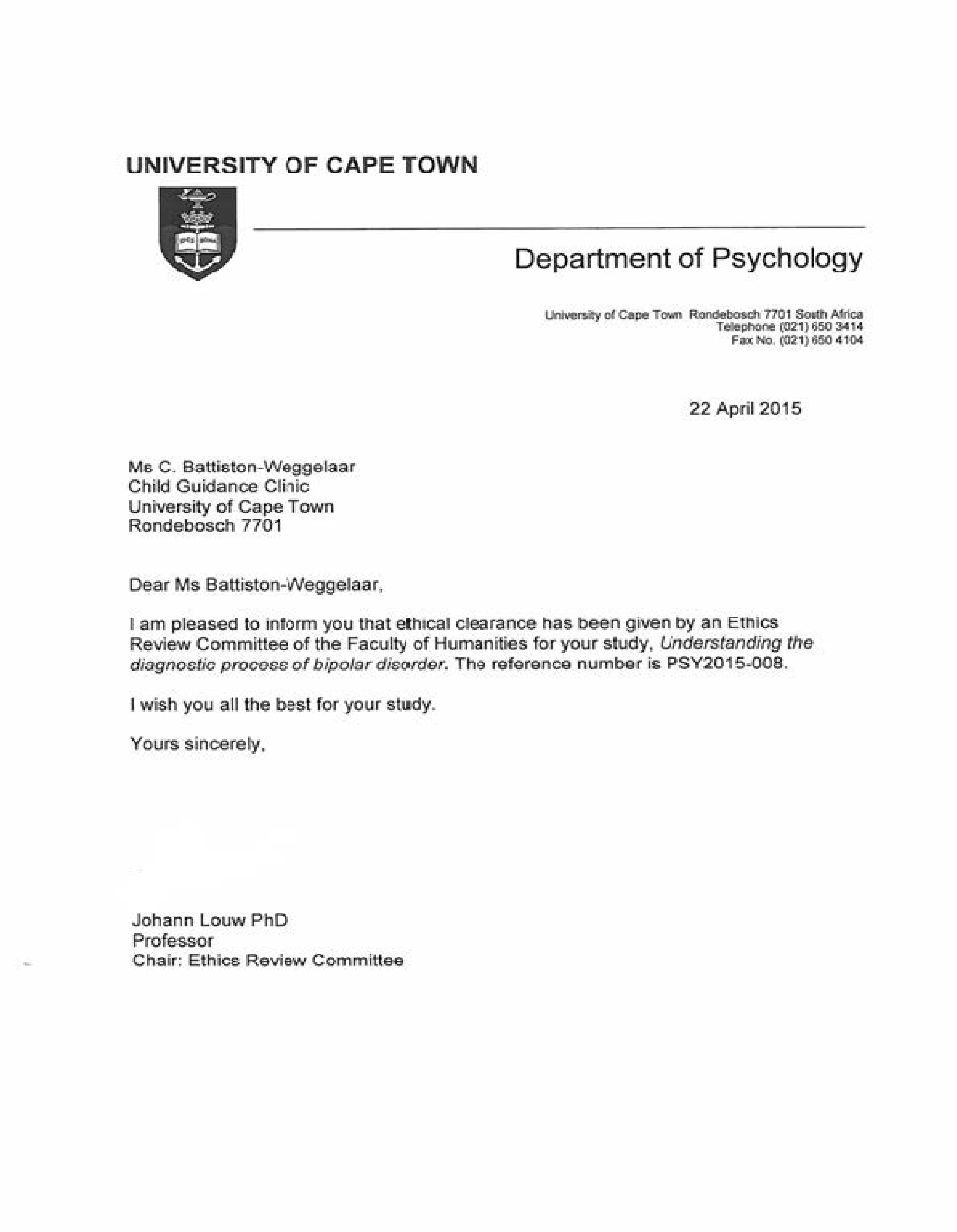
____

Signature of Participant

____

Date

APPENDIX D: ETHICS APPROVAL FROM UCT



UNIVERSITY OF CAPE TOWN

Department of Psychology

University of Cape Town Rondebosch 7701 South Africa
Telephone (021) 650 3414
Fax No. (021) 650 4104

22 April 2015

Ms C. Battiston-Weggelaar
Child Guidance Clinic
University of Cape Town
Rondebosch 7701

Dear Ms Battiston-Weggelaar,

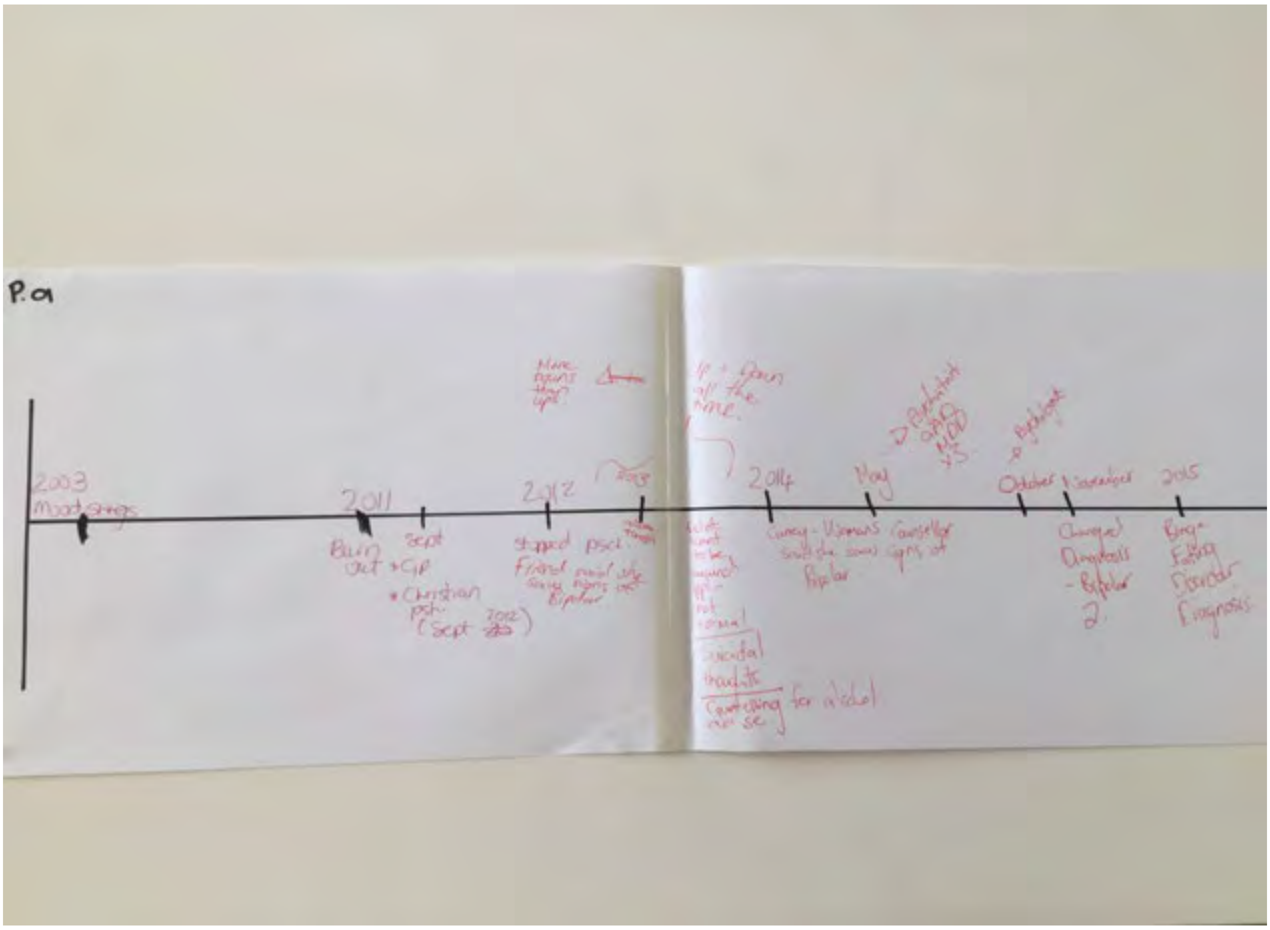
I am pleased to inform you that ethical clearance has been given by an Ethics Review Committee of the Faculty of Humanities for your study, *Understanding the diagnostic process of bipolar disorder*. The reference number is PSY2015-008.

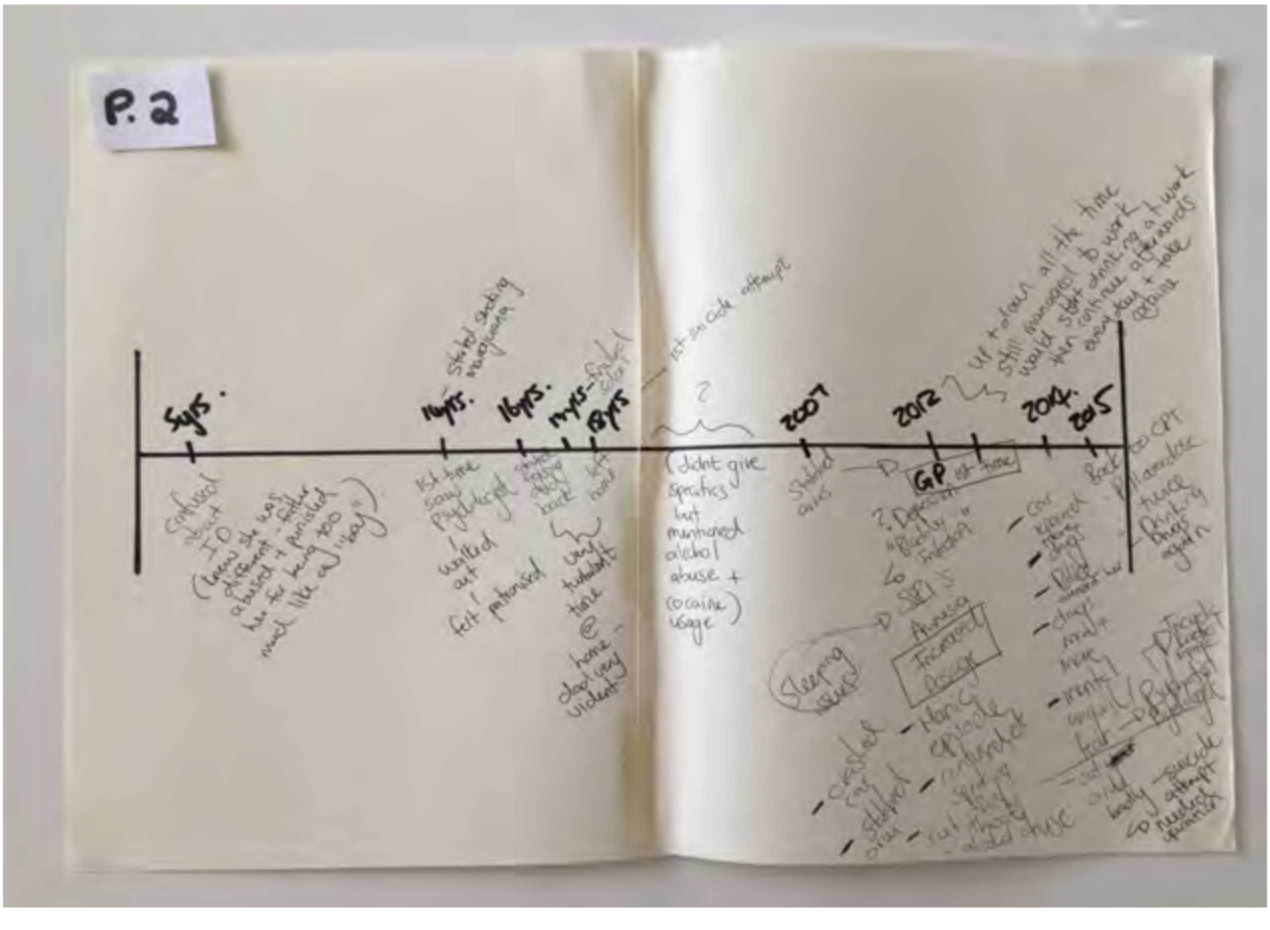
I wish you all the best for your study.

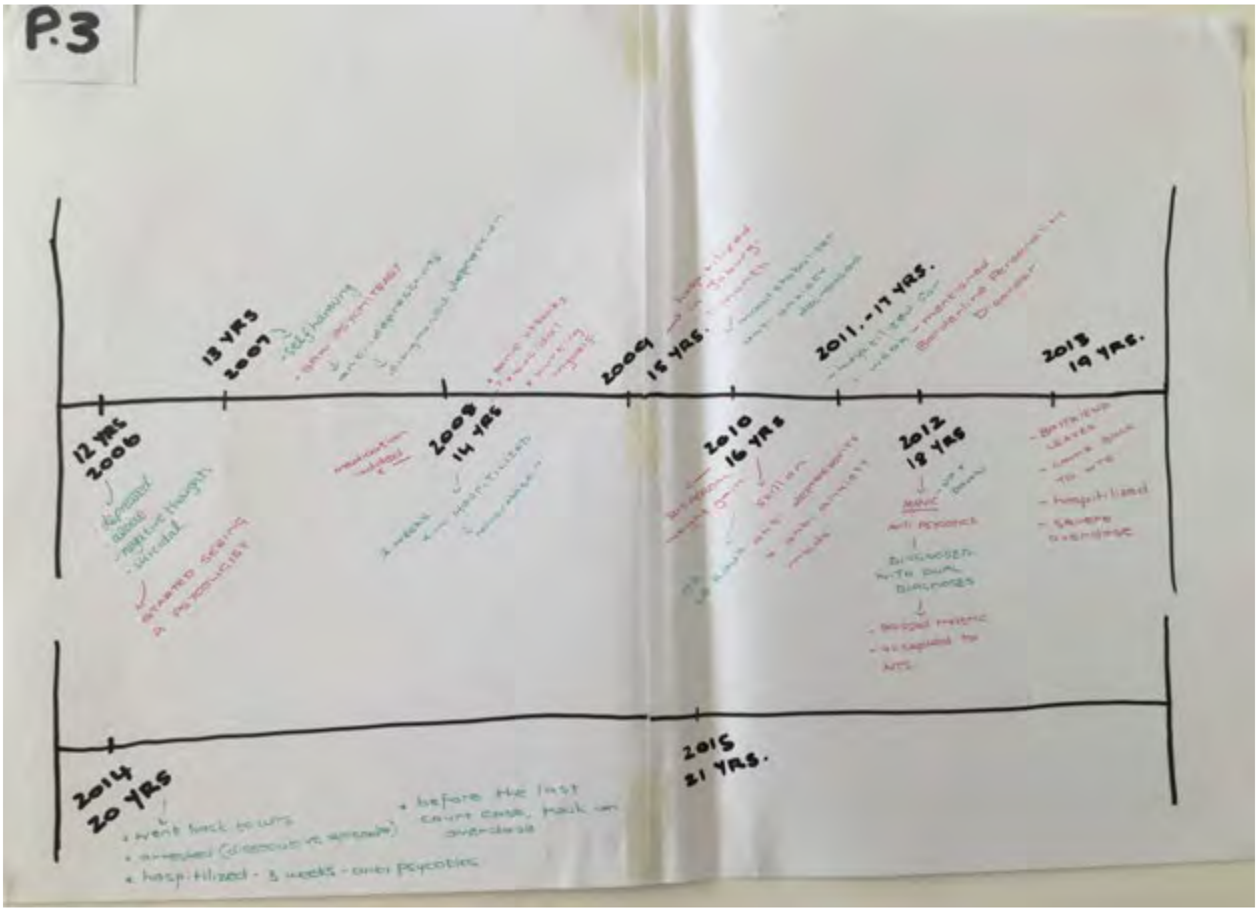
Yours sincerely,

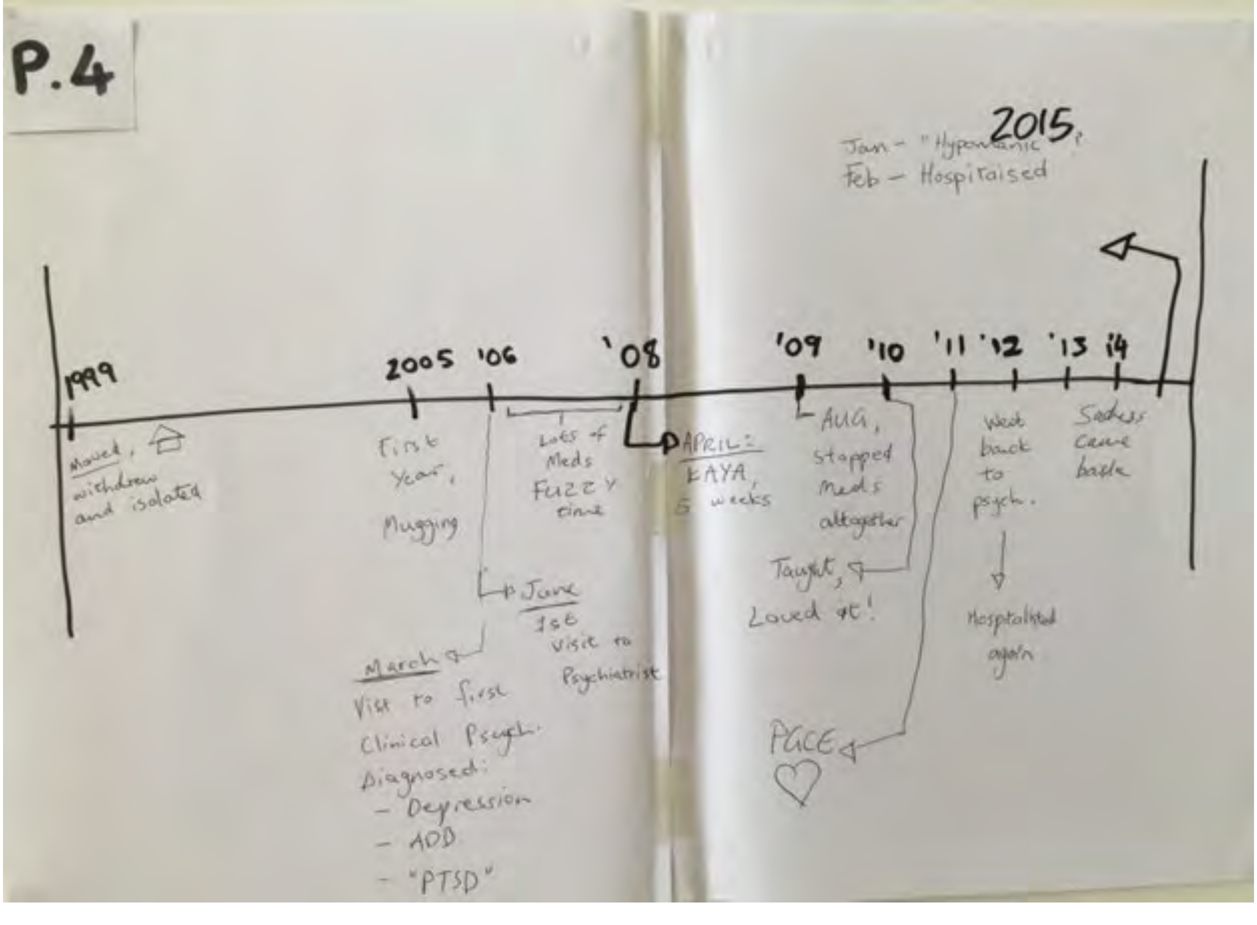
Johann Louw PhD
Professor
Chair: Ethics Review Committee

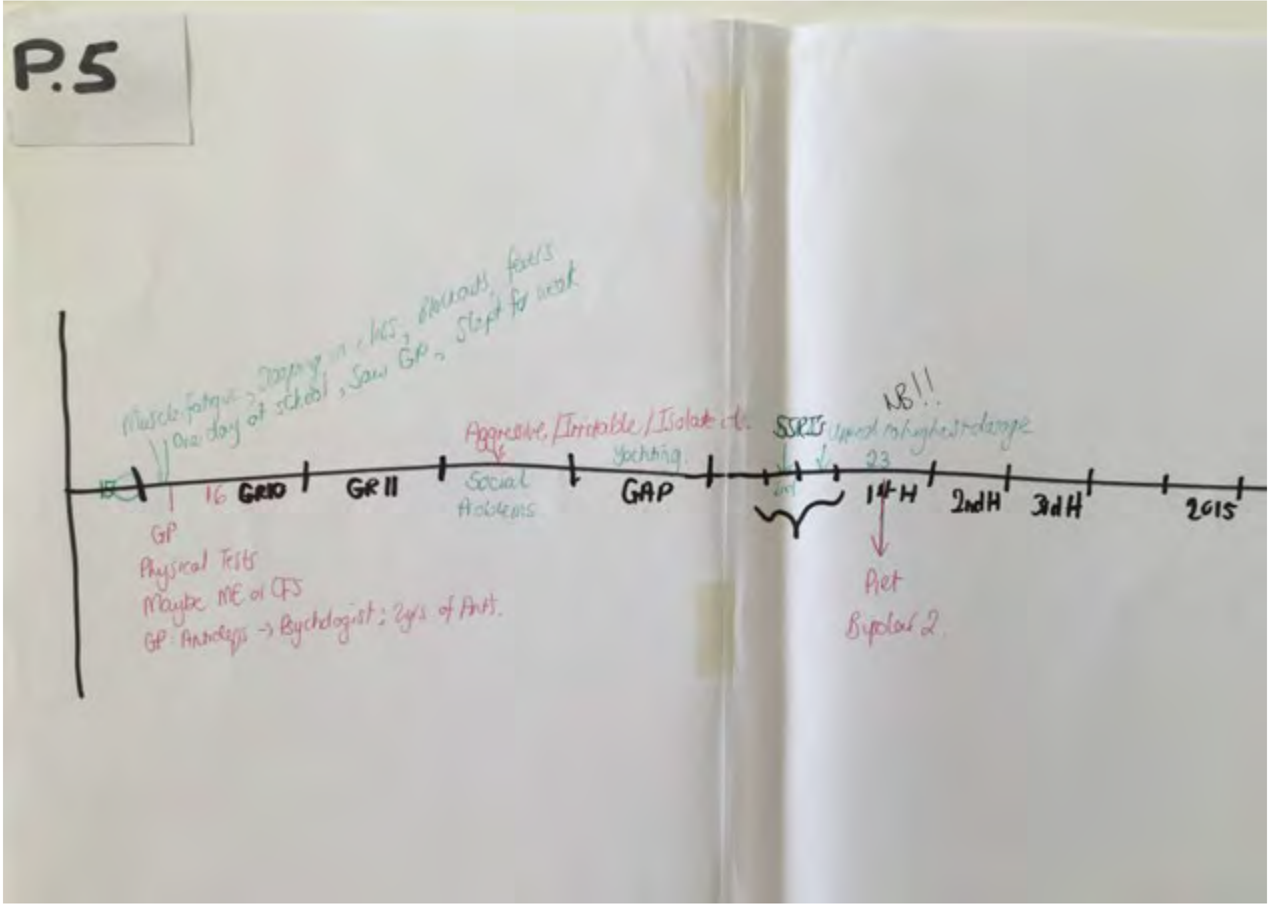
APPENDIX E: TIMELINES CONSTRUCTED WITH PARTICIPANTS

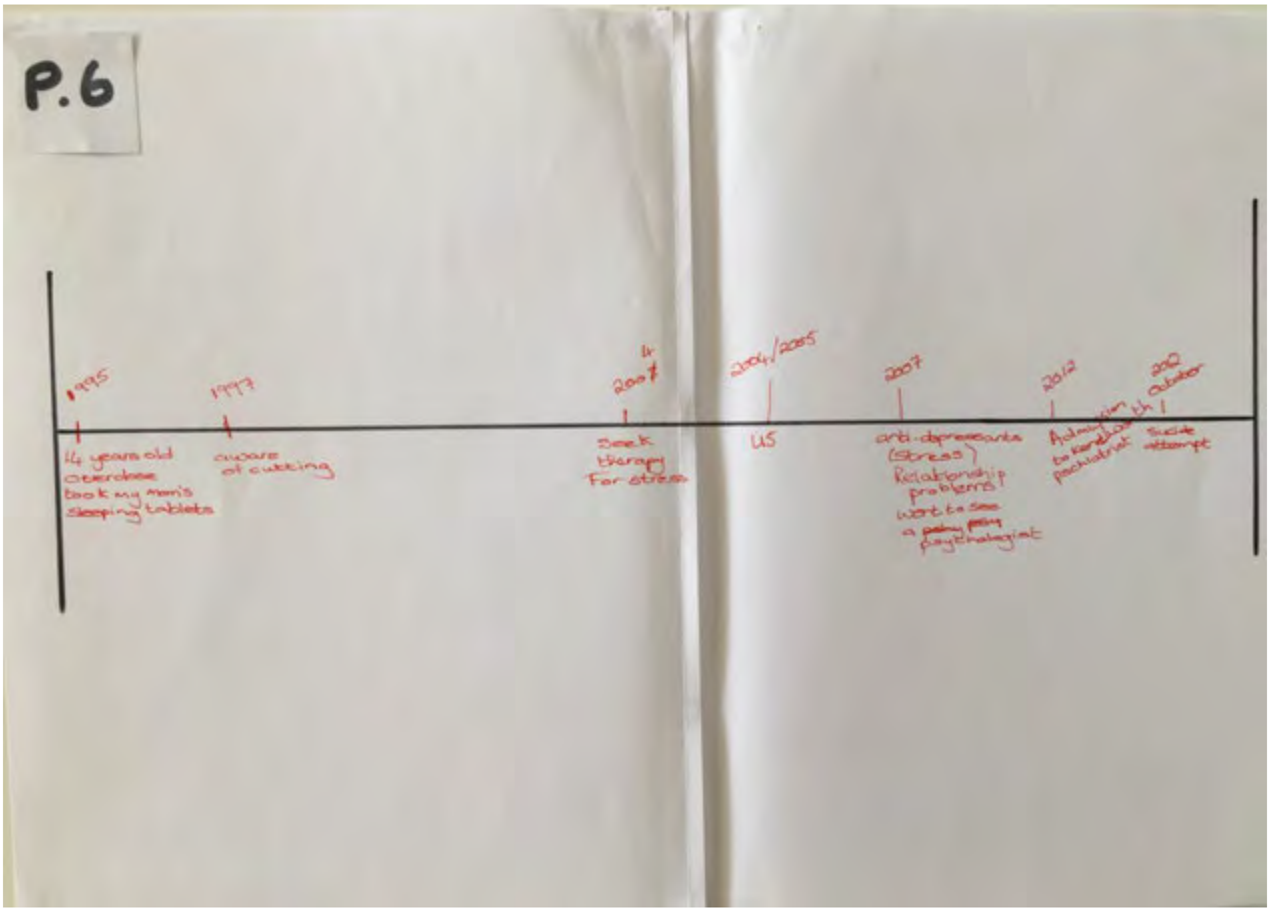


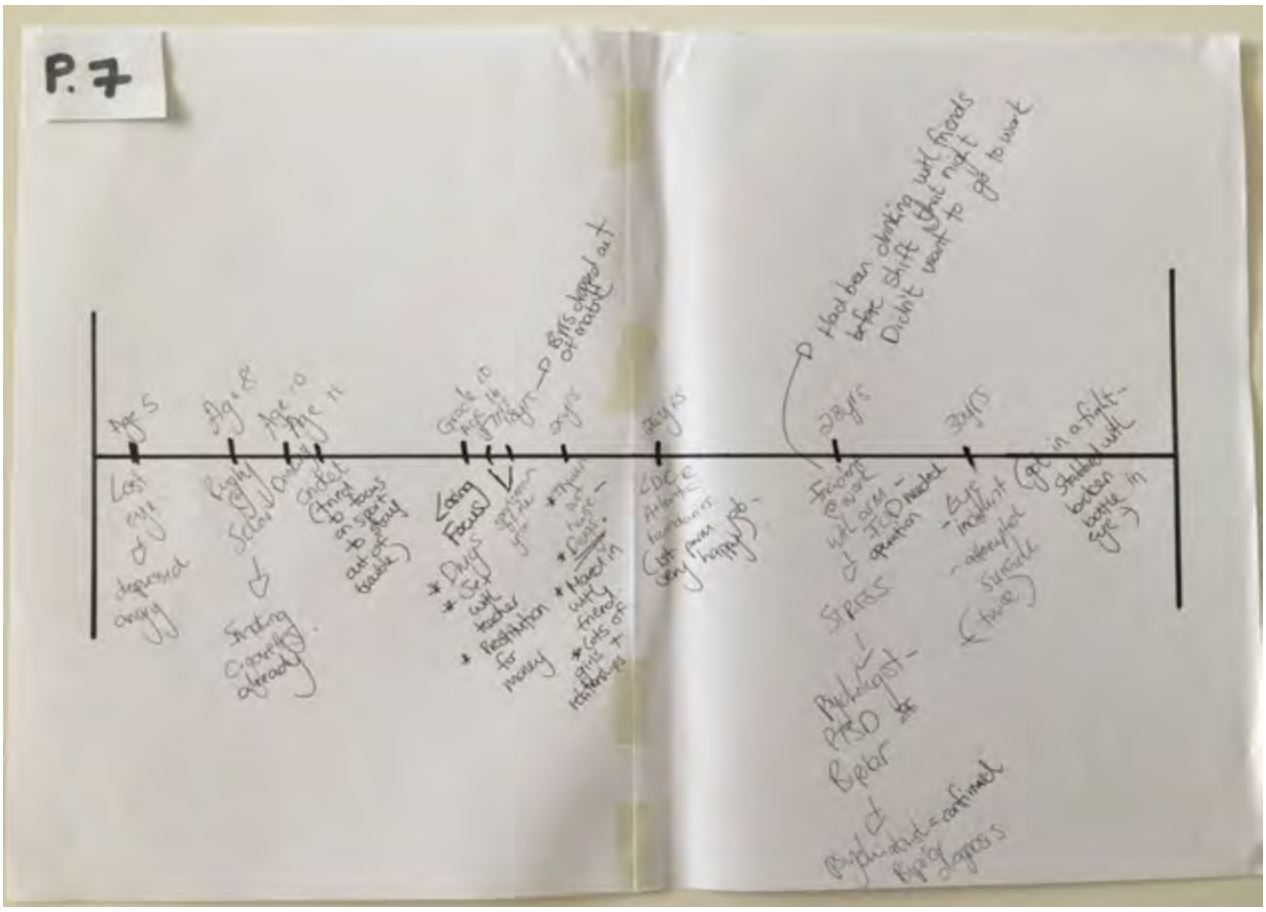


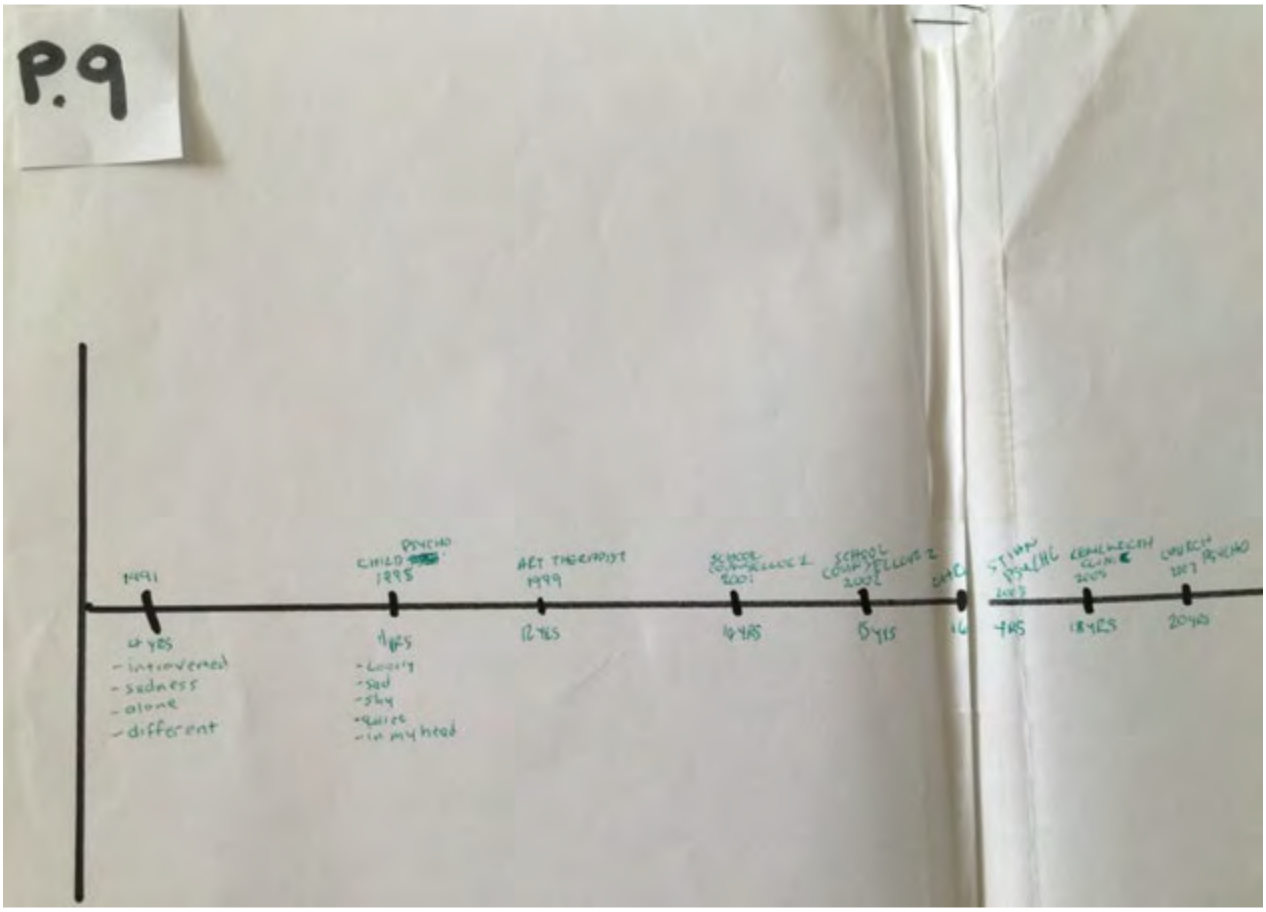

P.3
12 YRS 2006
- suicidal
- negative thoughts
STARTED SEEING A PSYCHOLOGIST
13 YRS 2007
· Self harming
2008 14 YRS
2009 15 YRS.
2010 16 YRS
2011. - 17 YRS.
Borderline Personality Disorder
2012 18 YRS
MANIC
ANTI PSYCHOTICS
DIAGNOSED WITH DUAL DIAGNOSES
2013 19 YRS.
- BOYFRIEND LEAVES
- hospitilized
- SEVERE OVERDOSE
2014 20 YRS
• hospitilized - 3 weeks - anti psycotics
• before the last court case, took an overdose
2015 21 YRS.

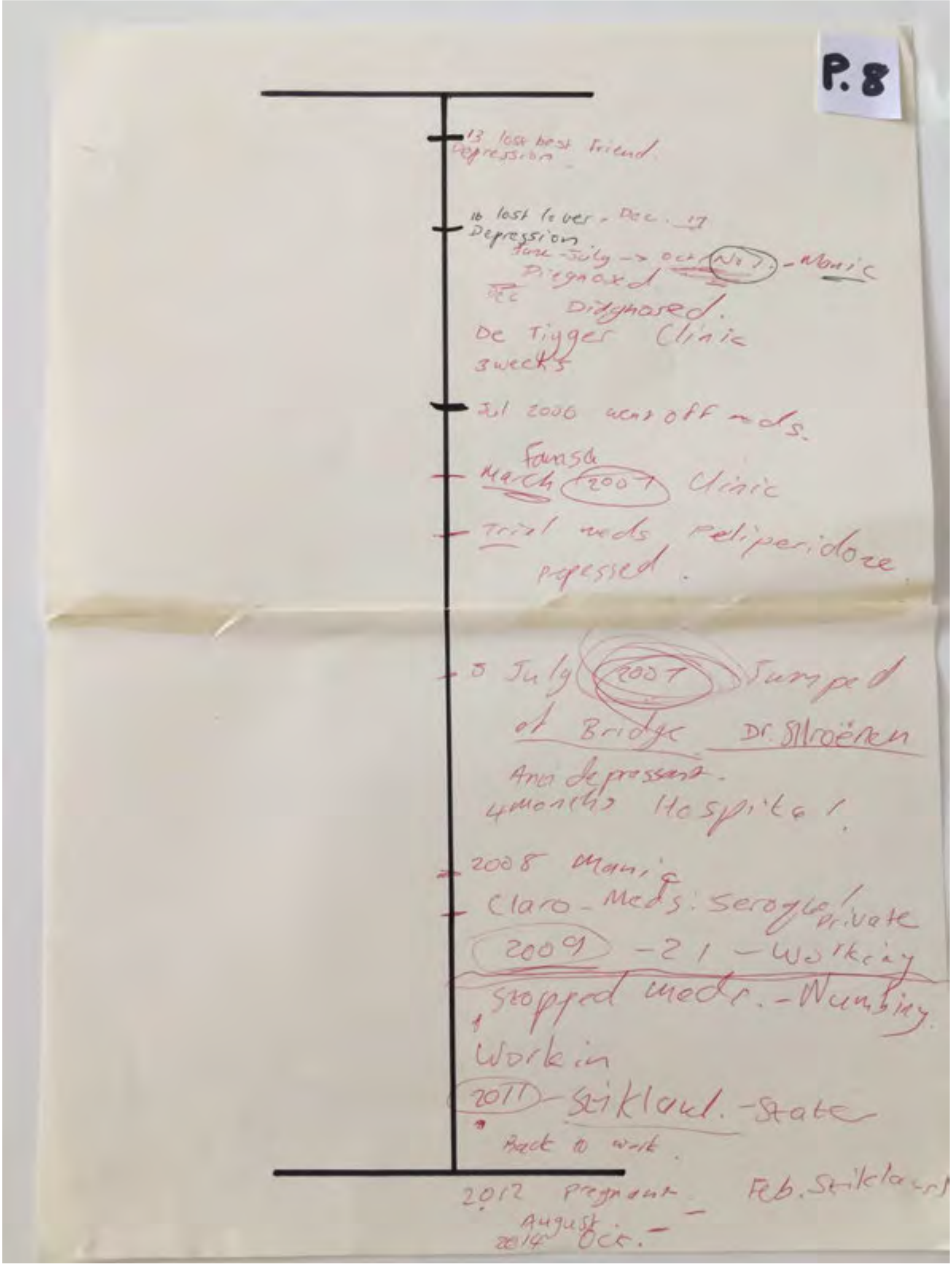

P.4
1999
Moved, withdrew and isolated
2005
First Year, Mugging
'06
March
Visit to first Clinical Psych.
Diagnosed:
- Depression
- ADD
- "PTSD"
June 1st visit to Psychiatrist
Lots of Meds Fuzzy time
'08
APRIL: KAYA, 5 weeks
'09
AUG, stopped meds altogether
'10
Taught, Loved it!
PACE
♡
'11
'12
Went back to psych.
Hospitalised again
'13
'14
Sadness came back
2015
Jan - "Hypomanic"
Feb - Hospitalised


P.5
Muscle fatigue, sleeping in class, blackouts, fevers
One day at school, Saw GP, slept for week
15
16
GR10
GR11
GAP
Aggressive / Irritable / Isolate etc.
Social Problems
Yachting
SSRIs
NB!!
upped to highest dosage
23
1st H
2nd H
3rd H
2015
GP
Physical Tests
Maybe ME or CFS
GP Antidep → Psychologist; 2yrs of Anti.
Piet
Bipolar 2


P.6
1995
14 years old
overdose
took my mom's
sleeping tablets
1997
aware
of cutting
2004
Seek
therapy
For stress
2004/2005
US
2007
anti-depressants
(Stress)
Relationship
problems?
went to see
a ~~psy~~ ~~psy~~
psychologist
2012
Admission
to Kenilworth
pschiatrist
2012
October
th
Suicide
attempt


P.7
Age 5
Lost eye
depressed
angry
Age 8
Right of School
Smoking cigarettes already
Age 10
Age 11
Cadet
Grade 10
Age 16
Losing Focus
* Drugs
* Sex with teacher
* Prostitution for money
20yrs
* Moved in with friend
* Lots of girls + relationships
BYRS dropped out of matric
24yrs
CDCE Atlantic
(Got paid very happy job)
28yrs
Had been drinking with friends before shift that night
Didn't want to go to work
Stress
Psychologist
PTSD
Bipolar
Psychiatrist = confirmed Bipolar diagnosis
34yrs
Eye incident
attempted suicide (twice)
Got in a fight
stabbed with broken bottle in eye


P.9
1991
4 YRS
- introverted
- sadness
- alone
- different
CHILD PSYCHO
1995
4 YRS
- Lonely
- sad
- shy
- voices
- in my head
ART THERAPIST
1999
12 YRS
SCHOOL COUNSELLOR 1
2001
14 YRS
SCHOOL COUNSELLOR 2
2002
15 YRS
16
PSYCHO
2003
YRS
18 YRS
CLINIC
2005
CHURCH PSYCHO
2007
20 YRS



P.8

13 lost best friend.
Depression

16 lost lover - Dec. 17
Depression
June-July -> Oct (No 7.) - Manic
Pregnant
Dec Diagnosed.
De Tijger Clinic
3weeks

Jul 2006 went off meds.

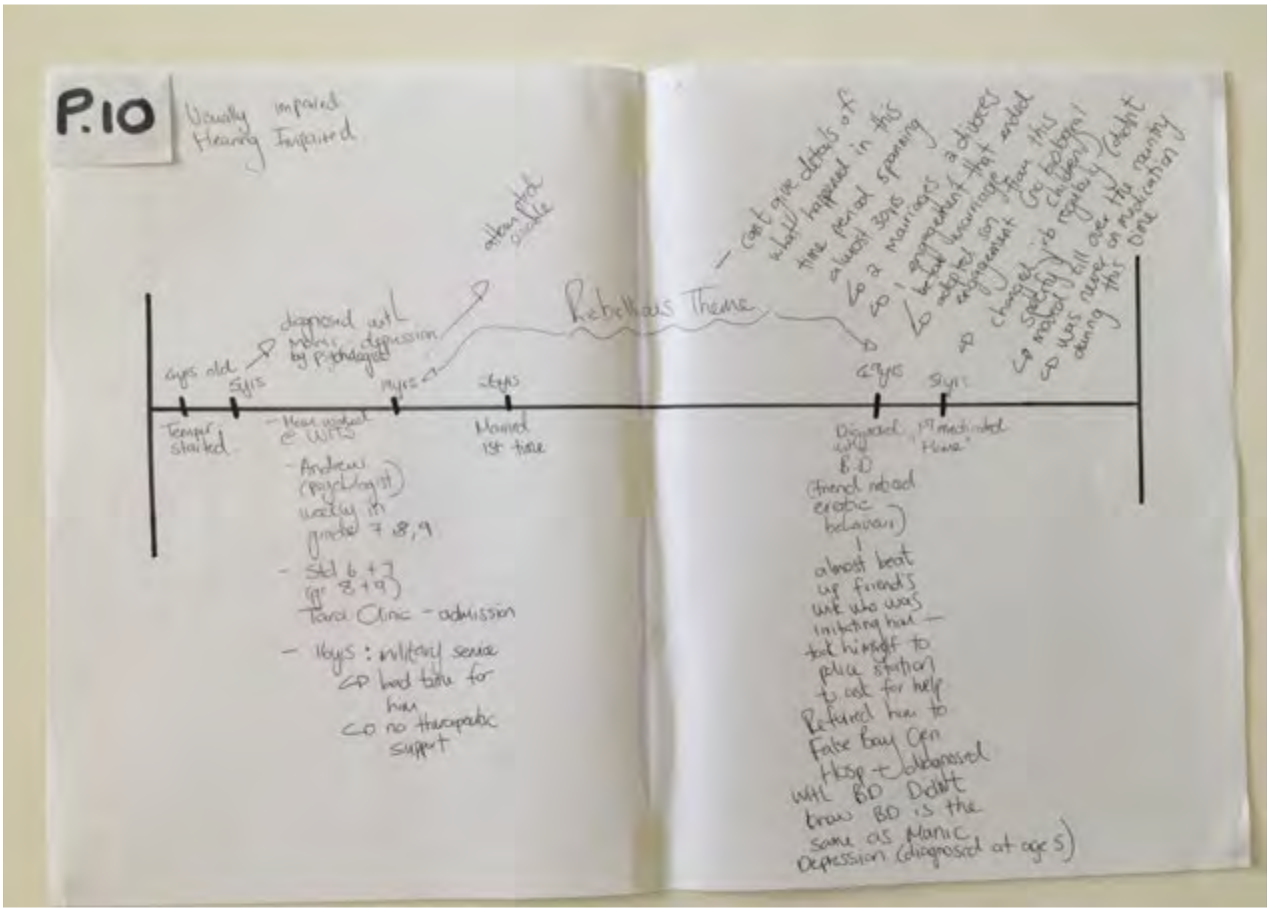
Fausa
March 2007 Clinic

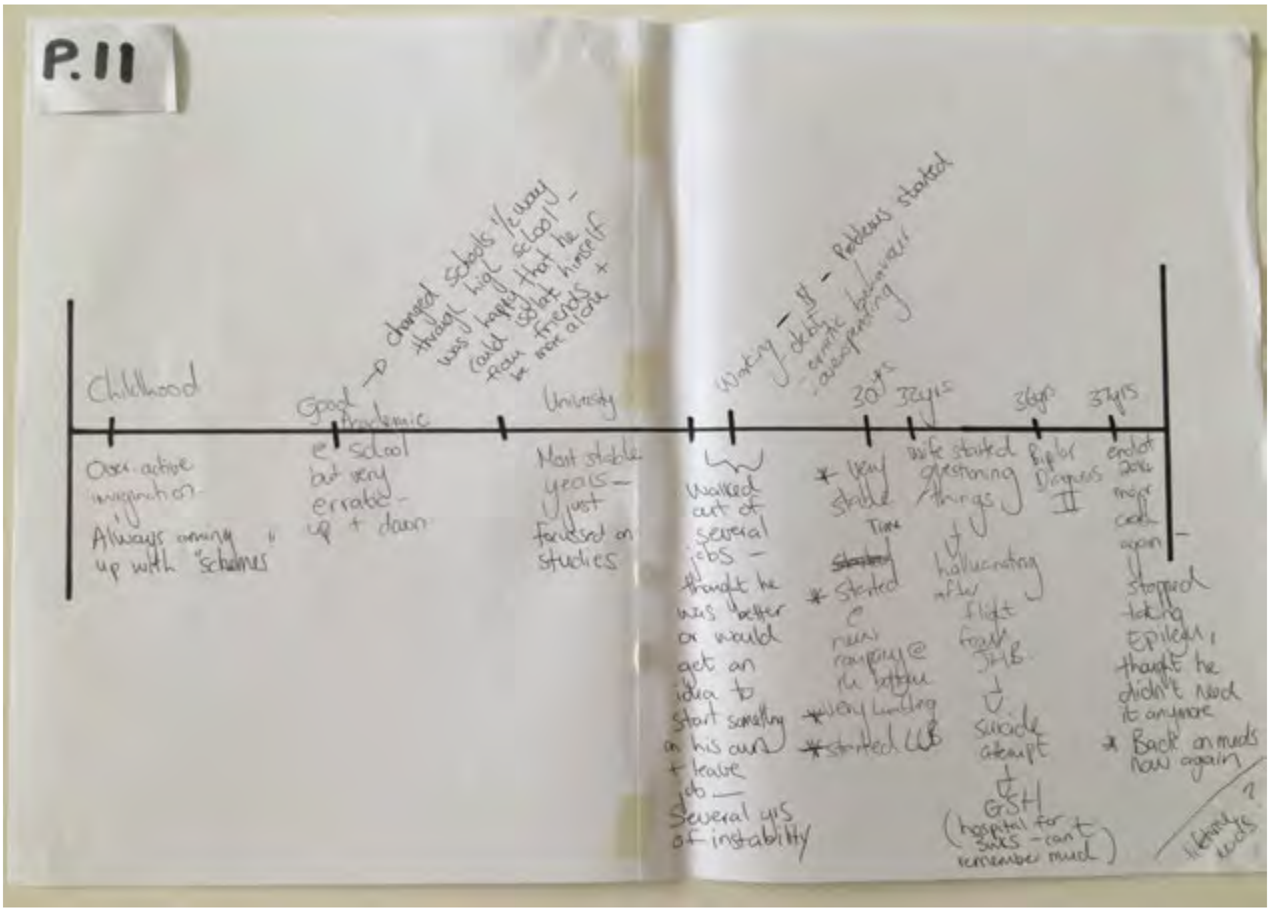
Trial meds Peliperidoze
Depressed.

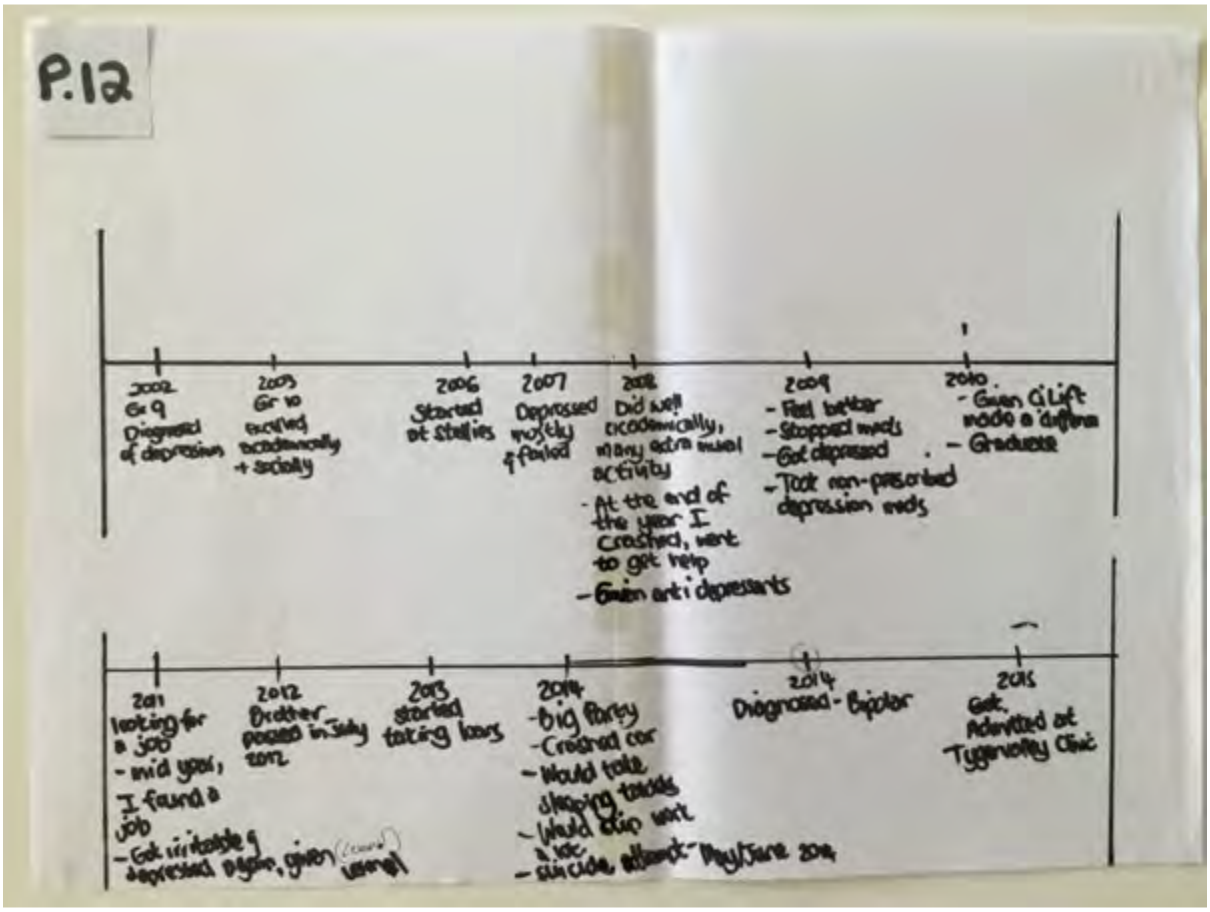
5 July 2007 Jumped of Bridge Dr. Sllroënen
Anti depressant.
4months Hospital.

2008 Manic
Claro - Meds: Serogle / Private
2009 - 21 - Working
Stopped meds. - Numbing
Workin
2011 - Stikland. - State
Back to work.

2012 Pregnant - Feb. Stikland
August 2014 Oct. -


P.10
Visually impaired
Hearing Impaired
4yrs old
5yrs
diagnosed with manic depression by psychologist
attempted suicide
14yrs
26yrs
Rebellious Theme
49yrs
51yrs
Temper started
- Hearing worked @ WITS
- Andrew (psychologist) working in grade 7, 8, 9
- Std 6 + 7 (gr 8 + 9) Tara Clinic - admission
- 16yrs: military service → bad time for him → no therapeutic support
Married 1st time
- can't give details of what happened in this time period spanning almost 30yrs
→ 2 marriages, 2 divorces
→ 1 engagement that ended
→ adopted son ([illegible] marriage)
→ engagement from this (no biological children)
→ changed job regularly
→ specifically (didn't [illegible])
→ moved till over the country
→ was never on medication during this time
Diagnosed with B.D (friend noticed erratic behaviour) almost beat up friend's wife who was irritating him - took himself to police station to ask for help. Referred him to False Bay Gen Hosp + diagnosed with BD. Didn't know BD is the same as Manic Depression (diagnosed at age 5)
1st medicated "Home"


P.11
Childhood
Over-active imagination
Always coming up with "schemes"
Good Academic @ school but very erratic - up + down
→ changed schools ½ way through high school - was happy that he could isolate himself from friends + be more alone
University
Most stable years - just focused on studies
Working - debt - erratic behaviour, overspending - 18 - Problems started
Walked out of several jobs - thought he was better or would get an idea to start something on his own + leave job - Several yrs of instability
30yrs
* Very stable Time
~~Started~~
* Started @ new company @ the [illegible]
* Very limiting
* Started LLB
32yrs
Wife started questioning things
hallucinating after flight from JHB.
suicide attempt
GSH (hospital for 3wks - can't remember much)
36yrs
Bipolar Diagnosis II
37yrs
end of 2016 major [illegible] again
Stopped taking Epilim, thought he didn't need it anymore
* Back on meds now again
[illegible] meds ?



P.12

2002
Gr 9
Diagnosed
of depression

2003
Gr 10
excelled
academically
+ socially

2006
Started
at Stellies

2007
Depressed
mostly
& failed

2008
Did well
academically,
many extra mural
activity
- At the end of
the year I
crashed, went
to get help
- Given anti depressants

2009
- Feel better
- Stopped meds
- Got depressed
- Took non-prescribed
depression meds

2010
- Given CiLift
made a differna
- Graduate

2011
looking for
a job
- mid year,
I found a
job
- Got irritable &
depressed again, given [illegible] Lexamil

2012
Brother
passed in July
2012

2013
started
taking loans

2014
- Big Party
- Crashed car
- Would take
sleeping tablets
- Would skip work
a lot
- suicide attempt - May/June 2014

2014
Diagnosed - Bipolar

2015
Got
Admitted at
Tygervalley Clinic

APPENDIX F: LETTER RECEIVED FROM PARTICIPANT'S MOM

Subject:

From:
Sent: 13 May 2015 01:28 AM
To:
Subject: .

J has had a long history of problems, starting when she was in primary school.
Compulsive eating was the beginning of it
Then hiding behind books, once the reading bug set in
This led to withdrawal and anti social behaviour at home and school
She never made any friends although always desperate to have friends
Very lonely and stubborn and negative attention seeking

In high school the cutting started. We were called in quite often by the school councillor who were worried. I took her to doctors and psychologists, but she never admitted that she had any kind of problem, always reclusive and when asked any question, her standard answer was I don't know. She never liked any of the people that were trying to help her, became even more of a hermit and her weight escalated during this time as well.

In her matric year she went to Kenilworth Clinic, mainly to support her brother I think, who kept on running away from there. KC was not the right place for her, or her brother, as most young adult there had drug issues, which thank goodness is not something either of them had.

Then she started at CPUT, wanting to become a teacher. All the while she was still cutting and being ill far too often, psychosomatic symptoms which were of course investigated, but never showed any medical reason. She would get very angry with me, sullen and unresponsive.

I cant remember at what age she started seeing the psychologist from the church, where she was very active in the worship team, and also a psychiatrist- who then emigrated to Canada. During this time various meds were tried and this is then also when she started to overdose, and then tell me when I came home from work at 10pm as to what she had done. Then it was a rush to go to a hospital, but they don't deal with self inflicted stuff. She also still cut herself, deeper these days, and a few times she landed in hospital to be stitched up – and sometimes the doctor on duty would be downright rude- but then Joanne was still seeking negative attention.

At one stage she landed up at GSH – I never got to speak to anybody treating her there, she was referred to the psych unit and had to see the doc, but the doc then told her that she must pull up her socks, as there was nothing wrong with her. Needless to say, that did not go down too well and she never went back.

Then she got to Dr G – who took over from the one that went to Canada. He was very into giving in to his patients, to the point where she could pull the wool over his eyes. During this time she landed in Crescent Clinic, where her mood swings were very up and down, often all different types of moods within a day. I began reading up on mental illness, trying to make some sense of all of this, as well as becoming increasingly more frustrated as no one would listen to me and as far as J s health was concerned, little improvement could be seen. She even broke her glasses while in crescent clinic and scratched herself to ribbons with the broken frame. It was during this time that I ASKED Dr G if she wasn't possibly bipolar, and he answered that bipolar people are on an up for an extended period of time, and then on a down for an extended period of time, and J s moodswings would take place within a day. He was thinking more in line of a personality disorder. So we battled along, ran out of money, as medical aid would not pay anymore,

which is when I insisted that she now be referred to Valkenberg. That took a while, but finally it happened. Even there she ??pretended?? to be a different person – up and down, in a good mood in a bad mood etc. By this stage she was so doped up with meds that she could hardly have functioned and again had been in and out of hospital numerous times with tummy aches, headaches, nausea etc, having scans and bloodwork and what have you done- and of course never a physical cause was found.

Dr G also insisted that she must live on her own, has to have a dog and all sorts of other conditions. I told him that we were in no position to do that, as finances were such that it was near to impossible to pay another x amount out of a budget that was way overstretched. J has not earned sufficient money in any month that she could sustain herself, has no drivers liscence let alone the means in which to get to doctors etc. At the time she then moved into the granny flat, she got her dog but things went according to my prediction. All enthusiastic for a very short time span, then the wheels fell off and once again she would either spend the majority of time in the main house, and the granny flat went to rack and ruin, to the point where the place was invaded by bugs. We were of course losing out on a tenants rent. After a few months, J moved back into the main house, and we could rent out the granny flat again.

At Valkenberg, they then decided she was schizophrenic, and she was duly treated as such. Again though, most people that were there had problems relating to drugs, which of course did not touch on her problems. Eventually, Valkenberg decided that they had mis diagnosed her, but couldn't give her a diagnosis other than that she suffered from depression!! This annoyed her as well as myself – She wanted to go back to G , but by then she was on the keycare program and G was not one of the keycare doctors, also I did not think that he had done her any good. That is when she landed up with Dr C , and on his first consult with her – he said he thought she was bipolar and would need to get the meds under control.

There have of course been many ups and downs since then and even to this day J spends most of her day in her room in bed, not being very cooperative nor participating when it come to doing things in the house. This I find extremely frustrating as I still get the feeling it is all about her, with little consideration towards her father or I who are still battling financially, my husband having been out of work for 3 years before finally getting a job that at least generates some income.

J does not take proper care of herself as far as hygiene goes, she appears not to have any drive or pride in herself, and when things go wrong-the wheels fall off. She is still very stubborn and head strong. She is very talented in so many different avenues, but does not have the confidence to persevere and get ahead. Yet she is my firstborn, and with all my kids – now adults- dearly loved by myself and her father.

There is of course much more that I could tell you, but I hope that I have been able to give you some insight.

Kind Regards