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Post-Psychosis Trauma and non-adherence in Bipolar I Disorder with psychotic features: patients and their families in Gauteng.

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Post-Psychosis Trauma and non-adherence in Bipolar I Disorder with psychotic features:

Patients and their families in Gauteng.

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The report is submitted in partial fulfilment of the requirements for the Degree of Doctor of Philosophy in the Faculty of Humanities at the University of Witwatersrand.

August 2019

DECLARATION

I declare that this thesis is my own, unaided work. It is being submitted for the degree of Doctor of Philosophy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination in any other University.

.....Bongiwe Mahlobo.....

.....01.....day of August 2019

Signature.....

DEDICATION

“Being confident of this, he who began a good work in me, shall bring it to completion” Philippians 1: 6

Emmanuel

To the one who knew me before he formed me in my mother’s womb, the one who predestined it all and made available and accessible all the special individuals who partook and helped in this wonderfully challenging journey, I thank you God.

ACKNOWLEDGEMENTS

My Mother, Nobantu thank you for believing in me and supporting me.

My children: NtandokaJehova and ThandolukaJehova, thank you for being my ‘sonshine’ and ‘diamond’.

My family: Grandfather, grandmother, Dr and Mrs Motlafi, sister and father, thank you for praying for me and encouraging me.

All the academics, friends and colleagues: I appreciate the opportunity to conduct this study as well as your support and critical feedback, from which I grew.

All the participants: this is about you and for you, none of it would exist without you.

My supervisor: thank you for your guidance.

Chris Hani Baragwanath Academic Hospital nurses, clerks, cleaners, psychologists, social workers, and doctors. I salute you.

ABSTRACT

Medication non-adherence continues to be one of the biggest challenges in the treatment of psychotic disorders. Bipolar I Disorder with psychotic features is no exception as treatment non-adherence is associated with longer term disability and poorer outcomes. Research has attempted to explore predictors of non-adherence with mixed findings. Concurrent with this research have been findings that suggest that psychotic episodes may be extremely distressing and potentially traumatic for patients and their support systems alike. Given the critical role that family members play in the care of people with Bipolar I Disorder with psychotic features, it is important to explore whether this distress is potentially a post-trauma PTSD, and whether this has any impact on drug adherence. This research particularly aimed to explore and document whether or not patients diagnosed with Bipolar I Disorder with psychotic features and their family members experience clinical threshold PTSD after psychotic episodes as well as whether this Post-Psychosis Trauma is associated with treatment adherence. Thirty-five patients and family member dyads (n=70) were recruited to participate in the study. A mixed methods design was employed to gain a better understanding of Post-Psychosis Trauma and non-adherence in the identified population. Using a measure of PTSD, the quantitative portion of the research explored whether there were clinical-threshold symptoms of Post-Psychosis Trauma in the participants. A secondary aim was to explore whether or not the experience of Post-Psychosis PTSD (PP/PTSD) would be associated with treatment adherence status (non-adherent vs adherent). The results found that clinical-threshold Post-Psychosis Trauma was present in 78.6% (n=55) of the total sample. Both patients and family members experienced PP/PTSD, with fewer participants presenting with an absence of PP/PTSD, supporting the first hypothesis of this research. However, no significant association was found between Post-Psychosis Trauma and non-adherence. Participant perceptions indicated that other factors contributing to non-adherence included poor insight, denial, confusion, and altered cognitions. Further, persistent negative emotional states including fear, anger, guilt and shame in relation to psychosis played a major role in how the patients perceived themselves and how they were perceived by those around them.

Key Terms: Adherence; Post-Psychosis Trauma; Bipolar I Disorder; Family Members.

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1. CHAPTER ONE: INTRODUCTION

1.1 Introduction and Rationale

One of the greatest challenges in the treatment of psychiatric illness is adherence to treatment. Research has highlighted treatment challenges and the impact of non-adherence to both the course and the prognosis of the disorder (Garcia et al., 2016). The treatment of psychosis remains particularly challenging (Kane, Kishimoto & Correll, 2013), especially in patients with a prominent mood disorder diagnosis. Research attempting to identify risk factors for non-adherence in the treatment of psychotic disorders has proliferated and is well-documented in a recent systematic review of 38 studies conducted in a total of 51,796 patients, written by Garcia et al. (2016). This review found that factors such as younger age, poor insight, substance misuse, cognitive impairment, lower education level, lower socio-economic status and intensity of paranoid delusions were some of the most robust predictors of non-adherence in the treatment of psychosis (Garcia et al., 2016). However, much of this research focuses on challenges to drug adherence in the treatment of psychotic disorders, with less focus on understanding adherence in mood disorders with psychotic features.

Literature has highlighted the need to improve medication adherence in the treatment of mood disorders with psychotic features, as poorly managed psychotic episodes are associated with poor prognosis (Gleeson et al., 2008; Tsang, Fung & Corrigan, 2006). It is therefore critical to investigate factors associated with poor prognosis. Mental illness has been identified as one of the leading contributors to South Africa's rising burden of chronic disease (Marais & Petersen, 2015). The South African Stress and Health (SASH) Study, conducted between 2002 and 2004, remains the only source providing nationally representative data on the prevalence of mental disorders in the country. From this, mood disorders, including Bipolar Disorder, were found to be the third most common mental disorders in South Africa, following Anxiety Disorders and Substance Use Disorders (Herman et al., 2009).

Evidence suggests that, with treatment, long-term disability and high costs of treatment in inpatient settings can be greatly reduced (Gleeson et al., 2008; Tsang et al., 2006). Bipolar I Disorder with Psychotic Features presents a very complicated clinical picture that incorporates unstable mood (depressive and manic episodes, irritability) as well as psychosis (American

Psychiatric Association, 2013). The synergistic combination of manic, depressive and psychotic episodes can be extremely challenging for the patient and their family, in some cases, the experience of psychosis in addition to the other symptoms can be traumatic.

Post-Psychosis Trauma entails PTSD symptomatology secondary to the experience of a psychotic illness (Lundy,1992). High rates of PTSD in severe mental illness have been noted in multiple studies, together with psychosis in patients with PTSD (Auxemery & Fidelle, 2011; Gliko, 2004; Lundy,1992; Shaw, McFarlane, Bookless & Air, 2002). Although there is some evidence attesting to a link between trauma and the experience of a psychotic episode, a considerable portion of the evidence is questioned and not classified as sufficiently evidence-based. Additionally, the directionality of this link is unclear, as the experience of traumatic events can serve as a stressor that triggers a pre-existing diathesis (vulnerability) for psychosis (Garcia et al., 2016). A need for further research in this area has been highlighted, as it will improve management and treatment of psychotic disorders.

Rodrigues and Anderson (2017) conducted a meta-analysis that found that a large proportion (up to 42%) of patients presenting with first-episode psychosis, regardless the diagnosis, evidenced symptoms consistent with traumatization and PTSD. They called for trauma-treatment to be included with patients presenting with first-episode psychosis. Post-Psychosis Trauma has rarely been studied in the literature and this meta-analytic review presented valuable insights from isolating and studying this phenomenon.

The deinstitutionalisation of mental-health care services has led to the burden of care for people with mental illness often resting with family members (Glyngdal, Sorensen & Kistrup, 2002). It is important to explore whether family members also experience the episode of psychosis as traumatic and whether this then impacts on their capacity to facilitate in the care of their loved ones, particularly as it pertains to drug adherence. Given that avoidance is one of the key symptoms of posttraumatic stress, unacknowledged, and unaddressed traumatization can therefore, at least in theory, pose challenges in treatment. The present study will particularly focus on exploring drug adherence as it pertains to Bipolar I Disorder with Psychotic Features. The first aim will be to document whether South African patients and their caregivers experience psychosis in Bipolar I Disorder as traumatic, as well as explore whether this is associated with drug adherence or not.

2. CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction to literature review

Human behaviour and underlying determinants or motivators can be extremely challenging to research. One of the greatest challenges is the highly complex interaction of multiple critical factors that influence areas of interest. As opposed to an attempt to isolate otherwise related factors, a process of embracing different facets co-occurring within a specific population is necessary. The different areas of interest in the present study have been individually structured for discussion within the literature review to facilitate optimum comprehension. This review unpacks three critical areas, the first being Bipolar I Disorder with Psychotic Features, as this is the key diagnosis for participants in the study. The second area is Post-Psychosis Trauma, which will unpack constructs such as Posttraumatic Stress Disorder (PTSD), trauma and psychosis-related trauma. The third area is treatment non-adherence. All three areas include factors influencing both patients and their family members, and these will be discussed accordingly.

2.2 Bipolar I Disorder

Bipolar I Disorder is one disorder that is significantly increasing the burden on the health care system. The average age of onset for both males and females was estimated to be 20 years, with no reports of differential incidence based on ethnicity or race (American Psychiatric Association, 2000). In the latest Diagnostic and Statistical Manual of Mental Disorders (DSM 5), the onset of the first Bipolar I Disorder mood disturbance episode was estimated to commence earlier, on average at approximately 18 years (American Psychiatric Association, 2013).

In addition to earlier development, research shows an increase in the global burden exerted by the illness. According to the World Health Organisation (WHO) global burden of disease 2004 update, Bipolar Disorder was estimated to be the 7th leading global cause of years lost due to disability for males, and the 8th for females worldwide. Additionally, it appeared as one of the

top 20 mental illnesses leading causes of disability globally (WHO, 2008). Bipolar Disorder forms part of the predominant mental health problems worldwide. In the UK, it was estimated that Bipolar Disorder affects 2.4 million people (NICE, 2014). According to the Global Burden of Disease Study (2015), estimated global trends for Bipolar Disorders showed a 14.9% increase in total Disability-Adjusted Life-Years (DALYs) from 2005 to 2015. In South Africa, Bipolar Disorder is recorded as one of the top five causes of mental health disability (Jack et al., 2014).

2.2.1 Diagnosis of Bipolar I Disorder

Bipolar I Disorder is a severe psychiatric disorder with a recurrent, cyclical and lifelong course (American Psychiatric Association, 2013). Studies that have looked at the aetiology of Bipolar Disorder have identified biological, genetic, and psychosocial factors as implicated in the development of the disorder. It is best understood as a syndrome characterised by the presence of mood symptoms that mark a significant difference in an individual's habitual functioning over weeks or months (Sadock & Sadock, 2015). The individual's sense of control is lost, and distress is experienced (American Psychiatric Association, 2013).

For an individual to be diagnosed with Bipolar I Disorder, a distinct period of persistent mood disturbance is observed. The degree of mood disturbance presence must be significant, with noticeable change from that person’s normal behaviour (American Psychiatric Association, 2013). According to the DSM 5, to be diagnosed with Bipolar I Disorder, an individual must experience a manic episode and meet the required criteria for such, they may also experience psychosis or a major depressive episode in their lifetime. Individuals experiencing a major depressive episode present with five or more of the following symptoms within a two-week period: loss of interest or pleasure in daily activities (anhedonia), self-reported or observable depressed mood most of the day, decreased or increased appetite or significant weight gain/loss, hypersomnia or insomnia, observable psychomotor retardation or agitation, low energy, feelings of worthlessness or inappropriate guilt, poor concentration and thoughts of death or suicide (American Psychiatric Association, 2013). In contrast, when experiencing a manic episode, the individual presents with symptoms such as grandiosity, expansive or elevated mood, flight of ideas, increased energy, decreased need for sleep, distractibility,

talkativeness, inflated self-esteem, over-involvement in activities with high risk for negative consequences, and increased goal-directed activity or psychomotor agitation. An individual whose manic symptoms are not severe enough to cause impairment in occupational or social functioning, and has no psychotic features, is said to have hypomania (American Psychiatric Association, 2013). Bipolar I Disorder is therefore diagnosed when a person has a history of at least one manic episode. While a history of major depressive episodes is not a diagnostic requirement for Bipolar I Disorder anymore, many patients with the disorder do present with a history of major depressive episodes and it is rare to find patients who only present with the mania (American Psychiatric Association, 2013).

Although the exact prevalence rates are not known, Bipolar Disorder is thought to affect up to 3-4% of the South African population (*SADAG,* n.d.). Despite its high prevalence, research indicates that it is poorly recognised and difficult to diagnose, with misdiagnosis occurring on average 3.5 times before a correct diagnosis is made (NICE, 2014). In Bipolar I Disorder, a manic episode may be preceded or followed by major depressive episodes. A major depressive episode must last at least two weeks, while a manic episode must last at least one week or any duration if requiring hospitalisation (American Psychiatric Association, 2013). The disturbance in mood must not be attributable to the physiological effects of substances such as drugs or medication. Lastly, other areas of functioning that are affected include cognitive abilities, speech, and vegetative functions, impairing interpersonal, social and occupational functioning (Sadock & Sadock, 2015).

Bipolar I Disorder and Bipolar II Disorder are mainly distinguished as follows: while the former is characterised by a clinical course of one or more manic episodes and sometimes depressive episodes, the latter is characterised by a clinical course of one or more major depressive episodes and hypomania with no history of mania (American Psychiatric Association, 2013). Bipolar I Disorder may be diagnosed for a single manic episode, or a specific type of recurrent episode, such as most recent episode (depressed or mixed), depending on the symptoms of the most recent episode (American Psychiatric Association, 2013).

2.2.2 Bipolar I Disorder with psychotic features

Psychosis may be understood as grossly impaired reality testing, whereby an individual may incorrectly evaluate the accuracy of their thoughts and perceptions, making incorrect inferences about external reality, even when faced with contradictory evidence. Different terms are used to categorise experiences during psychosis. These include delusions, where the patient develops rigidly held false beliefs about the self or others; and hallucinations, where the patient may have distorted sensory experiences such as hearing, seeing, or feeling things that are not actually there. The patient may also present with bizarre behaviour and formal thought disorder (Sadock & Sadock, 2015).

A psychotic patient may present with affective flattening (a severe reduction in emotional expression), alogia (a lack of meaningful speech), and/or avolition (an inability to be goal oriented or take action). Patients may be poorly groomed, demotivated and socially withdrawn. Additionally, psychosis may include Schneiderian symptoms, a list of symptoms compiled by Kurt Schneider in 1939 and 1957, for the diagnosis of Schizophrenia (Tschoke, Uhlmann & Steinert, 2011). Schneiderian symptoms comprise; delusions of being controlled, mind reading, thought broadcasting, thought insertion and thought withdrawal (Carlson, Kotov, Chang, Ruggero & Bromet, 2012). These symptoms can be observed in severe trauma disorders such as Dissociative Identity Disorder (DID), Borderline Personality Disorder (BPD) and Posttraumatic Stress Disorder (PTSD) (Tschoke et al, 2011). This may pose a challenge to clinicians who may struggle to accurately diagnose a patient.

Delusions and hallucinations have been viewed as characteristic for Schizophrenia. However, these psychotic symptoms also occur in other psychiatric conditions such as depression, mania, dementia and chronic alcohol abuse. Psychotic symptoms in Bipolar I Disorder are experienced during severe manic or depressive episodes. One must specify whether the psychotic symptoms are mood-congruent, or mood-incongruent (American Psychiatric Association, 2013). If psychotic symptoms are mood congruent, it means that they are consistent with the presenting mood. For example, a depressed patient may hear voices (auditory hallucinations) saying that the patient is useless and worthless, which would be consistent with a low mood. In contrast, if psychotic symptoms are mood-incongruent, their content will be inconsistent with the presenting mood (American Psychiatric Association, 2013). Bipolar I Disorder may be

diagnosed with mood-congruent or with mood-incongruent psychotic features. For ease of reference, the present study will refer to "with psychotic features" as the two types of psychotic features will not be differentiated in this study.

While some patients may return to a previous level of functioning, others function reasonably well with some decline, and others experience substantial disability and suffering (American Psychiatric Association, 2000). A majority of individuals on treatment function well between episodes; however, it is estimated that 30% continue to experience mood lability and other residual symptoms, which then adversely affects their functioning (American Psychiatric Association, 2013). Different factors contribute to clinical outcomes. The presence of psychotic features in Bipolar I Disorder has been associated with poorer outcomes, which includes less adequate intermorbid functioning, more relapses and greater illness chronicity. Additionally, mood-incongruent psychotic symptoms have been associated with poor prognosis in Bipolar I Disorder (Marneros, Rottig, Rottig, Tscharntke & Brieger, 2009).

Bromet et al. (2005) identified factors associated with longer time to remission, including younger age of onset, history of childhood psychopathology, higher Brief Psychiatric Rating Scale (BPRS) depression or anxiety scores, i.e. severity of depression or anxiety symptoms at baseline, and use of medication during follow-up. Factors associated with shorter time to relapse included higher BPRS scores, higher Hamilton depression scores, admission episode not involving mania, depressive symptoms at re-admission, and childhood internalising type problems with symptoms of depression during childhood. They emphasise that these results may only be generalised to hospitalised patients with Bipolar Disorder with psychotic features (Bromet et al., 2005).

Carlson et al. (2012) investigated factors predicting clinical outcomes for patients admitted with Bipolar I Disorder psychotic features over a four-year period. In contrast to other studies, they found that mood incongruent psychotic features and age of mood disorder onset were not significantly associated with worse clinical outcomes. However, they also had some similar findings suggesting that childhood psychopathology, psychotic symptoms at baseline, depressive phenomenology, and younger age at first hospitalisation may be associated with worse outcome (Carlson et al., 2012). It is clear that individual characteristics of each patient

presenting with Bipolar Disorder are important in making the diagnosis, determining the prognosis and planning appropriate treatment strategies.

One other challenge in the management of both mood and psychotic disorders is that of suicidality. In a study looking into psychosis-related suicide, 40% of the participants responded that they had experienced suicidal ideation and 31% reported that they had attempted suicide as a result of their psychotic illness. Reasons provided for suicide attempts included depression, hopelessness, frustration, response to auditory hallucinations, and a desire to join a significant other who had died (Tarrier, Khan, Cater & Picken, 2007). A statistically non-significant but important association between PTSD and suicidality was that 58% of those who met PTSD criteria were suicidal, compared to 35% of those who did not. No significant associations were found between suicidal ideation and loss, change and disruption to life, reduction in hopes and aspirations, experience of physical harm or violence, the experience of stigma or social exclusion, symptoms of depression, DUP and duration of hospitalisation. However, a significant association between suicidal ideation and the experience of prior trauma was noted, although this was not related to the severity of the trauma (Tarrier et al., 2007). These findings highlight the significant challenge of suicidality in treating people with psychosis. It is likely this challenge is amplified in patients with mood disorders and psychosis as is the case with Bipolar I Disorder with psychotic features. The findings also emphasise the adverse role of prior and current PTSD in predicting suicidality in patients with psychosis.

2.2.3 The course, costs and consequences of Bipolar I Disorder

While patients may recover from symptoms and have euthymic periods, approximately 30% have chronic functional impairment. Despite levels of education equivalent to the general population, Bipolar I Disorder patients experience lower socioeconomic status due to cognitive impairments that may contribute to poorer vocational performance and functioning (American Psychiatric Association, 2013). Studies have consistently shown high Bipolar Disorder relapse rates which result in significant psychological, social and economic costs (WHO, 2008; WHO, 2017). Patients diagnosed with Bipolar Disorder suffer substantial personal costs, financial strain and occupational instability. It has been shown that approximately 25% of the patients

do not achieve complete functional recovery, they face stressful life events and have poor social support systems. All these factors influence the cycling of Bipolar Disorder (Prerost & Song, 2012).

Studies suggest that insight and compliance are affected by the emotional state of patients with Bipolar disorder (Ghaemi & Resenquist, 2004). For example, although patients may derive pleasure from mania, they may lose sight of the importance and benefits of treatment compliance (Bulteau et al., 2018). Patients may further perceive mania as a double-edged sword, with the benefits of increased motivation, energy, and creativity on one hand, and disadvantages such as poor self-control leading to significant neglect of other important areas in their lives on the other (Johnson et al., 2016). It is suggested that health care practitioners need to be cognisant of these factors within each diagnostic picture as well as in treating the patients.

In a study investigating length of hospital stay of psychiatric admissions in Ethopia over a ten-year period, it was found that patients with Bipolar Disorder and psychotic disorders had longer hospitalisation periods (Addisu, Wondafrash, Chemali, Dejene & Tesfaye, 2015). Other associated factors included cost of hospitalisation incurred by patients, where those who got free medical care were likely to stay longer in hospital. Additionally, those suffering from medication-induced extrapyramidal side-effects stayed longer. A steady increase in admissions over a 10-year period was evident, with severe mood disorders and psychotic disorders accounting for most admissions (Addisu et al., 2015). Bipolar I Disorder with psychotic features is a combination of severe mood disorder and psychotic symptoms, placing these patients at greatest risk of lengthy psychiatric admissions and higher burden of care costs if the condition is not adequately managed. It is for this reason that the present study seeks to focus on patients with Bipolar I Disorder with psychotic features.

One of the commonly cited impacts of Bipolar I Disorder is the increased risk of death by suicide, particularly when individuals are in a depressed state, accounting for one-quarter of

successfully completed suicides (American Psychiatric Association, 2013). In 2015, there were almost 800 000 suicide deaths, making suicide one of the leading causes of death. Some suicides were linked to depression, a disorder estimated to affect 311 million people worldwide (WHO, 2017). During a depressive state, a patient may feel hopeless, worthless, and see no reason to live. It is during such a state that the patient may lack the motivation to adhere to treatment and attempt suicide during the course of a Bipolar illness (Tarrier et al., 2007).

Suicide was identified as the 16th leading cause of death for people of all ages worldwide (WHO, 2008). Statistics indicate that, in comparison to the general population, individuals with Bipolar Disorder are estimated to be 15 times more at risk for suicide. Whereby, while an estimated 0.017% of the international population dies by suicide annually, a much higher estimate of 0.4% of people with Bipolar Disorder die by suicide (NICE, 2014). It is argued that Bipolar Disorder may account for a quarter of completed suicides (American Psychiatric Association, 2013). This makes it pivotal to direct substantial efforts towards reducing the prevalence of suicidal behaviour and ideation in this population.

Advances in treating Bipolar Disorder will contribute to decreasing the high rates of suicide, years lost due to disability, and the burden on the health care system. However, one of the greatest challenges in treating Bipolar Disorder is non-adherence (Lawson & Bland, 2004; Scott & Pope, 2002). It has been found that non-adherent patients have a higher relapse rate and a poorer prognosis, especially those with psychosis (Gleeson et al., 2008; Tsang et al., 2006). It is important to explore factors contributing to non-adherence in patients diagnosed with Bipolar I Disorder with psychotic features, as these factors increase their vulnerability.

2.2.4 Impact of Bipolar Disorder on psycho-social wellbeing

In a study by de Almeida Rocca et al., (2008), comparing a group of euthymic patients diagnosed with Bipolar Disorder to a group of individuals from a general, non-clinical population, there were no significant differences between the two groups in terms of level of education, age, gender and intelligence. Among patients with Bipolar Disorder, the mean level of education was 12.6 years of schooling (SD = 1.7), and the average intelligence quotient (IQ)

was 101.9 (SD = 9.4). For the control group, the mean level of education was 11.74 years of schooling (SD = 2), and the average IQ was 97.23 (SD = 9.5). However, differences in the two groups were noted when comparing their social skills. It was found that patients with Bipolar Disorder had significantly lower scores for the domains that assessed social self-confidence and ability to openly engage in novel social situations (de Almeida Rocca et al., 2008).

People diagnosed with Bipolar Disorder scored lower on questions related to their ability to maintain a conversation and to confront new situations. Additionally, they displayed inhibited and over-attentive/cautious behaviour in relation to other people and their environment. Such behaviour is likely to have a negative impact on their level of psychosocial wellbeing. However, there were no significant differences between the two groups in terms of how participants responded to questions related to their capacity to decipher rules and norms applied to manage social situations, perceive relationships between events in social situations, and the ability to react to aversive stimuli with reasonable anger regulation and in a socially competent way. These findings did not correlate with the clinical variables such as duration of illness, number of hospitalisations, number of depressive and manic episodes, or psychotic symptoms (de Almeida Rocca et al., 2008). This displays the extent to which interpersonal relationships and social interactional patterns of individuals diagnosed with Bipolar Disorder may be impacted by their condition.

Similarly, in comparing parents with Bipolar Disorder to parents without Bipolar Disorder, it was found that parents with Bipolar had significantly lower self-concept (Prerost & Song, 2012). They struggled more with self-doubt, had more concerns about work/academic performance, and were more likely to struggle to succeed in various settings. Additionally, they perceived themselves as physically diminished, inadequate, alienated and unworthy. A sense of alienation from their families was reported, as they questioned their value in the family role, and how they could be fully functional family members if they felt out of control with regards to their symptoms. The low self-concept and beliefs surrounding it inhibited meaningful communication and may have contributed to limited social support. It was suggested that Bipolar parents may perceive themselves as ‘bad’ people (Prerost & Song, 2012). It is important to consider each patient’s roles and responsibilities within his or her family structure, and how these are impacted on by a diagnosis of Bipolar I Disorder.

Taken together, this section has highlighted the significant vocational, occupation, social and emotional challenges that people with Bipolar Disorder experience in their daily lives. These challenges often leave them significantly impaired and often dependent on the very social nexus' that they often struggle to feel connected to, presenting significant challenges to the treatment and management of this serious, chronic mental disorder.

2.2.5 Trauma, psychosis and Bipolar I Disorder

In the fifth edition of the DSM (American Psychiatric Association, 2013), the chapter on Bipolar Disorder has been placed between chapters on psychotic disorders and those on depressive disorders. The linking symptoms, family history and genetics between these disorders continue to arouse much interest and stimulate debate. The symbolic placement of this chapter in the latest diagnostic manual acknowledges Bipolar Disorder as a disorder forming a bridge between these two diagnostic categories (American Psychiatric Association, 2013). In addition to experiencing disturbance in mood, Bipolar I Disorder patients may experience symptoms of psychosis.

Links between trauma and the experience of psychotic symptoms have been explored in patients with schizophrenia (Morrison, Frame & Larkin, 2003). However, there is a scarcity of literature exploring possible traumatisation in patients diagnosed with Bipolar I Disorder with psychotic features. This is an area requiring further research, especially considering that the addition of psychotic experiences to a prominent mood disturbance can be very distressing for patients and their family. The literature review will include relevant information on studies conducted for Schizophrenia and other psychotic illnesses, as it may assist in exploring and understanding related factors in Bipolar I Disorder with psychotic features.

There is growing evidence suggesting psychosis may be significantly traumatic, leading to PTSD-type symptoms, also referred to as Post-Psychosis Trauma Symptoms (PPTS) (Jackson, Bernard & Birchwood, 2011). Although Post-Psychosis Trauma is a growing area of interest in studies and literature, it remains a subject not well understood, arousing much theoretical and clinical debate. Research in this area is contributing to its developing conceptualisation,

definition and understanding, with suggestions that links between psychosis itself and trauma are multidimensional and complex (Auxemery & Fidelle, 2011; Shaw et al., 2002).

In addition to expanding on factors affecting patients diagnosed with Bipolar I Disorder with psychotic features, factors impacting on their family members are important. Families remain an integral part of successful psychiatric and psychological treatment plans, although it has been recorded that they are often excluded (Corcoran et al., 2007). Their experiences and perceptions will be explored in the current study.

2.3 Treatment of Bipolar I Disorder with Psychotic Features

2.3.1 Psychopharmacological considerations

Lifelong pharmacotherapy with a mood stabiliser is standard in treating Bipolar I Disorder with Psychotic Features. Although mood stabilisers should be prescribed after a patient receives the diagnosis, this is not always the reality. There are records showing instances where Bipolar Disorder patients were prescribed incorrect medications and noticeable improvement was only observed once they were prescribed the correct medication (Russell & Browne, 2005). Historically, the main mood stabilising psychotropic drugs include lithium, divalproex, and olanzapine (zyprexa), often used in combination with antipsychotic drugs such as quetiapine and olanzapine (Sadock & Sadock, 2003; Scott & Pope, 2002). Contemporary pharmacological treatment shows continued use of lithium, second-generation antipsychotics (lurasidone, olanzapine plus fluoxetine, and quetiapine), and some anticonvulsants (divalproex and carbamazepine), with continued controversy regarding the use of antidepressants due to the risk of probable switch from depression to mania (Baldessarini, Tondo & Vazquez, 2019).

Much focus has been placed on the development of pharmacological interventions for treating psychosis, resulting in an increased availability of different types of medication (Janssen et al., 2006). Antipsychotic drugs were introduced in the early 1950s; this revolutionised the treatment of patients experiencing psychosis and led to a reduction in the use of straightjackets, as violent patients would be significantly contained with the use of the drugs (Sue, Sue & Sue, 2003). The first-generation antipsychotic drugs, such as chlopromazine (Thorazine) and

haloperidol, continue to reduce the severity of symptoms such as delusions and hallucinations (Sue et al., 2003). Second-generation antipsychotic drugs were released for use in the 1990s, including risperidone, quetiapine, olanzopine and clozapine. It has been documented that these newer drugs have less side effects (Sadock & Sadock, 2003).

Ideally, after the first psychotic episode, the patient is diagnosed and started on appropriate treatment. However, not all individuals who experience the first episode of psychosis are immediately brought to mental health care facilities. For example, research conducted in Kwazulu Natal showed that 38.5% of those with mental illness first consulted traditional healers before turning to formal psychiatric institutions for treatment; such a delay may negatively impact on the course and outcome of the illness (Burns, 2011). This delay in getting treatment while a patient is presenting with psychotic symptoms is referred to as the Duration of Untreated Psychosis (DUP) (Corcoran et al., 2007).

DUP is common, and it is associated with worse outcomes, as it is during this period when significant neurological and psychosocial damage may already have occurred. It is beneficial for an individual experiencing psychosis to be identified and treated early in the course of their illness. The purpose of early intervention is to detect emerging symptoms, reduce the DUP, promote better access to effective treatment, reduce deterioration, improve prognosis by reducing further damage and promote better functioning (Bird et al., 2010).

Although there is no cure for Bipolar I Disorder with Psychotic Features, antipsychotic drugs assist in alleviating and stopping the psychotic features. It is therefore important that patients diagnosed with this disorder adhere to the prescribed antipsychotic drugs. However, these drugs may have adverse side effects such as an increased risk for Type 2 diabetes, insulin resistance, impaired glucose tolerance, cardiovascular disease, obesity and hypertension (Jerrell & McIntyre, 2007). Other side effects are dystonic movements, which are involuntary movements of the neck, jaw, tongue, or the entire body. Patients may also experience acute akathisia (a subjective feeling of muscular discomfort leading to agitation, relentless pacing, or sitting and standing up in rapid succession). Another side effect is tardive dyskinesia, which involves abnormal and irregular muscle movement of the head, limbs and trunk (De Hert, Detraux, Van Winkel, Yu & Correll, 2012; Sadock & Sadock, 2015).

Torrent et al. (2011) investigated the effects of atypical (newer generation) antipsychotics on neurocognition in euthymic Bipolar patients and found cognitive deficits associated with drugs such as olanzapine and risperidone. They suggest that drugs with lower risk of adverse cognitive effects should be prescribed for Bipolar Disorder patients (Torrent et al., 2011). It has been recommended that the choice of specific drugs for a patient be influenced by its effectiveness, tolerability, and the patient's preference (Janssen et al., 2006). These recommendations are not always adhered to, especially in the public health system, as medication that could be more effective in treating certain patients may not always be available or cost-effective. Burns (2011) argues that within broader health care systems, mental health care resources are often sacrificed for more important resources such as surgical procedure tools. Globally, mental health receives a disproportionately small portion of health budgets; therefore, mental health services receive low priority, as other medical conditions are viewed as more urgent in comparison to psychiatric illnesses and psychological problems (Burns, 2011).

2.3.2 Psycho-social considerations in the treatment of Bipolar Disorder

Research has shown that treatment of Bipolar Disorder is most effective when pharmacotherapy is combined with psychosocial interventions such as supportive therapy, psychoeducation, cognitive behavioural therapy, group therapy, family therapy and even social media/network or other technological advances (bin Jabal et al., 2018; Chisholm, 2005; Garety, Fowler, Freeman, Bebbington & Dunn, 2008; Saunder & Geddes, 2016;). It is within psychosocial interventions that psychoeducation is incorporated, mainly empowering the patient and his/her support structure on understanding the illness and its management. Research has shown that psychoeducation reduces recurrence of mood episodes. This effect is said to be limited to individuals who are in the early stages of a Bipolar illness and have achieved near remission following an acute episode (Saunder & Geddes, 2016).

Strong social support systems are important for Bipolar Disorder patients, these may include family members, friends, community members, colleagues and employers, to name a few. Most research has focused on family members as a support structure, and treatment structures

targeting families have been designed and evaluated. One of those treatment approaches is Family Focused Therapy (FFT). This approach involves both the patient and his/her caregivers, with the aim of relapse prevention (bin Jabal et al., 2018). Therapy and training for family members improves patient-family relationship, resulting in effective harmonising of the patient's primary group (Cornutiu, 2013).

The active components of FFT include the Health Care Professionals' (HCP) skill in teaching communication and problem-solving skills and in imparting psycho-educational material in a way that is individualised to the patients' needs. Further, it is recommended that the HCPs' attitude while administering FFT reflects a good balance between session structure, pacing, and didactics with alliance building, empathy, and appropriate exploration of affective responses. Such an attitude is especially critical when the illness is complex, highly comorbid, or treatment resistant (Miklowitz, 2012). FFT is a time-limited treatment consisting of modules addressing psycho-education, communication enhancement training and problem-solving skills. The efficacy of FFT as an adjunct to pharmacotherapy for patients with Bipolar Disorder has been displayed through controlled trials (Morris, Miklowitz & Waxmonsky, 2007).

One of the terms used in studies evaluating the efficacy of family interventions is Expressed Emotion (EE). EE is defined as a measure of the emotional attitudes directed towards a family member with a psychiatric condition by his/her caregivers/relatives. A relative expressing a high number of critical comments, showing emotional over-involvement (i.e., overprotective, exaggerated emotional responses, or excessive self-sacrifice) or making one or more statements of hostility when describing interactions involving the patient, is categorised as "high EE" (Onwureme et al., 2009). Such family environments have been shown to negatively affect patients with psychotic disorders and have even been implicated as a significant aetiological factor (Patterson, Birchwood & Cochrane, 2000). High EE has been implicated in Bipolar Disorder. In an article reviewing the evidence for expressed emotion (EE) as a prognostic indicator in Bipolar Disorder, it was illustrated that families receiving FFT exhibited improved frequency of positive interactional behaviours during direct interchanges where nonverbal communications such as smiling or speaking in an encouraging tone of voice, were observed (Morris et al., 2007).

Family member expressed emotion during acute Bipolar Disorder episodes has been associated with rates of recurrence among Bipolar patients (Morris et al., 2007). It has been recommended that Family Focused Treatment should be used to assist adolescent patients and family members in avoiding blame and to strengthen the protective influences of family relationships. This approach is reputed to be of particular importance in the early course of the illness, when the balance of risk and protective factors can have significant long-term consequences for the adolescent's development (Morris et al., 2007).

The onset of Bipolar Disorder is estimated to occur during childhood or adolescence in about 50% of patients. Early-onset forms of the disorder are associated with a poorer prognosis than adult-onset forms and they are frequently characterised by comorbid substance abuse (Miklowitz, 2012). The use of FFT in late adolescents with Bipolar Disorder and polysubstance dependence has been investigated. The treatment of this group of patients and their family members required adaptation of the FFT approach to consider the family's structure, dysfunctional alliance patterns and unresolved conflicts from the family's history. The importance of conducting manual-based behavioural family treatments with a psychotherapeutic attitude, including addressing unstated emotional conflicts and resistances that may impede progress, was illustrated (Miklowitz, 2012). In case of relapse, it was recommended that it is critical to resume FFT as soon as possible and communicate that the treatment's objectives can still be achieved. It is also important for FFT Clinicians to emphasise that relapses are an expected part of the course of mood and substance use disorders. Although family members are often frustrated and desire to continue with their own lives, they need to be informed that relapse does not mean that the treatment did not work. They must also be informed that relapse does not mean that the patient should be treated individually, as opposed to utilising FFT (Miklowitz, 2012).

Multifamily group psycho-education (MFG), another intervention involving both patients and their family members, has been shown to reduce relapse rates among individuals with first-episode psychosis (Breitborde et al., 2011). This intervention entails cognitive demands such as learning and applying a structured problem-solving activity, which may be impeded upon by cognitive deficits that accompany psychotic disorders. To maximise the magnitude of clinical benefit derived from this intervention, the addition of cognitive remediation, which has been shown to improve cognitive functioning among individuals with psychotic disorders, has

been recommended. Secondary benefits may include improvement in the following areas: social and vocational functioning, health-related quality of life, service utilisation, independent living status and reduced caregiver burden, anxiety, and depression (Breitborde et al., 2011).

Although family interventions have been shown to be effective, the extent to which they are cost-effective needs to be demonstrated. Sufficient health care professionals need to be well trained and available to implement, monitor and improve family interventions. Castle et al., (2007) states that a 12-week, structured, group-based therapy is a cost-effective way of delivering psychosocial treatments to people with Bipolar Disorder particularly if they have psychotic features. This intervention has contributed to reduced rates of relapse, improved function as measured by the Global Assessment of Functioning (GAF), and improved quality of life. Similar to findings on cognitive remediation, this finding provides some cautious optimism that such interventions may assist in reducing the impairment that is seen in Bipolar Disorder (Castle et al., 2007).

Online support groups for mental illness are a developing platform. Research shows these groups may be used to provide reassurance and they may help patients get to know other people with similar illnesses. Online groups may also assist patients in finding information about the disorder, as well as getting expert opinions and management strategies for the illness (Menon, Isharma, Chandra & Thennarasu, 2014). The development of reliable, scientifically validated, ethical and professionally managed online groups may be the most cost-effective approach, as it would reach a large number of affected individuals. However, those in disadvantaged communities and with limited internet accessibility may not have the same access to such online forums.

In the USA and UK, in addition to family interventions, the use of CBT is highly recommended as part of routine clinical services (Garety et al., 2008). Areas addressed by CBT include changes in self and other perception, cognitive biases, individual sensitivity in interpretation of future life experiences, and other cognitive factors increasing psychological vulnerability (Tarrier et al., 2007). Treatment manuals drawing on the CBT approach are aimed at reducing relapse rates, reducing the impact of negative caregiving and reducing high levels of expressed emotions (Onwureme et al., 2009).

A psychosocial approach that shifts power and authority towards patients and regards them as experts in their own lives, is called the 'Stay Well Plan'. It refers to a specific approach to managing diverse types of chronic illnesses, including psychiatric conditions, focusing on wellness, and not on sickness (Russell, 2008). This plan is not prescriptive, rather, it takes the format of a guide, whereby the development of a plan to stay well is facilitated by health-care professionals, actively involving the patient, family and friends. This facilitation process is fundamental, as it empowers patients in making health choices. When employed, the Stay Well Plan needs to be updated and revised regularly in line with evolving individual circumstances that are suitable to the participants' social, economic and cultural contexts (Russell, 2008).

Strategies developed by patients based on their needs and social contexts may include: acceptance of the diagnosis, education about Bipolar Disorder, identifying both triggers and warning signs, adequate amounts of sleep, managing stress, medication and support networks. 'Staying well' is subject to individual interpretation: to one it may mean being free of symptoms, to another it may mean behaving 'normally', or it may mean having the ability to make choices and take control of their illness through managing symptoms (Russell & Browne, 2005). Improved symptom management leads to patients becoming less anxious/fearful of the illness. Staying well involves participants being mindful of their illness, being aware of themselves and how they are responding to their physical, mental, emotional, social and physical environment, together with being able to observe minor changes in these areas. The availability of a range of support networks is important, coupled with knowing when and who to ask for help. With time, experience and insight, patients utilising a Stay Well Plan learn to minimise the impact that the illness has on their lives (Russell & Browne, 2005).

Technological advances may be exploited in collaboration within Stay Well Plans. Mood monitoring has been used by patients for many years, but the emergence of smartphones and the widespread availability of mobile networks has transformed data capture in Bipolar Disorder. A large number of applications have been developed for mood monitoring, medication alerts and sleep tracking. Early studies suggest that using such technologies to monitor mood and other related variables such as activity, is widely accepted by patients. The integration of self-monitoring with clinical care has the potential of enhancing joint clinical decision-making and earlier identification of and intervention for relapse (Saunder & Geddes,

2016). Continual access and use of such resources may increase the patients' sense of control over the illness

Harrop, Ellett, Brand and Lobban (2015) argue that poor friendships can potentially be a causal and/or maintenance factor for psychotic symptoms. They state that people who have a psychotic disorder typically lose their friends early on, and after this suffer reduced social networks for life. Since social network and social self-image play a major role in symptoms and prognosis and based on the belief that friendships and love relationships would help people a lot more than medication and professionals, they developed the 'friend's interventions'. These interventions actively involve the expert opinions of friends and young people with psychosis, allowing them to draw knowledge from their lived experiences. They note that little is known about the friends themselves and recommend further studies aimed at discovering the characteristics of friends that lend themselves towards remaining in contact when their friends have psychosis, as well as the characteristics of those who do not remain in such friendships (Harrop et al., 2015).

An additional tool that aids access to friends has been identified through technological advances, as a variety of social media applications have been created. Social networking may be a way of enhancing social support and a feeling of well-being. Facebook has been reported as the most popular site used to seek emotional support, based on the frequent updates of emotional content that users put in their profile. It is also used for getting information about psychological and psychiatric conditions, treatment and possible interaction with experts. Through Facebook, individuals may experience enhanced accessibility to existing friends at times of distress (Menon et al., 2014). The extent to which online updates of personal emotional content may lead to negative feedback that adversely affects its users' needs to be investigated, together with the relevance of all the psychosocial treatment discussed above, considering that many associated factors are dynamic and constantly evolving.

2.3.3 Towards a holistic approach: a summary

In sum, it is clear that treatment of Bipolar I Disorder with Psychotic Features requires a very holistic, integrated and multidimensional approach to treatment, long-term management and relapse prevention. Such an approach involves adherence to psychotropic medications such as mood stabilisers and anti-psychotics, psychological support, and strong consideration for enhancing social support for the patient as all these have been implicated in better prognostic outcomes. The family has been demonstrated to be a particularly important resource in both Bipolar Disorder and in psychotic disorders, with evidence suggesting good outcomes when they are included in treatment. However, treatment adherence remains the single biggest factor challenging the treatment, course and prognosis of Bipolar I Disorder with psychotic features, even with the involvement of family members. It is important to unpack and understand the challenges that patients with this disorder and their family members experience in adhering to treatment regimens.

2.4 Psychosis and Trauma

The experience of psychotic episodes as distressing and potentially traumatic has been briefly discussed early in this report. This section will present a review of the trauma theory and its applicability in understanding post-psychosis experiences. Connections between traumatic experiences and mental illness have been explored from as early as 1859 (Gingrich, 2009). It has been hypothesised that post-psychosis trauma can affect treatment compliance and that traumatic symptoms can lead to exacerbations of psychosis (Meyer, Taiminen, Vuori, Aijala & Helenius, 1999; Shaner & Eth, 1989). However, it is not clear whether these post-psychosis trauma experiences accord with the DSM model for trauma and PTSD. This section begins with a discussion of trauma as understood in the literature. Thereafter, connections between trauma and psychosis will be discussed. These connections have been explored in a variety of ways. While some researchers have focused on the presence of traumatic experiences creating vulnerability to future psychosis, others explored the vulnerability of psychotic patients to future trauma (Morrison et al., 2003; Palmier-Claus, Dunn & Lewis, 2012). There is minimal research specifically looking into psychosis being experienced as traumatic by patients

diagnosed with Bipolar I Disorder, although more researchers have explored this for individuals diagnosed with Schizophrenia and other psychotic disorders. Some of their findings will be included as they may shed some light on the subject of the current study.

2.4.1 DSM models of trauma and PTSD

Posttraumatic Stress Disorder (PTSD) is a psychiatric disorder that develops post-exposure to a traumatic event. It first appeared in 1980, in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III), where a traumatic event had to be an identifiable stressor that would evoke significant symptoms of distress in almost everyone. The stressor had to be beyond usual human experience in intensity. Examples of such stressors included rape, assault, military combat, torture, bombing, car accidents, earthquakes, floods, etcetera (American Psychiatric Association, 1980). Since that time, academics and health care professionals have sought further clarity regarding types of events that should be considered traumatic.

In the revised third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R), examples of events that would be considered traumatic in criterion A, were expanded to include the following: threat to physical integrity (personal autonomy and one's self-determination over his/her body), threat to significant family members and friends, and seeing someone who has either been recently, or is being seriously injured or killed due to an accident or violence (American Psychiatric Association, 1987). The linguistic expression selected appears more inclusive, perhaps driven by a need to categorise and treat what was observed in individuals who presented with PTSD symptoms, despite non-exposure to stressors previously categorised as traumatic.

The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) highlights that the essential feature of Posttraumatic Stress Disorder is the development of characteristic symptoms succeeding exposure to a traumatic experience. The trauma would be an experience witnessed or confronted by an individual, involving actual or threatened death or serious injury, or a threat to the physical integrity of self or others (Criterion A1), whereby

Criterion A2 specifies the individual's response as involving intense fear, helplessness, or horror (American Psychiatric Association, 1994; American Psychiatric Association, 2000). This shift reflects development in conceptualising trauma, where beyond directly experiencing the trauma, individuals who witnessed, were confronted, or were threatened by the event, could be better understood. Furthermore, the impact of the trauma on one's physical integrity of the self, continues to be validated as much as impact on one's life itself.

The psychoanalytic view asserts that traumatic experiences reactivate unresolved early childhood conflicts, which includes experiences that may have been unconscious. These emotional responses would include aggression and anxiety, and the use of defences such as denial and repression. To reduce the anxiety, the ego would repeat the experience in an attempt to gain mastery (Kaplan & Sadock, 1988). This view may be used to understand symptoms such as re-experiencing and avoidance, which will be explained shortly. Blum (2003) warns that at one extreme, trauma may be so loosely defined as to accommodate any event as traumatic. On the other hand, it may be narrowly defined, such that the completely overwhelmed ego is rendered incapable of registering the traumatic event. It is proposed that psychic trauma is classically understood as an experience in which the ego has been overwhelmed and flooded by a stimulus of danger coming from either an internal or external source. The internal source is specified as an immediate traumatic situation, not a persistent internal condition (Blum, 2003). The consideration of internal sources of trauma suggests that stimuli that may not be physically tangible or evident to the naked eye, but are experienced as real within an individual, are accounted for. Each individual's experience and reaction to threatening stimuli is validated, broadening the frame through which trauma is defined.

In the fifth edition of the diagnostic manual, a threat to the physical integrity of self or others, and a response involving intense fear, helplessness or horror, were not included in the diagnosis of PTSD. Criterion A requires direct exposure to, witnessing, or learning that events involving actual or threatened death, serious injury, or sexual violence, occurred to close family members or close friends. An individual may also experience repeated or extreme exposure to disturbing trauma-related details, especially work-related exposure. However, other non-work-related forms of media exposure (e.g. television, pictures, movies, social media, etcetera) are explicitly excluded (American Psychiatric Association, 2013). Criterion A appears to exclude psychosis itself as a possible traumatic event. It does not recognise threat to psychological integrity,

perceived threat, or threats from internal stimuli. However, criteria B-E are more inclusive in expressing PTSD-type symptoms that patients with psychotic experiences and their family members may present with.

2.4.2 Diagnosing PTSD

In addition to the symptoms of Criterion A specified above, PTSD is characterised by the development of specific symptoms, specified in criteria B, C, D, and E, after an individual is exposed to a traumatic event (American Psychiatric Association, 2013). The individual is required to present with the following symptoms directly associated with the traumatic event, for more than one month. The presence of one or more intrusion symptoms (recurrent, involuntary and intrusive memories or dreams, dissociative reactions, intense psychological distress, and marked physiological reactions) (Criterion B). One or two avoidance symptoms (avoidance or efforts to avoid external or internal trauma reminders) (Criterion C). Two or more symptoms indicating negative alterations in cognitions and mood (persistent and negative beliefs or expectations about oneself, others, or the world; distorted cognition about the cause or consequences of the traumatic event, an inability to remember an important aspect of the traumatic event, persistent negative emotional state, persistent inability to experience positive emotions, feelings of detachment from others, and marked diminished interest or participation in important activities) (Criterion D). Two or more symptoms indicating marked alterations in arousal and reactivity (irritability and anger outbursts, reckless behaviour, hypervigilance, poor concentration, poor sleep, and exaggerated startle response) (Criterion E). A diagnosis of PTSD is warranted only when the disturbance leads to significant distress or impairment in psycho-social functioning. Additionally, physiological effects of other substances or linked to other medical conditions, must be excluded (American Psychiatric Association, 2013).

2.4.3 PTSD and psychiatric illness

Although PTSD is one of the severe forms of psychological disturbance, research has demonstrated that it is frequently overlooked in patients diagnosed with severe psychiatric

disorders. Mueser et al. (1998) reported that of a sample of 275 people with Severe Mental Illness (SMI), 98% had at least one traumatic life experience and 48% had PTSD symptoms, yet less than 1% had been diagnosed with PTSD. Again, Mueser et al. (2004a) reported that in a sample of 782 people with SMI, there was a high prevalence of traumatic life experiences: A whopping 84% reported lifetime physical assault and 52% reported lifetime sexual assault. An overall number of 34.8% SMI patients met PTSD diagnostic criteria. Despite such findings, treatment focus is generally put on resolving the classified symptoms of other psychiatric conditions such as Schizophrenia and Bipolar Disorder, while trauma symptoms are neither significantly explored nor treated. These findings suggest a very intricate relationship between the experience of trauma, PTSD and mental illness. It is acknowledged that trauma may predispose a person to mental illness, it may precipitate psychiatric illness and may play a big role in exacerbating psychiatric conditions.

Generally, trauma and PTSD are largely excluded in treatment plans for chronic psychiatric illness such as Bipolar I Disorder with psychotic features. Research has explored psychosis and co-morbid PTSD, where PTSD has been acknowledged as a potential stressor that may provoke relapse (Sin, Abdin & Lee, 2012; Mueser et al., 2004a). This finding has been replicated in other diagnoses. One study investigated the association between PTSD diagnosis and substance use among a psychiatric inpatient sample of 188 adolescents and found that adolescents exposed to trauma were more likely to engage in alcohol and marijuana use compared to their non-trauma-exposed counterparts. Although PTSD diagnosis was not significantly associated with substance-use diagnosis, it was associated with substance-use symptoms. The association between PTSD diagnosis and substance use symptoms was moderated by negative cognitions. PTSD and high negative cognitions, including negative views of self, world and future, were significantly positively associated with substance use symptoms. Analyses to exclude results being accounted for by depression as opposed to PTSD, were conducted and depression was not significantly related to either alcohol or marijuana symptoms (Allwood, Esposito-Smythers, Swenson & Spirito, 2014). These studies suggest that untreated PTSD may be a risk factor for the development of psychiatric illness, exacerbate symptoms and lead to poorer outcomes.

However, research cited above has explored PTSD in relation to non-illness related traumatic events such as prior trauma. This research has not explored whether the symptoms themselves

are experienced as traumatic and whether it is possible to diagnose PTSD in the aftermath of distressing psychiatric symptoms such as psychosis. Psychosis related trauma symptoms may manifest after a psychotic episode, following psychosis related hospital treatment, and/or after an individual is diagnosed with a psychotic illness. Morrison et al., (2003) highlights the existing controversy about the relationship between the symptoms of psychosis and the symptoms of PTSD, and the probable direction of causality. Three areas of investigation have been identified and will be addressed in the discussion. They are: exploring whether psychosis can result in PTSD, exploring whether trauma can cause psychosis, and lastly, exploring if both PTSD and psychosis are possibly part of a spectrum of responses to a traumatic event (Morrison et al., 2003). It is important to note that these three areas tend to overlap and feed into each other; traces of interlinking will be evident in the discussion.

2.4.4 Pre-existing trauma, psychosis and vulnerability to future trauma

According to stress-vulnerability models of psychosis, life stress may act on an underlying genetic predisposition (diathesis) to trigger the experience of psychosis (Zubin & Spring, 1977; Nuechterlein & Dawson, 1984). The stress vulnerability model proposed by Zubin and Spring (1977) propose that an individual has unique biological, psychological and social elements, including strengths and vulnerabilities for dealing with stress. If an individual has a low vulnerability to stress, they can withstand a high amount of stress while an individual with high vulnerability to stress, cannot (Zubin & Spring, 1977). For example, an adult with a childhood history of abuse and loss of parents, is likely to have higher vulnerability to stress compared to an adult who had a good childhood, with supportive parents and no exposure to abuse.

Stress-vulnerability models of psychosis propose that once an individual has experienced their first psychotic episode, the stress threshold needed to elicit future symptomatic responses becomes substantially reduced, and they may be particularly sensitive to everyday stress. Research has found that these patients suffer from greater emotional responses to stress when compared to their relatives, healthy controls, and other psychiatric patients without psychotic features. Minor stressors are often associated with subsequent changes in symptom severity (Nuechterlein & Dawson, 1984; Palmier-Claus et al., 2012; Zubin & Spring, 1977).

The models above demonstrate the link between trauma occurring before an initial psychotic episode and the vulnerability to future trauma which then triggers future episodes of psychosis. Prevalence estimates of PTSD that ranged from 14% to 43% were reported in a summary of studies investigating the PTSD prevalence in patients with severe mental illness, the lowest rate (i.e. 14%) being for index (first-time) patients (Mueser et al., 2004b). This suggests that having had a mental illness for some time, may not reduce the likelihood of being traumatised and developing PTSD symptoms. On the contrary, it has been reported that those suffering from mental illness are more likely to be exposed to traumatic events compared to the general population (Mueser et al., 2004a; Tarrier et al., 2007).

During a psychotic episode, the patients' judgment is often impaired. Some people may take advantage of the patients during this period when they may be unable to protect themselves. Many psychiatric patients suffer serious physical assault from different people including their partners, family members and even mental health care staff members (Mueser & Rosenberg, 2003). Many female psychiatric patients are sexually assaulted, and about a third are raped. further, approximately a quarter of male psychiatric patients are sexually assaulted as adults (Read, van Os, Morrison & Ross, 2005).

Stress as a significant precipitator of psychosis has been well documented in previous studies (Kilcommons & Morrison, 2005; Lu et al., 2013; Marks, Steel & Peters, 2012; Read et al., 2005). Researchers have been interested in understanding the origins of specific psychotic symptoms or complaints, to avoid minimising the impact of previous psychosocial factors experienced by patients (Read et al., 2005). Studies have shown that there is a strong relationship between child abuse and psychosis, whereby the presence of child abuse is related to symptom severity (Newman, Turnbull, Berman, Rodrigues & Serper, 2010). Similarly, childhood maltreatment (emotional, physical and/or sexual abuse together with emotional and physical neglect), has been associated to Bipolar Disorder (Fisher & Hosang, 2010). Although concerns about the accuracy of child abuse disclosure by psychiatric patients have been raised, it has been found that these reports are reliable and that psychiatric patients tend to under-report, as opposed to over-reporting abuse (Read et al., 2005).

In a study investigating mental health clients with SMI and probable PTSD, the following were common types of traumatic experiences. Car accidents and childhood physical abuse were

reported at similar frequencies by both men and women. Men more frequently experienced robbery, stranger assault, being threatened, combat and other accidents, while women more often experienced domestic violence, childhood sexual abuse, adult sexual assault and stalking. The traumatic event most frequently endorsed as a distressing event across gender, was childhood sexual abuse (22%), followed by the sudden death of a loved one/friend (20%). Age, gender, diagnosis (psychotic versus other), and index trauma identified as most distressing, were not significantly related to PTSD symptom severity (Lu et al., 2013).

Similarly, the overall rate of trauma exposure was high in a study by Kilcommons and Morrison (2005). They found 94% of patients reported exposure to at least one traumatic event during their lives, with patients experiencing an average of 3.6 different types of traumatic events, counting traumatic events occurring in childhood and adulthood separately. There were no gender differences in the number of different types of trauma to which the patients were exposed in their lifetime, adulthood, or childhood. However, there were significant differences in the specific types of trauma experienced. Women were more likely to have experienced sexual abuse as adults (4% in men, 57.1% in women) and sexual assault over their lifetime (16% in men, and 57.1% in women) (Kilcommons & Morrison, 2005). Further, Kilcommons and Morrison (2005) found that while 94% of their sample reported a history of at least one traumatic event, the prevalence of PTSD at the time of the research was 53%. Severity of trauma was associated with severity of PTSD and with psychotic experiences suggesting that trauma may precipitate and exacerbate psychosis. In terms of specific symptoms of psychosis, physical abuse was associated with positive psychotic symptoms, while sexual abuse was specifically related to hallucinations. Dissociative processes and negative beliefs formed because of trauma, were associated with psychotic experiences (particularly hallucinations) (Kilcommons & Morrison, 2005). These findings are consistent with the suggestion that psychosis may be trauma-induced.

In a literature review conducted by Read et al. (2005), several studies looking at childhood trauma, psychosis and Schizophrenia are cited. They argue that research has noted marked similarities between PTSD and Schizophrenia. For example, combat veterans with PTSD have been found to present with more symptoms of Schizophrenia, particularly hallucinations and paranoia, as compared to other people with PTSD (Read et al., 2005). Some cognitive models of psychosis suggest possible factors through which PTSD may influence the development and

maintenance of symptoms of psychosis. The experience of humiliation and threat, specifically at an interpersonal level, may provide foundation for the development of negative beliefs about other people and oneself. This may be associated with withdrawal, increased vigilance and increased anxiety. Furthermore, a basis for emerging paranoia, either as a direct extreme exaggeration of beliefs related to the threat, or as an attempt to maintain a coherent positive self-image in the context of a perceived threat to that image, may arise. Another developmental course for hostile and critical voices may be through suffering from the unwanted intrusive memories, re-experiencing socially threatening experiences or humiliating experiences that may have occurred in the individual's history (Steel, Fowler & Holmes, 2005).

Intrusive memories or flashbacks related to a traumatic experience are one of the critical characteristics of PTSD. There is a high prevalence of intrusive memories in individuals diagnosed with severe mental illness. It has been suggested that individual differences in information processing styles, specifically weakened contextual integration, may form a basis for the frequency and content of trauma-related intrusions, contributing to different psychiatric outcomes (Marks et al., 2012; Steel et al., 2005).

Contextual integration is defined as the processing and storing of incoming information in an organised manner, within a meaningful spatial and temporal context, such that it may be intentionally retrieved when needed. This process facilitates voluntary recall. The individual features of incoming information are bound within a spatial and temporal context in the hippocampus. This enables a person to remember associated information, as meaningful relationships are developed with previous information and processed by the amygdala. Contextual integration is disrupted by trauma during moments of peak intensity (worst moments of the trauma), and data-driven process (i.e. processing of sensory impressions) is enabled. As a result, involuntary recall of trauma-related information becomes the content of intrusive experiences (Ehler & Clark, 2000; Grey, Holmes & Brewin, 2001).

From a neurobiological perspective, it has been argued that in times of intense distress, information is processed directly through the amygdala to facilitate quicker stress hormone release. This results in the memory being disconnected from the flow, which can make it difficult to remember voluntarily, but is subject to being involuntarily triggered under specific situations. (Brewin, 2001; Layton & Krikorian, 2002). Information processing is argued to be

relatively weak in individuals suffering from psychosis. It is said that they become overwhelmed and more vulnerable to experiencing intrusions from material stored in the long-term memory (Brewin, 2001; Jones, Hemsely & Gray, 1991).

In an investigation of processes underlying positive psychotic symptoms and their relationship to traumatic intrusions, in the absence of confounding variables such as general cognitive deficits, medication and non-specific illness-related factors, it was found that due to weak contextual integration within an information processing style of schizotypal individuals, they were vulnerable to intrusive experiences, even following mild traumas. This suggests that mild daily stressors may negatively impact on an already weak level contextual integration in individuals suffering from psychotic disorders, leading to the occurrence of intrusive memories (Marks et al., 2012). Taken together, prior trauma experiences can predispose patients to experiencing subsequent stressors as traumatic, thereby perpetuating both the PTSD and psychiatric conditions.

This warrants examination for symptomatic presence or absence of intrusive memories by clinicians treating patients with psychotic disorders. However, since clinicians require more than the presence of intrusive memories to diagnose PTSD, it is pivotal to explore other PTSD symptoms and other traumatic incidents that patients may have experienced, given the vulnerability of this population. Through appropriate identification, PTSD symptoms linked to other traumatic experiences should be treated for the patient's wellbeing. Further studies to investigate protective factors that might minimise vulnerability to trauma, are recommended in order to help this population more effectively.

The co-occurrence of PTSD with psychosis has been shown in different studies discussed above, although at varying prevalence rates. In addition to contextual differences, the variation may be explained by methodological differences between the studies in measuring PTSD. Nonetheless, these findings provide evidence to support the view that PTSD may increase vulnerability to psychosis (especially in genetically vulnerable individuals), but also that psychosis may increase vulnerability experiencing stressors as traumatic and to developing or perhaps exacerbating pre-existing PTSD.

According to Kilcommons and Morrison (2005) negative appraisals (negative cognitions about the self) are associated with some psychotic experiences (predominantly with hallucinations). This suggests that beliefs formed by individuals because of trauma may lead to vulnerability to the development of psychosis. Additionally, dissociative experiences were associated with psychotic experiences, notwithstanding that after controlling for the cumulative effect of trauma, hallucinations were significantly related to depersonalisation. Overall, this suggested that individuals responding to trauma through dissociation are more likely to experience hallucinations (Kilcommons & Morrison, 2005). It has been suggested that dissociation, thought suppression, major depression and trauma content may be associated with this psychosis, which differs from PTSD flashbacks, but is symbolically associated with the trauma experience (Tschoke et al., 2011).

Kilcommons and Morrison (2005) continued to demonstrate that underlying psychological processes, which may mediate the relationship between trauma exposure and symptoms of psychosis together with PTSD symptoms, seem to be present in both disorders. Post-trauma beliefs (particularly negative cognitions about self) and dissociation (particularly depersonalisation) were associated with both psychotic experiences and PTSD symptoms. Based on the above, it was tentatively concluded that trauma can lead to the development of psychotic experiences, and that both PTSD and psychosis may be part of a spectrum of responses to a traumatic event. This did not however rule out other possible variables, such as other psychological, biological or social factors, in increasing vulnerability to both PTSD and psychosis (Kilcommons & Morrison, 2005).

In summary, studies suggest that psychotic symptoms may arise following childhood or adulthood traumatisation as these traumas may trigger an existing diathesis. Additionally, psychotic-like symptoms may result from the disintegration caused by traumatic experiences, suggesting a symbiotic relationship between trauma and psychosis.

2.4.5 Post-Psychosis Trauma

Studies that consider the stressful impact of psychotic symptoms themselves and links thereof to PTSD, particularly for Bipolar I Disorder with psychotic features, are limited. Most studies tend to include samples containing patients diagnosed with Schizophrenia, Bipolar Disorder and other psychotic disorders. Generally, these studies argue that psychosis itself may be traumatic and lead to PTSD-like symptoms. They state that patients may be traumatised by hospitalisation as a result of psychosis and other psychosis-related adverse experiences, or by the level of threat contained in paranoid delusions (Gliko, 2004; Steel et al., 2005; Tarrier et al., 2007).

Jeffries (1977) is credited for being the first to bring the subject of Post-Psychosis trauma to light. He noted that psychotic experiences change the patient's concept of his/her own mind. After experiencing a disorder in thought process, the patient may doubt his ability to think straight, thus distrusting his thought process even after it has been restored to normal through pharmacological treatment. Post psychosis, the patient is informed that he/she had hallucinated. Unlike other people, this individual will not be able to take for granted the occasional unexpected strange sound, questioning whether it is real or originating from his mind (Jeffries, 1977).

Lundy (1992) further demonstrated that psychosis can induce PTSD in patients through discussing a case of a sixteen-year-old male named James, who was diagnosed with Schizophrenia. James developed symptoms of PTSD as a result of the psychotic experience. The young man described painful and terrifying memories, where he feared he was coming apart. These included the songs that continuously played inside his head, over which he had no control, causing him to fear that his brain would be worn out. He related a fear of disintegrating and being dispersed by the wind (Lundy, 1992). James presented with observable anxiety when he recounted the trauma experienced during psychosis. He also presented with symptoms of avoidance. He explained that because he started hearing the songs in the shower, he had been actively avoiding the shower since then. James used muttering as a distraction to keep intrusive thoughts that frightened him, at bay. The patient admitted that he was non-adherent to medication to avoid being reminded of the symptoms of psychosis that the medication was used to treat, as reminders produced significant distress in him. It was noted that following an

open discussion of the 'traumatic experience', the patient agreed to take medication and responded well to it (Lundy, 1992). This raises the question of whether treatment non-adherence may be a manifestation of the avoidance spectrum of PTSD symptoms. This would need to be explored systematically in subsequent research.

Schwartz (2008) states that psychotic symptoms are among the most distressing and confusing, as they are disorganising and frightening and can lead to increased suspiciousness and anxiety in patients. Experiencing these symptoms is likely to evoke feelings of horror, intense fear, or helplessness in both the patient and those around him/her. Initial responses to a psychotic breakdown include confusion, intense emotions and trauma-type reactions (Gliko, 2004; Tarrier et al., 2007). Based on the belief that the subjective meaning attributed to an experience determines its traumatogenicity (Sadock & Sadock, 2003), a psychotic episode can, therefore, be experienced as traumatic by the patient and by family members.

Psychosis and PTSD are traditionally viewed as conceptually distinct disorders. The development of PTSD has been mainly attributed to the traumatic quality of an external event, as opposed to internal events. Internal events may include hallucinations and delusions. Morrison et al., (2003) propose that, similar to traumatic experiences, hallucinatory and delusional experiences can shatter how an individual views himself or herself, others and the world. It has been further argued that the DSM-IV criteria for PTSD, including intense fear, helplessness and horror, can be met by individuals who had psychotic experiences, as the psychotic experience itself and/or hospitalisation in a psychiatric ward, may be sufficient traumatic events (Gliko, 2004; Mueser & Rosenberg, 2003). This argument could also be applied to the revised DSM 5.

Trauma related to the symptoms of psychosis has been documented in case reports, interviews and through the use of psychometric tools. It has been recorded that patients who had experienced multiple psychotic episodes, reported that the most distressing symptoms of the events were delusions and hallucinations (Putts, 2014). Above 50% of those patients reported fears over a loss of touch with reality, self-harm behaviour and thoughts that others were conniving against or out to get them. Additionally, the patients reported fear of distressing behaviour that they described as strange, violent or embarrassing, fear-inducing hallucinations

and fear of voices that instructed them to carry out certain actions (Lu et al., as cited in Putts, 2014)

The existence of Post-Psychosis Trauma has been supported by a study conducted on a non-psychiatric population. Post-Psychosis PTSD (PP/PTSD), as opposed to classic PTSD, has been identified in survivors of intensive care, who had psychotic experiences during their treatment. These patients were found to be more traumatised by frightening hallucinations and delusions than by real events. They reported vivid, frequent, long-lived, distressing intrusive memories of hallucinations and delusions that were often persecutory (Wade et al., 2015). The experience of psychotic symptoms may not be deeply distressing for all patients, as some may report feelings of annoyance as opposed to distress. However, the perceived lack of control over the self and lack of control over how one interacts with others due to psychotic symptoms, has been recorded as central to distress during the acute phase of First Episode Psychosis (FEP). During psychosis, the patient's sense of self appeared fragmented and could be associated with ambiguity, disbelief, uncontrollability, and feeling surreal and disconnected from their personal identity, other people and the world (Dunkley, Bates & Findlay, 2015).

In a study where 35 patients suffering their first episode of psychosis were interviewed to understand the subjective consequences of this event, the results showed that due to the onset of their illness, 77% of the patients indicated they had suffered loss or disruption to their life, 60% were disillusioned about their future aspirations, 38% had suffered violence or harassment, 53% had suffered stigma and 50% social exclusion. Eighty percent of the patients felt they had been traumatised by their treatment and 38% had PTSD symptoms. In this sample, PTSD symptomatology was significantly associated with involuntary hospitalisation, but not with psychotic symptoms (Tarrier et al., 2007).

Studies show different prevalence rates of PTSD among patients recovering from a first episode of psychosis. In a study conducted in Singapore, 19.7% of patients were diagnosed with PTSD. Hospitalisation for treatment, whether compulsory or otherwise, did not increase the rate of PTSD. The Chinese ethnic group had lower risk of developing PTSD (Sin et al., 2010). In contrast to several studies, Dunkley et al., (2015) found that the traumatic nature of FEP was extended beyond the acute episode and that it was not linked to symptoms of PTSD. They argue that the diagnosis of PTSD does not capture all aspects of distress following FEP. They

suggest that the impact of FEP must be viewed as ongoing, as opposed to focusing on the acute episode. They continue to state that disruption occurs in the individual's views of the self, view of others, relationships and worldview.

Other studies examine the distress of FEP from the perspective of symptoms emerging after exposure to a discrete traumatic event, as specified in Criterion A. However, Dunkley et al., (2015) found that the traumagenic distress of FEP is not confined to a brief period but can be described as enduring or long lasting. Key factors emerging from their study include a sense of loss and deficit, a struggle which requires ongoing management, slow progress and a sense of disempowerment and hopelessness (Dunkley et al., 2015).

The above-mentioned factors appeared more relevant to the expressed distress associated with FEP, than to the episode itself. Intense fear and horror were not described in response to the psychotic episode. Neither were PTSD symptoms of re-experiencing and hyper-arousal described by participants. A range of other negative emotional reactions were identified, such as perceived vulnerability, hopelessness, disempowerment, loneliness, disconnectedness, anger, uncontrollability, disbelief, ambiguity, insecurity, helplessness, unlikability and shame. While estrangement was identified, numbness and avoidance of stimuli characteristic of PTSD, were absent. This research suggests that PTSD fails to capture all aspects of the distress of FEP; however, post-psychotic PTSD cannot be ruled out. This may account for the low prevalence of diagnosis of PTSD in patients with psychotic disorders (Dunkley et al., 2015). Additionally, the DSM is a nosological classification system that primarily delineates the types of events that constitute a "traumatic event" and these criteria have traditionally precluded experiences such as psychosis. This may also account for this low prevalence of recorded PTSD in patients with psychotic disorders.

In addition to the symptoms of psychosis being experienced as traumatic by the patients, treatment for psychosis has been found to be distressing. Some studies found evidence for both sources of trauma in their samples. The following factors experienced during hospitalisation are said to exacerbate the distress encountered by psychotic patients: being restrained, fear of other patients, fear of being hospitalised, police insensitivity, adverse staff attitudes, being forced to take medication, etcetera. These factors form part of the psychiatric treatment process

and have been well documented in psychological literature (Gliko, 2004; Sin et al., 2010; Tarrier et al., 2007).

Variation in the hospitalisation and treatment experiences of psychotic patients may be influenced by the fact that some patients may be cooperative, whereas others may be highly disorganised and aggressive, requiring restraint and seclusion. Those patients who are more psychotic, are more likely to experience coercive treatments. People who are more psychotic may also be less able to rationalise treatments and may therefore become more distressed (Berry, Ford, Jellicoe-Jones & Haddock, 2015).

Psychotic symptomatology may contribute to patient distress. For instance, symptoms could cause suspiciousness and fear of staff and other patients. Medication side effects, as well as perceived enforced medical treatment, whereby patients may be subjected to outside intrusive and impersonal discipline, enforced treatment and monitoring, could lead to them feeling angry, fearful, unheard and disempowered (Dunkley et al., 2015). Shaw et al. (2002) found no significant differences in relation to involuntary status, treatment setting, or number of admissions when comparing participants with and without PP/PTSD for hospital experiences, psychotic/manic symptoms, and the distress and intrusion associated with those experiences and symptoms. Participants with PP/PTSD rated their hospitalisation experiences as more distressing and had more intrusive memories of them. They also rated their symptoms as more distressing and had significantly more intrusive memories about these symptoms, even though they were not exposed to more potentially unpleasant experiences in hospital (Shaw et al., 2002).

Tarrier et al., (2007) found that in their sample, 80% of participants reported that they felt they had been traumatised by being hospitalised and 66% of those indicated that the trauma was severe. The major reason for this traumatisation was attributed to the following factors: being confused/ scared by being hospitalised (31%), police insensitivity (11%), fear of other patients (9%), adverse staff attitudes (9%) and being forced to take medication (9%). Of the participants who indicated that they had been traumatised, 38% met symptomatic criteria for PTSD (Tarrier et al., 2007). In another study, 98% of the participants reported experiencing at least one negative experience in hospital. Ten percent named seclusion as the most common distressing hospital experience, followed by restraint (8%), being admitted to hospital (8%), physical

assault from other patients (8%) and being forced to take medication (8%). Eighteen percent met criteria for PTSD with a hospital experience as the traumatic event (Berry et al., 2015).

Of the participants, Berry et al., (2015) found that 82% identified positive psychotic symptoms as their most distressing symptom. Auditory hallucinations were the most commonly named as distressing symptoms by 34% of participants, followed by persecutory beliefs (24%) and then other unusual beliefs (12%). Twenty four percent of the participants met criteria for PTSD with a psychotic symptom as the traumatic event. A significant negative correlation was found between psychosis-related PTSD symptoms and length of current admission. However, there was no significant association between psychosis-related PTSD symptoms and negative symptoms (Berry et al., 2015).

No significant correlations were found between psychosis-related PTSD symptoms and total number of traumas, nor between hospital-related PTSD and total number of traumas. The study aimed at establishing the incidence of psychosis-related and hospital-related PTSD, and identifying factors associated with PTSD symptoms in long-stay secure settings. There was no evidence of associations between PTSD and previous trauma found. Total number of distressing hospital experiences was associated with hospital-related PTSD. Severity of psychosis was associated to hospital-related PTSD symptoms. Consistent with previous studies, the experience of psychosis and hospitalisation was found to be highly distressing. Severity of psychosis was also an independent significant predictor of both psychosis-related and hospital-related PTSD symptoms in regression models (Berry et al., 2015).

Another study identified a significant association between PTSD and being detained under the Mental Health Act. Patients detained under the act had significantly more severe avoidance symptoms and a trend towards more intrusive symptoms, although there were no significant differences on arousal symptoms. In contrast to other studies, no significant associations were identified between PTSD and positive, negative or general psychotic symptoms, nor were DUP and duration of hospitalisation associated with PTSD. However, patients with PTSD had significantly greater reduction in their hopes and aspirations, despite having no differences in loss, change and disruption to life, and the experience of stigma or social exclusion (Tarrier et al., 2007).

Distress generated by an experience is central to the onset of PTSD related to that event. While some studies combined, others compared psychosis and hospitalisation in examining the aetiology of Post-Psychosis PTSD symptoms. In a sample of participants who had been hospitalised following a psychotic episode, it was found that all participants found both psychosis and hospitalisation highly distressing, where 52.3% of the participants met the criteria for a PP/PTSD. Their symptoms were not associated with demographic factors (such as duration and age of onset of the illness, and exposure to most hospital experiences), previous trauma, treatment or insight. Participants who experienced more distress due to psychosis and hospitalisation had more pronounced PTSD symptomatology (Shaw et al., 2002).

Similar to the above study, Sin et al. (2010) found no significant differences in demographic details such as age, gender, marital and employment status, or types of psychotic disorders between patients with and without PTSD. While 25% of their participants cited the hospitalisation as the main traumatic event, 75% cited psychotic symptoms as the main traumatic event. Lastly, there was no difference in the Beck Anxiety Inventory (BAI) or Beck Depression Inventory (BDI) scores of those with and without PTSD (Sin et al., 2010).

Experiencing a psychotic episode may have a negative subjective impact, having the potential of resulting in loss in multiple areas such as social roles, aspirations, future hopes, yielding significant short-term and long-term personal consequences. The index of a psychotic illness results in changes in how the patient perceives him/herself and how he/she is perceived by others in terms of their abilities. This has a direct impact on self-image and one's motivation to achieve goals. In some cases, individuals experience rejection and hostility from society (Hardy & Mueser, 2017; Tarrier et al., 2007).

In patients with psychotic disorders, factors such as loss, insight and fear of mental deterioration have been associated with depression, demoralisation, low self-esteem, social isolation and increased suicide risk. Positive psychotic symptoms have been associated with harassment, stigma and social exclusion (Tarrier et al., 2007). Furthermore, suicidal thoughts have been identified as significantly more common in patients with Post-Psychosis PTSD who rated hospital treatment and their psychosis symptoms as more distressing and the cause of more intrusive memories (Shaw et al., 2002).

Mueser, Rosenberg, Goodman and Trumbetta (2002) propose a model that discusses the direct and indirect effects of PTSD on the course of severe mental illness. This model is an extension of the stress-vulnerability model, where direct influences involve specific symptoms of PTSD. The authors state that the avoidance component of PTSD can lead to reduced social contact and isolation, and that a lack of social contact is a strong predictor of symptom relapse and rehospitalisation in persons with SMI. Mueser et al., (2002) write that hypervigilance leads to physiological over-arousal, which in turn can lead to the inability to accurately assess possible threat. Finally, the authors state that the re-experiencing of a particular trauma can be thought of as a chronic stressor and that chronic stress is linked to a poor prognosis in those suffering from SMI. This model represents an interesting and clinically useful conceptualisation of the relationship between PTSD and psychosis, an issue paramount in the treatment of Post-Psychosis PTSD.

There are psychometric scales, self-report measures and screen tools that may be used to assess for PTSD in individuals with psychotic disorder. For example, Sin et al., (2012) suggest that the PTSD Symptom Scale - Self-report (PSS-SR) can be a useful screening instrument for PTSD in patients recovering from their first psychotic episode. The Clinician-Administered Posttraumatic Stress Disorder (PTSD) Scale (CAPS), and the PTSD Checklist (PCL) were suggested by Mueser and Rosenberg (2001). It is important to note that these tools cannot replace conducting an appropriate clinical interview regarding trauma history. Ideally, both the tools and the interview may be used concurrently. It is recommended that assessment for trauma history in individuals with a psychotic disorder should be a routine and ongoing aspect of treatment. It may be used to establish baseline symptoms, and then recurrently to monitor treatment efficiency and patient progress (Putts, 2014).

As previously discussed, individuals with psychotic disorders have increased rates of exposure to trauma, and their experiences of psychosis may put them at further risk for traumatic experiences. Thus, clinicians working with this population need to remain conscious of their role in assessing for traumatic experiences. Much work needs to be done to improve recognition of PTSD symptoms in patients with psychotic disorders. Two main areas have been identified for improvement, these being "(a) expanding the current Criterion A definition of a traumatic event or designating a new diagnostic category that encompasses traumatic symptoms related to the experience of a coexisting psychotic disorder and (b) increasing research on and

developing new screening tools for detecting trauma symptoms in individuals with psychotic disorders" (Putts, 2014, p. 88).

Although a psychotic experience has been viewed as undoubtedly traumatic, there are several challenges to diagnosing PTSD due to psychosis. These include the probable double counting of symptoms, which would exaggeratedly inflate co-morbidity estimates; the presence of an internal, as opposed to an external 'traumatic' event; current restrictions in the definition of trauma and PTSD diagnosis criteria; lack of clarity and accuracy in describing and distinguishing aspects of psychopathology within Post-Psychosis Trauma and its interaction with comorbid illnesses; controversy and questionable reliability and validity of trauma reports for patients diagnosed with severe mental disturbance; and questioning the accuracy of memory that may be possibly entangled with a delusional system (Hardy & Mueser, 2017; Putts, 2014; Tarrier et al., 2007).

In conclusion, the line between Pre-Psychosis Trauma, vulnerability to future trauma following psychosis, and Post-Psychosis Trauma, is not clear. However, the high prevalence of PTSD symptomatology in individuals with psychotic disorder is supported by a number of studies. Others propose that PP/PTSD symptoms, such as the content of intrusions, is associated both to previous trauma as well as to the positive symptoms of psychosis, such as delusions (Marks et al., 2012; Steel et al., 2005). This supports the idea of an existing continuum, within which PTSD and psychosis are possibly part of a spectrum of responses to a traumatic event and symbiotically to each other. Despite recorded high prevalence of PTSD symptoms, marked under-detection in this population persists (Kilcommons & Morrison, 2005). As a result, patients do not receive treatment for what they are not diagnosed. Yet the need is paramount.

2.4.6 Treating trauma comorbid with psychosis

Considering the subject matter of the current study, in addition to treating symptoms of Bipolar I Disorder with psychotic features, symptoms of PTSD would need treatment. This further increases the complexity in how patients may present and how they would need to be treated. There is also complexity in how comorbid disorders interact and impact each other. For

example, as previously discussed, PTSD symptoms may intensify stress, specifically intrusions and hyper-arousal, thus leading to more severe symptoms of the psychotic disorder (Mueser et al., 2002).

In cases of comorbid psychosis and PTSD, the prognosis appears poorer, marking a severe and chronic condition with higher service use and more severe symptoms. Comorbidity appears to increase the vulnerability of this population. For example, in an investigation of first-episode psychosis, suicidal ideation was reported by 40% of participants and 31% reported attempting suicide. Suicidal behaviour was greater in participants with PTSD symptoms, and it was significantly associated with the experience of trauma prior to the onset of their psychosis, but not to the severity of that trauma (Steel et al., 2005; Tarrier et al., 2007). There is debate about how to best formulate, treat, and manage cases where PTSD and psychosis are comorbid. This section will look at how Post-Psychosis Trauma may be treated, based on suggestions from different studies.

Following a psychotic episode, in addition to medication, psychosocial interventions may be used to equip patients with psychotic disorders, with effective skills that improve their subjective quality of life and independent functioning. Similar to treatment options previously discussed for Bipolar Disorder, these interventions consist of evidence-based practices, including vocational rehabilitation, family intervention, skills training, Cognitive Behavioural Therapy (CBT) and case management (Tsang et al., 2006). The services are offered by a multi-disciplinary team including psychiatrists, psychologists, social workers, nurses and occupational therapists. However, the team members are not always able to offer their best services due to limited resources, large workloads and burn-out (Burns, 2011).

It is recorded to be the first study to investigate perceptions of clinicians treating young people with first-episode psychosis for Posttraumatic Stress Disorder, and treatment barriers and useful support requirements were explored. The perceptions were sought to support the development of a Posttraumatic Stress Disorder intervention for young people with first-episode psychosis. It was found that increased mental health risks for clients with psychosis, workload pressures (time pressures, inadequate clinical/organisational resources and conflicting case management priorities) and poor client engagement were identified as treatment barriers (Gairns, Alvarez-Jimenez, Hulbert, McGorry & Bendall, 2015).

Targeted training and formal professional guidance/supervision were thought to best support intervention. It was recommended that Posttraumatic Stress Disorder intervention for first-episode psychosis clients should address engagement, make safeguarded provisions for family involvement and be sufficiently paced and flexible. Trauma-focused intervention is perceived with a degree of caution, is often not prioritised, lacks institutional support and requires more targeted training. It is important to conduct further research regarding the safety of trauma interventions alongside psychosis to address widespread concerns (Gairns et al., 2015).

It is important to adequately address the distress and negative impact of FEP. Clinicians can focus on the patient's perceived vulnerability, fear of relapse, feelings of hopelessness and lack of control in treatment (Dunkley et al., 2015). Systematic reviews have concluded that combining medication with psychological interventions, specifically CBT and family intervention, improves clinical outcome (Garety et al., 2008). However, different studies have demonstrated that many mental health care users default on both forms of treatment. Rummel-Kluge et al., (2008) suggest that ways of improving compliance and decreasing readmission rates include telephone interventions, ensuring adequate social support, home-based adaptation training, rationalising drug regimen, psychosocial interventions, and improving insight (Rummel-Kluge et al., 2008). This illustrates how multiple factors need to be carefully considered in treating each patient, together with good resource availability.

Mueser and Rosenberg (2003) propose that patients may avoid treatment if it reminds them of the traumatic experience of the psychotic episode and the possible trauma experienced from the treatment procedure. They state that open communication about this trauma, and intervention strategies targeting the negative beliefs developed from the trauma, could positively contribute towards treatment adherence (Mueser & Rosenberg, 2003). This finding has important implications as it suggests that avoidance symptoms must be especially explored as they may be associated with adherence to treatment.

Davoine (2012), a psychoanalyst with more than 40 years of experience working with trauma and psychosis in psychiatric hospitals, day care centres and private practice, describes what worked in addressing trauma. She looks at how symptoms can be transformed into assets used to access previously unreachable parts of history, through unexpected events occurring in the transference within the therapeutic relationship. This author argues that chemical treatments

and ECT have oversimplified the "philosophy of the problem" of mental illness. She advocates for treatment through dynamically oriented intensive psychotherapy, where symptoms are converted to assets. She argues that between the so-called healthy and mentally ill people, emotionally and mentally disturbed reaction only differs in degree and she encourages special consideration, sensitiveness and alertness for clinicians to understand what their patients want to convey (Davoine, 2012).

Davoine (2012) refers to the patient as principal investigator, while the therapist is co-researcher. She states that traumatic situations resist being recorded and are rather erased by their victims, who collude in the discourse of denial. From this perspective, psychosis may be considered as a fight against the deletion of all traces of a traumatic event by acting out what cannot be expressed in usual ways. This suggests that increased efforts to unpack and integrate patient history of traumatic experiences, may be beneficial to treatment (Davoine, 2012).

Eye Movement Desensitisation and Reprocessing (EMDR) has been found useful for treating symptoms of PTSD comorbid with psychotic illness. Patient improvement and maintained treatment effects have been shown at 3-6 year follow up. One of the cases was a non-adherent patient with Bipolar Disorder, who significantly improved and became adherent after EMDR (Laugharne, Marshall, Laughrne & Hassard, 2014). Other studies argue that an intervention that draws from CBT is more effective in increasing compliance and reducing relapse rates (Gleeson et al., 2008).

CBT has been found to be particularly useful for patients with early psychosis and patients with PTSD and psychosis (Bird et al., 2010; Callcott, Standart & Turkington, 2004; Garety et al., 2008; Valmaggia, Van Der Gaag, Tarrier, Pijnenborg & Sloof, 2005). Ehler and Clark (2000) propose a CBT model with three main stages that may be used to treat trauma within psychosis, with adjustments in timing and speed in therapy progression, and taking psychotic symptoms into account.

Ehler and Clark's (2000) first stage involves identification and changing of personal negative appraisals, identifying emotional hot spots, socratic questioning, behavioural experiments and imagery modification. Hot spots are defined as specific parts of the trauma memory that cause high levels of emotional distress, that may be difficult to recall deliberately to mind, and that

are associated with intense reliving of the trauma and associated meanings (Grey et al., 2001). The second stage entails elaboration of trauma memory through imaginal reliving, were patients learn to discriminate triggers of re-experiencing symptoms from what occurred during the trauma. In the last stage, patients are encouraged to inhibit maintaining behaviours while strengthening their cognitive strategies (Ehler and Clark, 2000).

With a similar motive of improving interventions, Jeffries (1977) proposed three-phase therapeutic approach in managing the trauma of being psychotic. He based his proposal on his clinical experience working with patients diagnosed with Schizophrenia, who presented with PTSD symptoms. In the first phase, medication was the main treatment vehicle to settle the patient's acute symptoms of psychosis. In the second phase, it was proposed that focus be placed on vocational counselling, social skills training, family counselling, encouraging medication compliance, and didactic psychotherapy. In the didactic psychotherapy, the clients would be assisted in understanding their diagnosis and would be offered a space in which to express their thoughts and feelings regarding their illness, including processing and resolving Post-Psychosis Trauma. The clients' negative attitudes and behaviours would be identified and appropriately resolved. In the last stage, the focus of treatment would be continued medication and follow-up psychiatric appointments (Jeffries, 1977). It is interesting to note that although bio-psychosocial treatment approaches have been recommended for many years, implementation of such proposals within different contexts has been a challenge.

Adding to interventions focused on treating psychosis, the Maastricht approach has been proposed to process auditory hallucinations. This approach was developed by Marius Romme, a psychiatrist, and Sandra Escher, a researcher from Maastricht in the Netherlands. The use of the Maastricht approach entails a process where the treating clinician actively communicates with the voice through the patient. The clinician maintains a dialogue with the voice through several sessions from which, amongst other benefits, an understanding of the source, history and role of the voice in the patient's life, will be gained. It has been reported that patients feel acknowledged and relieved through this approach. As opposed to deteriorating after this type of intervention, patients have been found to improve (Corstens, Escher & Romme, 2008; Steel, 2017).

Swan, Keen, Reynolds, and Onwumere (2017) conducted a systematic review of fifteen studies evaluating the application and efficacy of evidence-based PTSD interventions (originally developed and tested on treating patients without comorbid psychiatric conditions) on patients with psychotic disorders. The use of the following interventions was found safe and effective in reducing post-traumatic stress symptoms, namely: Cognitive Behaviour Therapy, Prolonged Exposure Therapy, Eye Movement Desensitisation and Reprocessing and Written Emotional Disclosure. Support for the implementation of trauma-focused psychological interventions in groups of people with severe mental health problems, is growing (Swan et al., 2017).

In implementing any treatment plan, evaluation and adjustment are critical. In an 8-bed tertiary mental health facility for youth aged 16-18 years in the South Island of New Zealand, data was gathered to determine if patients undergoing treatment in the facility received targeted psycho-education on their diagnosis, medication, diet, outpatient follow-up, and alcohol/drug use. They found adequate information on diagnosis, medication and outpatient follow-up, but a lack of information about diet, and lower than expected awareness on relapse preventions and the impact of alcohol/drug use. The results surprised them because they believed they were giving enough information. However, the youth may need different approaches to get the message regarding substance abuse. Feedback on audit outcomes allowed the facility to reflect on, re-evaluate and restructure their timing, language and psycho-education approaches/modality, improving them to attain better outcomes (Swadi, Bobier, Price & Craig, 2010).

In closing, more research testing treatment efficacy, implications and limitations within different settings, is indicated. More researchers working in the area of Post-Psychosis PTSD are needed as there remains a grave paucity of research. This will aid a move from theoretical to practical treatment strategies that treat PTSD, post-psychosis PTSD and the symbiosis between them. Studies raise awareness among clinicians with the hope of promoting early recognition and treatment of PTSD, to potentially improve outcomes for patients. Studies that will adjust treatment strategies, aid the development of more strategies and investigate which strategy would be most effective and under which circumstances, are urgently needed.

2.5 The challenge of treatment non-adherence

One of the major challenges in the treatment of patients with psychiatric disorders, and specifically Bipolar I Disorder, is non-adherence. The terms ‘compliance’, ‘adherence’ and ‘concordance’ are used synonymously in some literature, and differentiated in other (Lawson & Bland, 2004; Rummel-Kluge, Schuster, Peters & Kissling, 2008). The terms ‘adherence’ and ‘concordance’ are used as broader concepts including the patient’s attitude and habits towards therapeutic strategies. Criticism of the term ‘compliance’ is that it infers an authoritarian and paternalistic attitude. In contrast, ‘concordance’ is said to involve mutual understanding, respect and shared decision between the doctor and the patient, resulting in a good therapeutic alliance (Rummel-Kluge et al., 2008).

Much controversy has been present in the area of compliance, as some writers would advocate for the use of a concordance model, as opposed to a compliance model. The concordance model refers to a shared decision-making process and consensual agreement between patients and doctors, as equal parties. In contrast, the compliance model refers to the patient following the doctor’s orders (Bissell, May & Noyce, 2014). Segal (2007) argues that the term ‘concordance’ is a “sham” (p. 82), stating that it was disguised to achieve compliance and get the patient to desire prescriptions and take the medication, as opposed to sincerely treating the patient's beliefs more respectfully. It is argued that pharmaceutical companies make use of this term to increase sales of their drugs. A term that has been used since the mid 1990's is ‘adherence’, and it is suggested that this term is a more neutral and non-ideological concept, more inclined to sensitively considering the patient’s rights and beliefs (Segal, 2007).

Although compliance was previously seen as an all-or-nothing behaviour, the term ‘partial compliance’ has recently emerged, acknowledging the behaviour of taking some, but not all the prescribed medication, and following some, but not all the recommendations given by a health care professional. Patients who are partially compliant also have a higher relapse rate as compared to compliant patients (Rummel-Kluge et al., 2008).

Scott and Pope (2002) define partial adherence as the individual having missed 30% or more of the prescribed medication within the past month. In their sample, they found that under 50% of the participants acknowledged non-adherence in the past two years, while 32% reported

partial adherence. A history of non-adherence was more common in partially adherent individuals. Fear of side effects, as opposed to the experiencing of actual side effects, increased the risk of non-adherence (Scott & Pope, 2002). Adherence involves prescriptions based on careful consideration of the patient's desires after the patient has been informed about their condition, that they understand and accept the diagnosis and the benefits of the proposed treatment, that their questions and concerns are sufficiently addressed, and that they agree with the Health Care Professionals' recommendations (Segal, 2007). This suggests that, ideally, the treating HCP would have allocated sufficient time and effort into understanding the patient and sharing information in a manner that the patient would be able to understand, allowing questions and providing answers. Furthermore, the HCP would have all the required resources available, including different treatment options from which to recommend what would best suit each patient.

It is for the above reasons that the term 'non-adherence' has been selected for the current study. However, the term 'compliance' will be used when discussing literature in which the term was originally used. The extent to which health care professionals use these terms to truly reflect the originally intended meanings, or whether they use the terms interchangeably while their behaviour towards patients remains unchanged, needs further research.

It has been noted that failure to adhere to prescribed medication is the most serious problem in health care, but there has been little improvement in addressing this problem to date (Segal, 2007). Non-adherence may be defined as the failure to adhere to the treating physician's clinical recommendations. These recommendations include factors such as entering into a treatment programme, participating in the treatment programme, keeping appointments as scheduled, taking medication as prescribed, and following other recommended changes in diet or behaviour (Sadock & Sadock, 2015; Tsang et al., 2006).

One of the criticisms of the concordance model is that physicians cannot allow clients to agree or disagree with following their orders, particularly regarding standing by and watching patients with contagious diseases choose not to take medication as directed, thus infecting more people (Segal, 2007). While patients experiencing psychosis may not infect others with psychosis, some may pose a danger to themselves or others during a psychotic episode. Although they may not be inherently violent, a delusional patient, for example, may attack

other people as part of persecutory ideation; they may even attempt suicide as part of command hallucination, such as voices commanding them to kill themselves (Sadock & Sadock, 2015). It is therefore in the best interest of the patient and others, for the patient to take medication as prescribed.

Informed decision-making regarding compliance to psychiatric treatment can only come from well-informed individuals. The patient's own capacity for making insightful decisions, especially during periods of relapse, may be compromised in patients with Bipolar I Disorder with Psychotic Features. Patients may gain more insight into their illness during remission, when they are better able to engage with the HCP and partake in psychoeducation (Nichita & Buckley, 2007).

2.5.1 Predictors of treatment non-adherence

Instead of adopting a theoretical stance in understanding non-adherence, it is useful to explore empirical factors associated with poor compliance. Non-adherence in mental health care users has generated much interest among researchers. Rummel-Kluge et al. (2008) cites ten studies showing that psychiatric patients who do not take their prescribed antipsychotic medication have a much higher relapse rate as compared to patients who adhered to their treatment. Furthermore, it has been shown that patients who are non-compliant have an increased risk of re-hospitalisation as compared to those who are compliant (Tsang et al., 2006). Hospitalisation then increases costs, as inpatient mental care health is more expensive than outpatient care. Increased risk factors for persistent psychosis necessitate prolonged inpatient care for individuals experiencing psychosis (Gleeson et al., 2008).

Rummel-Kluge et al. (2008) conducted a study to investigate factors contributing to non-compliance, in which psychiatrists were asked to complete questionnaires consisting of 10 questions, which were analysed for their findings. According to the psychiatrists, 68% of patients had a lack of insight into the need for prophylactic medication, this being found to be the most significant problem contributing to non-compliance. They also found that a large percentage had a lack of insight or denial of the mental illness. The participating psychiatrists

reported that 62% of the patients felt embarrassed about having to take the prescribed medication on a daily basis, and 48% were living in circumstances that were inappropriate for compliance. A staggering 62% of the patients needed someone to remind them to take their medication, and 55% had cognitive deficits contributing to their non-compliance. Only 34% of the participants in this study had comorbid substance abuse (Rummel-Kluge et al., 2008).

Churchill (as cited in Gray, Wykes & Gournay, 2002) argued that the different methods of measuring compliance were not satisfactory and not always reliable, including physicians' assessment, patients' self-report, pill counts, and urine and blood reports. He further stated that both patient self-report and physician assessment were inaccurate and consistently overestimated compliance. More vigorous research methodologies accompanied by consistent findings from different studies, strengthen beliefs regarding how best to measure compliance.

Tsang et al. (2006) aimed to develop a comprehensive and accurate scale, measuring the compliance of patients with psychotic disorders to psychosocial interventions, to be completed by case managers. They also sought to evaluate the psychometric properties of this scale. They argue that patients with these diagnoses may avoid psychiatric services to reduce the chances of being stigmatised. This avoidance was found to be more common in individuals with low self-esteem, low self-efficacy and high self-stigma. It was deduced that high self-esteem and high self-efficacy are good indicators of treatment adherence. Other factors that contribute to non-compliance are poor insight, and the patient's negative attitudes towards the prescribed medication (Tsang et al., 2006).

As previously discussed, Bipolar I Disorder with psychotic features is a chronic disorder requiring prolonged administration of psychotropic drugs (American Psychiatric Association, 2000). This has an important influence on the choice of medication, specifically considering the patient's subjective attitudes towards the drugs and long-term adherence (Sue et al., 2003). Other factors identified as influential in adherence behaviour include relationship with staff, and the patient's experience of admission to hospital (Janssen et al., 2006).

Comorbidity is an additional factor influencing adherence, it is defined as the occurrence of two syndromes in the same patient, whereby diagnosis with one does not categorically exclude diagnosis with the other (American Psychiatric Association, 2013). Research has found a

significant correlation between medication compliance and substance abuse, especially in Bipolar Disorder (Lawson & Bland, 2004). It showed that reduced substance abuse significantly increased the probability of remission and medication compliance. However, persistent substance abuse is strongly associated with non-compliance and reduces probability of remission (Janssen et al., 2006). Frank, Prien, Kupfer, and Albert (1985) note that patients who are not in a relationship, not married, male and young are most likely to be non-adherent, highlighting the critical role played by the social network.

Co-morbidities in Bipolar Disorder have negative medical and psychological prognostic implications, they require treatment and may contribute to disturbance in mood. Munoli, Praharaj, and Sharma (2014) found that 43.3% of the Bipolar Disorder participants in their study had co-morbid psychiatric disorders. While 64.2% had physical illness, the most common co-morbid psychiatric disorder was substance abuse (27.5%), where tobacco and alcohol were the most frequently used substances. Males were found to be the most common substance abusers (87.9%), compared to females (12.1%). There was a significantly earlier age of onset and age at first hospitalisation in patients with co-morbid substance abuse. Over ten percent had co-morbid anxiety disorders, 4.2% being unspecified anxiety disorder and 2.5% generalised anxiety, while only 0.8% had PTSD. The most common co-morbid physical illness was cardiovascular disorder, with twenty percent of the sample presenting with it (Munoli et al., 2014).

Snow, Smith, and Branham (2008) argued that women with Bipolar Disorder using psychoactive drug substances, are at increased risk of social stigma, suicide and arrest. Both disorders need to be addressed in treatment. Ideally, prevention of substance abuse and dependency is more likely when accurate diagnosis of Bipolar I Disorder is made, and adequate mood stabilising medications and psychosocial treatments are initiated timeously (Snow et al., 2008). Continued use of cannabis was found to be statistically significantly associated with elevated mood and inferior global functioning at one year follow for patients with recent onset Bipolar I Disorder in first treatment (Kvitland et al., 2015).

A significant association has been identified between medication non-compliance and involuntary admission, history of aggression, low education levels, and pronounced or negative symptoms (Janssen et al., 2006). Other factors increasing the risk of non-adherence include

negative attitudes towards any medication, specific resistance to the idea of mood stabiliser prophylaxis, denial of disorder severity (may reflect general insight or aspects of neuropsychological functioning), longer period of being on mood stabilisers (more common in early onset), along with previous experimentation with non-adherence (Scott & Pope, 2002). Focus on the last three factors allowed 4 out of 5 participants to be correctly classified on their adherence status, suggesting that these three factors may be used routinely in clinical practice. In their study, Scott and Pope (2002) found that one in three patients on mood stabilisers was not fully adherent. Non-adherence appeared to be a result of the patients' attitude and views regarding their conditions, together with potential treatment benefits and life impact as described by the health belief model (Scott & Pope, 2002).

Support structures are pivotal in patients' treatment adherence. The relationship between the patient and the treating health care practitioner is crucial, where patients who trust that the treatment will improve their wellbeing and empower them to return to their daily routines, are more likely to be adherent (Cornutiu, 2013). As alluded to earlier, supportive family members are essential in assisting patients with adherence to treatment. Research has demonstrated that family members who are educated about the illness and assisted by professionals to develop skills of managing the illness, are better able to recognise early signs of relapse and seek appropriate help for the patient, maintaining a supportive family environment (Gleeson et al., 2008). Lastly, a community's attitude toward the mentally ill plays a vital role in treatment seeking, drug adherence and in rehabilitation (Kanwar, 2015).

Gray et al., (2002) highlight that no evidence exists that the act of telling patients to take medication results in adherence; however, helping them to make decisions that are right for them, appears more effective. Facilitating adherence is advocated for through adopting a collaborative approach when working with patients, where patients are appropriately and sufficiently given information about their illness and their treatment, ensuring that their recommended medication regimes are tailored to suit them, and compliance therapy techniques, such as exploring ambivalence and testing beliefs about medication, are applied (Gray et al., 2002). Although there is consistency in literature regarding these suggestions, multiple reasons within different medical contexts stand as mammoth obstacles to successful application and significant improvement in adherence behaviour.

Sajatovic, Bauer, Kilbourne, Vertrees, and William (2006) concluded that adherence to medication is a multi-dimensional entity, including patient characteristics and patient-provider interaction. This does not only hold the patients responsible for their adherence, but places some of the responsibility on health care providers to present and encourage good alliance with patients in order to facilitate good adherence. The involvement of patients' familial supportive structures in treatment and psychoeducation appears to also be an important aspect of holistic treatment of Bipolar I Disorder.

2.6 Family members, burden of care and traumatisation

Family members have become an integral part of treatment within the mental health care system. As much development has occurred in psychiatric medication, a shift has occurred from focusing on institutional psychiatric treatment, to deinstitutionalisation, leading to treatment within the community (Glyngdal et al., 2002). This move places a huge responsibility on family members to provide care for their loved one with a psychiatric condition. Historically, interventions in mental health have primarily focused on the patients, leaving their family members feeling marginalised, as their needs are frequently neither recognised nor met (Askey, Holmshaw, Gamble & Gray, 2009).

In a literature review conducted by Corcoran et al. (2007), it was noted that there were few retrospective qualitative studies focusing on first-episode psychosis patients and their family members. Corcoran and his colleagues then sought to examine the perceptions of family members of patients' trajectory of symptoms over time and impact on family members' coping and help-seeking patterns. They emphasised that it was important to understand these patterns, as family members would typically instigate help-seeking for psychotic individuals. Their sample was made up of individuals diagnosed with Schizophrenia, Schizoaffective Disorder, and psychotic disorders not otherwise specified (Corcoran et al., 2007).

Corcoran et al. (2007) found that family members frequently first took note of mood symptoms and withdrawal in their reasonably normal, but vulnerable loved one. These family members would turn to prayer or other available social networks, for help. If the individual who was

displaying symptoms of psychosis was a teenager, it was found that family members often made assumptions about the adolescent just going through a phase. Some family members tried to reason with their loved ones, to prove to them that the psychotic symptoms were not true. It seemed that for most families, when the illness began, it was taken lightly. What provoked entrance into the mental health system was the escalation of symptoms leading to crisis (Corcoran et al., 2007).

Studies suggest that family members are concerned about the care and services available for their ill loved ones. Family members were found to have increased feelings of stress, burden and guilt when standard care was poor or when sufficient help was not provided when needed (Corcoran et al., 2007). Family members commonly experienced inpatient wards (hospitalisation) as frightening environments that did not aid recovery. Furthermore, the process that patients experience when they are being admitted, was also viewed as traumatic. Another area of concern for family members was preparation for discharge, as most felt that their relatives were discharged prematurely and without sufficient planning (Askey et al., 2009). Overall, it seemed that family members express dissatisfaction with services provided in mental health care, and they had limited expectations about the future (Corcoran et al., 2007).

The extent to which family members of people with psychiatric disorders, especially with psychosis, are exposed to aggression (verbal and physical) and the effects of this exposure on their psychological wellbeing, is poorly characterised. In a study conducted by Loughland et al. (2009) in Australia, 106 carer relatives were asked to complete questionnaires assessing socio-demographic details and perceived prevalence of aggression experienced in their caring roles within a twelve-month period. Carers with moderate to severe levels of aggression were re-approached to complete two assessments with respect to the aggressive incident(s) specified in the first part of their study. They used the first assessment tool to further assess Posttraumatic Stress Disorder (PTSD) symptoms, and the second tool to assess their coping strategies. It was found that 51.5% had symptoms of PTSD, with a high likelihood of PTSD diagnosis (Loughland et al., 2009).

Studies that investigate how family members are impacted, demonstrate that witnessing their loved ones' psychotic episode, being part of the disturbing process, and receiving the diagnosis, are all life altering experiences tapping into different negative emotions (Askey et al., 2009;

Corcoran et al., 2007; Loughland et al., 2009). The family members may also mourn the loss of possibilities previously dreamt of regarding what their ill relative would have achieved if they had not become psychiatric patients (Askey et al., 2009; Corcoran et al., 2007).

It has been found that trauma symptoms among carers of people with psychosis may be reduced through writing about experiences of the first episode of psychosis. In a sample where 35.1% of the carers had PTSD symptoms, avoidance was identified as one of the key symptoms where change was observed after the intervention. Where avoidance was identified as a contributing factor to the inhibition of emotions and cognitive processes, writing became a means for emotional disclosure and encouraging exposure to previously avoided events (Barton & Jackson, 2008). The effects of avoidance symptoms of PTSD in the caring process and impact thereof in facilitating adherence have not been explored in the literature.

It was found that family members in the writing group were significantly less likely to avoid reminders and feelings associated with their relative's episode at follow-up. However, those who wrote about emotive experiences did not experience fewer intrusions or hyper-arousal than those who did not. It was suggested that written emotional disclosure can help carers who are experiencing trauma symptoms following a relative's first episode of psychosis. In addition to the present study supporting the use of this intervention to alleviate trauma, it provides evidence that carers can also experience trauma as a result of witnessing a psychotic episode in their relative (Barton & Jackson, 2008).

In examining the load carried by caregivers and types of care during both the symptomatic phase and the remission phase of mental illness (Schizophrenia, affective disorders and Psychosis not otherwise specified), it was found that caregiving did not significantly differ based on the diagnosis. There was, however, a change in caregiving demands between the symptomatic phase and the remission phase. In the symptomatic phase, family members focused on physical and medical care, while in the remission phase, they focused on social and psychological care (Janardhana, Raghunandan, Naidu, Saraswathi & Seshan, 2015).

Physical care involves assistance with basic areas of functioning such as grooming, needing help with personal hygiene and appearance (including urinating and defecating). This necessitates that the caregiver should be highly alert and consistently watchful. Medical care

requires assistance and monitoring of taking medication, observation and reporting of side-effects, accessing diverse sources of help including the church, other faith healers and hospitals. Psychological care is caring for the person in a loving and affectionate manner, comforting and encouraging them, engaging them in meaningful communication and feasible activities, and involving them in decision-making. Emotional support and care assist in gaining confidence and strength. Lastly, social care focuses on preventing any form of abuse from the community, advocacy, safeguarding property rights, and helping and respecting needs to lead a 'normal' life by encouraging inclusion in social behaviour. Involving changes in perception from the community as a whole makes social care more intricate (Janardhana et al., 2015).

With regards to factors negatively affecting caregivers, it has been found that higher burden of care was related to lower life satisfaction, poorer physical health and higher distress. When caregivers had to provide daily care, they had poorer physical health. Furthermore, caregivers with a higher number of diagnoses and symptom unpredictability to address, presented with higher carer distress. Older caregiver age was associated with poorer carer health and higher distress. Similarly, greater reliance on avoidance coping was associated with lower positive affect and life satisfaction, poorer health and higher distress. In contrast, factors that assisted caregivers included: higher caregiver choice, which was associated with greater life satisfaction, and higher social support, which was associated with higher positive affect and life satisfaction, better health and lower distress (Mackay & Pakenham, 2011).

In a small pilot investigation of the feasibility of a needs-driven brief, interactive and structured intervention for community-based caregivers of people with psychosis intervention was examined. The intervention focused on facilitated carer access to reliable information about psychosis, goal setting and adaptive problem solving. Individual goals identified by caregivers included returning to paid employment, saving money, studying and improving sleep quality. There was improvement noted following the intervention, for example one participant had returned to full-time study, and two of the caregivers reported that they had less difficulty falling asleep following the intervention. In comparison to baseline scores, post-intervention scores indicated reduced levels of carer distress and depressive symptoms. Caregivers reported high levels of acceptability and satisfaction with the intervention. Further studies are required to evaluate the impact of such interventions on a larger number and wider range of caregivers (Roddy, Onwumere & Kuipers, 2015).

The thematic analysis found that the caregivers emphasised the importance of being given time and space to talk about their individual needs, as opposed to largely spending their time focused on meeting the needs of others, including the needs of their family members with psychosis. The caregivers wanted to use the intervention sessions to think about and problem-solve how they might make time to achieve their own personal goals, although they reported feeling guilty about prioritising those personal goals. The importance of receiving support at various points throughout their relatives' condition and not just at times of crisis, was highlighted by carers as a function that aids them in coping better (Roddy et al., 2015).

It has been noted that lack of information, together with exclusion from the treatment and management process, increases distress to family members and caregivers of patients with psychiatric disorders (Miklowitz, 2012). Increased distress in family members cannot benefit patients, instead, it increases patient distress and may lead to relapse. Thus, clinicians are encouraged to incorporate families in treatment strategies, acknowledging their care giver roles holistically, with the aim of improving long-term outcomes.

2.7 Mental health stigma

Stigma is a critical area to consider when exploring issues influencing cognitions and behaviour within mental health care service provision. Mental health stigma may be explained as an externally focused pattern of behaviours from others, which is associated with being discredited by people and society in general because of one's mental illness (Dunkley et al., 2015). Stigma may be understood from a cognitive economy conceptual approach. Cognitive economy refers to the ability to process the flood of information assimilated in every second, through simplification, filtering and organisation. This serves multiple functions, such as minimising potential dangers without much cognitive effort and forming an opinion of another in a social context. For example, in the development of stereotypes about mentally ill individuals, negative characteristics are weighted stronger than positive ones. Characteristics which are recognised in one person may be generalised to the whole group, reducing their characteristics to only a few 'typical' ones (Baumann, 2007).

When accepted norms, values and expectations are disrupted by people with unusual behaviour, people feel the desire to separate from them, forming a high social distance towards them, which is characterised by a strong aloofness, mostly connected with fear. In contrast, when people conform to accepted expectations, a low social distance is formed, characterised by feelings of a common identity and belonging to a group. The latter is based on the idea of shared experiences, where the other can access sympathy, openness and understanding (Baumann, 2007).

Public stigma is a widely endorsed public perception of fear, derision and avoidance of the mentally ill, whereby patients are negatively labelled and rejected. There are many reasons why such perceptions exist, one being a lack of awareness. Unfortunately, certain perceptions are further perpetuated by the media. For example, movies sometimes suggest that people with mental illnesses are murderers, homicidal, violent drug abusers, have themselves to blame for the illness, or that they are being punished by an unforgiving god (Kanwar, 2015). In addition to lack of awareness and lack of understanding, Kanwar (2015) postulates that stigma is perpetuated by illogical generalisations and disrespect for the heterogeneity of life.

Stigma may also be understood through the social construction of strangeness, which possesses both cognitive and positional elements, and defines something which is not close, not familiar, and not one's own. The dominant feature of 'strange' is that it cannot be put into existing orders. In an encounter with a strange person, human beings try to cope with their cognitive irritation by developing a social construction of strangeness. However, when a 'strange' person is placed into a familiar category, communication can continue (Baumann, 2007).

Reactions to strangeness can be fear as well as fascination and curiosity. Only when the distance between the strange and the other is significantly reduced, does uncertainty exceed a certain inner threshold. Thereafter, the feeling of threat and the need for security prevails over curiosity and a desire to know. The positional aspect, meaning the demarcation between one and the stranger, leads to exclusion. It has been suggested that the cognitive aspect of strangeness needs to be addressed to aid a process of accepting the other, as aimed by anti-stigma campaigns. From this, people with mental illness may be perceived as other members within the larger social group, not as strangers. In this sense, otherness becomes interpreted as

strangeness, making individuals diagnosed with psychiatric conditions the interpreted and accepted other (Baumann, 2007).

When negative perceptions are internalised, self-stigma develops. In this case, stigma progressively eats away at the sense of self-worth or social relevance. It works at various levels of the self to instil a deep level of insecurity (Kanwar, 2015). Self-stigma involves negative self-labelling, having a destructive attitude towards mental illness and its treatment, and believing that one is unappealing to others because of one's mental illness (Dunkley et al., 2015). As such, internalised stigma may increase non-adherence attitudes and behaviour.

A qualitative exploration of the perspectives of mental health professionals in Malaysia on stigma and discrimination of mental illness revealed that the main perpetrators of stigma include family, friends, employers and health-related alliances. Patients have difficulty maintaining different types of existing relationships including those with their family members, friends and colleagues. In the work sector, they are often viewed as a liability to the organisational productivity. In the health care sector, they may experience labelling from health care workers, including the use of derogatory terms such as 'crazy' and 'nuts'. Furthermore, insurance policies in Malaysia do not allow persons with mental illness to acquire health insurance, nor does the coverage include psychiatric services (Hanafiah & Van Bortel, 2015).

Kleinman et al. (2009) make a case that the word 'stigma' has been overused and has lost its true meaning, thus proposing the use of an alternative term, namely 'social death'. This term unites the sociological and psychological models. They propose that stigma is a moral experience, encompassing a set of social norms and obligations that constitute what is important to people living within a certain community. The moral view postulates that stigmatised individuals experience social death when other members of society hold negative attitudes and display behaviour that turns the stigmatised individual into the 'other' or a 'non-person' (Kleinman et al., 2009).

Social death is characterised by exclusion, where the mentally ill population are excluded from the following basic needs: healthcare, employment and housing. They are further exposed to risks including malnutrition, drug abuse, violence and homelessness. To avoid such exclusions

and risks, patients may select nondisclosure, which further limits their access to the necessary support (Hanafiah & Van Bortel, 2015; Kanwar, 2015).

Shunning people with mental illness from key areas of life due to stigma, renders them without any platform for independence, dignity and participation in wider civil society and the economy. Their self-perception and self-empowerment are adversely affected, possibly influencing help-seeking behaviour and compromising their recovery. Stigma results in patients being trapped in a vicious cycle of discrimination leading to detrimental consequences not only for the individual, but also for their families, communities and society at large (Hanafiah & Van Bortel, 2015).

Studies suggest that lack of education and awareness, as well as negative media portrayals be addressed to reduce stigma (Hanafiah & Van Bortel, 2015). However, even the 'knowledgeable' have been found to stigmatise the mentally ill. The general public cannot bear all the blame for stigma, as stigma has been observed in trained professionals, including those from mental health disciplines (Kanwar, 2015). Stigma is a major contributing factor associated with low rates of help-seeking and poorer quality of physical healthcare among people with mental illnesses. People with mental illness report encountering negative attitudes among mental health staff about their prognosis. They also experience 'diagnostic overshadowing', which is the misattribution of physical illness signs and symptoms to concurrent mental disorders, leading to underdiagnoses and mistreatment of the physical conditions. The combination of high rates of physical illness and low rates of effective treatment leads to the fatal consequences of discrimination and neglect (Thornicroft, Rose & Kassam, 2007).

For several decades it has been recognised that having been admitted to a psychiatric hospital can have an adverse effect on a person's reputation. Unpleasant or even dangerous side-effects and labels given to the mentally ill, contribute to the blemished reputation (Thornicroft et al., 2007). Individuals with Bipolar Disorder who receive antipsychotic medications may believe that antipsychotics are 'Schizophrenia drugs', and thus an inappropriate treatment for their condition. In addition to negative societal reaction related to having mental illness, the socially undesirable side-effects associated with antipsychotic medication treatment worsen stigma associated with treatment. While attitudes towards antipsychotic drugs may be positive in individuals who recognise therapeutic drug effects, other individuals diagnosed with Bipolar

Disorder may view medications negatively due to a sense of stigma (Sajatovic & Jenkins, 2007).

Stigma affects relationships at multiple levels, becoming intensely anti-therapeutic when it affects the patients mind and the interaction between doctor, patient, family and society. Accurate diagnosis as well as medical and psychological treatment are insufficient. Incorporating the social aspect is important in addressing the complex relations between comfort, security, self-esteem and dignity to maximise therapeutic effect and allow improved function recovery in psychotic patients. Amongst other rights, mental health care patients have the right to choose a therapist, the right to an explanation of the disease, the right to an explanation of the treatment, the right to consent to treatment, and the right to refuse treatment. It is believed that exercising these rights contributes to reduce self-stigma. Reduction in self-stigma empowers the patient in their social functioning, validating him/her socially by altering perception to the disease and lowering his stigma (Cornutiu, 2013).

In reviewing anti-stigma endeavours, it is important to ask the following questions: What message is distributed to community members? Which mental disorders are targeted? Who forms part of the target groups? In what position are those who are affected? What contribution is made to research? Is treatment and rehabilitation promoted? (Lauber & Sartorius, 2007).

In South Africa, negative perceptions about mental illness, driven by ignorance, lack of awareness and fear, are a barrier to reducing stigma. The South African policy framework remains unclear on how to address stigma. Instead, there are disparities between provinces in terms of how stigma is addressed, together with a shortage of staff to drive existing anti-stigma programmes (Marais & Petersen, 2015). South Africa has several challenges in improving mental health services and care, which will contribute to improved adherence.

2.8 Psychiatric illness within the South African context

Statistics South Africa (Stats SA) estimated the 2017 mid-year population at 56.52 million, with approximately 51% (approximately 28.9 million) females. The Gauteng province had the largest share (25.3%) of the South African population (Stats SA, 2017). This is the province where Chris Hani Baragwanath Academic Hospital (CHBAH) is situated, well known as the

third largest hospital in the world. CHBAH provides health care services to a large population, provides training to health care professionals and contributes to research and development of South African health care services (*Chris Hani Baragwanath Hospital,* n.d.).

In Africa and Asia, a gross inadequacy of beds exists for individuals who require hospitalisation due to mental illness. In African countries, the median number of beds was 0.34 per 10 000 population. While in Europe, the median number of beds was 8 per 10 000 population. In comparison to other African countries, South Africa was in a better position, having 2.1 beds per 10 000 population (Burns, 2011).

The South African Mental Health Care Act was adopted in 2002. It was an important step towards addressing mental health as a public health issue and in advancing the human rights of those requiring mental health care, including the right to access to care (Department of Health, 2004). However, there have been multiple challenges, predominantly with respect to implementation and enforcement in an already overburdened health system (Marais & Petersen, 2015).

In 2007, South Africa became a signatory to the Convention on the Rights of Persons with Disabilities (CRPD) at the United Nations Convention (Burns, 2011). The CRPD advocates for the protection of the dignity, worth and equal rights of persons with disabilities as members of the family of human beings. People with disabilities are fully entitled to basic human rights, without any form of distinction, including civil, cultural, economic, political and social rights. They are free to enjoy the benefits of inclusion, equality and non-discrimination like other people (Convention on the Rights of Persons with Disabilities and optional protocol, 2007).

Individuals diagnosed with psychiatric disorders form part of the population/group of persons with disabilities. The South African government thus committed itself to transform the treatment approach of all individuals with disabilities. Burns (2011) argues that the South African government has failed to carry out their obligations and responsibilities as signatories of the CRPD, stating that the rights of these individuals are regularly violated, and that they remain stigmatised and isolated.

In 2013, South Africa adopted a new Mental Health Policy Framework (MHPF) and Strategic Plan 2013–2020. This policy is South Africa's first officially endorsed Mental Health Policy following the demise of the apartheid regime. The policy was developed based on a review of the previous policy, South African mental health service literature, a situational analysis of the mental health system, and the opinions of key mental health stakeholders. International guidelines provided by the World Health Organisation (WHO) informed the format and content of the policy, and it was based on sound evidence (Department of Health, 2013).

The MHPF aims to give guidance to all South African provinces for the promotion of mental health, prevention of mental illness, treatment and rehabilitation. This would support task sharing and the integration of mental health into primary health care services, whereby mental health care would be accessible and affordable. The MHPF was set to make use of methods that are practical, scientifically sound and socially acceptable. This approach was organised to reduce exclusion and social disparities in a people-centred, intersectoral and collaborative manner (Department of Health, 2013). In essence, the policy was structured to aid the process of implementing the Mental Health Care Act of 2002.

Some of the principles outlined in the Strategic Plan 2013–2020 are: the provision of maximum support for families and carers of those with mental illness; involving mental health care users in the planning, delivery and evaluation of mental health services; encouraging self-help, peer support and advocacy groups; and providing sufficient support for mental health care users and their associates to represent themselves (Department of Health, 2013). Such principles paint a progressive and highly inclusive picture for mental health users within the South African context. However, the reality is that implementation has been abysmal.

In a study conducted by Marais and Petersen (2015), key participants were identified to explore systemic factors that are likely to facilitate or impede the implementation of integrated mental health care in South Africa. The selection of participants was based on their positions of power and responsibilities in relation to the South African Department of Health and the Department of Social Development, at national, provincial and district level. After selection, the participants were interviewed. These participants agreed that both the Mental Health Care Act of 2002 and the Mental Health Policy Framework of 2013 emphasise integration of mental

health into primary health care. However, multiple challenges at national, provincial and district levels were identified (Marais & Petersen, 2015).

Resources available for mental health care are limited in South Africa, with disparities noted from one province to another in terms of resource allocation. There is an insufficient budget and inadequate infrastructure from tertiary to community level service points, where both quantity and quality of infrastructure are compromised. There is poor accessibility, shortage of mental health care professionals and specialists to implement policy, and a shortage of human resources to deliver community-based services. Additionally, the existing professionals are confronted by high workloads, rigid staff structures that do not smoothly accommodate the creation of new posts for district level mental health teams, and insufficient funds to appoint more staff. These factors contribute to negative attitudes, resistance among staff and high staff turnover (Marais & Petersen, 2015). Other challenges include poor coordination in terms of planning and service provision between national, provincial and district levels. Mental health care service providers are not sufficiently involved in planning. They also lack training and patient-centred orientation. There is a lack of communication about the policy, insufficient capacity to translate policies into plans, and breakdown in communication between hospitals, clinics and pharmacies, resulting in inconsistent provision of medication. Resistance was further identified from mental health care users, families and communities and there was uncertainty about how best to engage with them. Overall, there was a lack of monitoring mechanisms at all levels (Marais & Petersen, 2015). This indicates the multiple levels at which improvement is indicated within South Africa to achieve the desired mental health care services as outlined in the MHPF.

Findings from studies conducted in other countries may assist in understanding and improving mental health care services in South Africa. For example, Ng, Setoya, Koyama and Takeshima, (2010) discuss the ongoing development of community mental health services in Japan. Japan was noted to have the highest number of psychiatric beds and highest ratio of beds per capita in the world. The Japanese mental health system was reported to be characterised by high bed ratio numbers, low supportive housing facilities, a strong emphasis on physical treatments rather than psychosocial treatments, and relatively low levels of staff working in the community (Ng et al., 2010). The Japanese mental health system has several strengths representing good practice in community mental health care. Similar to South Africa, at the

national level, the Japanese government is committed to the shift of emphasis from a hospital-based mental health service system to a community-based system. A difference in actions taken by the two governments exists. In Japan, funding incentives were created for private hospitals to treat acute patients for shorter hospitalisation periods. Nursing outreach visits were provided and community-oriented services in private hospitals and clinics were established to support early discharge. The numbers of psychiatric day care centres and private psychiatric outpatients' clinics also increased, together with the number of social rehabilitation facilities. Furthermore, mental health hospitals were renovated to provide a comprehensive range of services to meet patients' needs (Ng et al., 2010). This demonstrates the extent to which funding aids successful implementation of plans. Despite all the progress made in Japan, they too have shortfalls to address (Ng et al, 2010).

Unfortunately, studies indicate that although different types of psychosocial interventions and medication exist to meet the needs of individuals with mental health conditions, many of them do not receive mental health care (Mental Health Foundation, 2016). The Life Esidimeni tragedy of 2016 highlighted the horrific manner in which mental health users were failed by governance and management in the South African Gauteng Department of Health. Following the cancellation of the Gauteng Department of Health's contract with Life Esidimeni, psychiatric patients were transferred from the Life Esidimeni facility into facilities that did not meet the requirements for providing care for the patients. The so-called 'Gauteng Marathon Project', where poor decision-making, inadequate planning, disregard of the rights of the patients and their families, and chaotic implementation processes were evident, ultimately resulted in the loss of lives of vulnerable mental health care users (Barron & Padarath, 2017). It was observed that in this process of deinstitutionalisation, certain officials, Non-Government Organisations, and processes had violated the Constitution and contravened the National Health Act and the Mental Health Care Act (Barron & Padarath, 2017). This tragedy put a spotlight on what appears to be a mammoth task of implementing existing policies and the urgent need for improved mental health care in South Africa. The use of existing research that is relevant to the population and context to explore further and expand scientific data from which recommendations can be made, is imperative.

In a study conducted by a psychologist in South Africa, the relationship between trauma and non-compliance in cancer patients was explored. Benjamin (2006) found a relationship

between trauma and compliance, and she developed a Medical Trauma Debriefing Model based on the Wits Trauma Intervention Model, as an intervention to assist the patients. Her findings showed an improvement in the compliance of the patients after implementing the intervention. She suggested that Medical Trauma Debriefing should be integrated routinely into the treatment of certain medical and surgical conditions (Benjamin, 2006).

A high rate of non-adherence, frequent hospital re-admissions and increased costs in psychiatric patients diagnosed with psychotic disorders has been observed in several studies, as discussed in the literature above. This is a global problem, affecting the patients, their family members and the community at large. In South Africa, limited information is available regarding the patients' and family members' experiences and perceptions of Post-Psychosis Trauma and its potential relationship to non-adherence. There is also limited information on effective interventions in addressing these issues. Given the complex and symbiotic relations between traumatic experiences and the experience of psychosis, it is important to explore how these relations manifest in the treatment of patients with Bipolar I Disorder with psychotic features, especially given the very complex socio-political, resource limited context of South Africa.

2.9 Aims and objectives of the present study

In sum, patients with Bipolar I Disorder in conjunction with psychotic symptoms are at risk for long-term disability, suicidality, lengthy hospital admissions and chronically impaired levels of insights and capacity for consent (Addisu et al., 2015, Lawson & Bland, 2004; Scott & Pope, 2002, Tarrier et al., 2007). Research has demonstrated that a large majority become dependent on their support network in the management of the disorder (bin Jabal et al., 2018; Chisholm, 2005; Garety et al., 2008). In the South African context, family caregivers have been found to take on this burden of care as research validates the significant role they play in facilitating treatment. Research also suggests that the experience of psychosis may be very traumatic for both the patient and the family (Askey et al., 2009; Corcoran et al., 2007; Loughland et al., 2009). The effects of Post-Psychosis Trauma on the patient are beginning to be better understood as research is beginning to explore these links. However, there is no research

documenting how Post-Psychosis Traumatization in family member affects them, and more importantly how it affects their capacity to fulfil their caregiver roles in treatment adherence. The present study therefore, seeks to investigate whether South African patients with a diagnosis of Bipolar I Disorder with psychotic features report Post-Psychosis Trauma, whether their families report diagnosable Post-Psychosis Trauma, and whether this impacts on their capacity to make decisions that facilitate treatment adherence. The research will used standardized measures of PTSD to explore whether the research participants evidence diagnosable PTSD as a function of their experiences of psychosis. The findings will allow for reflections about the current status quo in the South African psychiatric system, where although patients and their families may receive crisis interventions, interventions for additional prominent challenges such as Post-Psychosis Trauma or even comorbid PTSD, are not offered.

2.10 Research questions and hypotheses

The present study will explore the following research questions:

Using quantitative methodologies with associated hypotheses

1. Do South African patients diagnosed with Bipolar I Disorder with psychotic features experience diagnosable Post-Psychosis PTSD (consistent with the trauma framework proposed by the DSM)?

2. Do family members of patients with Bipolar I Disorder with psychotic features experience diagnosable trauma in relation to the patients' psychotic episode?

   H_1: It was hypothesised that psychosis itself, when used as the target on the PTSD Symptom Scale Interview (PSSI), will yield symptoms consistent with diagnosable symptoms of PTSD in patients with Bipolar I Disorder with psychotic features and their families.

3. What is the prevalence of Post-Psychosis Trauma in this sample of patients with Bipolar I Disorder with psychotic features?

4. What is the prevalence of Post-Psychosis Trauma in the family members of patients with Bipolar I Disorder with psychotic features?

5. Is treatment adherence status associated with Post-Psychosis Trauma symptoms?

   H_2: Treatment adherence, as measured by the DAI, is expected to be correlated with trauma symptomatology as measured by the PSSI.

6. When patients are classified as adherent or non-adherent using clinical indicators, can adherence status increase the odds of or against the presence or absence of diagnosable PTSD?

   H_3: The odds for treatment adherence as classified according to clinical indicators will be higher in the absence of diagnosable PTSD.

7. Can other demographic and clinical characteristics indicators such as education, social support, history of receiving psychotherapy, insight and employment status predict adherence or the presence or absence of diagnosable PTSD?

   Using qualitative methodologies

8. What are patients' perceptions of factors influencing non-adherence?
9. What are the family members' perceptions of factors influencing non-adherence?
10. What are patients' and family members' perceptions and experiences of psychosis in Bipolar I Disorder?

3. CHAPTER THREE- METHODOLOGY

3.1 Introduction to methodology

> "T*he theoretical framework is a foundation from which all knowledge is constructed for a research study*" (Grant & Osanloo, 2014, p.12)

This foundation resonates with all fragments of the research process. It informs the topic selected, provides guidance for the literature review and informs the research questions developed, the research design, as well the analysis plan for the study (Adom, Hussein, & Agyem, 2018). Grant and Osanloo (2014) stress the importance of theory-driven thinking and acting, arguing that such a process informs and provides crucial guidance from the successful completion of a dissertation. From the above statement, pragmatism stood as a suitable framework for the current study. The first section of this chapter outlines pragmatism and its link to mixed methods applied in the study. The second section specifies the research questions and objectives. This is followed by a discussion of the study design, all measures employed, the sample and data analysis. Lastly, ethical considerations will be briefly outlined.

3.2 Research Framework

3.2.1 Pragmatism

Pragmatism stands out as a movement that had a significant impact on academic clusters such as philosophy, education, law, political theory, religion, social theory and the arts. It is known as the philosophical school founded by three philosophers from America namely: Charles Sanders Peirce (1839-1914), William James (1842-1910) and John Dewey (1859-1952). These three contributed to the formation and articulation of pragmatism, each of them occupying an important component in its development. While Peirce is referred to as the first spokesman of pragmatism, James is known as the one who translated pragmatisms to a wider audience, and Dewey is the well-known advocate of the movement. The three expressions of pragmatism are in basic agreement in terms of interpreting knowledge and in accounting for its function in

experience (Sundin & Johannisson, 2005; Thayer, 1981). The current study sought to provide an account for the participant's lived experiences and provide an interpretation contributing to scientific knowledge on the subject matter.

Peirce, James and Dewey were all interested in examining practical consequences and empirical findings to help in understanding philosophical positions. Their interests were driven by a desire to help in deciding which action to take next as one attempts to better understand real-world phenomena including social, psychological and educational phenomena (Johnson & Onwuegbuzie, 2004). In addition to the above-named philosophers, the philosophical school of pragmatism has been further developed by others such as Davidson, Rescher, Putnam and Rorty. These philosophers drew inspiration from different sources, some form insights gained from their experiences, others from desires to solve particular problems (Sundin & Johannisson, 2005; Johnson & Onwuegbuzie, 2004).

Goodman (1995) postulated that there is no essence linking all pragmatic writers, rather, sense was identified in linking a series of characters postulated by the different writers. For the current study, a select group of ideas arising from the different contributors of pragmatism, their origins cited, the consequences of applying those ideas and conclusions that were drawn on, inform the selected theoretical framework. Only the relevant ideas will be discussed in the section.

Pragmatism is a distinct and consciously conceived method of philosophising. It is a movement that insists on contravening the boundaries between philosophy, science, politics and morality. It is also a strong advocate for democracy as the goal towards which all human activity should strive. To a pragmatist, to be instrumental does not mean to give priority to instrumental values while violating intrinsic values or other fundamental actions, instead, all values and actions are acknowledged as instrumental to human purposes. Therefore, to judge the truth of an idea from a pragmatist standpoint is to judge the extent to which the idea serves a certain purpose. Judging the truth of an idea or belief is a question of whether it makes any difference to practice or not, and whether it provides people with a useful tool or not (Thayer, 1981; Sundin & Johannisson, 2005).

To respond to a problem, pragmatism made three fundamental contributions: firstly, it provided a philosophical contextualism, secondly, it provided an instrumental interpretation of scientific knowledge, and lastly, it gave a theory of value and valuation. It has been commonly said that knowledge is power, pragmatism continues to say that the value of thought or knowledge rests upon its practical uses. This is just another aspect and cannot be used to limit human thought and knowledge as subject to a norm of practical results, where standards of usefulness are tests of significance in rational matters. Although pragmatists judge certain human activities through the notion of practical and useful results, they are not exclusively preoccupied with this notion. Thus, declaring pragmatism as the philosophy of the useful alone would be less than informative (Thayer, 1981).

Similar to other schools of thought, pragmatism was born from a specific social environment, where intellectual debates were informed by historical factors which are critical in its identity. Pragmatism is additionally referred to as a theory for clarifying the meaning of certain classes of signs. It introduced into philosophy a procedure of deciding and ruling on the meaning of beliefs, ideas and uses of language, whereby empirical consequences of using, experimenting with or acting upon an idea under specific circumstances are formulated (Thayer, 1981). Through pragmatism, a researcher can apply the sensible effects or outcome-oriented rule through thinking. This entails thinking about what will happen if one embarks on specific action, observing what happens in ones' experience when action is taken i.e. practical experience, or either formally or informally trying a rule and observing the consequences or outcomes i.e. conducting experiments (Johnson & Onwuegbuzie, 2004).

3.2.2 Mixed methods from a pragmatic view

Pragmatism suggests the compatibility thesis, whereby it argues that differences and divisions between qualitative and quantitative paradigms are not as wide as portrayed by the paradigm purists. Some practical reasons include reflecting on how both approaches have been found to be useful by multiple researchers for many years, validating their contribution in the pursuit of knowledge development. Both approaches have weaknesses and despite these, both have produced significant results influencing policies and important historical lessons. Paradigm

purists, on the other hand, firmly stand against the mixing of methods. They argue that compatibility between qualitative and quantitative approaches is impossible due to different underlying philosophies, assumptions and methods in the two. This is commonly referred to as the incompatibility thesis. Further, purists envisage researchers employing mixed paradigm approach as guaranteed to fail in their pursuits (Tashakkori & Teddie, 1998).

Taking into account that for both qualitative and quantitative data, a number of different theories may be employed to decipher meaning, as the world is complex and multidimensional. Using one approach and claiming complete understanding often proves extremely challenging, particularly in social and behavioural research. The easing of hostility between qualitative and quantitative approaches has positively influenced research development, allowing researchers to use methods appropriate for their studies, as opposed to relying only on the exclusive use of only one approach (Tashakkori & Teddie, 1998).

Pragmatism gives hope for the fruitful mixing of research approaches, allowing a researcher to fit together the insights provided by both qualitative and quantitative research into a workable solution. This places one in a position of being able to take advantage of the two paradigms in advancing knowledge. The researcher is at liberty to choose the combination or mixture of methods and procedures that works best for answering his/her research questions (Johnson & Onwuegbuzie, 2004).

It has been noted that in describing methodology, pragmatists frequently employ vague language (Tashakkori & Teddie 1998). To overcome this, the researcher of the current study followed a number of steps which will be outlined as clearly as possible. The first step was evaluating her motive for selecting a mixed methods approach. Greene, Caracelli, and Graham (1989) propose two motives for the use of mixed methods, triangulation and complementarity. Triangulation refers to the use of multiple methods possessing counteracting biases to investigate one conceptual phenomenon, such that the validity of the results obtained regarding that investigating is strengthened (Greene et al., 1989). The current study had more than one conceptual phenomenon to investigate. Therefore, complementarity was selected as the motive for employing a mixed approach for the current study, as it best accommodates an enquiry into conceptually different but overlaying phenomena.

Complementarity was found useful to measure overlapping but somewhat different facets of Post-Psychosis Trauma and non-adherence in patients diagnosed with Bipolar I Disorder with psychotic features and their family members. The presence of multiple layers of interacting facets is evident in the population investigated in the study. Through adopting complementarity, the understanding of results could be enriched, elaborated, enhanced, illustrated, and clarified through information gathered from both qualitative and quantitative data sets (Greene et al., 1989).

As recommended by Johnson and Onwuegbuzie (2004), the mixed methods research process model made up of eight steps was followed. Firstly, research questions were determined, secondly, it was determined that a mixed design would be appropriate, thereafter, a mixed-method or mixed-model research design was selected. The fourth step was data collection, followed by data analysis and then the interpretation of data, step five and six respectively. The seventh step was legitimation of data, which entailed evaluating the trustworthiness of both the qualitative and quantitative data and succeeding interpretation. The last step was drawing conclusions and writing the final report (Johnson & Onwuegbuzie, 2004). Figure 1 below displays the mixed-model design used.

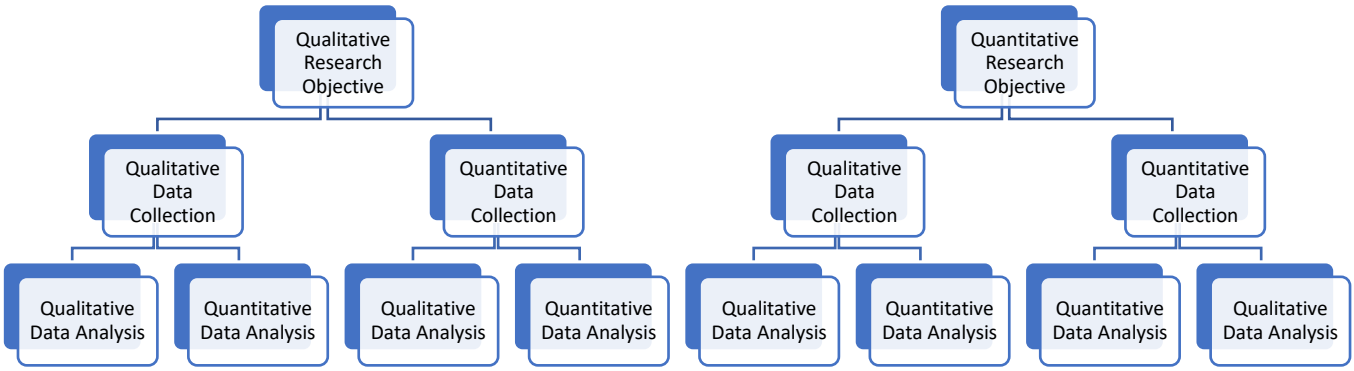


Figure 1: Mixed-model design

Within the above mixed methods research process model, Onwuegbuzie and Teddlie's (2003) seven-stage conceptualization of the mixed methods data analysis process was incorporated. The seven data analysis stages are as follows: (1) Data reduction, this involves reducing the

dimensionality of the qualitative data (e.g. through exploratory thematic analysis) and quantitative data (e.g. through descriptive statistics). (2) Data display, it involves describing data in a simplified and accessible manner, this may include but is not limited to matrices, pie charts, graphs, lists, tables and graphs. (3) Data transformation, in this stage quantitative data are converted into narrative data that can be analysed qualitatively and/or qualitative data are converted into numerical codes that can be represented statistically. (4) Data correlation involves the quantitative data being correlated with the transformed qualitative data and/or the qualitative data being correlated with the transformed quantitative data. (5) In data consolidation, both quantitative and qualitative data are combined to create joint variables or data sets. (6) Data comparison comprises comparing qualitative and quantitative data. (7) Data integration is the last stage, whereby both quantitative and qualitative data are integrated into either coherent whole or two separate sets (Tashakkori & Teddlie, 2003).

Onwuegbuzie and Johnson (2006) proposed a typology of legitimation types in mixed research, one deemed useful for the current study was 'inside-outside legitimation' (p.g 57). In this typology, from an insider's perspective, an emic viewpoint is provided (i.e. group member's viewpoint), while the outsider perspective can provide the etic viewpoint (i.e. an "objective" outsider looking at and studying the group). Inside-outside legitimation refers to the degree to which the researcher accurately presents and utilizes both emic and etic viewpoints. On one hand, the ability to do this can be compromised when a researcher is judging the group solely by the values and standards of one's own culture. On the other hand, when a researcher becomes so involved with the group that he or she abandons his/her own culture, adopting that of the group (Onwuegbuzie & Johnson, 2006).

To optimise inside-outside legitimation, the researcher of the current study was assisted by the involvement of an experienced clinical psychologist, outside the CHBAH environment, acting as a supervisor. The supervisor was available for discussion and reflection processes, through which the researcher was able to maintain a well informed and balanced perspective when collecting, analysing, and interpreting data. Additionally, the supervisor assisted in critically examining the interpretations, conceptualizations and conclusions that were made, for the qualitative, the quantitative part and when the parts were put together or integrated

Onwuegbuzie and Johnson (2006) suggest that while quantitative research often seeks the etic view, qualitative research often seeks the emic view and mixed research seeks to balance these two viewpoints. However, mixed methods are not without limitations. Of note, three overall challenges have been identified, (i) the problem of representation (difficulty in capturing lived experiences using words and predominantly in using numbers), (ii) the problem of legitimation (difficulty in obtaining findings and/or making inferences that are dependable, transferable and/or confirmable), and (iii) the problem of integration (where the first two problems may be exacerbated by the presence of disadvantages from both quantitative and qualitative components, which may increase research threats) (Onwuegbuzie & Johnson, 2006). To minimise the impact of these limitations, a combination of standards set by reputable researchers in mixed methodology were outlined and adhered to, as recommended by Johnson, Onwuegbuzie, and Turner (2007). Furthermore, the researcher did not aim to obtain all answers, but to contribute to knowledge development by exploring different angles of the subject matter.

3.3 Research design

The mixed methods design was employed to gain a better understanding of Post-Psychosis Trauma and non-adherence in patients diagnosed with Bipolar I Disorder with psychotic features and their family members. Through this approach, data was collected and analysed using research techniques from both qualitative and quantitative research approaches (Bryman, 2006). The quantitative aspects included approaching the research with a specific hypothesis and null-hypothesis, collecting data through predetermined instruments, reducing the collected data to specific variables and employing statistical analysis procedures. Concurrently, stemming from the intent to provide a comprehensive analysis of the research problem, the researcher employed qualitative aspects including exploring meanings from individual experiences and identifying common themes from the qualitative data (Creswell, 2003).

As opposed to committing to either qualitative or quantitative philosophy systems, the researcher sought to draw from both sets of assumptions to obtain relevant information from

different data sources. Data collection and analysis through mixed methods enriched and added to the depth of understanding the research questions.

This study is primarily exploratory in nature. The qualitative aspects sought to elicit the participants' in-depth narratives of their experiences in the complex areas of Post-Psychosis Trauma and non-adherence. This allowed the researcher to obtain information on the participant's experiences within their specific subjective context (Willig, 2001). Through this approach, the researcher sought to explore the participants' feelings, perspectives/perceptions, behaviours, and experiences in relation to Post-Psychosis Trauma and non-adherence.

Holloway and Wheeler (2002) argue that although scientists may strive for absolute objectivity, this may be futile, as their own biases and experiences invariably intrude on their studies. Although the quantitative approach was employed to test the hypothesis of the current study, and to explore numerical factors related Post-Psychosis Trauma and non-compliance in Bipolar I Disorder with psychotic features, the researcher avoided treating perceptions of the social world as neither objective nor absolute, opting to test the hypothesis taking into account the research context and subjective interpretations within the study, through adopting an interpretive research paradigm (Schwandt, 1994). In addition to the pragmatic approach, the interpretive research paradigm was found useful as it is founded on the human sciences and philosophy, centred on the ways human beings make sense of and attach meaning to their subjective reality (Holloway & Wheeler, 2002).

The current study possesses a correlational aspect. After data collection, the participants' information was divided into two categories. The first category consists of information gathered from adherent patients diagnosed with Bipolar I Disorder with psychotic features and their families in CHBAH. The second category consists of information gathered from non-adherent patients diagnosed with Bipolar I Disorder with psychotic features and their families in CHBAH. Patients who did not follow instructions set by the health care practitioners treating them, who stopped taking their treatment and had relapsed within February 2014 to September 2014, were categorized as the non-adherent group.

While some of the non-adherent patients participated in the study as out-patients, most non-adherent patients came from the psychiatry in-patient register. They only participated in the

study after receiving treatment and being assessed as apsychotic by their treating psychiatrist. Patients who consistently took their treatment, appropriately attended their appointments and displayed behaviour showing that they followed instructions set by the health care practitioners treating them and consequently had not relapsed within the same period were categorized as the adherent group.

3.4 Sample

Patients diagnosed with Bipolar I Disorder with psychotic features in CHBAH, whose acute psychotic symptoms were in remission after assessment and treatment by a psychiatrist at CHBAH, together with their family members, were invited to participate in the study. Information from patient files together with information from their treating HCP's was used to ascertain that this criterion was met. Additionally, only participants who were sufficiently competent in English were included in this research as a level of proficiency was required to successfully administer measurement tools only available in English, bearing in mind the eleven official languages within the South African context, amongst which English is a common language of education. However, some participants required translation in isiZulu to better understand and answer a few questions. Their needs were accommodated by the researcher, whose home language is isiZulu.

In order to be eligible for participation, patients needed to have been diagnosed with Bipolar I Disorder with psychotic features within the identified four-year period of data collection (December 2010- December 2014), as access to accurate records, treating HCP's and participants could be maximised during that period. Patients who experienced psychosis before the specified period were excluded and only patients who experienced their first psychotic episode within these four years were included. Additionally, patients with a co-morbid or pre-morbid primary diagnosis of a psychotic disorder were excluded. As previously stated, participants were invited from the inpatient and the outpatient psychiatric units at Chris Hani Baragwanath Academic Hospital. In the final sample, 54.3% were in-patients while 45.7% were out-patients. No differences between the two groups were found on any of the target study variables.

The sample included males (n= 10, 29%) and females (n= 25, 71%) patients and their family members with ages ranging from 18 to 70 years. Individuals within this age group were able to give consent for participation and engage with the research requirements appropriately.

A *prior* power analysis was conducted using the G*Power 3 statistical program to calculate an appropriate sample size for the current study (Faul, Erdfelder, Lang & Buchner, 2007). Holding power (β) at .80, and α at .05, a minimum required sample size of 14 patient/family dyads was required to detect at least moderate sample sizes. The final sample consisted a total of 70 participants (35 patients and 35 family members) for the quantitative portion of the research. The qualitative portion aimed to include 20% of this sample, so 14 participants (7 patients and their family members) were individually interviewed.

Table 1: Demographic details of interviewed participants

Participant	Pseudonym	Age	Gender	Adherence	Family Member Relationship
P1	Londi	51	Female	Adherent	Mother
P2	Mandisa	27	Female	Adherent	Husband
P3	Bafana	19	Male	Non-adherent	Aunt
P4	Anna	19	Female	Adherent	Father
P5	Peter	23	Male	Non-adherent	Mother
P6	Martha	33	Female	Non-adherent	Husband
P7	Clare	23	Female	Non-adherent	Grandmother

3.5 Measures

The participating patients and their family members were requested to complete consent forms, a questionnaire, assessment scales, and interviews. The researcher sat with the participants throughout completion of all required measures and provided assistance when needed.

The general information questionnaire was completed by the patients only, together with four scales (see Appendix 2, 3, 4, 5 and 8). Their family members completed three scales (see

Appendix 5, 6 and 8). Only seven patients and their family dyads participated in the open-ended interview (see Appendix 7a and 7b).

3.5.1 The General Information Questionnaire (Appendix 3) (Patients only)

The General Information Questionnaire was designed by the author of the current study. Its purpose was to obtain information such as demographic details, education, occupation, clinical characteristics and access to a support structure. This assisted in describing the demographic and clinical characteristics of non-adherent as compared to adherent patients diagnosed with Bipolar I Disorder with psychotic features and their families in CHBAH. Some of this information was used to explore associations with treatment adherence status to answer Research Question 6.

3.5.2 Modified Mini Mental State Examination (3MS)(Appendix 4)(Patients only)

The 3MS was devised by Teng and Chui in 1985. It was derived from the Mini Mental State Examination (MMSE), which was designed by Folstein, Folstein and McHugh in 1975. Both tools have been widely used in clinical practice and in research and have been found to be valid and reliable (Folstein et al., 1975; Jeong, Cho & Kim, 2004). Similar to the MMSE, the 3MS may be used as a screening tool to assess mental and cognitive status. The MMSE is an eleven-question measure, testing five areas of cognitive functioning namely: orientation, registration, attention and calculation, recall and language (Folstein et al., 1975). The 3MS incorporates four additional test items namely: personal information, verbal fluency, abstract or conceptual thinking and long-term recall. Furthermore, some minor modifications have been made to some of the original test, including counting forward and backward instead of serial calculations and acceptance of closeness of response as opposed to the original correct/incorrect scoring (Teng & Chui, 1985).

Psychometric comparison of the MMSE and the 3MS yielded comparable reliability estimates. Also, the additional tests and modifications do not significantly increase test administration time (Tombaugh, McDowell, Kristjansson & Hubley, 1996). Similar to the MMSE, the 3MS is not a diagnostic tool. It heavily relies on reading, writing and verbal responses. Therefore, patients who complete this need to have English literacy, be able to read and write, and not suffer from other communication disorders that could negatively impact on their performance (Kurlwicz & Wallace, 1999). It is important to use the tool carefully and appropriately.

When scoring the 3MS, Individuals are awarded points for correct answers, and highest obtainable score is 100, with a score of 77 or below indicating cognitive impairment (Tombaugh et al., 1996). In the current study, the 3MS was employed as a screening tool to assist in excluding patients who performed poorly as this was indicative of factors such as, significant challenges with English literacy, difficulty engaging in tasks requiring reading, writing or the provision of appropriate verbal responses, or impairment in specific cognitive functions as assessed by the tool. These factors may have resulted in misunderstanding and poor performance on the other assessment tools. Patients who obtained a score of 77 or below were excluded from the study, while those obtaining a score of 78 or above were included. It is important that participants who were included in the study were well oriented, able to understand test instructions, read, write and give appropriate responses. This was the first test administered on the participating patients and the patients engaged well in it, demonstrating their ability to understand and follow instructions appropriately.

3.5.3 Drug Attitude Inventory - 30 (DAI-30) (Appendix 4)

The DAI is a self-report questionnaire designed by Hogan in 1983. It includes 30 questions pertaining to various aspects of the patient's perceptions and experiences of treatment to which a patient may answer “true” or “false”. The scale was developed for a psychiatric population, with a sample made up of patients diagnosed with Schizophrenia. Of these 30 questions, 15 are negatively scored and the other 15 items are positively scored (15 items when endorsed by an adherent patient would indicate a positive subjective response to medication and 15 items that when answered “false” would indicate a negative subjective response to medication). Each true

or false answer is coded as either positive or negative for each question. The positive is scored as a plus one, and the negative is scored as a minus one. A sum of these scores represents the total score, with a positive total indicating adherence, while a negative total score indicates non-adherence. The DAI has been found to be reliable and valid (Hogan, Awad & Eastwood, 1983). Use of the tool has continued in recent studies, whereby the validity and reliability were confirmed for use in individuals diagnosed with other psychiatric conditions, including Bipolar Disorder (Sajatovic, DiBiasi & Legacy, 2017; Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010; Tempier et al., 2010). Additionally, this tool has been used in research conducted within the South African context (Paruk & Roojee, 2018). In the current study, it was used to explore the participants' attitudes towards their treatment together with their perceptions and experiences.

3.5.4 Depression Anxiety and Stress Scale (DASS – 21) (Appendix 5)

This inventory was developed by Lovibond and Lovibond in 1995. It is a self-report measure composed of 21 items, which are group statements designed to assess three dimensions of mental health namely: depression, anxiety and stress. While depression is categorised by factors such as: low positive affect, low self-esteem, hopelessness and lack of incentive. Anxiety is categorised by factors related to: autonomic arousal and fearfulness. Lastly, irritability and over reactivity categorise stress (Lovibond & Lovibond, 1995).

This tool is a revised version of the original DASS, which was composed of 42 items. Its administration time has now been reduced and it has been used in a variety of research projects since its publication (Lovibond & Lovibond, 1995; Ng, Trauer, Dodd, Callaly, Campbell & Berk, 2007). When the psychometric properties of the DASS-21 were evaluated in clinical and non-clinical samples, acceptable validity and reliability were demonstrated (Antony, Bieling, Cox, Enns & Swinson, 1998; Ng et al., 2007). In the current study, this tool was employed to assess symptoms of depression, anxiety and stress within the participants. This was useful in comparing to results on other scales, enriching understanding and statistically controlling for the effects of these three mental health dimensions on overall research findings. The measure has been widely used in clinical and non-clinical settings and its use in the South African

context is well documented (Dithole & Thupayagale-Tshweneagae, 2015; Kretchy, Owusu-Daaku & Danquah, 2014; Norton, 2007; van Zyl et al., 2017).

3.5.5 Positive and Negative Affect Schedule (PANAS) (Appendix 6)(Family only)

This scale was developed in 1988 by David Watson, Lee Anna Clark and Auke Tellegen for the purpose of assessing two dimensions of affect, namely Positive Affect (PA) and Negative Affect (NA), which are considered to be important indicators of psychological functioning. PA shows the extent to which an individual feels alert, active and enthusiastic. When a high score is obtained on the PA, it reflects a state of high energy, pleasurable engagement and full concentration. However, a low PA score reflects a state of low energy and sadness. On the other hand, a high NA score reflects subjective distress and unpleasant engagement including a variety of aversive mood states such as anger, disgust, guilt, contempt, fear and nervousness. A low NA score represents a state of calmness and serenity. Short-term (e.g. today or right now) and long-term (e.g. general or past year) instructions are used to look into mood changes and trait-like factors respectively (Watson, Clark & Tellegen, 1988).

In developing this scale, there was an aim to select terms that were relatively pure markers of either PA or NA. Preliminary reliability analysis convinced the developers that 10 items for PA and NA respectively would be sufficient for the PANAS. They made it to be a 20-item self-report measure. In their study, they found the PANAS to be an efficient tool possessing internal consistency and excellent convergent and discriminate correlations. It was also demonstrated to have appropriate stability over a two-month period, with good reliability and validity (Watson et al., 1988). Crawford and Henry (2004) conducted a study to evaluate the reliability and validity of the PANAS. They included the adult population in their study and compared their results to those of Watson et al. 1988, who had used a student sample in developing the tool. They also found the PANAS to be a valid and reliable tool to measure the PA and NA construct (Crawford & Henry, 2004).

This tool has been used across diverse time sets and cultural contexts (Lichev et al., 2014; Ripper, Boyes, Clarke & Hasking, 2018). It has additionally been used in studies investigating

emotional expression, indicating a correlation in PANAS scores and emotional expression (Reijntjes, Stegge, Terwogt, Kamphuis & Telch, 2006; Segal, Tucker & Coolidge, 2009; Serafini, Malin-Mayor, Nich, Hunkele & Carroll, 2016). In the current study, the PANAS was used to assess the family members' positive and negative affect states, and the impact of these emotional states on their psychological functioning and ability to care for the patients. As it is indicated in the literature, high emotional expression (EE) is characterized by negative attitudes that impact on family members' role as carers and negatively impacts on the patients' wellbeing. Positive affect leads to increased accessibility of positively natured material, while negative affect makes negatively natured material more accessible (Carver & Scheier, 2015). This suggests family members with a high negative affect are more likely to engage negatively with patients, drawing from their negative emotional states such as anger, disgust, guilt, contempt, fear and nervousness. The positive and negative affect scale was selected to assist in gaining some insight into the extent to which these emotional states impact on the family members' and on their care giver roles. This was further unpacked through the analysis of content discussed by family members who were interviewed.

3.5.6 Interview Schedule (Appendix 7) (14 participants)

In order to respond to the research questions that required more qualitative methods, a subsample of 14 participants (seven patient and family member pairs) were interviewed using an open-ended interview schedule. Separation during interviews assisted participants to openly engage in the interview process without possible fear of offending their family member or exposing any information that they were not ready to discuss with the family member, and in getting information that was not influenced by what the other participant had already mentioned. Participants were interviewed in English in the researcher's office at CHBAH. The researcher translated some questions in the isiZulu language when requested to do so by the participants. Although the parcipants were competent in the English language, they requested translation when the questions were not clearly understood, as it enabled them to answer relevantly. Some participants provided certain responses in isiZulu, which were translated to English by the researcher during transcribing. The researcher's fluency in both isiZulu and English allowed a process of back-translation to take place, where the translation occurred from

to English to Zulu and Zulu to English, comparing the two translations until they were deemed equal. The researchers' subjectivity is acknowledged as a possible limitation in this regard.

3.5.7 PTSD Symptom Scale Interview (PSSI) (Appendix 8)

This scale is made up of 17 items that diagnose PTSD according to DSM-III-R, designed to assess the presence and severity of PTSD symptoms. Foa, Riggs, Dancu and Rothbaum (1993) compared the psychometric properties of the interview and the self-report version of the PSSI. They found that the interview version yielded high interrater agreement and excellent convergent validity. Both versions had good test-retest reliability, satisfactory internal consistency and good concurrent validity (Foa, Riggs, Dancu & Rothbaum, 1993).

When the PSSI was compared with the Clinician-Administered PTSD Scale (CAPS), it was found that both measures have high internal consistency and high inter-rater reliability. While the PSSI displayed slightly higher sensitivity to PTSD, the CAPS had slightly higher specificity. The PSSI is a shorter and time efficient tool that possesses good reliability and validity (Foa & Tolin, 2000).

In answering the PSSI, respondents are required to specify a traumatic event and then to answer questions in relation to it (Foa et al., 1993). In the current study, participants were requested to specify the psychotic episode as the traumatic event. This was selected to yield results specifically related to the psychotic episode, allowing access to relevant key information. All participants were required to complete the PSSI. The total score as well as three sub-scale scores were used in analysis. These three subscales (Avoidance, Hyperarousal and Re-Experiencing) are consistent with the main symptom clusters in the diagnosis of PTSD (American Psychiatric Association, 2013).

3.6 Data analysis

Given the employment of the mixed methods design to gain a better understanding of Post-Psychosis Trauma and non-adherence in patients diagnosed with Bipolar I Disorder with

psychotic features and their family members, appropriate procedures were used to analyse both qualitative and quantitative data.

3.6.1 Quantitative research analysis

3.6.1.1 Coding and scoring of data

Following data collection, raw material obtained was first organized in preparation for analysis. This entailed coding and scoring of data, where raw material was transformed into meaningful digits that could be used for hypothesis testing (Pallant, 2010). All raw scores and codes were captured on excel. Each item was assigned an exclusive variable name, e.g. Gender. Responses obtained from the variables were assigned numerical codes (e.g. Gender: 0 = male and 1 = female). All psychometric tools were scored according to scoring instructions provided by the respective authors.

3.6.1.2 Statistical analyses

Descriptive statistics

Statistical assistance was sought from a private statistician and the Medical Research Council of the Witwatersrand University. The Statistical program used was IBM SPSS Statistics 23. In the preliminary analysis, descriptive statistics were generated to describe the demographic and clinical characteristics of the sample, providing answers to Reseacrh Questions 1, 2, 3 and 4. For categorical variables, frequency tables were used to display the number of participants giving certain responses. Where sufficient, only frequencies and percentages were provided. However, crosstabulations were found more useful in indicating the direction in which certain portions of the participants would be distributed, where the frequencies and percentages of one variable across additional relevant variables could be displayed. For continuous variables, the means (the sum of a set of scores divided by the total number of scores in a set) test was run together with the determination of standard deviations, these were provided to give an overall representation of the sample (Levin & Fox, 2011; Pallant, 2010).

Parametric assumptions testing

In the administration of statistical procedures, it is important to test for all relevant assumptions to determine which procedures to employ. The first assumption needing testing was normality. This refers to the bell-shaped curve, where the greatest frequency of scores are found in the middle, with smaller frequencies towards the two extremes (Pallant, 2010). The Shapiro-Wilk's test was used to test for normality. While normality could be assumed according to the central limit theorem (that states that samples of 30 and over begin to approximate the population distribution and normality), the assumption could be questioned due to the absence of normality in the distribution of some key variables according to the Shapiro-Wilk test results (Pallant, 2010).

Inferential statistics that allow for estimation of population parameters are called parametric tests. These tests allow for generalised inferences about the greater population from where the sample is drawn. Advantages of nonparametric statistical techniques include the following: due to assumptions about the population being unnecessary, and statistics that are not greatly affected by outliers because they are computed based on signs or ranks, there is less of a possibility to reach incorrect conclusions. However, nonparametric methods are associated with the following disadvantages in comparison to parametric methods: they can have lower statistical power, they provide fewer analytical strategies, actual differences in a population cannot be known, data is not fully utilised, and information acquired is limited (Nahm, 2016).

In summary, "nonparametric methods are always valid, but not always efficient, while parametric methods are always efficient, but not always valid" (Francis Sahngun Nahm, 2016, p. 10). In the statistical analysis for the current study some parametric and some nonparametric tests were employed, with reasons justifying each choice outlined. These are discussed in the results chapter.

Reliability

Reliability testing was conducted for all continuous variables in the scales used and Cronbach's Alpha values were displayed. Reliability is concerned with the ability of an instrument to measure consistently. It is important to note that an instrument cannot be valid unless it is reliable. Alpha was developed by Lee Cronbach in 1951 to provide a measure of the internal consistency of a test or scale, it is expressed as a number between 0 and 1. Internal consistency

describes the extent to which all the items in a test measure the same concept or construct and hence it is connected to the inter-relatedness of the items within the test (Tavakol & Dennick, 2011).

Main Analyses

Pearson (parametric) and Spearman (nonparametric) correlation tests were conducted to test for associations between quantitative measurements of relevant variables (Artusi, Verderio & Marubini, 2002). These correlations were used to address Research Question 5. Research Question 6 required participants to be grouped into Adherent vs Non-Adherent groups, and to be classified according to their PTSD status. This allowed for these categories to be compared as required by the research question. To compare the distribution of the categorical variables in the sample, a nonparametric method namely, the Fisher`s Exact test, was run as powerful procedures to use with analysis of smaller samples. Although Fisher's Exact is applied only in analysis of small samples, it is valid for all sample sizes. If the distribution of the categorical variable is not much different over different groups, one may conclude that the distribution of the categorical variable is not related to the variable of groups. When more than 20% of cells have expected frequencies of less than 5, one needs to use Fisher's Exact test because applying approximation method is inadequate (Kim, 2017).

Lastly, in order to answer Research Question 7 further, Binomial Logistic Regression analysis was conducted. This analysis is predictive, and it is conducted when a dependent variable is dichotomous (binary). In this instance, the dependent variables were adherence or non-adherence as well as PTSD presence or absence. The independent variables (predictors) can be categorical, continuous or a combination of both. Binomial Logistic Regression is used to describe data and explain the relationship between the selected dependent variable and one or more independent variables (Pallant, 2010). Given the rich data obtained from multiple variables, the motive behind conducting this analysis was to explore additional (clinical and demographic) variables as potential predictors of adherence status and Post-Psychosis Trauma in this sample. However, it is important to note that due to the small sample size, the interpretation of results focused on odds ratios, which will be presented in the next chapter.

3.6.2 Qualitative research analysis

For the qualitative aspect of the study, thematic content analysis was employed. According to Kruger and Welman (2001), thematic content analysis may be defined as the systematic examination of the contents of sources to record relative frequencies of themes and the way in which these themes are portrayed. After all audio recordings were transcribed verbatim and pseudonyms were allocated to the participants, the process of data analysis was separated into three stages described below.

In the first stage, each interview was carefully read and summarised, eliminating irrelevant material from the fourteen transcripts. This eliminated information was found to have no link to the research questions and would make no contribution to the focus of the study. The researcher sought to focus only on information giving insight the experiences of the participants within the research context and on answering the research questions.

The second stage entailed systematic examination of the transcripts again, now grouping each participant's responses into conceptual clusters. Dividing the data into discrete sections from which categorical themes emerged (Breakwell, Hammond & Fife-Schaw, 1995). After responses focusing on similar ideas from each participant were grouped together, the conceptual clusters were compared and grouped together for all the participants, leading to the categorization and coding of data. The second stage involved going beyond what seemed relevant, moving towards identifying relevant themes.

In the third stage, the researcher compared the information arising from the different respondents, identifying the frequency and manner in which particular themes were portrayed. Common themes that were explicitly and implicitly related to Post-Psychosis Trauma and non-adherence in patients diagnosed with Bipolar I Disorder with psychotic features and their family members were then grouped together and assigned relevant titles. These are the titles presented and discussed in Chapters 4, 5 and 6.

Although this is portrayed as a linear process, the researcher had to go back and forth through these stages before reaching the final outcome. In all the stages, interpretation was employed. The term interpretation refers to the process during which the researcher attempts to make sense

of the collected information and unite it by either relating the findings to an existing theory or hypothesis, or by formulating a new hypothesis that would best account for the data (Mouton, 1996). The use of interview transcripts allowed the researcher to obtain relevant information directly from the group of individuals affected by the subject of the study. Great caution was taken during interpretation, considering individual differences, different perceptions and being culturally sensitive. As discussed in the research design, the interpretive research approach allowed the researcher to be mindful of possible bias and to accommodate the subjective nature of the responses, giving priority to the discovery and understanding of the participants' experiences (Fossey, Harvey, McDermott & Davidson, 2002).

3.7 Ethical considerations

Ethical considerations are essential requirements for any research, especially with regards to having human participants. To ensure that ethical issues were addressed, the following considerations were made. An ethics approval application was submitted to the University of the Witwatersrand's Medical Human Research Ethics Committee (HREC), which granted the researcher ethical clearance to conduct the study (Appendix 9). Further, a written letter of approval from the head of psychiatry and the CHBA Hospital board was formally requested and obtained to gain access to the sample (Appendix 10). Participants were provided a participant information sheet (Appendix 1a) and they signed informed consent forms for participation and recording, as assurance that their participation was voluntary and that they understood the procedures and aims of the study (Appendix 1b and 1c). Participants were not obliged to answer all questions. They had the right to ask for clarity. They also had the right to discontinue the process if they wished. All information revealed during the research process is stored in a locked cabinet in the researchers' office. This raw data is only accessed by the researcher and her supervisor. In order to ensure confidentiality, the true names of the participants are only known by the researcher and her supervisor. Participants were given pseudonyms when writing the results of the study. Participants were informed that there would be no individual benefits from partaking in the study although some participants in need were given taxi fare, not above R50, depending on where they resided within Gauteng. In the event that the participants encountered emotional difficulties as a result of the study, counselling arrangements were made with the clinical psychologists working at CHBAH. The researchers

training in clinical psychology contributed to the sensitivity with which the research was carried out.

4. CHAPTER FOUR: QUANTITATIVE RESULTS

4.1 Introduction

The following chapter presents the quantitative results in the first section and the qualitative results in the second section. These results will be used to address research questions and the hypotheses set out in the previous chapter. In the quantitative section, the results of statistical analyses undertaken to explore the relationship between Post-Psychosis Trauma and non-adherence in Bipolar I Disorder with psychotic features will be presented. The quantitative section will be divided into two main sections. The first section will present the preliminary analyses including, but not limited to, the descriptive statistics and relations between all key variables. The second quantitative section will present the hypotheses testing results as well as post-hoc tests. The second part of the results section will present the qualitative results, categorised and presented according to themes that arose in the interviews.

4.2 Preliminary analyses

4.2.1 Descriptive statistics

The sample will be described in this section, and the means and standard deviations of key demographic details will be presented. An initial pool of 186 psychiatry patients were identified as prospective participants in this study through in-patient and out-patient records. A majority (n = 97, 52%) of these patients (who had been previously diagnosed with Bipolar I Disorder and treated at CHBAH) were not available on contact numbers provided in their hospital records. Some in-patients (n = 26, 14%) had been transferred from CHBAH to other mental health care facilities. Successful contact was established with 63 identified in- and out-patients who were continuing to receive treatment from CHBAH. Of the 63 potential participants, 28 patients were excluded as they did not meet the inclusion criteria for the research as specified in the previous chapter. Importantly, for patients to qualify for inclusion in this study, they were required to score a minimum of 78 on the 3MS. The 35 patients that participated in this sample had met the criteria for inclusion having scored 78 or more on the 3MS. This left a final

sample of 35 patients diagnosed with Bipolar I Disorder with psychotic features and their 35 family member caregivers.

4.2.1.1 Age and gender distribution

The participants' gender and age ranges were distributed as indicated in Table 2 below. Patient ages ranged from 18 to 51 years, with a mean age of 28.9 years (SD = 8.8). Family members had a mean age of 44 years (SD =14.5). Family members' ages ranged from 21 to 70 years. Table 2 below suggests that on average, patients were more likely to be younger than family members, and more likely to be female than male, while family members were on average more evenly split between males and females.

Table 2: Age and gender averages and percentages for patients and family members

	Age in years			**Gender**	
	M	***SD***	**Range**	**Female n (%)**	**Male n (%)**
Patients	28.9	8.8	18-51	25 (71.4%)	10 (28.6%)
Family	44.0	14.5	21-70	17 (48.6%)	18 (51.4 %)
Totals				*42 (60%)*	*28 (40%)*

4.2.1.2 Depression, Anxiety and Stress distribution

Table 3 below depicts the reference ranges used to assess the severity of mean levels of depression, anxiety and stress in the patient and family member samples (Lovibond & Lovibond, 1995).

Table 3: Depression, Anxiety and Stress severity reference range (Lovibond & Lovibond, 1995)

	Depression	**Anxiety**	**Stress**
0 = normal	0-4	0-3	0-7
1 = mild	5-6	4-5	8-9
2 = moderate	7-10	6-7	10-12
3 = severe	11-13	8-9	13-16
4 = extremely severe	14+	10+	17+

The mean levels of depression, anxiety and stress suggest that, on average, the patient sub-sample reported moderate levels of depression, severe levels of anxiety, and mild levels of stress. Interestingly, the family members evidenced moderate levels of depression and anxiety with mild levels of stress (Table 4).

Table 4: Severity of Depression, Anxiety and Stress

		M	***SD***	**Severity**
Depression	Patient	9.77	6.51	Moderate
	Family	7.11	6.44	Moderate
Anxiety	Patient	8.97	5.83	Severe
	Family	6.34	5.27	Moderate
Stress	Patient	8.94	6.02	Mild
	Family	8.97	5.83	Mild

In the results obtained for family member age and severity of depression, the age group 30-39 had most normal levels, ages 20-29 experiencing significant symptoms, and the age group 50-70 had the highest severity as compared to the younger family members.

4.2.1.3 Means and standard deviations

Table 5 below demonstrates all the means and standard deviations of all key variables of this study for each of the two study sub-groups (patients and family members). All patient data is shaded in grey for ease of reference.[1]

Table 5: Key variable Means and Standard Deviations (n= 35 patients and 35 family)

Sub-group	Variable	Mean	Std Dev	Minimum	Maximum
Patient	1. DAI	15.6	11.13	-18	30
Patient	2. Depression	9.77	6.51	0	21
	3. Anxiety	8.97	5.83	0	20
	4. Stress	8.94	6.02	0	19
Family	5. Depression	7.11	6.44	0	21
	6. Anxiety	6.34	5.27	0	19
	7. Stress	8.97	5.82	0	19
Family	8. Pos Aff	30.97	9.28	11	49
	9. Neg Aff	22.43	9.37	10	45
Patient	10. PTSD total	20.83	12.56	1	46
Family	11. PTSD total	22.06	11.55	0	46
Patient	12. Reexperiencing	5.8	3.87	0	14
	13. Avoidance	9.94	5.68	1	20
	14. (Hyper)arousal	5.09	4.57	0	15
Family	15. Reexperiencing	6.34	3.76	0	13
	16. Avoidance	9.23	5.15	0	20
	17. (Hyper)arousal	6.49	4.09	0	15
Patient	18. 3MS (mini mental)	87.06	6.73	78	97

[1] Key: Std Dev – standard deviation, DAI – Drug Attitude Inventory, Pt – patient, Fm – family member, Pos Aff – positive affect, Neg Aff – negative affect, Reexp – re-experience, Avoid – avoidance, Arousal – hyper-arousal, PSSI - PTSD Symptom Scale Interview, 3MS - Modified Mini Mental State Examination.

4.2.1.4 Adherence status informed by clinical indicators

The DAI scores were compared to patient adherence status based on clinical indicators, informed by clinical records, adherence related responses on the general information questionnaire, and collateral information from family members and treating HCPs. It was found that even some of the known non-adherent patients scored as adherent, because they knew the right answers to give even when those answers did not correspond to their actual behaviour. Due to this, adherence status based on the DAI scores were used with great caution, significantly limiting their contribution in answering the research questions. However, Figure 2 below provides a representation of adherence status based on clinical indicators.

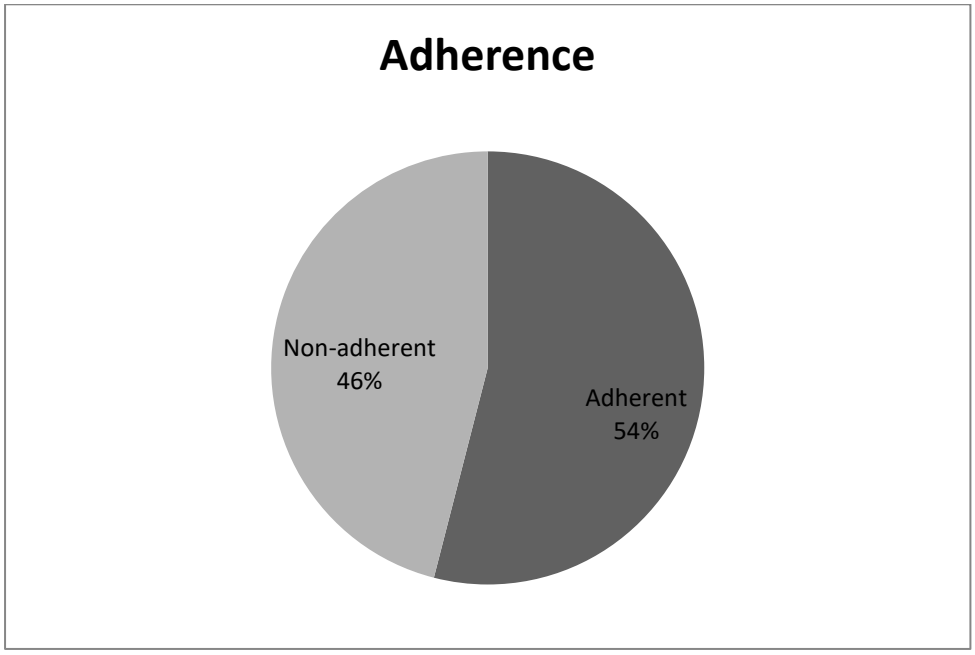


Figure 2: Adherence status

More than half (n = 19; 54.3%) of the patients in this sample were classified as "adherent", while (n = 16; 45.7%) were classified as "non-adherent".

4.2.1.5 Patient education and employment history

Most of the patients (n = 24; 68.6%) had achieved a Grade 12 level of education. A total of 17 participants (48.6%) reported a history of failing or repeating a grade in their schooling career. Most participants had a history of pursuing different levels of studies, attempting to acquire different types of qualifications. A higher number of participants (n = 18; 51.4%) successfully engaged in further studies, while seven (20%) had attempted but failed, and 10 (28.6%) had not engaged in studying further. Most failed attempts were located between ages 18-29, with highest successful attempts between ages 29-39. It appears that although the age group 18-29 were likely to possess a grade 12 education, they struggled with obtaining qualifications thereafter. Most of the patients had not managed to obtain any qualification, however, a few obtained certificates and diplomas, and only one (2.9%) patient obtained a degree. Lastly, a high number (n = 22; 62.9%) of the patients were unemployed and reported that they were struggling to cope with demands of daily living and to find positive activities to engage in.

4.2.1.6 Patient reported support structure

Patients that participated in this study were asked several questions in the General Information Questionnaire, that explored different sources of support. The majority (n= 30, 85.7%) of the patient sample reported feeling supported by their family, 19 (54.3%) reported good support from friends, and 16 (45.7%) reported that they received good social support specifically from their churches. In the area of intimate relationships, 17 (48.6%) were single, while eighteen (51.4%) were in relationships. A total of 14.3% (n= 5) felt they had no support at all.

Table 6: Perceptions of support

Support	**Family**	**Friend**	**Society**	**Relationship**
No	5 (14.3%)	16 (45.7%)	19 (54.3%)	17(48.6%)
yes	30 (85.7%)	19 (54.3%)	16 (45.7%)	18(51.4%)

4.2.1.7 Diagnosis and hospitalisation history

The patients had a history of being diagnosed with Bipolar I Disorder with psychotic features during the four years targeted (2010 to 2014), with a slightly higher percentage (n=11, 31.43%) diagnosed in 2014. As demonstrated in Figure 3 below, a higher percentage (n=22, 62.86%) of participating patients were hospitalised in 2014. Within the sample, one (2.86%) patient was never admitted, while the remaining 34 (97.14%) had been hospitalised within a three-year period of the data collection. When looking at the length of hospitalisation for the group of patients who received in-patient care, (n = 10, 28.57%) stayed for 15-30 days, while (n = 13, 37.14%) stayed for more than 30 days.

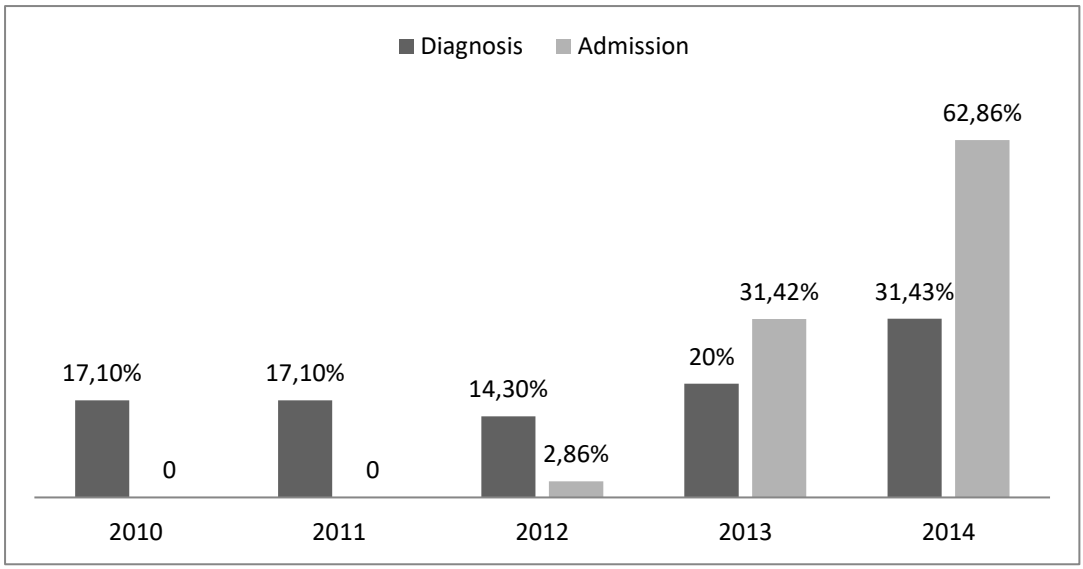


Figure 3: Patient diagnosis and hospital admission period

A total of 19 (54.3%) of participants were in-patients, while 16 (45.7%) were out-patients at the time of data collection. Just above 45.7% (n=16) of the patients were only diagnosed with Bipolar I Disorder with psychotic features while the remaining 54.3% (n=19) had additional (comorbid) diagnoses. The most common dual diagnosis was substance abuse (n= 10), followed by HIV (n= 4), lastly followed by a combination of these two (n= 2). In terms of gender, 15 (60%) of the 25 female participants did not have a dual-diagnosis, while a majority (n=9, 90%) of the 10 males had a dual-diagnosis of substance abuse.

4.2.1.8 Relapse reasons

Relapse in relation to non-adherence was indicated for 68.6% (n=24) of the participants. Additionally, sixty percent (n=6) of male participants relapsed in relation to substance abuse, as opposed to only four percent (n=1) of the female participants. A total of six (24%) females relapsed in relation to family related factors such as conflict with family members and financial problems within families. Information elicited during the patient interviews together with clinical indicators allowed the researcher to rank patient insight levels. It surfaced that 48.6% (n=17) of patients had no insight about their illness, while 51.4 % (n=18) demonstrated fair insight levels. No insight was rated as 0, fair insight as 1, and good insight as 2. The mean for insight was 0.51 with a standard deviation of 0.51, placing the participants between poor and fair insight levels. This affected results on insight factors that would significantly contribute to adherence and other relevant components for the current study.

4.2.1.9 Childhood experience and trauma history

Participants reported on their childhood experiences and exposure to traumatic experiences when responding to the general information questionnaire. A high number (n=16, 45.7%) of patients reported unstable childhood experiences, such as being abandoned by parental figures, poverty and being abused. While 54.3% (n=19) reported fairly-good childhood experiences, including good education opportunities with available and supportive parents. Further, only the females had a history of sexual trauma (n=7, 28% of participating females).

4.2.2 Reliability testing

Reliability testing was conducted for the sub-dimensions of all key interval variables in the scales used. These alphas were computed for the patient sub-sample, the family sub-sample, and for the total sample. Table 7 below displays the Cronbach's α values accordingly. The

values suggest modest to excellent reliability for all the domains used in this sample and for both sample groups.

Table 7: Cronbach's α for variable domains (per subgroup and total sample)

Variable domain	Group	Cronbach's α	No: of Items
Depression	Family	0.901	7
	Patient	0.870	7
	Combined	0.886	7
Anxiety	Family	0.807	8
	Patient	0.833	8
	Combined	0.835	8
Stress	Family	0.834	7
	Patient	0.833	7
	Combined	0.830	7
Pos. affect.	Family	0.881	10
Neg. affect.	Family	0.878	10
Reexperiencing	Family	0.785	5
	Patient	0.691	5
	Combined	0.728	
Avoidance	Family	0.738	7
	Patient	0.774	7
	Combined	0.744	
Hyperarousal	Family	0.712	5
	Patient	0.798	7
	Combined	0.762	

4.2.3 Intercorrelations

A series of analyses were conducted to test whether parametric assumptions for Pearson's product moment correlation were met. It was determined that the data met these parametric assumptions as follows:

a. The variables were continuous variables
b. No outliers were identified using tolerance and variance inflation statistics
c. The assumption of homoscedasticity was met
d. The Shapiro Wilk statistic tests the null hypothesis that the distribution of a particular variable approximates normality. The null hypothesis is rejected by a significant result (under 0.05), indicating non-normality (Shapiro & Wilk, 1965). The assumption of normality was met for some but not all key variables. Normally distributed variables included patient depression, family stress, positive affect and family trauma variables. It is important to mention that Pearson's *r* is very robust to violations of the assumption of normality as it is a test of linear dependence; a test that is not dependent on normality. Results of the Shapiro-Wilk test of normality are indicated in Table 8 below:

Table 8: Shapiro-Wilk's test of normality

Variable	Shapiro Wilk's W	P value
Drug attitude	0.899	0.003
***Patient depression**	0.947	0.093
Patient anxiety	0.938	0.049
Patient stress	0.929	0.027
Family depression	0.898	0.004
Family anxiety	0.921	0.015
***Family stress**	0.947	0.091
***Positive affect**	0.981	0.800
Negative affect	0.932	0.032
Patient PSSI	0.920	0.014
***Family PSSI**	0.979	0.751

*Normally distributed

The p-values, as shown in Table 8 above indicate that for patients, drug attitude, anxiety, stress and trauma variables were non-normally distributed. For family members, depression, anxiety and negative affect variables were non-normally distributed. It is important to note that these non-normal distributions are consistent with what the literature suggests would be expected, even if repetitive sampling of similar populations were drawn and normality statistics were

tested. It would not be expected that the levels of drug attitude, anxiety, stress and trauma in Bipolar I Disorder patients with psychotic features is normally distributed. Similarly, family members' levels of depression, anxiety, and negative affect would not be expected to be normally distributed. Additionally, skewness and kurtosis statistics were within limits associated with normality. Lastly, it is important to mention that Pearson's *r* is robust to violations of normality as mentioned above; especially in samples were data would be expected to be non-normally distributed. Spearman's correlations were also computed for each of these. However, they were only included and discussed where there were differences.

Firstly, a correlation procedure was conducted across the main variables present in the DASS and the PSSI scales that were completed by the entire sample. Secondly, a correlation procedure for variables in the patient group was conducted. Lastly, a correlation procedure for variables in the family member group was conducted. The correlation results are depicted in the tables below and discussed accordingly.

4.2.3.1 Total sample correlation analysis (Pearson's correlation)

Table 9 below shows the intercorrelation matrix for the entire sample (patients and family members) for depression, anxiety, stress, PTSD (PSSI), and the three symptom clusters of PTSD (re-experiencing, avoidance and hyperarousal). Results suggest strong positive bivariate correlations (ranging from *r= .552 to* r= .898) with all pairs of variables, as would be expected as they all are theoretically thought to share similar underlying latent traits such as neuroticism (Blake et al., 1995; Foa et al., 1993; Lovibond & Lovibond, 1995; Roelofs, Huibers, Peeters & Arntz, 2008).

Table 9: Total sample DASS and PSSI Inter correlation matrix (Pearson)

	DEP	ANX	STR	PSSI	REEXP	AVOID
DEP	1					
ANX	.720**	1				
STR	.786**	.761**	1			
PSSI	.683**	.712**	.729**	1		
REEXP	.552**	.690**	.674**	.862**	1	
AVOID	.682**	.612**	.640**	.898**	.641**	1
AROUS	.555**	.601**	.626**	.890**	.707**	.674**

**Correlation is significant at the 0.01 level (two tailed) [2]

4.2.3.2 Patient sample correlation analysis (Pearson's and Spearman's rank order correlations)

A series of Pearson's bivariate correlations were computed to compare all pairs of variables in the patient sample with one another to test for linear dependence (Table 10 below). As expected, and similar to the total sample analysis, the Depression, Anxiety, Stress, PSSI (PTSD), ReEXP, AVOID and AROUS were all strongly correlated with each other. However, DAI (attitude towards medications) was NOT significantly correlated to any of the psychological distress or trauma variables. Patient age was also not significantly correlated to any of the abovementioned variables.

[2] DEP – depression, ANX – anxiety, STR – stress, REEXP – re-experience, AVOID – avoidance, AROUS – hyper-arousal, PSSI - PTSD Symptom Scale Interview.

Table 10: Patient intercorrelation matrix (Pearson)

	DEP	ANX	STR	PSSI	REEXP	AVOID	AROUS	DAI
DEP	1							
ANX	.665**	1						
STR	.794**	.814**	1					
PSSI	.683**	.707**	.687**	1				
REEXP	.511**	.717**	.651**	.822**	1			
AVOID	.617**	.533**	.536**	.910**	.582**	1		
AROUS	.678**	.674**	.671**	.923**	.690**	.768**	1	
DAI	-.091	-.212	-.266	.044	.062	.062	-.007	1
PT AGE	-.297	-.292	-.277	-.227	-.221	-.187	-.205	.256

**Correlation is significant at the 0.01 level (two tailed)[3]

Additionally, a series of Spearman's rank correlation coefficients were calculated using nonparametric statistical estimates (Table 11 below). Results suggested that while the DAI remained non-significantly correlated with any variables of interest, patient age was negatively correlated with anxiety (older patients evidenced lower levels of anxiety in this sample), and positively correlated with attitudes towards medication (older patients had more positive attitudes towards their treatment).

[3] Key: PT – patient, DEP – depression, ANX – anxiety, STR – stress, REEXP – re-experience, AVOID – avoidance, AROUS – hyper-arousal, PSSI - PTSD Symptom Scale Interview, DAI – Drug Attitude Inventory.

Table 11: Patient inter correlation matrix (Spearman)

	DEP	ANX	STR	PSSI	REEXP	AVOID	AROUS	DAI
DEP	1							
ANX	.663**	1						
STR	.798**	.816**	1					
PSSI	.657**	.694**	.646**	1				
REEXP	.512**	.679**	.629**	.766**	1			
AVOID	.599**	.519**	.531**	.896**	.538**	1		
AROUS	.612**	.650**	.610**	.888**	.646**	.700**	1	
DAI	-.122	-.297	-.301	.22	-.051	.030	-.075	1
PT AGE	-.216	-.348*	-.237	-.184	-.209	-.212	-.217	.385*

*Correlation is significant at the 0.05 level (two tailed)

**Correlation is significant at the 0.01 level (two tailed)

Signifiant correlations with the nonparametric tests only are highlighted in grey.[4]

4.2.3.3 Family sample correlation analysis (Pearson's and Spearman's rank order correlations)

A similar series of bivariate correlation analyses were conducted with the family sample. Table 12 below presents the Pearson's intercorrelation matrix of the family subsample. As expected, all psychological distress and trauma variables were positively correlated with one other very strongly. When looking at positive affectivity, a negative correlation was found with depression and a positive correlation with patient age was found. This suggests that family members with higher levels of positive affectivity, were less likely to be depressed, and more likely to be older. Negative affectivity was positively correlated with all three psychological distress variables (depression, anxiety and stress) as well as with all trauma variables (PSSI and each of the three symptoms clusters of PTSD). This is consistent with what would be expected as

[4] Key: PT – patient, DEP – depression, ANX – anxiety, STR – stress, REEXP – re-experience, AVOID – avoidance, AROUS – hyper-arousal, PSSI - PTSD Symptom Scale Interview, DAI – Drug Attitude Inventory.

negative affectivity is thought to underlie them all. Negative affectivity was not related to positive affectivity, demonstrating that they are not simply two ends of a spectrum.

Table 12: Family member Inter correlation matrix (Pearson)

	DEP	ANX	STR	PSSI	REEXP	AVOID	AROUS	POS AFF	NEG AFF
DEP	1								
ANX	.754**	1							
STR	.812**	.748**	1						
PSSI	.740**	.792**	.778**	1					
REEXP	.652**	.742**	.700**	.907**	1				
AVOID	.760**	.715**	.763**	.897**	.727**	1			
AROUS	.531**	.655**	.593**	.861**	.726**	.606**	1		
POS AFF	-.406*	-.081	-.252	-.177	-.109	-.321	.003	1	
NEG AFF	.727**	.822**	.792**	.749**	.671**	.693**	.625**	-.148	1
FM AGE	.091	-.011	.045	-.031	.009	-.055	-.026	-.442**	.060

*Correlation is significant at the 0.05 level (two tailed)

**Correlation is significant at the 0.01 level (two tailed)[5]

In order to further explore the above bivariate relationships using nonparametric statistics, a Spearman's rank correlation analysis was conducted (Table 13 below). The results supported all the findings of the Pearson's analysis, with one extra findings. The Spearman correlation further indicated that a significant negative relation between positive affectivity and avoidance

[5] Key: FM – family member, DEP – depression, ANX – anxiety, STR – stress, REEXP – re-experience, AVOID – avoidance, AROUS – hyper-arousal, PSSI - PTSD Symptom Scale Interview, POS AFF – positive affect, NEG AFF – negative affect.

symptoms on the PTSD cluster. Therefore, in the family member sub-sample, participants that reported higher capacity for positive affect, reported lower levels of avoidance symptoms.

Table 13: Family member Inter correlation matrix (Spearman)

	DEP	ANX	STR	PSSI	REEXP	AVOID	AROUS	POS AFF	NEG AFF
DEP	1								
ANX	.721**	1							
STR	.795**	.740**	1						
PSSI	.736**	.818**	.778**	1					
REEXP	.608**	.781**	.712**	.886**	1				
AVOID	.765**	.754**	.774**	.890**	.699**	1			
AROUS	.532**	.662**	.609**	.871**	.729**	.628**	1		
POS AFF	-.394*	-.139	-.224	-.211	-.119	-.351*	-.021	1	
NEG AFF	.722**	.736**	.805**	.735**	.612**	.692**	.658**	-.140	1
FM AGE	.018	-.069	.019	-.034	.017	-.064	-.028	-.432**	-.072

*Correlation is significant at the 0.05 level (two tailed)

**Correlation is significant at the 0.01 level (two tailed)[6]

Significant correlations with the nonparametric tests only are highlighted in grey.

[6] Key: FM – family member, DEP – depression, ANX – anxiety, STR – stress, REEXP – re-experience, AVOID – avoidance, AROUS – hyper-arousal, PSSI - PTSD Symptom Scale Interview, POS AFF – positive affect, NEG AFF – negative affect.

4.3 Main analysis

4.3.1 Hypothesis testing

In the following section, analyses were conducted within the hypothesis testing paradigm with the aim of testing the following hypotheses and answering the research questions (RQ) - *represented here for ease of reference*:

4.3.1.1 Post-Psychosis PTSD in Bipolar I Disorder

- *RQ $_{1 \text{ and } 2}$: Do South African patients diagnosed with Bipolar I Disorder with psychotic features and their family members experience diagnosable Post-Psychosis PTSD? $H_{1:}$ It was hypothesized that they will present with diagnosable Post-Psychosis PTSD.*

The PSSI scale was used to assess for Post-Psychosis Trauma in patients and their family members. For PTSD to be categorised as present, each participant must score one re-experiencing symptom, at least three avoidance symptoms, and a minimum of two arousal symptoms. Table 14 below illustrates the distribution of presence and absence of diagnosable PTSD in both patients and family members.

Table 14: PTSD presence in total sample

PTSD	**Patient**	**Family**	**Total**
Present	27 (77.1%)	28 (80.0%)	55 (78.6%)
Absent	8 (22.9%)	7 (20.0%)	15 (21.4%)
Total	*35*	*35*	*70 (100%)*

As illustrated in Table 14 above, Post-Psychosis Trauma was present in 78.6% (n=55) of the total sample. A high proportion of patients (77.1%) reported symptoms consisted with PTSD after a psychotic episode. A similarly high proportion of family members (80%) also evidenced symptoms consistent with a PTSD diagnosis post-psychosis. These findings suggest that a very

high number of patients and family members experienced Post-Psychosis PTSD, with fewer participants presenting with an absence of PTSD, supporting the first hypothesis of this study.

4.3.1.2 Prevalence and severity of Post-Psychosis Trauma

- *$R_{3 \text{ and } 4}$: What is the prevalence and severity of Post-Psychosis Trauma in this sample of patients with Bipolar I Disorder with psychotic features and their family members?*

Figure 4 below provides a breakdown of Post-Psychosis PTSD severity levels within the sample. PSSI severity reference ranges were in accordance with literature guidelines (Foa et al., 1993; Hembree et al., 2002; Schneider, n.d.).

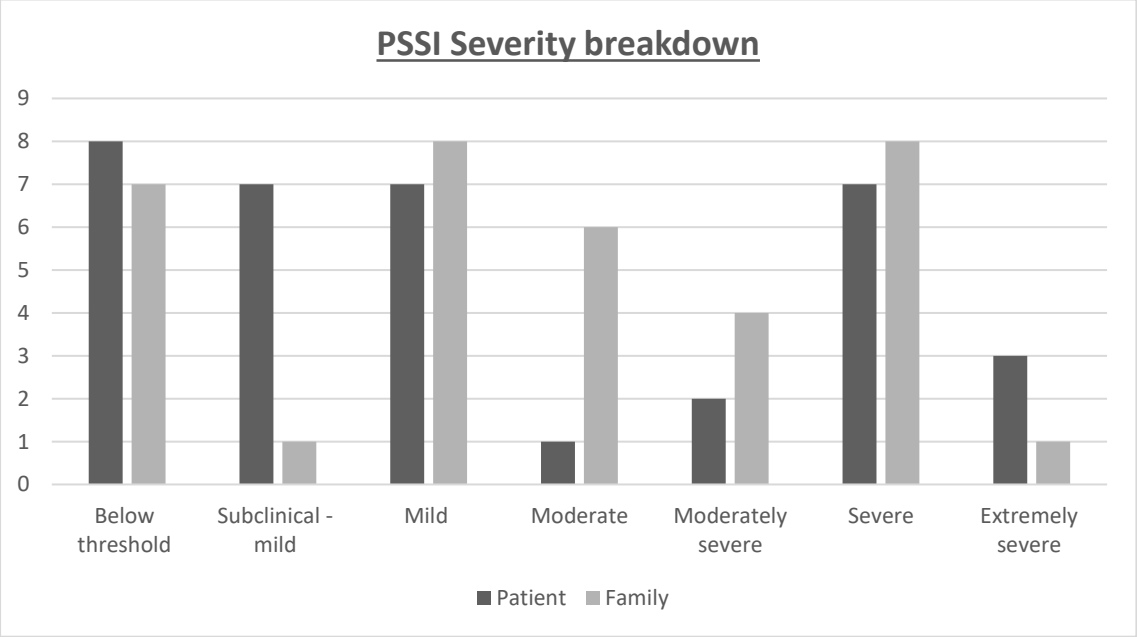


Figure 4: PSSI severity levels

A total of 27 (77%) of patients and 28 (80%) of family members had PTSD symptoms above the clinical threshold. A smaller number of patients, 17 (48.6%) as compared to 26 (73.7%) of

family members fell within the mild-severe category, demonstrating the higher likelihood for family members in the sample experiencing more PTSD symptoms than the patients.

4.3.1.3 Adherence and Post-Psychosis Trauma

1. *$R_{5\ and\ 6}$: Will treatment adherence, as measured by the DAI be significantly associated with patient overall trauma levels (PSSI)? Will treatment adherence status increase the odds of or against the presence or absence of diagnosable PTSD? H_3: The odds for treatment adherence as classified according to clinical indicators will be higher in the absence of diagnosable PTSD.*

A Pearson's correlation analysis found no significant linear relations between drug adherence as measured by the DAI and patient overall PSSI (*r= 0.04).* Non-significant correlations were also found for re-experiencing symptoms (*r*= 0.06) avoidance symptoms (*r= 0.06)* and hyperarousal symptoms *(r= -0.01).* This suggests that drug attitude or adherence as operationalised in this study (score on the DAI) was not associated with post-traumatic stress symptoms after psychotic events in this sample. The limitations arising from questionable DAI scores were considered.

In order to address the above research question, patients were classified as either adherent or non-adherent based on clinical indicators. Given the underpowered sample, additional analyses were done using non-parametric statistics which are less sensitive to sample sizes. Chi-Square tests are also reported below, although the Fisher`s Exact test results will be focused on as Pearson`s Chi-Square criteria had limitations when used with smaller sample sizes.

Table 15: Chi-Square and Fisher's Exact Tests

	PT/FM	Value	Asymptotic Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Chi-Square	PT	1.177[a]	0,278		
	FM	1.036[a]	0,309		
Continuity Correction[b]	PT	0,464	0,496		
	FM	0,353	0,553		
Likelihood Ratio	PT	1,179	0,278		
	FM	1,071	0,301		
Fisher's Exact	PT			0,424	0,248
	FM			0,415	0,280
Linear-by-Linear Association	PT	1,144	0,285		
	FM	1,007	0,316		

a. 2 cells (50.0%) have expected count less than 5. The minimum expected count is 3.66.
b. Computed only for a 2x2 table

Through the Fisher`s Exact test results, the relationship between both patient Post-Psychosis Trauma and family Post-Psychosis Trauma with adherence was found to be non-significant, with *p* scores of 0.42 (2 sided) and 0.25 (1 sided), together with 0.41 (2 sided) and 0.28 (1 sided) respectively. The pattern of PTSD and non-compliance in the sample is illustrated in Table 16 below:

Table 16: Adherence and PTSD symptoms in patients and family members

Adherence	Patient PTSD symptoms		Family member PTSD symptoms		Total
	Absent	Present	Absent	Present	
Adherent	3(4.3%)	16(22.9%)	5(7.1%)	14(20.0%)	38(54.3%)
Non-adherent	5(7.1%)	11(15.7%)	2(2.9%)	14(20.0%)	32(45.7%)
Total	8(11.4%)	27(38.6%)	7(10.0%)	28(40.0%)	70(100%)

Most research participants had PTSD symptoms above threshold in both the adherent and the non-adherent group. In the adherent group, 22.9% (n=16) patients and 20.0% (n=14) family members had PTSD symptoms above threshold. In the non-adherent group, 15.7% (n=11) patients and 20.0% (n=14) family members had PTSD symptoms above threshold. Both adherent and non-adherent patients and their family members may experience Post-Psychosis PTSD.

4.3.2 Predicting the odds of adherence and Post-Psychosis PTSD

- *R_7: When patients are classified as adherent or non-adherent according to clinical indicators, what are the odds of adherence status or PP/PTSD in relation to other demographic and clinical indicators such as education, social support, history of receiving psychotherapy, insight and employment status?*

4.3.2.1 Adherence status

Binary logistic regression was performed to assess the impact of several factors on the odds that the respondents would be adherent or non-adherent to treatment. The model contained nine independent variables namely: employment, student, coping, insight, family support, society support, therapy history, childhood experience and educational difficulty history[7]. Dummy coding was used to appropriately separate employment and student variables under occupation. Educational difficulty history entailed whether a participant had a history of failing or repeating any grade in their schooling career.

The full model containing all predictors was statistically significant X^2 (9, N = 35) = 25.18, p < .005, indicating that the model was able to distinguish between respondents who were adherent vs non-adherent. The model as a whole explained between 51.3% (Cox and Snell R^2) and 68.6% (Nagelkerke R^2) of the variance in adherence, and correctly classified 82.9% of cases. As shown in Table 16 below, only society support made a unique statistically significant contribution to the model, recording an odds ratio of 16.06. This indicated that the non-adherence odds for respondents who reported poorer perceived society support were 16 times higher than those who reported good society support, controlling for all other factors in the model. Although not statistically significant, employment is worth noting as it came close with a p value of 0.055, with an odds ratio of 41.12. This suggests that non-adherence odds for respondents who were unemployed were 41 times higher than those who were employed, controlling for all other factors in the model.

[7] Key: Employment – employment status, student – enrolment status, coping – perceived coping, society support – including community members, colleagues and employers.

Table 17: Logistic Regression Predicting Odds for Adherence

	B	S.E.	Wald	Sig.	Exp(B)	95% C.I. for EXP(B)	
						Lower	*Upper*
Employment	3.72	1.94	3.68	**0.05*	41.12	0.92	1830.86
Student	-26.44	18262.19	0.00	*0.99*	0.00	0.00	
Coping	1.38	1.64	0.71	*0.40*	3.97	0.16	98.24
Insight	1.99	1.53	1.69	*0.19*	7.28	0.37	145.25
Family support	3.37	2.25	2.24	*0.14*	29.07	0.35	2405.01
Society support	2.78	1.38	4.06	**0.04*	16.06	1.08	239.36
Therapy history	0.31	1.25	0.06	*0.80*	1.37	0.12	15.89
Childhood exp	-1.83	1.36	1.81	*0.18*	0.16	0.01	2.31
Education diff	-2.11	1.37	2.38	*0.12*	0.12	0.01	1.77
Constant	-5.35	2.95	3.29	*0.07*	0.01		

[8]

4.3.2.2 Family member post-psychosis trauma

Binary logistic regression was performed to assess the impact of several factors on the odds that family members would present with Post-Psychosis Trauma. The model contained six independent variables namely: coping, family support, history of trauma experiences, employment, student, and diagnosis year. The statistical analysis separated each year of diagnosis as well as the two types of traumatic experiences. All independent variables were reported by the patients based on their own experiences and perceptions from the general questionnaire. The full model containing all predictors was not statistically significant on the Omnibus Tests of Model Coefficients with X^2 (10, N = 35) = 11.91, p > .005, indicating that the model was not able to distinguish between family members who reported Post-Psychosis Trauma and those who did not. However, the model was significant on Hosmer and Lemeshow Test, suggesting some usefulness of the model with X^2 (7, N = 35) = 1.82, p > .005. The model

[8]Key: Employment – employment status, student – enrolment status, coping – perceived coping, Family support – family members only, society support – community members, colleagues and employers, Therapy history – has received psychotherapy, Childhood exp – stable or unstable childhood experiences, Education diff – education difficulty history evidenced by failing.

as a whole explained between 28.9% (Cox and Snell R square) and 45.6% (Nagelkerke R squared) of the variance in family Post-Psychosis Trauma, and correctly classified 88.6% of cases. As shown in Table 18 below, none of the variables made a unique statistically significant contribution to the model suggestion more complex inter-relationships. It is however interesting to note, with caution, the direction of the variable relationships. The odds for family members to present with Post-Psychosis Trauma were higher when the patients reported that they were receiving good family support, and when the patients reported a history of sexual trauma as compared to other types of trauma. Furthermore, the odds for Post-Psychosis Trauma in family members of patients who reported that they were unemployed, not students, and that they were not coping, were higher. Lastly, the admission history odds ratios suggested that for patients admitted more recently, family member Post-Psychosis Trauma was three times higher, controlling for all other factors in the model. Suggesting the level of involvement and burden of care matters.

Table 18: Logistic Regression Predicting Odds for Post-Psychosis Trauma in family

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	*Upper*
Coping	-3.57	1.97	3.28	1	*0.07*	0.03	0.001	1.34
Family support	1.69	1.96	0.74	1	*0.39*	5.39	0.12	249.37
History of trauma experiences			3.12	2	*0.21*			
trauma experiences(other)	2.48	1.64	2.29	1	*0.13*	11.98	0.48	299.96
trauma experiences(sexual)	2.82	1.88	2.25	1	*0.13*	16.69	0.42	660.29
Employment	-1.74	1.59	1.19	1	*0.27*	0.18	0.008	3.96
Student	-2.5	1.83	1.86	1	*0.17*	0.08	0.002	2.98
Diagnosis year			1.02	4	*0.91*			
Diagnosis yr(2011)	23.21	13513.84	0	1	*0.99*	1.2E+10	0	.
Diagnosis yr(2012)	-0.48	1.73	0.08	1	*0.78*	0.622	0.021	18.51
Diagnosis yr(2013)	-0.52	1.81	0.08	1	*0.77*	0.592	0.017	20.62
Diagnosis yr(2014)	1.28	1.90	0.45	1	*0.5*	3.608	0.086	150.47
Constant	-0.46	2.15	0.05	1	*0.83*	0.629		

[9]

4.3.2.3 Patient Post-Psychosis Trauma

Binary logistic regression was performed to assess the impact of several factors on the odds that patients would present with Post-Psychosis Trauma. The model contained eight independent variables namely: occupation, coping, family support, society support, childhood experience, therapy history, educational difficulty history, and history of trauma experiences. Similar to the previous logistic analysis, relevant independent variables were separated in the analysis, namely: occupation, educational difficulty history as well as the two types of

[9] Key: Employment – employment status, student – enrolment status, coping – perceived coping, Family support – family members only, History of trauma – exposure to previous traumatic experiences, trauma experiences (other) – exposure to traumatic experiences excluding sexual trauma, trauma experiences (sexual) – exposure to sexual trauma, Diagnosis yr – in which patient was diagnosed with Bipolar I Disorder.

traumatic experiences. All independent variables were reported by the patients based on their own experiences and perceptions from the general questionnaire. The full model containing all predictors was statistically significant on the Omnibus Tests of Model Coefficients with X^2 (9, N = 35) = 21.65, p < .005, indicating that the model was able to distinguish between patients who reported Post-Psychosis Trauma and those who did not. The model was also significant on Hosmer and Lemeshow Test, suggesting further usefulness of the model with X^2 (7, N = 35) = 5.62, p > .005. The model as a whole explained between 46.1% (Cox and Snell R square) and 70.0% (Nagelkerke R square) of the variance in family Post-Psychosis Trauma, and correctly classified 85.7% of cases. As shown in Table 18 below, none of the variables made a unique statistically significant contribution to the model. It is however interesting to note the direction of the variable relationships. The odds for patient Post-Psychosis Trauma were higher when they reported that they received poor family support, when they were not studying despite having a history of not failing when they were students, when they reported no history of psychotherapy and that they were generally not coping. Furthermore, the odds for patient Post-Psychosis Trauma were seven times higher for those who reported a history of sexual trauma, controlling for all other factors in the model.

Table 19: Logistic Regression Predicting Odds for Patient Post-Psychosis Trauma

	B	**S.E.**	**Wald**	**df**	**Sig.**	**Exp(B)**	**95% C.I. for EXP(B)**	
							Lower	*Upper*
student	-22.65	22769.75	0.00	1	*0.99*	0.00	0.00	
coping	-1.59	1.74	0.84	1	*0.36*	0.20	0.01	6.15
Family support	-20.22	15494.63	0.00	1	*0.99*	0.00	0.00	
Society support	0.54	1.56	0.12	1	*0.73*	1.72	0.08	36.45
Childhood experience	1.06	1.76	0.37	1	*0.55*	2.89	0.09	91.25
Therapy history	-20.95	9791.95	0.00	1	*0.99*	0.00	0.00	
Educational diff	-0.73	1.51	0.24	1	*0.63*	0.48	0.03	9.21
History of trauma experiences			1.04	2	*0.59*			
Trauma experiences (other)	1.52	1.89	0.64	1	*0.42*	4.56	0.11	188.62
Trauma experiences (sexual)	2.05	2.34	0.77	1	*0.38*	7.79	0.08	758.01
Constant	40.71	18329.37	0.00	1	*0.99*	4.78E+15		

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[10] Key: student – enrolment status, coping – perceived coping, Family support – family members only, society support – community members, colleagues and employers, Therapy history – has received psychotherapy, Childhood exp – stable or unstable childhood experiences, Education diff – education difficulty history evidenced by failing, History of trauma – exposure to previous traumatic experiences, trauma experiences (other) – exposure to traumatic experiences excluding sexual trauma, trauma experiences (sexual) – exposure to sexual trauma.

Factors contributing to statistically non-significant results will be further discussed in the research limitations section.

In summary, the statistical analyses undertaken to explore the relationship between Post-Psychosis Trauma and non-adherence in Bipolar I Disorder with psychotic features demonstrated the demographic and clinical characteristics of the participants, which were found useful in depicting a comprehensive view of important components identifying the population whose perceptions will be discussed in the qualitative results section. For example, although (n = 24; 68.6%) had successfully completed grade 12, pointing to an underlying potential to achieve academically prior the onset of Bipolar I Disorder, they commonly struggled to further their education and most (n = 22; 62.9%) were unemployed. This substantiates their perceptions on the impact of the diagnosis on the self-actualisation. Additionally, non-adherence was found to be associated to unemployment. The quantitative results further confirmed presence of Post-Psychosis PTSD in patients and their family members, however, no association between adherence and Post-Psychosis trauma was found.

5. CHAPTER FIVE: QUALITATIVE FINDINGS

5.1 Qualitative findings

The following section reports on the qualitative results of the study. These results have been primarily categorised and presented according to themes that arose from the interviews, incorporating some data from patient records. The first part will address the experience of psychosis as traumatic, followed by a discussion on how being diagnosed with Bipolar I Disorder and the process of gaining insight into the diagnosis and its implication may add to the trauma experienced by the patient and family members. Thereafter, negative emotional and cognitive implications will be unpacked, as well as implications on social wellbeing and participation, with a focus on avoidance as a coping tool. Additionally, implications of the disorder on parental roles will be addressed, together with the participants' strong desire for a cure. Lastly, non-adherence and insight will be discussed.

5.1.1 Psychotic episodes as traumatic experiences

Participants reported exposure to actual or threatened significant injury and even threatened death during psychotic episode experiences. Most of the interviewed family members reported that they were directly involved as the psychotic episodes unfolded, while others were informed telephonically of the episodes and later became directly involved as they would rush to the indicated scene. Family members reported being verbally and/or physically threatened by their psychotic loved ones, especially when attempting to reduce exposure danger. Some of the family members directly witnessed violent actions taken by the patients. Examples of exposure to threats of death or serious injury discussed by the participants included: suicide attempts linked to commanding voices and/or hallucinations, suicide attempts linked to depression, attacking loved ones linked visual hallucinations distorting the patient's perception of the family members, carrying of weapons such as knives, threats to stab their loved ones, and exposure of children to danger and burning of family property linked to distorted perceptions of the property and beliefs informed by delusions.

Martha's husband narrated his experience as follows: *"She becomes angry…she takes things and burns them. These voices tell her what to do, to kill herself or burn the house... You can't hold her … She has a knife in her pocket... You can get frustrated at times, but you hold yourself because you see she is sick... But it hurts".* In the above scenario, there is evidence of clear danger. It is a home environment lacking a sense of safety and predictability. Martha managed to burn her children's clothes, the furniture, and other items needed for the daily use within their household.

Her husband, acting as the sole breadwinner through temporary jobs, providing for above four children, explained that the psychotic episode added financial strain on a family that was already struggling to make ends meet. He said *"… she takes, she burns…. stuck, I am working for one thing… It is painful. But we understand she is not intentionally doing this".* He continued to explain that Martha had burnt their property on previous psychotic episodes. Just as they would recover from one disruptive incident, another would follow upon her relapse. The husband communicated feelings of hopelessness and helplessness, together with a pervasive sense of being stuck in a painful cycle. In addition to the financial strain, there appeared to be persistent emotional strain for the family.

Clare's grandmother expressed some of her concerns during a period when her granddaughter had relapsed as follows: "…*I was locking my room because she told me, she used to keep a screw driver in her bed, a big one … She was travelling with the screw driver in her bag. That was a time when she used to tell me that she hears voices … She told me, I was crossing over the bridge today, I heard a voice telling me I must jump over* ..." This illustrates feelings of fear, helplessness, together with some confusion and horror as this grandmother would sleep with her door locked, afraid that her granddaughter might attack her and stab her with that huge screw driver during the night. In addition, there was fear that the granddaughter could commit suicide as instructed by the voices to jump from the bridge.

While some patients were at risk of attempting suicide due to command hallucinations, others attempted suicide in the depressed phase of Bipolar I Disorder. Peter's mother mentioned that her son attempted suicide four times within a space of three months during which he was depressed. She said: *"he tried to commit suicide four times... he said to me, mom I can't take it. I need to be the same person*". Both Peter and his mother had observed significant changes,

Peter was no longer the person he used to be since his index episode. This was devastating for Peter, and he believed it would be better to die. Peter's mother described the suicide attempts as additional traumatic experiences, after being traumatized by the psychotic episode itself. Similarly, Clare's grandmother expressed experiencing her granddaughter's suicide attempt as traumatic.

Male family members similarly experienced psychosis as traumatic. Bizo's father explained his daughter's psychotic episode as follows: *"she was restless, switching the lights on and off. Running around the yard, she wanted to go out through the gate... Yoh, it was bad! … the first time I see my child like she is mad you see? You wonder that no no no. I was traumatized, that's why I decided to take her to Bara. Yoh yoh yoh, that was a bad, that was very bad*". This father was horrified by the sight of his beloved daughter behaving strangely during her first psychotic episode. Seeing his child "mad" was overwhelming for him and he struggled to verbally articulate his emotional experiences during the interview. He explained how he had to physically restrain her to protect her because he was worried that if she managed to run away from the yard while in that mental state, she would be in danger of further harm. Despite how overwhelmed and traumatized this father figure was, he had to find ways of protecting and helping his daughter.

In interviewing family members, the theme of being 'strong' in the midst of fear and confusion, consistently came through. It was demonstrated by a mother, grandmother, father and a husband. Mandisa's husband had to maintain a position of strength, reassurance, protection and provision during his wife's psychotic episode. He described his experience as follows: "…*it was cold that night, she was just sleeping on the floor outside, crying, shouting, she went to the park, I followed her... I was confused … Not that I cried, but I was confused, the way she is behaving…I talked to her, I was promising that everything will be ok …"*

This husband followed his wife as she walked to an unsafe township park at night, at which both their lives could have been in danger. Similar to Bizo's father, Mandisa's husband understood that his wife would be exposed to harm if she left their home alone in her mental state. Although he did not restrain her, he too took on the responsibility of protecting her by following her wherever she went. Although he was overwhelmed and confused, he had to suppress those feelings and maintain his position of 'strength'.

Like family members, there were instances where patients felt that they had to be strong despite experiencing emotions of fear and sadness. Martha described a day when the police came to take her from her house to the hospital, after her husband had requested their help during one of her psychotic episodes, she said: *"I was scared, but just, I was strong...it was not his first time... my children, yoh! I felt sad. I felt my heart break, like, if they take me and I don't come back, who will look after my kids? I was very worried. That really stressed me! It stressed me"* Martha tried her best to be strong despite her internal distress in that situation, particularly recognising that her children needed her.

Additionally, while psychotic, Martha believed she was special and chosen, that a lot of money had been deposited into a secret bank account, and that her husband wanted this money and was going to harm her in order to get it. She said: *"...I felt bad, because this boy (referring to her husband) told me this history about money being sent to me. I felt it was because I had all this money. That maybe I am being destroyed for that..."* She strongly believed her life was in danger. She explained that she perceived being taken to the hospital as a way for her husband to access the money, and she did not trust him. While admitted in the psychiatric ward, this belief remained strong, preventing her from trusting him and having meaningful communication with him whenever he visited. She was often angry and rejected him. This illustrated that due to certain delusions, patients may believe that those who are trying to help them are sources of danger. As a result, they may reject support from their loved ones, and resist assistance from health care professionals.

After hospital admission, Peter explained that as the psychosis persisted, he was paranoid about blood being taken from him. He explained: "...*I still remember, there was an article about people from the United States taking blood from African people… how the genes go about. To me it was us, they were using our blood … I didn't want to give it to them..."* He continued to describe how he became rebellious to treatment in the psychiatric ward due to delusional beliefs about what the blood samples were being used for. It appears that the provision and acceptance of care and support may be compromised during psychosis, particularly due to fear and the lack of trust.

Post psychosis, Clare could remember the auditory hallucinations she had experienced. She remembered being overwhelmed by fear during her episode and explained it as follows: *"It*

was scary because I didn't know what these people would think. I would try and ask them in way that I'm just making a conversation... I was also scared that I was vulnerable. To like forces and spirits and stuff like that. Because they heard and even knew what was going on in my mind..." This demonstrates that certain memories of what was seen, heard and felt during a psychotic episode may remain post psychosis. Clare expressed being terrified of the powerful 'forces' that had the most intimate access to her, access to her mind. She expressed being afraid that while the forces knew what she was thinking, she did not know what they were thinking. She felt vulnerable.

In contrast, while most family members experienced negative emotions associated with their loved ones' psychotic episode, one of the interviewed family members described feeling initially excited when her son's psychosis commenced, believing that he was expressing his intelligence through brilliant ideas. The patient had been talking about "*realizing that there are so many resources in South Africa that need to be exploited*". The family members' excitement did not last, as she became more concerned about his odd behaviour and confused about the hallucination he had at the time. She described him as "*talkative, aggressive ...lack of sleep... pushy, and rude. He had a lot of energy... Seeing stuff that I don't see ...carrying around the bible as well...but I couldn't understand...He just had, I don't know, power or he was just aggressive... If you stop him, he gets irritable*". Like other family members, the patient's mother was distressed when she realized that her son was ill.

Both patients and their family members expressed traumatic aspects of psychosis, particularly involving actions arising from visual and auditory hallucinations, paranoid delusions, aggression, and impulsivity. Concerns regarding exposure to real and/or threatened harm were raised, as well as the pervasive sense of vulnerability, alienation and helplessness rooted in the unpredictable nature of psychotic experiences.

5.1.2 Diagnosis, insight and trauma reactions

A wide variety of emotions were experienced by the participants in relation to receiving the diagnosis of Bipolar Disorder, ranging from emotions associated with trauma to emotions

associated with relief. It was however noted that for most patients and family members, being diagnosed with Bipolar Disorder was not initially traumatic. This was attributed to a lack of knowledge and understanding of the diagnosis.

Emotions arising at diagnosis were predominantly characterised by a state of confusion, together with a sense of being overwhelmed. Bizo said "*I felt a bit overwhelmed, because I didn't understand what Bipolar was. I didn't know what it was at all...*" The lack of understanding delayed the shock response for others, like Peter who said, "*at the time I was not familiar with the term Bipolar or what Bipolar was, so, ayiiii*[11]*, it's one of those things in nature*". Emotions arising as participants gained understanding of what it meant to have Bipolar Disorder appeared encircled by devastation. When Peter began gaining insight he said *"...when I sat down and started reading and understanding what Bipolar was, then it hit me...*" Only then was he shocked and distressed by the perceived inescapable implications of the diagnosis on his life.

In contrast, a sense of relief was expressed by some patients when they were diagnosed. For these participants, the moment of diagnosis was a moment when their negative life experiences were finally given a name. Validating their distress and behaviours as conducted without intension or desire to cause harm. Their experiences could be contextualised and understood as an existing illness, and there was hope for appropriate intervention to alleviate the symptoms. Clare explained it as follows, "*In a way I was happy to know that ...what... That I have something, that I'm not just, cause I used to feel like people were thinking I'm just acting up … that made me think less of myself. So, it's good to know ... There is something wrong with you, and now we can get help for that*". Similarly, Mandisa said "*Initially I was relieved because my whole life, I always thought there was something wrong with me, but I didn't know what it was...*"

Similar to patients' responses, family members expressed different experiences when comparing their reactions when they were first informed of the diagnosis to the changes in their emotional state with information gained. Bizo's father explained, "*I didn't feel that bad*

[11] Key: '*Ayiiii'* - An expression used for taking a dismissive stance

because I didn't understand exactly what Bipolar is... It was a bit worrying, but I wanted to know more about what this Bipolar was...".

Bipolar and its symptoms were found to be generally unknown to the participants before diagnosis. All interviewed family members and patients reported that they had no knowledge or understanding of Bipolar until it was introduced in their personal lives following the index episodes. Bafana's grandmother explained "*When he started, I didn't think he has Bipolar you understand? I thought maybe it was the adolescence stage ... I started bringing him here ... He was diagnosed then, otherwise, I wouldn't have known*"

A psychiatric condition that most participants had better knowledge of was depression. It appeared more socially acceptable to be sad, as negative personal life experiences could be used to explain the emotions of sadness and behaviour associated with depression. Clare was first diagnosed with depression. It seemed that she had accepted this diagnosis, but she struggled to accept the diagnosis of Bipolar. She said, "*I don't experience highs, so I don't know; I don't wanna say the doctors are wrong, but my mood is very low, so to me it's more of a depression*". Upon further enquiry, symptoms of mania had been experienced by Clare. However, it was still difficult for her to admit her diagnosis of Bipolar Disorder.

Similarly, Peter exhibited a greater willingness to accept a diagnosis of depression, saying "...*I don't believe I even have that diagnosis myself, but then it's more of, I could say I have depression. I'm also trying to figure myself out, so the diagnosis itself I don't see it as a problem for me to be more depressed, so the Bipolar doesn't affect me as much, even having to take the medication*". Peter contradicted himself in the above statement, there appeared to be a struggle with understanding his identity in relation to the diagnosis. It was not clear whether he perceived the Bipolar Disorder diagnosis as forming part of who he is or not, leaning more towards Bipolar and its treatment being set aside as not affecting him. It may be seen as a part of his life he would rather reject, while depression was accommodated as the non-problematic part of life.

In looking at his history, it surfaced that Peter had defaulted his medication several times. During the interview, he stated that he had consulted traditional healers and the church in his search for answers, believing he may have been bewitched. He confirmed he did not believe

he had Bipolar Disorder. Both Clare and Peter could more readily engage with a diagnosis of depression as opposed to a diagnosis of Bipolar Disorder.

Other patients responded with shock, disbelief and complete denial of the diagnosis. Martha reported she was not informed by the doctor that she was admitted and being treated for a psychiatric illness, but she saw it written on her hospital file. Her reaction was expressed as follows: "*When I got to the ward, I read the files. I saw that these files were written, mental illness, this means they are saying I am crazy! I was surprised, just like that, I am now a crazy person on earth. Since growing up, I was never crazy, but now I am crazy*!?" When asked if she believed she had Bipolar she responded "*No, I don't have it. I am not crazy. I only get stressed, I don't want to lie, you see life stress? I get that*".

Mandisa expressed fluctuation in acceptance, denial and minimising, depending on the presenting circumstances for each day. "*Some days I laugh about it, like haha, I've got Bipolar, then some days it depresses me to think that I'm actually mentally ill. I always had a certain picture of mentally ill people … but now considering myself as a normal person, I can be categorized as a mentally ill person, ya*[12] *but sometimes I don't take it too much to heart … I know now that I have an illness that I have to manage*". When asked what her diagnosis was, she responded by distancing herself "*They say it's Bipolar I with psychotic features*". "They" referring to the professionals treating her. It appeared that even though other patients somewhat accept the diagnosis, the desire to disown it may persist in different degrees. Additionally, preexisting stereotypical beliefs about mentally ill individuals played a role in the acceptance process.

Similarly, family members struggled with accepting the diagnosis. Peter's mother said, "*this is too difficult to accept, but I had hope and faith that the whole thing would just blow over and he will be ok*". This statement suggests a desire in the family member for Bipolar Disorder to be a passing illness, as opposed to a chronic one. After Bizo's father had gained some understanding, he stated the following emotional experiences "*I'm feeling very very very very bad, because she is still young... More especially because amongst all my children, we knew*

[12] Key: *Ya* – yes

she is a brilliant child you understand? … let me just say it's very very very bad...” Displaying intense disappointment as well as being overwhelmed by the illness and its implications.

Receiving the diagnosis was significantly disturbing for those participants who associated it with uncontrollable `madness` that compromises the individuals' integrity. It was additionally portrayed as a loss of the loved one previously known, a loss of hopes and dreams, and a loss of certainty and security regarding one's future. The experience of loss was accompanied by feelings of hopelessness, helpless and disillusionment. Londi explained that when she was diagnosed with Bipolar Disorder, she “*was actually very upset about it. I was quite disappointed in myself, that it could happen to me… Like I'm letting myself down now… I was somebody that was in control of a lot of things ... I was always in control of things ... for me to let go and just lose everything like that...wasn't me*”.

Whether immediate or delayed, the response of being seriously disturbed by the Bipolar Disorder diagnosis was present. Although some participants felt a temporary sense of relief, this was typically followed by a sense of confusion. Following the naming/labelling of their experiences as a specific psychiatric condition, there remained multiple unanswered questions. Mandisa explained “... *I was confused, because ok like, what does this Bipolar thing mean? In the things that have happened in my life, who is responsible, is it Bipolar or is it me*?” Such a struggle with unanswered questions appeared common even amongst family members. What was further problematic was the lack of opportunities for family members to discuss some of their questions with health care professionals.

Three of the seven interviewed family members reported that they had never received psychoeducation or any information from health care professionals treating their loved ones. Only two members knew the name of the diagnosis, while the remaining two knew it was some kind of mental illness. Two family members reported that they used google to get information about Bipolar Disorder. Mandisa's husband explained, “*When she told me that she was diagnosed with Bipolar, I was like, well, what does that have to do with you? So, I tried to check google, what is Bipolar? cause I don't have the experience, then I realised that this is way out of what I expect*…” He expressed being overwhelmed by the information retrieved online about the diagnosis.

Other family members found it useful to get further information from the internet after discussions with health care professionals. For example, when Peter's mother was asked how she felt when her son was diagnosed with Bipolar Disorder, she responded "*I felt scared, I was emotional, and uhm I tried not to cry in front of him. Just to be strong for him... I googled to see if there is a cure*…" Her online search revealed that her son could regain stability through treatment, as opposed to her fear that *" losing reality is like, the person is insane, has lost his mind, has lost touch with the world, he is not going to be okay anymore. He will be a person that is bedridden or just fed drugs or drugged and drugged and drugged*."

Peter's mother found the information obtained through online resources helpful. It appears that when the health care professionals had explained to her that her son had lost touch with reality during his psychotic episode, she experienced intense fear and loss of control. However, she could not congruently express those emotions, as she believed she had to be strong for her son. In a state of being 'strong', she could not obtain clarity from the HCP. She selected to take advantage of advances in technology that have opened channels for people to easily access information. However, there are some individuals who do not have such access and others who are unable to make use it.

While many patients struggled with living with a diagnosis of Bipolar Disorder, some patients stated that they managed to accept it. Londi said, "*No now I'm dealing with it. I've accepted it and I'm working through it. Now I'm fine with it. It's not a problem for me now…. I don't ask questions anymore. I just accept things now and I move forward*". Although Londi claimed that she had accepted the diagnosis, one may question the depth of this acceptance, especially given the contradiction of 'working through it', yet not asking 'questions anymore'.

One may argue that asking questions and getting clarity is part of a process of working through something. It is important to acknowledge that through psychoeducation from treating professionals and other information sources, some of the patients and their family members were able to gain some insight into the illness. As they grew in understanding what having such a diagnosis meant, they appeared to vacillate between denial and acceptance of the diagnosis.

5.1.3 Negative emotions and altered cognitions about the self and the other

For family members, the psychotic episode appeared more traumatic, as they witnessed their loved ones' loss of touch with reality and strange behaviours. They more commonly experienced helplessness, hopelessness, confusion, fear, frustration and horror. In contrast, some of the patients experienced positive feelings during the psychotic episodes, particularly in relation to mania. However, these patients experienced negative feelings as they later reflected on the psychotic episode. The experience of psychosis altered how the patients viewed themselves and how they were viewed by others.

Peter explained that before hospitalisation he felt "*... excited, happy, free and on top of the world. It felt good*". After the episode, Peter reported feeling "*...disappointment, sad, angry again at myself...*" as he had acted out of character during the psychotic episode. He felt angry at himself, asking, "*how could I act in such a manner*?" As Peter spoke about his psychotic episode and reflected on his feelings, he cried and said "*I could say I am ashamed of the way I acted that day because I disappointed a lot of people in my life, that looked up to me. And also, the shame of causing such an embarrassment, if I could say, to my family. My mother more especially... feeling angry, it's more like feeling angry and bitter for myself. For what I've done*." Although Peter's behaviour was due to the psychosis, it was still shameful behaviour acted out by him. The heaviness of self-blame seemed to weigh him down.

Similarly, Bizo first experienced positive feelings which were followed by negative feelings. She explained that she initially felt like an important celebrity. In that state of reduced self-control, she shopped excessively, and she impulsively withdrew money from her bank account and gave it to strangers. Post psychosis, Bizo reported: "*I just feel like I was doing stupid things... the fact that I took out money and gave it away ... it makes me feel guilty ... It's making me feel bad about myself. It makes me feel that I am a bad person*". Again, the patient redefined herself and labelled herself negatively. Bizo now saw herself as a 'bad person', engulfed with feelings of shame, guilt and self-blame.

Similar negative emotions were experienced by Clare. When she reflected on her psychosis, she felt: "*... sadness, it makes me sad to tap out of my sense… I wasn't like this before. I don't know what a normal day is. And then guilt, I feel guilty too... I hurt myself, I didn't have to...*"

Additionally, she reported feelings of shame and anger. She explained that she was ashamed of not knowing what to do with her life, and not having a clear vision for her future career, especially at her age. She was angry that the illness put her in a position that she would have never personally selected. The loss of control was linked to the lack of achievements of certain age appropriate goals and the loss of potential to achieve in future. The patients' perception of how those around them viewed them, played an important role. Mandisa cried as she spoke of her feelings of shame saying: "*I'm ashamed of my life because I thought by this age, I would have finished my degree. I would have my own house at-least, and a car. None of that has happened and I have this feeling that my neighbours are just laughing at me*..."

The patients suffered significant loss of hopes and dreams, with this, there was a prominent sense of grief. The loss of control due to their psychiatric condition had a profound impact on them, and they frequently thought of how their lives would have been had it not been for the illness. Mandisa said: "*It makes me feel sad, I feel like I don't have control over my life. There's situations that are ruining my life… as soon as I have even one little situation, I'm completely emotionally paralyzed, I can't function*..." Since her index episode, she had been more vulnerable to relapse linked to triggers from other life challenges.

Both patients and their family members may experience self-blame in relation to the illness. Peter's mother mentioned that: "*there was a time when I was asking myself whether, is it my upbringing? ... I should have stopped him … I started blaming myself… I should have noticed something*". In addition to self-blame, she explained that she felt diappointed, confused and angry. Following the experience of a psychotic episode and diagnosis with Bipolar Disorder, patients and their family members appear to view of the world and themselves differently.

Mandisa said: "*My dreams are not as big as before. I don't believe in myself anymore, I have so much doubt. I'm no longer as energetic as I was before, like when you have those ideas and that creativity, I'm just, I'm just existing"*. She explained that her life was characterised by a loss of hope, dreams and brilliant ideas. This led to a perverse lack of motivation to pursue anything she would have as her 'old self', as she believed it would yield no positive outcome. Similarly, Clare spoke of loss of self-confidence and an increased self-doubt saying: "*I'm not so confident anymore. Uhm, I don't see myself the same anymore. I'm always questioning myself*".

There appeared to be a desire for participants to hold someone responsible for the condition. While they took the blame upon themselves at times, some blamed their parents and other factors at other times. Clare mentioned: "*I blame my mother, she's not here anymore, I feel like she made a decision and now she's not here anymore, for leaving me. For making the wrong decision... get married to some monster*". She later expressed how difficult it was for her to get through each day, and that her childhood dreams to change her life were unachievable. Furthermore, she reported that even in areas where she has made some progress, she, at times, felt all that progress was lost.

In some ways, the diagnosis became a stumbling block that the patients struggled to overcome. Consequently, they felt stuck. Other circumstances such as unemployment related to the diagnosis further confirmed the lack of progress. Martha stated: "*I feel guilty in my life. Sometimes I don't see myself being responsible in life. I am unemployed, I have to be supported, so I feel guilty*". Occupying a position of dependency due to their condition seemed to contribute significantly to the patients' negative emotions.

The patients and family members reported negative alterations in cognitions and mood associated with the psychotic episode and diagnosis. They discussed some persistent and exaggerated negative beliefs or expectations of themselves and/or other people. They struggled with a persistent inability to experience positive emotions. They further presented with distorted cognitions about the causes of the onset and consequence of the illness, mainly manifesting in either self-blame or other-blame.

5.1.4 Diminished social participation and estrangement

Following the psychotic experiences, there was evidence of markedly diminished interest or participation in significant activities, together with feeling detached or estranged from others. Family members confirmed their contributions to the limitations on social participation. Peter's mother mentioned that she would be insecure when he was not at home, as it was within their home environment where she could fulfil her need to constantly monitor him. Similarly, both Bizo's parents did not allow her to independently engage in society. They stated that in

an attempt to protect her, they restricted her engagement with extended family members and the community, controlling her daily movements and interactions.

Bizo said: "*well it's changed a lot because I'm not allowed to go anywhere on my own. My parents are afraid of what will happen, and before that I could go to many places on my own…now I can't even go anywhere, and that, that doesn't feel good. And sometimes I can't participate in church activities because there's no one to take me there*". One of the painful challenges that confront patients is a loss of independence. Family members presented with a loss of trust and confidence in the patients' capabilities to interact independently within society. It was not clear whether the family members primarily feared that the world was not a safe place for an individual with Bipolar Disorder with psychotic features, or if they feared that their loved one had lost the skills to be safe in the world, or if it was an interaction between the two possibilities. Family members were found to regress to treating patients like younger children needing constant guidance and protection.

Beyond experiencing restrictions from family members, some patients found it difficult to initiate and maintain interactions and relationships outside their homes. Peter struggled to socialize with his peers, he spoke of his struggle with his identity in relation to his condition saying: "… *I don't know like who I am, in a sense of like a social being, and what I can accomplish by myself. Yah, more like I'm emotionally detached … hence I've lost all my friends, … I'm always at home with my family. So, there's nothing that has meaning towards me. Like the type of person that I was ... Energetic, outgoing, never like giving up, perseverance, clothing, fashion and stuff… Dancing…the 'it' guy. With the 'it' somebody on the side*...".

Peter recognized how he had changed from being a livelier social being to what he perceived as a boring or uninteresting individual. It appeared that he missed his previous energetic self. When prompted to think about the kind of person he was before the high energy period in his life, he reported that he was 'normal' with standard levels of energy. Upon prompting, it surfaced that the normal had been forgotten, as the high energy period was enjoyed buy him and others who were impressed by it.

Mandisa and Londi described similar experiences of being the "*life of a party*". Londi described how her friends missed the energetic person they once knew, saying: "*I was on my worst*

behaviour, wasn't sleeping, I was hyper, I was loud... I've noticed that I'm not that same jolly person that I was... I've calmed down, I'm not that agro like I used to be. So, my friend says to me no, there's something wrong with you. You know for her it's not normal". When the energy levels and excitement reduced, some patients were no longer viewed by those around them as 'normal'. Patients appeared to struggle with this, like their friends, they may also missed the 'highs'.

When Mandisa was asked what she found helpful in her process of recovery, she responded with sadness, saying: "*I don't know how am I supposed to be feeling on this medication. I don't know what normal means. Because I'm used to having a lot of energy, me being the life of the party, now I'm just down, … nothing is interesting to me anymore, … everyone used to look to me. I was intelligent, I always had these brilliant ideas...but now ... I just watch TV, I sleep and I eat, only*". After changes in mood, energy levels and creativity, the patients may struggle to find meaning and redefine themselves positively. It seemed challenging for them to make sense of who they were and what they were still capable of achieving. Even though they had achieved in certain areas, it seemed like some of their past good achievements had lost meaning and a pessimistic view predominated. Similarly, family members may struggle with negative cognitive and emotional states, affecting their social functioning. Bizo's father reported that after his daughter's psychotic episode, diagnosis and treatment, he struggled engaging in activities previously enjoyed such as reading, outings and movies.

5.1.5 Avoidance as a coping mechanism

Patients and family members spoke of and demonstrated the different ways of avoiding or attempting to avoid distressing memories, thoughts, feelings and or external reminders of the traumatic psychotic episode.

5.1.5.1 Post-Psychosis intrusions and avoidance

The patients reported experiencing psychosis related intrusions. Bizo stated that she found herself involuntarily thinking about the psychotic episode almost every day. For Bafana, thoughts only came when triggered. He stated: "*something has to like trigger it...*" He continued to explain that the thoughts were accompanied by feelings of shame regarding actions carried out during the episode. Bafana found it difficult to acknowledge these emotions, but easier to portray an image of coping well.

Londi said: "*I really don't dwell so much on it... if I think about it too much, it's gonna upset me more, and confuse me more. I just wanna move forward. I don't want those things to like, play too much in my mind ... I need to focus on getting better… No! I just block it, I don't want to think about it… You just gonna feel bad about it... So just leave it and move on*". Londi tried with all her strength to supress the involuntary thoughts of the psychotic episode. Similarly, Mandisa's husband said: *"... if I could just flashback, I just ignore things. Let me just forge ahead*". It appeared that even after they received some help, it was difficult for him to become vulnerable and express how difficult the process was. He chose to "ignore things" and "forge ahead". When he re-experienced involuntary and distressing memories related to the psychotic episode, he actively disregarded those thoughts and feelings. This seemed to be a way of coping for him. This form of avoidance was common amongst patients and family members.

5.1.5.2 Disclosure and stigma avoidance

Some patients experienced indirect stigmatization, referring to when their peers would make negative comments about mental illness, or make fun of people with mental illness, without directly mocking them. While some disclosed their condition, most did not disclose their condition to avoid direct stigmatization. Bafana described his experience as follows: "*... at school, guys would … make fun of the teachers, if a teacher is in a bad mood and is shouting and everything, they say oh well, don't mind her, she's a Bipolar! I never had someone come up to me and say something to me directly... I've had a lot of indirect things… cause I mean I told everyone at school that I was Bipolar and stuff, but the way in which they treated me never*

changed. We were still friends and everything, and there wasn't this thing of you've got Bipolar and what what, so I've never been stigmatized directly or anything".

The above statement illustrates indirect stigmatisation. Despite disclosure, jokes and judgemental remarks about Bipolar were continuously expressed by his peers. When asked how he felt when these comments were made about others, he responded: "*Ya well obviously it doesn't feel nice, you know, the thing is people don't really know what Bipolar is, they just take it lightly. To me it's a big deal. I don't think it's something for people to joke about. I really don't think it's a laughing matter"*. He continued to explain that he was offended by the negative attitudes expressed towards individuals with mental illness. He belived this was perpetuated by a lack of knowledge, including understanding the genetic factors as opposed to blaming individual for bringing the illness upon themselves. He additionally admitted that he too had no knowledge or understanding of Bipolar Disorder until his index episode and diagnosis.

Peter described his experience in relation to stigma as follows: "*... they don't know if it's Bipolar. To them it's the weed that I'm smoking"*. While out with his peers*, " they started making jokes `ward 55 here`, `haa Bara here!`*[13] *... they are treating me in a different manner. Like a worthless person, or a person who is not going anywhere. So, I can see it and I can feel it*". Peter continued to describe the difficulty of adjusting and fitting in after diagnosis, saying: "*these people are looking at me in another way, I am no longer the person I was, ... now things are improving for most of my friends, they are having cars and stuff... they just leave me. So, I try to keep up with the times and be with them, but I can feel that thing that these people look at me with another eye*". Feelings of worthlessness, being negatively labelled as a substance abuser, as well exclusion from social activities, further alienate those with mental illness.

Similar to Peter, Clare experienced the following: "… *I haven't put myself out there and said listen I'm Bipolar. But people do have stigma about people with mental illness and I'll be sitting in the crowd, and hearing what they have to say, feeling pain for myself. ... at work*

[13] Key: *Ward 55* - referring to the male psychiatric ward at Baragwanath hospital

they'll say, 'this one is crazy, she's from hospital, ward 45[14]*, she's crazy'. And I'm thinking oh my word, if they only knew I come from ward 45, they'd also be saying I'm crazy*"

Clare made it clear that she would not want her colleagues to find out that she had a psychiatric condition, saying: "…*especially my colleagues, so if they had to find out, that would kill me...*" For her disclosure in that context would not be an option as she perceived the consequences as unbearable. Clare said: "...*I'm scared to go back to work because it was like just before I was admitted here. So, what if they think oh Clare is crazy, she is probably in a mental institution because the questions she was asking were actually very abnormal... what are people gonna think about me now*?"

In addition to concerns about how the patients may be negatively perceived, there were concerns raised regarding how stigma could potentially influence the possibilities of obtaining future employment. Bafana said: "*... in terms of work as well, some companies do take people with Bipolar and we are obviously considered as disabled... but I think in some places I might get rejected… because of my condition... I don't think it's important for anyone to know that I've got Bipolar, unless we're really close ... rejection, it's a concern for me*". Therefore, exclusion due to stigma was perceived as not only affected social interactions, but participtionin economic development as well.

For patients who were employed, a Bipolar Disorder diagnosis was seen to have negative implications on career development. Clare explained it as follows: "*the environment, like, everyone is happy except for me. You know it's a nice job but I'm not coping. So I ask myself what type of job will I be happy with? Which type of job am I going to be able to excel in? ... They acted as if they were doing me a favour... basically taking me for a fool... now they don't even respect me*". She reported feeling like an outcast at work. Unlike her colleagues, she struggled to meet the job requirements. As a result, she felt ridiculed by her colleagues. Competency within the work place may be affected by the illness for some, particularly those whose cognitive functioning had been compromised. This exacerbates the stigma, exclusion and the desire to avoid disclosure.

[14] Key: *Ward 45* - referring to the female psychiatric ward at Baragwanath hospital

5.1.5.3 Adherence serving relapse avoidance purpose

A common theme surfacing in the study was that the fear linked to a possible relapse became a strong driving force for patients and their family members to ensure that treatment was adhered to. Peter's mother said: "*I was checking each and everything that he was doing, trying to avoid him having a relapse... where are you? What are you doing? Are you drinking your medication? And sometimes even counting the tablets*". The fear of reexperiencing an episode can manifest as anxiety needing to be managed through strategies that may appear obsessive or compulsive.

Peter expressed irritation with his mother's behaviour as she struggled to find the balance between being supportive and being controlling or overprotective. However, when she "… *decided to step back*…" she noticed that stepping back was interpreted as uncaring, saying: "*I think he felt it's like he is on his own, I'm not supporting him. Of which I was trying to give him space, cause he is an adult*…". As such, negotiating and resolving the conflict between independence and dependence with the motive of avoiding relapse can be a challenging process.

5.1.5.4 Avoiding perceived weakness

In an attempt to avoid being perceived as weak, family members may avoid being in professional treatment themselves and opt for alternative ways of coping. Peter's mother mentioned that she was struggling to cope following her son's suicide attempt, and consulted a mental health practioner who prescribed medication for her that was similar to her son's. She explained: "… *I decided I'm not going to go get the medication. So it's entirely up to me to turn around the situation, it's either both of us will land up in hospital... I decided… reviving my belief and faith … it's just all a matter of the mind … I just have to change my mind set, be positive, try and motivate him*". It appeared that in her perception, taking medication similar to her son's meant defeat. She decided against further HCP treatment and selected a spiritual and self-help approach.

In summary, avoidance surfaced in four areas. Firstly, participants employed avoidance strategies in tackling post-psychosis intrusions. Secondly, they avoided disclosure to avert possible stigma. The third area of avoidance, bearing some benefits, was adherence to treatment encouraged by a strong desire to avoid future exposure to psychotic experiences. Lastly, family members avoided seeking psychological or psychiatric help for themselves to avoid perceived defeat and/or weakness. Although there was some 'benefit' attached to avoidance, the overall impact of avoidance was negative.

5.1.6 Psychiatric condition and parenthood

One of the areas that surfaced as significantly impacted by Bipolar Disorder was parenthood. Three concerns were raised by the participants regarding mental illness and parenthood. The first was how the illness affected plans for becoming parents for those who did not have children, the second was how the diagnosis affected those who already had children, and the last was how having parents with psychiatric conditions affected them.

In the interview with Bafana, he explained his concerns regarding appropriately planning for having children and disclosing his condition to his partner, he said: "*... I think it's very important for that person to know that I've got Bipolar, and if we are gonna have children then there's a 50% chance that they could also have Bipolar*". This patient had been psycho-educated about the genetic links in Bipolar Disorder, and although he was young, single and had no children at that time, he had to engage with the seriousness of this subject when thinking about his future.

Bizo's father also voiced concerns about his daughter having children in future, and the importance of involving others in the decision to become a parent, saying: "*... other information that came from the psychiatrist … is that if she wants to have a baby then she must tell them. So that they plan, because the medication that she is taking might affect the baby you understand? Things like that. I felt bad, very very bad*". The fact that his daughter would need involvement and intervention from professionals with regards to future reproduction weighed heavily on this father.

For some patients who already had children, it appeared that their psychiatric condition influenced their parenting roles. Londi noted that her daughter treated her differently because of her illness, associating this to a lack of understanding, saying: "… *She feels entitled of running the home, she is incapable of handling the money…so I feel now inadequate…I'm stigmatized as someone that can't do things… She will do something that will make me upset… I will give instructions…she will brush me off. I will tell her, listen here, don't treat me like a stupid. I'm not stupid*…!". Londi felt her daughter was treating her inappropriately and disregarding her competence as a mentally ill individual, as opposed to respecting her in her role as a mother. She expressed frustration, anger and sadness linked to being unheard, disrespected, disregarded and overlooked. A need to defend herself was present but she felt insufficiently validated by a family member with poor insight into her condition.

In relation to her experience of being parented by a mother with a psychiatric condition, Mandisa doubted the kind of mother she would become, given that she too was diagnosed with a mental illness, she said: "*I am … fearful ... I don't want to be like my mother. I want to be a loving mother. I want her to know that she can rely on me for anything… the things that she did to me hurt me and I thought its better if I leave her like that because she has never cared about me, why should I care about her? … I have cut her out of my life because anytime, anything that has to do with my mother always brings me pain*". Mandisa experienced fear and deep sadness regarding the possibility of becoming like her mother. She questioned herself and sat with anxiety about failure in successfully executing parental duties. She already had a child and was struggling with shame regarding the perceived lack of progress in her life. Although she had decided to completely separate herself from her own mother, the impact of that painful relationship (mother-daughter) on her relationship with her child remained evident.

Similar to Mandisa, Bafana reported that he did not have a close relationship with his mother who was diagnosed with a psychiatric condition too. For Peter, who did not live with his biological father, concerns about mental illness being linked to traditional requirements not met by the paternal family were raised. He, together with his mother, believed that there was a connection between his illness and the absence of his biological father.

It was noted that five of the seven interviewed patients had poor relationships with their parents. Although the biological fathers were absent in most of the cases, the patients could more easily

engage with the impact of the relationships with their mothers as opposed to their fathers. They were also able to speak about the psychiatric conditions their mothers had. It is unknown whether some of their fathers had psychiatric conditions or not, as they were absent.

5.1.7 A cure leading to a "normal" life

Participants spoke of a strong desire to have normal lives, they believed the main way for them to achieve this would be getting cured. Bafana said: "*If there was a cure, then ja*[15]*, that would be enough for me. If the cure is discovered, that would be really helpful. Apart from that, there's nothing* ..." Bafana felt that apart from discovering a cure for Bipolar Disorder, there was no further help that could be provided for him.

Londi demonstrated hope for being eventually cured. She believed that over time, the doctors would reduce the medication, and eventually stop. She noted that she had been informed of the importance of adherence in avoiding relapse and ensuring a shorter period within which she would need medication. It appeared that she took what she had been told about possible reduction in medication as eventually stopping the medication. She said: "... *I want to live a happy, live a fulfilled life, and hopefully eventually get off the medication, to live a normal life... maybe about a year, it depends on my progress … they will try and take me off it slowly, but it won't be a quick thing. They will do it over a period of time*..." The above statement was contradictory to the chronic nature of Bipolar Disorder and its treatment.

For Peter, his future hopes and pain regarding the desired 'normal' life was communicated as follows: "*to be alright, in the sense of getting well. To be in a state of mind where I can be social… convey my message across and be happy like everyone else... Find myself with someone. Have a family, work well… my younger siblings are growing up. I wanted to be a brother who will be there for them … to be proud of me as their big brother. So now I don't see such things, are they going to happen or? So, like, just like that, this thing hurts me*".

[15] Key: *Ja* – yes

The lack of the ability to achieve happiness was further perceived to prevent contributing to the happiness of loved ones, further confirming how Bipolar Disorder restricted them from becoming like other people in society. This was evident in Martha's statement: *"my future plan is to work, learn something, so that I can be supportive to my children. To become a responsible mother. I put my children first in my life. I love them... I can't afford anything that can make them happy, like other mothers who can make their children happy...*" Some of the patients' desires were not extraordinary. They are perhaps what those who do not live with such an illness take for granted. They primarily communicated a strong desire to function as 'normal'.

Clare said: "*...I don't feel normal. I feel abnormal. People always comment, people that don't even know that I have Bipolar...*" In the state of feeling abnormal, when asked about her future desires, she struggled saying: "*right now, to be honest, I don't know...*". Similarly, Mandisa said: "*When it comes to making future plans, I become very fearful because none of the plans I made since I left school have worked out. So, I'm just taking it a day at a time…*". It appeared that perceiving themselves as abnormal contributed to a loss of faith in the possibility of future prosperity.

5.1.8 Non-adherence and Insight

Although the majority of patients were able to name their diagnosis, they demonstrated poor insight on other factors regarding Bipolar Disorder. When Martha was asked what she had been diagnosed with, she responded: "*I heard the Indian doctor saying Bipolar*". A follow up question was then asked regarding what was explained to her, she responded: "*You know he didn't explain it to me, he didn't explain. I think it could be blood clots, maybe they were formed when I was injured. Maybe my blood is not flowing properly. I think so*". From statements like the one above, it appeared that some patients were not properly psycho-educated about their diagnosis. It is however important to note that although certain doctors and other health care professionals may attempt to psycho-educate the patients, some patients may continue to struggle with gaining understanding or improving insight. Patients participating in the current study generally struggled to demonstrate good insight, although a few displayed fair insight.

Six of the seven interviewed family members knew that the patients were diagnosed with a type of psychiatric condition. In contrast to the patients, only three of the interviewed family members could correctly name the Bipolar Disorder diagnosis. Three of the seven reported that they had never been psycho-educated by the treating health care professionals. Of these, two family members got information on Bipolar Disorder from the internet (google), while one had no information at all. Another family member reported receiving some information from HCPs but remained unclear. To get clarity, one mother used google to get extra information after speaking to health care professionals.

Processes that HCPs undergo to reach a specific psychiatric diagnosis may contribute to how well patients and family members understand and accept the diagnosis. Bizo's father expressed much frustration with the uncertainty of HCPs when Bizo was first admitted saying: "*the doctor was unsure, I complained that my daughter has been here for two weeks, and the people that she came with are improving, why isn't my daughter improving? That is when she said to me they are not actually sure what mental illness she has*". He continued to express frustration with the hospital system of frequently changing of treating doctors. Due to settings and systems in academic hospitals such as CHBAH, as well as challenges within the South African Department of Health, one patient may be attended to by different doctors throughout their treatment. Bafana's grandmother also expressed concerns about inconsistency in treatment arising from the frequent change of treating health professionals and the negative impact this has on patients, as they form bonds with some health care professionals.

Bizo's father additionally expressed frustration with the side effects of the medication saying: "*my daughter is getting fat. Ehhm, she was supposed to go and start at university...*" He struggled to accept and adjust to the changes brought about by her daughter's condition and the treatment thereof, together with the impact of the condition on her academic development. This father continued to express irritation with having to request appointments with the doctor only to be asked more questions as opposed to getting answers from the doctor. He said: "*what was irritating about the whole thing, they will tell you, upon request, that you have to make an appointment before we can meet... but still again, the doctor was asking me questions!... I was very disappointed that they had not determined what kind of illness she had*". The strong emotions aroused throughout the treatment process may influence the extent to which insight is gained. Together with HCPs who honestly do not know from the initial presentation what

the final psychiatric diagnosis will be, as investigations, collateral and observation form part of the process they must follow.

Once a diagnosis had been reached and HCPs provided psycho-education on what life style changes needed to be adopted, particularly in relation to substance intake, some patients struggled to adhere to the HCPs' recommendations. They found reasons to justify their continued use of substances. Bafana said: "*I have to like, to either reduce, or stop all together, doing certain things…drinking, I've had to, obviously it's bad for me, but ja, I've had to reduce…Ehh, well I've tried stopping weed*[16] *but it's really difficult… There's not really anything that I can say I've stopped you know*".

Some reasons were linked to denial. The patients struggled to accept the diagnosis and therefore struggled to stop doing certain things or engaging in activities that were said to exacerbate what they believed they may not have. Bafana justified his continued cannabis use by saying: "*cause even the first episode, they told me that it's the weed that triggered it. But then, I hadn't smoked, I mean, prior to me being admitted, I hadn't smoked in like a year and half. You know what I mean? It's only a year later that I got diagnosed with* Bipolar*. And that's when they tell me it's the weed. So, that's another thing that I don't understand…and the last time I got admitted it was because of stress, instead of weed, you know what I mean? When I stayed … without smoking, you know? But then I still got sick… I don't understand how it works*". Patients may be confused by factors linked to what led to the onset of their illness. They may look for causal factors as opposed to appropriately understand predisposing, precipitating and maintaining factors. It becomes difficult for them to develop insight when they struggle to fully comprehend all relevant factors related to their diagnosis.

A good support structure, including family, friends, colleagues, employers and the community, was identified as one of the factors positively influencing adherence. Peter's mother stated: "*… at work as well I've got a supportive boss. … I've got a supportive husband, … and support from my mother kept me going, up until this far*". It appears that the presence of social support,

[16] Key: *weed* – cannabis

not just for patients, but for family members as well, is important in dealing with Bipolar Disorder with psychotic features.

Additionally, belief systems contributed to factors affecting adherence. Beyond obtaining assistance from health care professionals, some participants had sought help from traditional healers and spiritual leaders in churches. Peter consulted a traditional healer and needed more money to continue with that intervention as he believed it would help him. Martha reported that she was forced by her husband to consult a traditional healer, unfortunately, she had a bad experience.

Five of the seven interviewed participants stated that they preferred western medical treatment as opposed to alternative approaches such as traditional healers. Stating that they relied on the scientific proof and trusted the medical approach, rejecting treatment without 'scientific evidence'. Others were open to interventions from traditional healers, as they believed in the possibility of the mental illness being a direct result of bewitchment. The five who preferred medical treatment displayed higher adherence behavioural patterns as compared to the two who were eager to pursue traditional forms of healing.

With regards to church related spiritual approaches, some participants reported that their faith in God was combined with a belief in the efficacy of medical psychiatric treatment. They found prayers and support from their churches beneficial. However, for Clare, a conflict regarding prayer arose, she said: "*I don't know what it is I get when I get prayers. Sometimes you end up feeling worse, because people are people, they can tell you, you must pray for yourself, you mustn't be weak and stuff like that. But at the end of the day, like, if they were going through the same thing, even to a pastor, you would also need help in some form or way*". When the 'support' from church members through prayers was experienced as judgmental, it left the patient feeling worse. This did not contribute to improved adherence.

In summary, factors contributing to non-adherence included poor insight, unanswered questions, denial, confusion, lack of hope and altered cognitions. Persistent negative emotional states including fear, anger, guilt and shame in relation to the psychotic episode experience and the diagnosis played a major role in how the patients perceived themselves and how they were perceived by those around them.

6. CHAPTER SIX: DISCUSSION

6.1 Scope of discussion

In this chapter, the findings from all analyses will be discussed, including the preliminary analyses, hypothesis-testing results, qualitative and quantitative findings. Firstly, the outcomes of the hypotheses for the current study will be outlined. Throughout the discussion, these outcomes will be contextualised and unpacked. The process will begin with a review of the definition of Post-Psychosis Trauma, where aspects specific to the current study will be discussed. Thereafter, the manner in which participants experienced psychosis as traumatic, their experiences of hospitalisation, and the manifestation of post-trauma symptoms will be unpacked. Following that, factors influencing patient adherence and the absence of an association between Post-Psychosis Trauma and adherence will be discussed. Linked to the detailed description of the demographic and clinical characteristics of patients diagnosed with Bipolar I Disorder with psychotic features and their families in CHBAH provided in Chapter 4, these characteristics will be discussed as additional findings from the study, which are deemed useful in understanding and treating individuals from this population. Limitations of the study and directions for further research will be presented in the latter part of this chapter.

6.2 Hypotheses outcomes

Results from the main analyses provided support for the first hypothesis of the study as clinically significant levels of Post-Psychosis PTSD were found in the sample of patients diagnosed with Bipolar I Disorder with psychotic features and their family members. This finding was in line with literature displaying that patients may be traumatised by psychosis and other psychosis-related adverse experiences, together with findings of high rates of PTSD in severe mental illness (Auxemery & Fidelle, 2011; Gliko, 2004; Steel et al., 2005; Tarrier et al., 2007; Auxemery & Fidelle, 2011). The finding further supports literature stating that carers may experience witnessing a psychotic episode and other psychosis related experiences in their relative as traumatic and life altering. This in turn compromises their ability to assist the patient

in their journey to recovery and wellness maintenance, highlighting the need for familiy member inclusion in treatment programs (Askey et al., 2009; Barton & Jackson, 2008; Corcoran et al., 2007; Loughland et al., 2009).

The present study failed to find support for the second and third hypotheses. There was no significant relationship between treatment adherence, as measured by the DAI, and trauma symptomatology as measured by the overall PSSI scale, neither was treatment adherence as classified according to clinical indicators higher in the absence of diagnosable PTSD. Instead, diagnosable PTSD was present in both the adherent and the non-adherent group of patients and their family members. Relevant points of discussion are unpacked below.

6.3 Psychosis as a traumatic experience

While some researchers have focused on the presence of traumatic experiences creating vulnerability to future psychosis, others explored the vulnerability of psychotic patients to future trauma. A few studies have specifically looked at psychosis being experienced as traumatic itself (Morrison et al., 2003; Palmier-Claus et al., 2012). The latter was the focus of the current study.

Patients and family members in the current study reported different aspects of experiences related to psychosis as traumatic, including the psychotic episode itself, hospitalisation, diagnosis and understanding the meaning of the diagnosis. Studies investigating how family members are impacted demonstrate that witnessing a loved ones' psychotic episode and receiving the diagnosis, are life altering experiences tapping into different negative emotions (Askey et al., 2009; Corcoran et al., 2007; Loughland et al., 2009). PTSD is characterised by the development of specific symptoms after an individual is exposed to, witnesses or learns about a traumatic event that involved actual or threatened serious injury or death of the self or another. In response to this, the individual experiences intense fear, helplessness or horror. Additionally, the individual presents with the following symptoms; re-experiencing of the traumatic event, avoidance of trauma related stimuli, numbing and increased arousal (American Psychiatric Association, 2013). As the patients participated in the current study after their

psychosis had remitted, they spoke of memories including cognitive, sensory, behavioural and emotional content of the psychosis, such as the fear and helplessness experienced.

Participants reported exposure to actual or threatened significant injury and even threatened death during psychotic experiences. Family members reported being verbally and/or physically threatened by their psychotic loved ones, especially when attempting to reduce exposure danger as an attempt to protect them. Participants reported attacking loved ones as a result of visual hallucinations distorting the patient's perception of the family members. Some of the family members directly witnessed violent actions taken by the patients. Examples of exposure to threats of death or serious injury discussed by the participants included: suicide attempts linked to commanding voices/hallucinations, suicide attempts linked to depression, attacking loved ones linked visual hallucinations distorting the patient's perception of the family members, carrying of weapons such as knives, threats to stab the loved ones, walking alone in unsafe environments and at risky hours, exposure of children to danger and burning of family property linked to distorted perceptions of the property and beliefs informed by delusions.

For family members, the psychotic episode appeared more traumatic, as they witnessed their loved ones' loss of touch with reality and strange behaviour. They more commonly experienced helplessness, hopelessness, confusion, fear, frustration and horror. In contrast, some of the patients experienced positive feelings during the psychotic episodes, particularly in relation to mania. However, these patients experienced negative feelings as they later reflected on the psychotic episode. The experience of psychosis altered how the patients viewed themselves and how they were viewed by their family members. Processes involved in psychosis which participants referred to included experiences of delusions and hallucinations. As stated by Schwartz (2008), delusions and hallucinations are among the most distressing and confusing symptoms of psychosis, as they are disorganizing and frightening and can lead to increased suspiciousness and anxiety in patients. This was demonstrated by the female patient who stated that during psychosis, she had paranoid delusions about her life being danger. She was afraid, suspicious and anxious. In an attempt to protect herself, the patient kept a big knife under her pillow. This behaviour affected her grandmother, who would lock herself in her bedroom in fear of being stabbed during the night. This was the same patient who attempted suicide led by commanding voices that instructed her to do so. This demonstrate the extent to which certain

symptoms of psychosis pose a danger to life as outlined in literature (Sadock & Sadock, 2015). The suicide attempt could have resulted in the patients' death.

One of the complexities of psychotic experiences being traumatic is that the stimuli of danger arises from an internal source, such as a delusion. However, to the individual experiencing it, it is perceived as arising from an external source. In the example of the female patient discussed above, she believed that her life was truly in danger. She perceived the voices and people wanting to kill her as real as one would perceive danger originating from external sources. Blum (2003, as cited in Tichler, 2008) defines trauma as an experience in which the ego has been overwhelmed and flooded by a stimulus of danger coming from an internal or external source. Regardless of the perception of the source, the patients participating in the current study reported experiences indicating a flooding and overwhelming of the ego. Although delusions may be categorized as internal stimuli of danger, they were experienced as real external stimuli.

Additionally, participants reported increased risk-taking behaviour linked to poor judgement and poor situational awareness during psychosis. Patients and their family members articulated emotional responses of intense fear, helplessness, or horror linked these experiences. It is recorded that many patients with a psychotic disorder find both psychosis and treatment for psychosis aspects to be traumatizing. Sadly, health care providers largely fail to recognize the symptoms of both types of trauma in this population (Putts, 2014). Despite the family members' exposure to overwhelming and traumatic experiences, they are in a position where their loved one needs their immediate care; they assume a position of strength as they navigate different ways of protecting and helping their loved ones. One of the participants was a father who had to physically restrain her daughter to prevent her from running away from their home. Others included a husband and a grandmother whose loved ones who walked in dangerous township areas at night.

Although these family members were overwhelmed, they had to find ways of protecting and helping their loved ones. Family members appeared to experience the psychotic episode as more traumatic as they directly witnessed their loved ones' loss of touch with reality and strange behaviour. The distress and confusion arising from a psychotic experience, evoked feelings of horror, fear, and helplessness in both the patient and their family members. The strict application of the term "trauma" for the diagnosis of PTSD within psychiatric

classification includes only exceptional, life-threatening or potentially life-threatening external events and those associated with serious injury, which are capable of causing a psychological shock in practically any individual to a greater or lesser extent (Frommberger, Angenendt & Berger, 2014). However, If the subjective meaning attributed to an experience determines its traumatogenicity (Sadock & Sadock, 2003), it follows that in addition to the generally accepted exceptional traumatic experiences, a psychotic episode may also be experienced as traumatic.

In the current study, Post-Psychosis Trauma was present in 78.6% (n=55) of the total sample. Overall, there was a greater percentage of participants in the current study reporting a presence of Post-Psychosis Trauma as compared to those reporting an absence of the same. A total of 27 (77%) of patients and 28 (80%) of family members had PTSD symptoms above threshold. The higher likelihood for family members experiencing more PTSD symptoms than the patients was demonstrated by the smaller number of patients (n=17; 48.6%) as compared to 26 (73.7%) of family members, falling within the mild-severe PTSD symptom category. In a study conducted on carer-relatives of people with psychosis, it was found that 51.5% of carers had symptoms of PTSD with a high likelihood of PTSD diagnosis (Loughland et al., 2009).

Comorbidity in psychiatric conditions is common, requiring greater use of health care resources. For example, Buturak and Kocak (2015) found that patients with Bipolar I Disorder with Anxiety Disorder comorbidity were found to more frequently make use of the health care system in comparison to those without Anxiety Disorder comorbidity. The lifetime comorbidity was found to be 32.4%, with Generalized Anxiety Disorder being the highest at 21.05% (Buturak & Kocak, 2015). In the current study, for both patients and family members, increased levels of Post-Psychosis Trauma were associated to increased levels of depression, stress and anxiety at 0.01 level of significance. Furthermore, correlation results indicated that increased negative affect in family members was significantly correlated to increased levels of Post-Psychosis Trauma, together with increased levels of depression, stress and anxiety at 0.01 levels of significance.

In assessing the impact of several factors on the odds that the family members would present with Post-Psychosis Trauma, it was indicated that it may be useful to consider the following: the extent to which the patient was coping, the support provided by family members, patients' history of other traumatic experiences, employment status of the patient, whether the patient

was a student, and the year in which the patient was diagnosed. With caution, it was noted that the odds for family members to present with Post-Psychosis Trauma were higher when the patients reported that they were unemployed, not students and that they were not coping. Additionally, for patients who were more recently admitted, those who stated that they were receiving good family support, and when the patients reported a history of sexual trauma as compared to other types of trauma, the odds for family member PPT appeared higher.

In assessing the impact of several factors on the odds that patients would present with Post-Psychosis Trauma, the following were identified: occupation, coping, family support, society support, childhood experience, therapy history, educational difficulty history, and history of trauma experiences. It appeared that the odds for patients to present with Post-Psychosis Trauma were higher when they reported that they were receiving poor family support, when they were not studying, when they reported no history of psychotherapy and when they were generally not coping. Furthermore, it appeared that the odds for patient Post-Psychosis Trauma were 7 higher for those who reported a history of sexual trauma. Of note, only female participants reported a history of sexual trauma.

Jackson (2011) noted that there is growing evidence suggesting psychosis may be significantly traumatic, leading to PTSD type symptoms, also referred to as Post-Psychosis Trauma symptoms (PPTS). Participants of the current study were found to experience Post-Psychosis Trauma (PPT) in line with the definition of trauma. The first part of the definition addresses trauma as an experience witnessed or confronted by an individual (Sadock & Sadock, 2003). In the current study, family members witnessed and were confronted with actions stemming from the psychotic episode while the patients were directly confronted by psychosis itself. Psychosis related experiences impacting both patients and their family members included delusions, hallucinations, hospitalisation, diagnosis, insight development and stigma. Based on the discussion above, it is apparent that not all patients and family members may directly experience psychosis itself as traumatic. Auxemery and Fidelle (2011) suggest that the links between psychosis itself and trauma are multidimensional and complex. More research is indicated in this field to identify and explore other possible dimensions. In the current study, hospitalisation during psychosis surfaced as one of the important dimensions.

Shaw, McFarlane, Bookless, and Air (2002) argue that psychological distress about the episode of psychosis appeared to play an important role in determining which patient would develop PP/PTSD. However, this distress was found present beyond those who had PP/PTSD, as components of hospitalisation such as separation from usual activities, separation from family members and seclusion were identified as equally troubling and traumatic experiences (Shaw et al., 2002). Participants of the current study spoke of traumatic experiences that occurred during hospitalisation in psychiatric wards. While some of these experiences were directly linked to the interaction between psychosis and hospital treatment processes, others were linked to treatment side-effects, resource limitations and HCPs. Patients demonstrated that due to impaired judgement and paranoia during psychosis, certain treatment procedures during hospitalisation were misunderstood and viewed as a threat. Post-psychosis, some patients clearly recalled the contents of their psychotic delusions and the fear and resistance elicited during the initial stages of in-patient treatment.

It has been reported that family members commonly experience inpatient wards as frightening environments that did not aid with recovery. Furthermore, the process that patients experience when they are being admitted has been viewed as traumatic by family members (Askey et al., 2009). This was confirmed in the current study as hospitalisation during psychosis was found to be traumatic for family members too, with the quantitative results suggesting that the odds for family member Post-Psychosis Trauma were 3 times higher for patients who were recently hospitalised. This included perceived neglect by HCPs and patients sustaining injuries and medication side effects. The lack of control and dependence on HCPs appeared to leave some family members feeling angry, helpless and hopeless. Negative hospitalisation experiences may be significant traumatic events, they may also exacerbate the Post-Psychosis Trauma symptoms.

Although PTSD is one of the severe forms of psychological disturbance, research has demonstrated that it is frequently overlooked in patients diagnosed with severe psychiatric disorders. While the trauma symptoms are not significantly explored or treated, focus is put on the classified symptoms of the severe psychiatric disorder. However, some studies have highlighted the potential of psychosis and co-morbid PTSD, in which PTSD may be a stressor provoking relapse (Sin et al., 2012). It is the argument of this thesis that psychosis related trauma in Bipolar I Disorder may be experienced during a psychotic episode, during psychosis

related hospitalisation, and/or when one is diagnosed with a psychotic disorder. Therefore, it is important to consider the possibility of the negative impact of post-trauma-type reactions in the recovery and relapse prevention in patients. Further, the current thesis asserts that it is equally as important to consider the possibility of the negative impact of post-trauma-type reactions in family members.

6.4 Post-Psychosis Trauma Symptoms

As previously outlined, the first part of the definition of trauma focuses on the experiences that an individual may either be directly confronted with or witness. The second part of the definition of trauma draws attention to experiences involving actual or threatened death or serious injury, or a threat to the physical integrity of self or others. The third part focuses on responses involving intense fear, helplessness, and horror (Sadock & Sadock, 2015). Findings of the current study support indications that psychosis may be a significantly traumatic experience directly confronting the patients and being witnessed by family members, involving the threats and responses similar to those manifested in other trauma experiences. In line with the argument that the DSM-IV criteria for PTSD may be met by individuals who had psychotic experiences (Mueser & Rosenberg, 2003), it is the argument of the current thesis that DSM 5 criteria for PTSD diagnosis may be met by individuals diagnosed with Bipolar I Disorder with psychotic features and their family members. As such, symptoms of altered emotions, altered cognitions, re-experience, and avoidance that participants presented with will be discussed below.

6.4.1 Altered cognitions

Morrison et al., (2003) proposed that similar to other types of traumatic experiences, hallucinatory and delusional experiences can shatter how an individual view the self, others and the world. In the current study, the experience of psychosis, the diagnosis with Bipolar Disorder and hospitalisation in a psychiatric ward altered how the patients viewed themselves,

how they were viewed by their family members, and how they were viewed within broader societal interactions.

In the DSM 5, negative alterations in cognitions associated with the traumatic event have been added to the required diagnostic criteria for PTSD. The negative alterations in cognition include persistent and negative beliefs or expectations about oneself, others, or the world; distorted cognition about the cause or consequences of the traumatic event; and an inability to remember important aspects of the traumatic event (American Psychiatric Association, 2013). In the current study, there were patterns of altered cognitions. The perceived loss of self was associated with thoughts/beliefs of worthlessness and hopelessness as the patients viewed themselves as incapable of achieving their pre-existing desires. There were patients who redefined themselves and labelled themselves negatively, for example, seeing the self as a 'bad person'.

The patients and family members reported negative alterations, they discussed some persistent and exaggerated negative beliefs or expectations of themselves and/or other people, presenting distorted cognitions about the causes of the onset and consequence of the illness, mainly manifesting in either self-blame or other-blame. Given the nature of Bipolar I Disorder with psychotic features, patients and their family members believed they were not "normal", they viewed themselves as prone to negative experiences which would be beyond their control, and they believed they were generally unable to cope with the demands of life. In a study by Russell and Browne (2005) it was found that despite the awareness of patients diagnosed with Bipolar Disorder that it could not be cured, they felt able to prevent relapses of illness through employing effective stay well plans. For many, separating themselves/their identity from their illness, was an important component in staying well, stating that Bipolar Disorder was not a character flaw, personality trait or sign of personal weakness. It was however noted that Bipolar Disorder was perceived negatively within the community, whereby the words 'Manic Depressive' or 'Bipolar' became a label that defined the whole person (Russell &Browne, 2005). It is in such instances where altered cognitions within broader society directly affect the wellbeing of patients. How the patients perceived themselves and how they were perceived by those around them in relation to the psychotic episode experience and the diagnosis played a major role in persistent negative emotional states.

6.4.2 Altered emotions

Altered emotional states were reported in relation to different aspects of Bipolar I Disorder with psychotic features. Some participants responded negatively to the initial diagnosis and associated experiences, others intensely reacted the more insight they gained into their diagnosis, while for others, the emotional impact of recalling the factors involved in psychosis was more unsettling. A wide variety of emotions were experienced by the participants in relation to receiving the diagnosis of Bipolar Disorder, ranging from emotions associated with trauma and grief to emotions associated with relief. Most participants reported that their initial diagnosis with Bipolar Disorder was not traumatic, attributing this to the initial lack of knowledge and understanding of Bipolar Disorder. However, some patients experienced the diagnosis as perturbing, highlighting emotions predominantly characterised by a state of confusion, together with a sense of being overwhelmed. Similar emotions were reported by the initially relieved participants, as their emotional state changed at points where insight was gained.

For patients who expressed relief at diagnosis, they explained that diagnosis was experienced positively because the moment of diagnosis was a moment when their negative life experiences were accurately labelled through medical terminology. This served a function of validating their distress and illness related behaviours as conducted without malicious intension. Once some knowledge and understanding of Bipolar Disorder as a diagnosis was gained, there was a sense of loss and deficit, accompanied by grief. Participants expressed a wide range of losses associated with different aspects of their lives and identities. Similarly, Dunkley et al., (2015) found that patients who had experienced a psychotic episode expressed the theme of loss and deficit to be present during the acute episode, but as mostly evident in the recovery phase. One of their participants reported viewing oneself differently following the experience of psychosis, including characteristics of timidity, no-longer as outgoing, shy, and having lost a sense of confidence (Dunkley et al., 2015). Other patients responded with shock, disbelief and complete denial of the diagnosis, disowning the ‘craziness’. It may be argued that the negative emotional responses are constituents of self-stigma, involving internalized negative beliefs about mental health manifesting through negative self-labelling, destructive attitudes towards mental illness

and its treatment, and beliefs that one is unappealing to others because of one's mental illness (Dunkley et al., 2015).

In contrast to negative emotional experiences during psychosis, some of the patients expressed experiences of positive feelings associated to the manic phase of the psychotic episodes. These experiences included feeling powerful, energetic and important. One patient described it as feeling "excited, happy, free, and on top of the world". Impulsive behaviours such as giving away money, dancing in streets, being talkative and lacking focus required to fulfil their tasks at work accompanied their positive emotional states. These emotions and behaviours were similar to those explained in literature regarding mania, whereby the individual is expected to present with symptoms such as flight of ideas, increased energy, expansiveness, heightened self-esteem, over involvement in pleasurable activities, increased mental and physical activity, and grandiose ideas (American Psychiatric Association, 2013). Following remission, on one hand, it appeared challenging for the patient and loved ones to adjust to reduced energy levels that were perceived as good and lively personalities. On the other, participants of the current study reported experiencing negative feelings such as shame and guilt, as they later reflected on the psychotic episode and their out of character behaviours, particularly those actions related to mania.

A psychiatric condition that most participants had a better attitude and emotions towards was depression. It appeared more socially acceptable to be sad, as negative personal life experiences could be used to explain the emotions of sadness and behaviour associated with depression. Whereas it was more challenging to explain Bipolar I Disorder with psychotic features in a socially acceptable manner. Some participants reported that they were first diagnosed with depression. Literature supports that despite the high prevalence of Bipolar Disorder, it is poorly recognised and difficult to diagnose, with misdiagnosis occurring on average 3.5 times before a correct diagnosis is made (NICE, 2014). Thus, similar delays in correct diagnosis were noted in the current study. Likewise, frustrations were expressed by some family members in relation to the processes that HCPs undergo to eventually identify the correct diagnosis, as they would have ideally sought prompt diagnosis and treatment of their loved one.

Following the psychotic experiences, there was evidence of markedly diminished interest or participation in significant activities, together with feeling detached or estranged from others.

Family members admitted to contributing to the limitations on social participation, stemming from their desires to protect their loved ones. Furthermore, occupying a position of dependency, i.e. being unemployed due to their condition, appeared to contribute significantly to the patients' negative emotions. As they were painfully confronted with a loss of independence. Family members presented with fear together with a loss of trust and confidence in the patients' capabilities to interact independently within society. One may wonder whether their fear was rooted in viewing the world as an unsafe place, fear that their loved one no longer possessed the skills to be safe in the world, or an interaction between these views. Family members tended to regress to treating patients like younger children needing constant strict monitoring and protection.

It became clear that family members struggled with accepting the diagnosis. They expressed a desire for Bipolar Disorder to be more of a passing phase, as opposed to a chronic diagnosis. They also reported feelings of fear, helplessness, and deep pain associated with exposure to the psychotic experience. It was additionally found that both patients and their family had feelings of shame and guilt linked to self-blame in relation to the illness. Although the behaviour exhibited by patients was due to psychosis, some family members felt ashamed and blamed themselves, considering possibilities of not being good enough parents. Some patients blamed themselves for their illness. As the participants spoke about their feelings of guilt, the heaviness of self-blame seemed to weigh down on them.

Emotions arising as participants gained some understanding of what it meant to have Bipolar I Disorder with psychotic features appeared encircled by devastation linked to a loss of hopes and dreams, together with uncertainty about their future. They presented with a loss of self-confidence and an increased self-doubt. In some ways, the diagnosis became a stumbling block that the patients struggled to overcome. There was also anxiety and hopelessness linked to the perceived lack of control. Consequently, they felt stuck. Other circumstances such as unemployment related to the diagnosis further confirmed the lack of progress. Having suffered a significant loss of hopes, dreams and perceived control over their destiny due to their psychiatric condition had a profound impact on them, together with their perception of how those around them viewed them. This loss of control was linked to the lack of achievements of certain age appropriate goals and the perceived loss of potential to achieve in future.

It was important to consider that the psychotic experience left participants feeling vulnerable. They expressed fluctuation in acceptance, denial and minimizing of the diagnosis, depending on the presenting circumstances for each day. It appeared that even though other patients somewhat accepted the diagnosis, the desire to disown Bipolar I Disorder with psychotic features persisted in different degrees. Temporarily, some participants felt a sense of relief, however, the relief was followed by confusion and despair. Although their experiences were given a name, there remained multiple unanswered questions. Whether immediate or delayed, the response of being certainly disturbed by the truth of Bipolar Disorder as part of their lives, was apparent.

It is concerning that some participants struggled with a persistent inability to experience positive emotions. According to stress-vulnerability models of psychosis, the stress threshold needed to elicit future symptomatic responses becomes substantially reduced in patients with the condition, and they may be particularly sensitive to everyday stress (Zubin & Spring, 1977; Neuchterlein & Dawson, 1984). Research has found that these patients suffer from greater emotional responses to stress when compared to their relatives, healthy controls, and other psychiatric patients without psychotic features. Additionally, minor stressors are often associated with subsequent changes in symptom severity (Palmier-Claus et al., 2012). For these reasons, the population of the current study remains vulnerable and in need of interventions targeting the reformation of healthier and protective cognitions and emotions.

6.4.3 Re-experience

Shaw et al., (2002) discussed findings highlighting the high levels of distress experienced by patients who are psychotic, whereby intrusive and distressing recollections relating to a psychotic illness and its treatment were common in both participants who did not qualify for the PTSD diagnosis and in those who did. The development of PP/PTSD phenomenology has been associated with the psychological distress of the experience, particularly as participants with PP/PTSD reported more distress and intrusive memories associated with illness and treatment experiences and had higher scores for anxiety and dissociative symptoms (Shaw et al., 2002). In the current study, some participants reported that they found themselves

involuntarily thinking about the psychotic episode almost every day. For others, the thoughts only came when triggered and they were frequently accompanied by feelings of shame regarding actions carried out during the episode. The participants reported that they selected to actively disregarded the re-experienced involuntary and distressing memories related to the psychotic episode. This seemed to be a way of coping for them which will be further discussed under avoidance.

6.4.4 Avoidance

Patients and family members spoke of and demonstrated the different ways of avoiding or attempting to avoid distressing memories, thoughts, feelings and or external reminders of the traumatic psychotic episode. Following the psychotic experiences, there was evidence of markedly diminished participation in previously enjoyed activities, together with being detached from those they would engage with before the psychosis related experiences. There was evidence of avoiding engaging in both thoughts and conversations that would remind them of the experience of psychosis, together with an avoidance of activities that would trigger such memories.

A common theme surfacing from both family members and patients was that the fear linked to a possible relapse became a strong driving force ensuring that treatment was adhered to. In contrast, literature suggests that patients may avoid treatment. Tsang et al., (2006) argued that patients with psychiatric diagnoses may avoid psychiatric services to reduce the chances of being stigmatized. They stated that this avoidance is more common in individuals with low self-esteem, low self-efficacy and high self-stigma. It was deduced that high self-esteem and self-efficacy were good indicators of treatment adherence. Other factors that were classified as contributing to non-compliance were poor insight, and the patient's negative attitudes towards the prescribed medication (Tsang et al., 2006). Such an avoidance of possible stigma was more evident in family members participating in the current study. In an attempt to avoid being perceived as weak, family members avoided being in professional treatment themselves and opted for alternative ways of coping.

Mueser and Rosenberg (2003) proposed that patients may avoid treatment if it reminds them of the traumatic experience of the psychotic episode and the possible trauma experienced from the treatment procedure. They state that open communication about this trauma and intervention strategies targeting the negative beliefs that developed from the trauma, could positively contribute towards treatment adherence (Mueser & Rosenberg, 2003). Although some participants of the current study were avoidant of possible relapse and thus channeled the avoidance towards compliance, they are likely to benefit from cognitive restructuring and strengthening of long-term compliance with better and healthier outcomes.

6.4.5 Conclusion on symptoms

Literature has noted that the effects of trauma in patients with psychotic disorders are rarely investigated, rather, they are often missed, undiagnosed and untreated (Callcott, Standart, & Turkington, 2004; Tarrier, et al., 2007; Lu et al., 2013). Findings from a study investigating the perceptions of patients who had experienced a psychotic episode indicates that they perceived that due to the psychotic illness, 77% had suffered change/disruption to their lives and persistent loss, 60% felt that their aspirations and hopes were no longer achievable, 53% had experience stigma and 50% suffered social exclusion. Insight was not significantly associated to the above-mentioned factors and there were no significant differences in arousal symptoms. However, there was a significant association between PTSD and being detained under the mental health act, as reflected in avoidance and intrusive symptoms (Gliko, 2004).

Laugharne, Marshall, Laughrne, and Hassard (2014) argue that many patients with a psychosis illness diagnosis are likely to have a history of trauma and symptoms of PTSD, with some possibly to be traumatised by their psychotic symptoms. PP/PTSD research findings further strengthen the need for the assessment and treatment of Post-Psychosis Trauma symptoms in patients with psychotic illnesses. Unfortunately, current treatment practices tend to prioritize psychosis symptoms in a way that marginalized trauma intervention (Gairns et al., 2015).

In contrast to several studies, Dunkley et al., (2015) found that the traumatic nature of FEP was extended beyond the acute episode and that it was not linked to symptoms of Posttraumatic

Stress Disorder. They argued that the diagnosis of PTSD does not capture all aspects of distress following FEP. They suggested that the impact of FEP must be viewed as ongoing, as opposed to focusing on the acute episode. They continued to state that disruption occurs in the individual's views of the self, view of others, relationships and worldview (Dunkley et al., 2015). Although the above study takes a different approach, there is agreement in psychosis possessing a traumatic nature and its severe impact in the affected individuals' life.

Given that the current study did not exclusively focus on FEP, it must be noted that similar to how recurrent exposure to trauma, for instance, recurrent sexual abuse, requires different forms of conceptualisation (Eagle & Michelson, 1997; Kaminer & Eagle 2010), so would recurrent exposure to psychosis. This is highlighted as an area for further research. Additionally, it should be noted that further research and clarity regarding psychosis fulfilling the requirements of criterion A1 for PTSD in accordance to DSM classification system is still necessary. Despite evidence of psychosis as a traumatic experience that can lead to PTSD-type symptoms, it has not yet been officially declared as such in the diagnosis criteria, however, it may be clinically useful when treating patients with psychotic disorders, and it may be helpful to consider extending DSM criteria to include a broader range of trauma-inducing events. Findings of the current study and other literature sources warrant further investigation and adaptation.

6.5 Adherence

One of the major challenges in the treatment of patients with psychiatric disorders, and specifically, Bipolar Disorder, is non-compliance (Lawson & Bland, 2004; Rummel-Kluge et al., 2008). It has been found that non-adherent patients have a higher relapse rate and a poorer prognosis, especially those with psychosis (Gleeson et al., 2008; Tsang et al., 2006). The current study punctuated from these concerns in exploring factors contributing to non-adherence in patients diagnosed with Bipolar I Disorder with psychotic features, as they are a vulnerable group. The definition of non-adherence entails the failure to adhere to the treating physician's clinical recommendations, including but not limited to entering into a treatment programme, participating in the treatment programme, keeping appointments as scheduled, taking medication as prescribed, and following other recommended changes in diet or

behaviour (Sadock & Sadock, 2015; Tsang et al., 2006). Non-adherence behaviour surfacing from the current study fell within the categories contained in the definition above. Relapse in relation to non-adherence was indicated for 68.6% (n=24) of total participants. This is line with literature highlighting the extent to which non-adherence remains a huge challenge in successfully treating individual with psychiatric illnesses.

Rummel-Kluge et al. (2008) highlights that patients who do not take their prescribed antipsychotic medication have a much higher relapse rate as compared to patients who adhered to their treatment. Furthermore, it has been shown that patients who are non-adherent have an increased risk of re-hospitalisation as compared to those who are adherent (Tsang et al., 2006). It is therefore in the best interest of the patient and others for them to adhere to treatment as recommended. Based on the patient's history, hospital records and collateral information from the family members, 54.3% (n = 19) of patients in the sample were adherent, while 45.7% (n = 16) were non-adherent. However, the Drug Attitude Inventory results showed that even some of the known non-adherent patients scored as adherent. It was noted that this scale was not a reliable measure of adherence as their responses aimed to give an impression of adherence, even when those answers did not correspond to their true behaviour.

In assessing the impact of several factors on the odds that the respondents would be adherent or non-adherent to treatment, the following factors were identified: employment, being a student, coping (stemming from the participants' responses regarding whether they perceived themselves as coping with general life demands or not), insight, family support, society support, therapy history, childhood experience (encompassing the participants' account of their childhood experiences) and educational difficulty history (whether a participant had a history of failing or repeating any grade in their schooling career). From these factors, society support came out as significantly contributing to the model of adherence, recording an odds ratio 16.06. This indicated that the odds that respondents who reported poor support from the society were 16 times higher for non-adherence than those who reported good society support. The importance of social support was further emphasized in the qualitative results, whereby a good support structure, comprising of family, friends, colleagues and the community, was identified as one of the factors influencing adherence.

Literature supports the importance of social support, cultivating an appropriate environment for optimal care (Janssen et al., 2006; Rummel-Kluge et al., 2008). For example, Frank, Prien, Kupfer, and Albert (1985) noted that patients who were not in a relationship, not married, male, and young were most likely to be non-adherent. In the current study, it appeared that the presence of social support, not just for patients, but for family members as well, is important in dealing with Bipolar I Disorder with psychotic features. As such, literature recommends interventions actively involving family members, friends and other community-based stakeholders (Janssen et al., 2006; Rummel-Kluge et al., 2008). The importance of supportive family members in assisting patients with adherence to treatment in undeniable. Research has demonstrated that family members who are educated about the illness and assisted by professionals to develop skills of managing the illness, are better able to recognize early signs of relapse and seek appropriate help (Gleeson et al., 2008). A common theme surfacing in the current study was the fear linked to a possible relapse being channeled towards prevention, this strong driving force yielded in patients and their family members ensuring that treatment was adhered to. However, one may question the extent to which this fear, without knowledge and understanding of the illness, would sustain continuous adherence. Future research may look into how long this fear typically encourages treatment adherence, and explore healthier ways of coping, addressing the fear and anxiety about the diagnosis.

Literature indicates that poor insight is one of the most significant problems, whereby patients neither recognize nor acknowledge the need for adherence in treating their condition, with some patients being in a state of denial of the mental illness (Rummel-Kluge et al., 2008; Tsang et al., 2006). The first step in an individual demonstrating some knowledge of one's condition is the ability to name it. In the current study, 94.3% (n=33) of the patients could name their diagnosis of Bipolar Disorder, with only 5.7% (n=2) patients not doing the same. It is important to consider that one may be able to accurately name a condition without understanding what it entails and without truly accepting it as personal condition. Within the frame of insight, denial was identified as one of the factors contributing to non-adherence in the current study. While some participants believed they were bewitched, not exclusively in a delusional state, but including periods of remission, they did not believe treating Bipolar was necessary. They then pursued their beliefs that dealing with bewitchment through traditional and spiritual approaches would resolve their psychiatric problems. Furthermore, it was noted that when patients were paranoid in the psychotic state, they tended to reject support from both family members and

HCP's, consequently they would also reject treatment, perpetuating the cycle of non-adherence.

To aid the process of developing good insight and adherence, patients need to be educated by HCPs on their illness to make informed decisions regarding their treatment. They also need to be well informed about side effects of medication and available alternatives or coping strategies (Nichita & Buckley, 2007). Participants of the current study voiced frustrations related to medication side effects such as weight gain, reduced creativity and decreased energy. Some expressed a desire to once again be the 'life of the party', as they used to be the centre of attraction at social gatherings. If not appropriately addressed, such frustrations and desires may lead to non-adherence. Since Bipolar I Disorder with psychotic features is a chronic disorder requiring prolonged administration of psychotropic drugs, it is important for treating HCPs to consider the patient's subjective attitudes towards the drugs and long-term adherence in appropriately selecting specific medication for individual patients (American Psychiatric Association, 2013; Sue et al., 2003). The findings of the current study indicated that the participants identified a gap in the fulfilment of the above recommendations, as some reported that they were never psycho-educated about the diagnosis and the medication. Factors related to existing challenges within the South African mental health context, such as limited financial and human resources, may be considered as possibly posing limitations in the application of recommendation as set by scientific literature (Burns, 2011; Marais & Petersen, 2015).

Research has found a significant correlation between medication compliance and substance abuse, especially in Bipolar Disorder. It showed that reduced substance abuse significantly increased the probability of remission and medication compliance. However, persistent substance abuse is strongly associated with non-compliance and reduced probability of remission (Janssen et al., 2006; Lawson & Bland, 2004). Similarly, in the current study, it was found that 60% of males relapsed in relation to substance abuse. Additionally, although not statistically significant, the importance of employment as a factor contributing to adherence was highlighted, as it came close with a p value of 0.055, with an odds ratio of 41.12. This suggested that the odds for respondents to be non-adherent were 41 times higher for those who were unemployed in comparison to those who were employed. Literature argues that including individuals with disability in economically significant activities such as employment positively contributes to their overall wellbeing (Hanafiah & Van Bortel, 2015; Kanwar, 2015).

Pertaining to the relationship between adherence and PP/PTSD, it surfaced that a majority of research participants had PTSD symptoms above threshold in both the adherent and the non-adherent group. The relationship between both patient Post-Psychosis Trauma and family Post-Psychosis Trauma with adherence was found to be non-significant, with p scores of 0.42 (2 sided) and 0.25 (1 sided), together with 0.41 (2 sided) and 0.28 (1 sided) respectively. It was concluded that both adherent and non-adherent patients and their family members may experience Post-Psychosis PTSD. Therefore, it is the argument of the current thesis that regardless of whether a patient is adherent or non-adherent, HCPs need to assess for and provide efficient interventions in addressing Post-Psychosis PTSD in patients diagnosed with Bipolar I Disorder with psychotic features and their family members.

Sajatovic, Bauer, Kilbourne, Vertrees, and William (2006), concluded that adherence to medication is a multi-dimensional entity, including patient characteristics and patient-provider interaction. This not only holds the patients responsible for their adherence, but places some of the responsibility on health care providers to present and encourage good alliance with patients to facilitate good adherence. In summary, the dominating factors identified as contributing to non-adherence in the current study included poor insight, lack of acceptance/denial, confusion, lack of psychoeducation, lack of a good support structure, lack of hope and altered cognitions.

6.6 Additional findings stemming from clinical and demographic characteristics

6.6.1 Cognitive and occupational functioning

A majority of patients participating in the current study (n = 24; 68.6%) had achieved a Grade 12 level of education. This achievement did not fall beneath the Grade 12 completion rate within the South African population (Stats SA, 2016), complementing conclusions by Castanho de Almeida Rocca et al. (2008) who found no significant differences between a group of euthymic patients diagnosed with Bipolar I Disorder comparison to a group of individuals from the general population, in terms of level of education, age, gender and intelligence. Among Bipolar patients, the mean level of education was 12.6 years of schooling (SD = 1.7), and the

level of education was 11.74 years of schooling (SD = 2) for the normal population (Castanho de Almeida Rocca et al., 2008). Suggesting that individuals who present with Bipolar Disorder symptoms and are diagnosed as such at different points in their lives may not necessarily be disadvantaged with regards the numbers of years of basic education they received. In fact, the 68.6% with completed high school education is slightly higher than the estimated national average of 55.1% (Stats SA, 2016).

Although the patients may be exposed to similar years of schooling, some may struggle during this period. A total of 17 (48.6%) participants in the current study reported a history of failing or repeating a grade in their schooling career. It appeared that although the age group 18-29 were likely to possess a grade 12 education, they struggled with obtaining qualifications thereafter. Most of the patients desired to further their education, with those who did not possess grade 12 wishing to pursue it, and those having it wishing to pursue other qualifications; however, 17% had no interest in studying towards any specific qualification.

Post grade 12, patients within the 18-29 age group reported significant challenges in obtaining qualifications despite attempts. Most participants had a history of pursuing different levels of studies and attempting to acquire different types of qualifications. While 51.4% engaged in further studies, 20 % had attempted but failed, and 28.6% had not engaged in studying further. Most of the patients had not managed to obtain any qualification, however, a few obtained certificates and diplomas, and only one (2.9%) patient obtained a degree. It was noted that the highest number of successful attempts in achieving a qualification was located between ages 29-39, while the most failed attempts were located between ages 18-29. This may be indicative of critical period during which patients may struggle to achieve their educational goals, however, it may also be indicative of hope for a period where they are likely to succeed.

While patients diagnosed with Bipolar I Disorder with psychotic features need medication to remain stable, certain types of medication have been found to adversely affect their cognitive functioning. Atypical antipsychotics such as olanzapine and risperidon have been associated with cognitive deficits in euthymic Bipolar Disorder patients. It is recommended that medication with lower risk of adverse cognitive effects be prescribed for Bipolar Disorder patients, with each choice influenced by its effectiveness, tolerability, and the patient's preference (Torrent et al., 2011; Janssen et al., 2006). Due to existing restrictions in the

availability of different types of medication within the South African public health care system, such recommendations may not necessarily be adhered to (Burns, 2011; Marais & Petersen, 2015).

Functional impairment may contribute to the difficulty patients reported in obtaining qualifications. As noted in literature, despite levels of education equivalent to the general population, vocational performance may be impacted by cognitive impairments in Bipolar I Disorder patients, leading to an inferior socioeconomic status (Prerost & Song, 2012). It is estimated that approximately 30% of Bipolar I Disorder patients on treatment face functional impairment between episodes, with persistent mood lability and other residual symptoms (American Psychiatric Association, 2000; American Psychiatric Association, 2013).

While some patients may be able to return to their previous level of functioning, others function reasonably well with minimum decline, and at a greater disadvantage are those who experience extensive disability and suffering (American Psychiatric Association, 2013). In the interviews, participants reported loss of control over their lives as manifested by the lack of achievement of certain age appropriate goals and the perceived loss of their potential to achieve in future, due to their psychiatric condition. The patients suffered significant loss of hopes and dreams which had a profound psychological impact on them.

Education related developmental challenges led to difficulty securing employment. A high number (n = 22; 62.9%) of the patients were unemployed and reported that they were struggling to cope with demands of daily living, including finding positive activities to engage in. In relation to gender, 15 (60%) of the females had no secondary qualifications, while 9 (36%) females obtained certificates in sewing, beauty, and other skill-based training. In comparison, 7 (70%) of the participating males did not achieve secondary qualifications. Literature indicates that in addition to high general socio-economic costs, patients with Bipolar Disorder suffer substantial personal costs, financial strain and occupational instability (Prerost & Song, 2012). Family members spoke of the difficulties of coping with financial strain, particularly when patients had made poor financial decisions during an episode. Patients further communicated feelings of guilt and remorse regarding those poor financial decisions and regarding being a financial burden on others. In summary, areas of functioning identified in literature and in the current study that were affected in individuals with Bipolar I Disorder with psychotic features

included their cognitive abilities, vegetative functions, interpersonal relationships, social and occupational functioning (Sadock & Sadock, 2003).

Considering that estimated global trends for Bipolar Disorders showed a 14.9% increase in total disability-adjusted life-years (DALYs) from 2005 to 2015 as noted in the Global Burden of Disease Study (2015), and that Bipolar Disorder was previously identified as the 7th leading global cause of years lost due to disability for males, and the 8th for females worldwide (WMH, 2008), it is understandable that the ability of a majority of participants to function as employed members of the society, contributing to the economy, was affected by the illness. When PTSD symptom severity occurring within Bipolar Disorder was considered regarding occupation distribution, the present study found that 80% of patients within the severe and extremely severe ranges of PTSD were the unemployed. The unemployed also formed 65% of those falling within subclinical-mild and moderately severe PTSD ranges. Interestingly, all participants engaging in student activities had PTSD symptoms below threshold. Eighty percent of the patients with PTSD symptoms falling within moderately severe and extremely severe ranges reported that they were not coping with the demands of life.

It is important to note that according to literature, the majority of individuals with Bipolar Disorder on treatment function well between episodes; however, it is estimated that 30% continue to experience mood lability and other residual symptoms which then adversely effects their functioning (American Psychiatric Association, 2013). While some patients are able to return to previous level of functioning, others function reasonably well with some decline, and others experience substantial disability and suffering (American Psychiatric Association, 2000). Different factors contribute to clinical outcomes. In the current study, the odds for non-adherence in unemployed participants were 41 times higher than those who were employed, however, the opposite could also be true, in that the odds for non-adherent patients to obtain employment may be lower.

Psychosis has been identified as a significant factor contributing to poorer clinical outcomes of Bipolar I Disorder patients, including less adequate intermorbid functioning, more relapses and greater illness chronicity (American Psychiatric Association, 2013). As such, psychosis was a compounding factor for participants of the current study. Additionally, mood-incongruent psychotic symptoms have been associated with poor prognosis in Bipolar I Disorder (Marneros,

Rottig, Rottig, Tscharntke & Brieger, 2009). The findings of the current study suggest that PTSD symptom severity and occupation may be further investigated as factors contributing to poorer occupational functioning for Bipolar I Disorder patients. The majority of the patients were unemployed and dependent on family members for financial support, with age groups 40-59 supporting unemployed patients. This suggested that the older family members had a greater burden of financial care in addition to other responsibilities.

Patients who were employed reported that a Bipolar Disorder diagnosis may have negative implications on their career development as competency within the work place appeared affected by the illness, particularly those whose cognitive functioning had been affected. Supported employment, which identifies and provides placement and support for individuals with disabilities into competitive vocational opportunities, has been recognized as an efficient recovery-orientated strategy in reducing hospitalisation, improving functioning and economic inclusion for individuals with Bipolar I Disorder with psychotic features amongst others (Hanafiah & Van Bortel, 2015; Kanwar, 2015; WHO, 2015). It has been suggested that such strategies should be contextualised to their social and cultural environment, using a multisectoral approach (education, housing, business, etc.), through formal and non-formal recovery-oriented interventions (WHO, 2015). Non-specialist health care providers may be trained to facilitate opportunities for the patients and their families/caregivers to be included in economic activities. Through research, evidence showing that vocational rehabilitation increases social and cognitive functioning has been found. Additionally, supported employment has been found to be more effective than pre-vocational training in helping severely mentally ill people to obtain competitive employment (WHO, 2015).

It is the suggestion of the current thesis that supported employment approaches may be beneficial within the population of the current study, as most patients communicated a desire to engage in educational and employment opportunities. They also expressed the desire to contribute to their personal and family member financial needs, and to pursue future development. Their prognosis may be improved through multisectoral active involvement in supported employment strategies.

6.6.2 Social functioning

Following active symptoms related to Bipolar I Disorder with psychotic features together with related experiences such as hospitalisation, diagnosis and treatment, participants of the current study reported markedly diminished interest and participation in significant social activities, together with feeling estranged from others within their social environment. Castanho de Almeida Rocca et al. (2008) found differences in the patients with Bipolar I Disorder in remission and individuals from the normal population when comparing their social skills. It was found that patients with Bipolar Disorder displayed inhibited and over-attentive/cautious behaviour in relation to other people and their environment, they also had lower social self-confidence and social openness scores (Castanho de Almeida Rocca et al., 2008). The findings of the current study support the supposition that such behaviour has a negative impact on the patients' level of social functioning and quality of life.

Castanho de Almeida Rocca et al. (2008) noted that although there was no difference between the two groups pertaining to their capacity to decipher rules and norms that regulate social situations, perceiving cause-and-effect relationships in social situations, and their ability to react to aversive stimuli with reasonable anger control and in a socially competent way, their low self-confidence and cautious behaviour significantly inhibited their social engagement. It was reported that these findings did not correlate with clinical variables such as duration of illness, number of hospitalisations, number of depressive and manic episodes or psychotic symptoms (Castanho de Almeida Rocca et al., 2008). Correlations disputing the lack of association with the above-mentioned clinical variables were absent in the current study. Instead, qualitative results confirmed the cautious and inhibited social engagement driven by low self-confidence.

Family members confirmed their role in limiting patient social participation, which manifested as a heavy weight of loss of independence on both the patient and their loved ones. Family members presented with a loss of trust and confidence in the patients' capabilities to interact independently within society, regressing to treating patients like younger children needing constant monitoring, guidance and protection. It was not clear whether the family members predominantly feared that the world was not a safe place for an individual with Bipolar Disorder with psychotic features, or if they feared that their loved one had lost the skills to be

safe in the world. It is probable that their fear stemmed from an interaction between the two possibilities.

Beyond experiencing restrictions from family members, the patients reported difficulty in initiating and maintaining interactions and relationships outside their homes. After changes in mood, energy levels and creativity, the patients reported struggles with redefining themselves and building up self-confidence. Prerost and Song (2012) stated that Bipolar patients struggled with self-doubt, concerns about work/academic performance, and with an inability to succeed in various settings. It seemed challenging for the participants of the current study to make sense of who they were in relation to others and what they were capable of achieving in comparison to others. They were predominantly estranged from social interaction as they presented with self-doubt. Even though some patients had achieved in certain areas of their lives including personal development, they were pessimistic about their future.

Estrangement has been identified as primarily present in the recovery phase of Bipolar, associated with feelings that other people did not understand or relate to the illness experience, hindering their ability to provide support. It was further indicated that diagnosed individuals found it difficult to communicate about their illness. These circumstances maintain the cycle of exclusion from fruitful social participation. Mental health care users have been reported to feel different due to the illness, treatment and/or symptoms, resulting in isolation and disconnection from those around them, such as pre-existing friends (Dunkley, Bates & Findlay, 2015). In closing, patients diagnosed with Bipolar I Disorder with psychotic features may struggle to express themselves and connect with those in their social environment, their family members may also struggle to find the balance between their supportive efforts and their controlling or overprotective behaviour.

6.6.3 Social support

Strong social support systems have been highlighted as essential in the wellbeing of patients diagnosed with Bipolar Disorder, including family members, friends, community members, colleagues, employers, etcetera (bin Jabal et al., 2018). The lack of a good support system has

a reputation of negatively affecting the cycling of Bipolar Disorder, yet approximately 25% of Bipolar Disorder patients face stressful life events within contexts of poor social support systems (Prerost & Song, 2012). When answering the items in the general questionnaire exploring their different sources of support in the current study, 30 (85.7%) of the patients stated that they had good family support, this is higher than literature findings, as 14.3% of the participants reported poor support. In addition to family support, 19 (54.3%) reported good support from friends, and 16 (45.7%) reported that they received good social support specifically from their churches.

Harrop, Ellett, Brand, and Lobban (2015) argue that poor friendships can potentially be a causal and/or maintenance factor for psychotic symptoms. They state that people who have a psychotic disorder typically lose their friends early on, and after this suffer reduced social networks for life. They continued to state that social networks, love relationships and social self-image play a major role in symptoms and prognosis (Harrop et al., 2015). Findings regarding intimate relationships in the current study showed that seventeen (48.6%) patients were single, while eighteen (51.4%) were in relationships. Intimate relationships did not stand out as an independently significant factor in the findings, however, it was incorporated under the social support umbrella, as some participants reported good support from their intimate partners.

Further research aimed at understanding the characteristics of friends that lend themselves towards remaining in contact when their friends that are diagnosed with psychotic illnesses, as well as the characteristics of those who do not remain in such friendships, has been recommended (Harrop et al., 2015). The development of a newer platform for the provision of and access to social support has surfaced as part of the digital era. Online support groups for mental illness present opportunities for the application of more cost-effective strategies (Menon, Isharma, Chandra & Thennarasu, 2014). However, more studies are needed in the development and application of this type of social support. None of the participants of the current study reported participation in or benefit from online support groups, however, some participants reported gaining useful information about Bipolar from online sources. In closure, existing literature was confirmed in that the presence of social support, not just for patients, but for family members as well, was raised as an important in dealing with Bipolar Disorder with psychotic features.

6.6.4 Parenting

It has been found that low self-confidence does not only affect individuals diagnosed with Bipolar in a social context, but within their family environments as well. In a study comparing Bipolar parents to non-Bipolar parents, it was found that parents with Bipolar had a significantly lower self-concept (Prerost & Song, 2012). Similarly, participants of the current study expressed feelings of frustration, anger and sadness linked to being unheard, disrespected, disregarded and overlooked by their children, who inappropriately discounted their competence due to mental illness.

Prerost and Song (2012) state that Bipolar parents perceived themselves as physically diminished, inadequate, alienated from their loved ones and unworthy. They questioned their value in the family role, and how they could be fully functional family members if they felt out of control with regards to their symptoms (Prerost & Song, 2012). A participant who had bad experiences from being a child of a mentally ill parent, expressed fear, self-doubt, shame and deep sadness regarding the possibility of becoming like her mother. The participant had decided to cut all ties with her mother as their relationship was too strained by the perceived inability to fulfil parental duties. Recognising that she was a mentally ill parent herself, she questioned if she would 'fail' like her mother. She felt out of control of her life and considered possible poor parenting outcomes due to her diagnosis.

It has been suggested that Bipolar parents may perceive themselves as 'bad' people. The low self-concept and negative beliefs possibly inhibit meaningful communication and may have contributed to the limited social support they could provide to their children (Prerost & Song, 2012). In the current study, parents diagnosed with Bipolar Disorder struggled to communicate their feelings and thoughts regarding their parenting roles. Although they felt a desire to be more assertive, they felt insufficiently validated by family members with poor insight into their mental condition. Further, participants who were not yet parents raised concerns about how the illness would affect their plans to become parents. They had information about the genetic factors in Bipolar Disorder which led to the importance of diagnosis disclosure to future

intimate partners. Lastly, the need to actively involve HCPs with regards to future reproduction was seriously considered accompanied by sadness in acknowledging possible implications.

Their concerns regarding reproduction were justified. Kenna, Jiang, and Rasgon (2009) conducted research investigating reproductive and metabolic abnormalities associated with Bipolar Disorder and its treatment. They found that women with Bipolar Disorder had high rates of reproductive and metabolic dysfunction. The medications commonly used in the treatment of Bipolar Disorder can have deleterious effects on reproductive functions, they are also associated with weight gain, insulin resistance, and other metabolic side effects that further compound the neuroendocrine system dysregulation (Kenna et al., 2009). In the current study, concerns were not limited to females, as males voiced concerns, indicating that research regarding reproductive implications for males with Bipolar Disorder may be useful.

6.6.5 History of abuse

A high number (n=16, 45.7%) of patients reported unstable childhood experience, such as being abandoned by parental figures, poverty and being abused. While 54.3% (n=19) reported fairly-good childhood experiences, including good education opportunities with available and supportive parents. Although some literature suggests a relationship between Bipolar Disorder and childhood maltreatment, including emotional abuse, sexual abuse, physical abuse and emotional/physical neglect, there has been a lack of sufficient evidence to confirm that individuals exposed to maltreatment would experience Bipolarity or that a majority of those with Bipolar had had such exposure (Read et al., 2005; Fisher & Hosang, 2010).

Although concerns about the accuracy of child abuse disclosure by psychiatric patients have been raised, it has been found that these reports are reliable and that psychiatric patients tend to under report as opposed to over reporting abuse. It has been concluded that other bio-psycho-social factors need to be considered in the aetiology of Bipolar, and that it may be helpful to explore these in conjunction with childhood maltreatment (Read et al., 2005; Fisher & Hosang, 2010). These conclusions are concurred with in the current study, as there was a lack of

evidence suggesting a significant association between Bipolarity and childhood maltreatment in isolation.

Mueser et al. (2004a) reported that in a sample of 782 people with SMI, there was a high prevalence of traumatic life experience, where 84% reported lifetime physical assault and 52% reported lifetime sexual assault. An overall number of 34.8% SMI patients met PTSD diagnostic criteria. Lu et al. (2013) stated that the traumatic event most frequently endorsed as a distressing event across gender, was childhood sexual abuse (22%), followed by the sudden death of a loved one/friend (20%). In the current study, only the females reported a history of sexual trauma (n=7, 28%), and no sodomy/sexual trauma was reported by males. Similarly, Kilcommons and Morrison (2005) found that women were more likely to have experienced sexual abuse as adults (4% in men, 57.1% in women) and sexual assault over their lifetime was 16% in men, and 57.1% in women. Other studies have shown that there is a strong relationship between child abuse and psychosis, whereby the presence of child abuse was related to symptom severity (Newman, Turnbull, Berman, Rodrigues & Serper, 2010). It is recommended that the impact of a history of abuse be carefully assessed when treating patients with Bipolar I Disorder with psychotic features.

Carlson et al., (2012) investigated factors predicting clinical outcomes for patients admitted with Bipolar I Disorder with psychotic features over a four-year period. They found that among other clinical variables, both childhood psychopathology and depressive phenomenology may be associated with worse outcome (Carlson et al., 2012). The following section considers depression, together with anxiety and stress in relation to the prognosis of the participants.

6.6.6 Depression, Anxiety, Stress and prognosis

The current study explored the presence and severity levels of depression, anxiety and stress in patients diagnosed with Bipolar I Disorder and their family members, finding varied severity levels amongst the participants. Patients and family members scored within the moderate range for depression, with patients scoring higher. Similarly, patients scored higher on anxiety,

falling within the severe range, while family member scores fell within the moderate range. Both patients and family members scored within the mild stress severity range.

In identifying factors associated with longer time to remission that may only be generalised to hospitalised patients with Bipolar Disorder with psychotic features, Bromet et al. (2005) found younger age of onset, history of childhood psychopathology, higher Brief Psychiatric Rating Scale (BPRS) depression or anxiety scores, i.e. severity of depression or anxiety symptoms at baseline, and use of medication during follow-up. Factors associated with shorter time to relapse included higher BPRS scores, higher Hamilton depression scores, admission episode not involving mania, depressive symptoms at re-admission, and childhood internalising type problems with symptoms of depression during childhood (Bromet et al., 2005). Although shorter time to relapse and longer time to remission in the current study were not measured in line with the above-named clinical factors, depression, anxiety and stress levels were measured at the time of data collection, the results of which indicated higher levels of depression and anxiety and lower levels of stress. Taking the findings by Bromet et al. (2005) into account, it may be expected that the presence of depression and anxiety symptoms, particularly severe anxiety scores for patients, in conjunction to other clinical variables, suggest substantial risk for shorter time to relapse and longer time to remission.

A higher number of patients in the current study presented with a longer time to remission, with (n = 13, 37.14%) who stayed for more than 30 days in hospital, while (n = 10, 28.57%) stayed for 15-30 days. Hospitalisation increases costs, as inpatient mental care health is more expensive than outpatient care. Additionally, increased risk factors for persistent psychosis, necessitating prolonged inpatient care for individuals experiencing psychosis are well documented (Gleeson et al., 2008). The participants of the current study had a history of being diagnosed with Bipolar I Disorder with psychotic features between 2010 to 2014, with a slightly higher percentage (n=11, 31.43%) diagnosed in 2014. Within the sample, n=34 (97.14%) patients had been hospitalised within a three-year period of the data collection, with a higher percentage (n=22, 62.86%) of participants hospitalised in 2014. This demonstrates the financial implications of providing inpatient care on the South African health care system.

Beyond presence if patients, depression, anxiety and stress are found in family members. Mackay and Pakenham (2011) conducted a longitudinal research into how carers of an adult

with mental illness adapt to caregiving, examining changes in carer adjustment over 12 months through comparing DASS-21 depression, anxiety, and stress scores. The carers completed questionnaires at Time 1 and 12 months later (Time 2). They found that 20% (n=17) carers reported ‘‘severe’’ or ‘‘extremely severe’’ depression at Times 1 and 2, and anxiety levels in these ranges for 15% (n=13) at Time 1 and 18% (n=16) at Time 2. A significant change was noted with regards to stress, with 24% (n=21) carers who reported ‘‘severe’’ or ‘‘extremely severe’’ stress at Time 1, and 15% (n=13) who reported these levels of stress at Time 2 (Mackay & Pakenham, 2011). Results showed that on average, the mental health carers reported significantly lower life satisfaction than the normative sample at both time points and that having a female carer was associated with higher distress (Mackay & Pakenham, 2011). In the current study, results obtained for family member age and severity of depression showed that the age group 50-70 had the highest severity as compared to the younger family members. The age group 30-39 had the most normal levels, while those aged 20-29 were experiencing significant symptoms of depression. This suggests that it may be useful for clinicians to assess and further investigate increased vulnerability for depression in younger and the older family members.

Janardhana et al., (2015) found a high number of the caregivers (40.8%) above the age of 51 years, and about one-fourth (23.9%) were below 35 years, indicating the prevalence of aged caregivers. In contrast, the current study indicated a higher number of middle-aged carers, with the age groups 20-29, 50-59 and 60-70 having n=6 (17.1%) each, while the age groups 30-39 and 40-49 had n=9 (25.7%) and n=8 (22.9%) respectively. Janardhana et al., (2015) also found that female caregivers were slightly more in number (52.7%) compared to male caregivers. They noted that there were 47.3 % of male caregivers. They explained the strength of the family relationships manifesting through female carers availing themselves when males needed caring, and males availing themselves when females needed caring (Janardhana et al., 2015). The same may be true in the current study as n=18 (51.4 %) were male carers and n=7 (48.6%) were female carers.

The female participants in the current study tended to score higher on severity scores in comparison to male participants. When considering all scores above normal ranges, a total of 82.4% (n=14) female family members had above normal anxiety scores as compared to 44.4% (n=8) male family members. Furthermore, nine (52.9%) of these females scored in the

extremely severe score range while none of the males were in that anxiety score range. Similarly, 70.6% (n=12) female family members scored above normal ranges for depression while the males in similar ranges were 44.4% (n=8). The above results suggest that female and older family members may be at greater risk for higher depression and anxiety severity.

The results of the current study indicated a significant relationship between sypmtoms of PTSD and Depression, Anxiety and Stress. Similarly, Bantjes, Kagee, McGowan, and Steel (2016) identified an important relationship in PTSD, Anxiety and Depression symptoms in a population of South African university students. This suggests that when clinicians identify symptoms of depression and anxiety in patients diagnosed with Bipolar I Disorder and in their family memebers, it may be useful to further explore, identify and tease out PTSD symptoms.

6.6.7 Family member emotional state

Family members with high levels of depression, anxiety, stress and negative affect are likely to foster family environments with high levels of expressed emotion. This would be an environment with a high number of critical comments, emotional overinvolvement, or one or more statements of hostility when describing interactions involving the patient. High EE has been shown to negatively affect patients with Bipolar Disorder (Morris et al., 2007; Onwureme et al., 2009).

It was noted that family members desired to portray themselves in a positive light when responding to the PANAS, thus their positive and negative affect scores were interpreted with caution. Their negative affect levels fell within normal and high ranges, with more towards the high range as compared their positive affect scores that fell more on the normal range. Above 50% (n=19) of family members had normal levels of positive and negative affect, none had low negative affect, but 17% (n=6) had low positive affect and 46% (n=16) had high negative affect. The results suggest that in addition to depression, anxiety and stress, some family members may struggle with negative affect.

Family member positive affect was significantly correlated to their depression and age. As family member age increased, so did their positive affect at 0.01 level of significance.

Additionally, as family member positive affect increased, depression levels decreased at 0.05 levels of significance. The Spearman correlation further indicated that as family member positive affect increased, avoidance decreased. Mackay and Pakenham (2011) found that higher social support was associated with higher positive affect and life satisfaction, better health and lower distress, while higher threat appraisals were associated to lower positive affect and lower life satisfaction in carers. Therefore, family members need support to empower them in successfully accomplishing their roles as carers. The current study revealed that in an attempt to avoid being perceived as 'weak', family members may avoid seeking professional assistance, they may seek to avoid the stigma of also being 'psychiatric patients,' although they may benefit from treatment options.

Historically, interventions in mental health have primarily focused on the patients, leaving their family members feeling marginalized, as their needs neither frequently recognized nor met (Askey, Holmshaw, Gamble & Gray, 2009). Families are an integral part of successful treatment plans; however, it has been recorded that they are often excluded (Corcoran et al., 2007). Similarly, some family members participating in the current study reported that they were excluded from treatment plans, this result in them feeling frustrated. Although literature notes the importance of including them, challenges with application persist.

Studies suggest that family members are mainly concerned about the care and services available for their ill loved ones, and they were found to have increased feelings of stress, burden and guilt when standard care was poor or when sufficient help was not provided when needed, expressing dissatisfaction with services provided in mental health care, and having limited expectations about the future (Corcoran et al., 2007). Another area of concern for family members was preparation for discharge, as most felt that their relatives were discharged prematurely and without sufficient planning (Askey et al., 2009). Similar concerns were indicated in the current study, where family members reported feeling helpless and guilty about their dependence on health care services that did not attend to their needs in a satisfactory manner. Another aspect evoking feelings of helplessness and guilt in family members was patient suicidal behaviour.

6.6.8 Suicidality

Considering that Bipolar I Disorder has been linked to an increased risk of death by suicide, with individuals with Bipolar Disorder estimated to be 15 times more at risk for suicide in comparison to the general population (American Psychiatric Association, 2000; American Psychiatric Association, 2013), instances where participants of the current study voiced concerns regarding suicide were noted. There were patients who reported having attempted suicide, whose reports were confirmed by their family members.

Family members expressed that they experienced the patients' suicide attempts as traumatic. This was exacerbated when suicide was attempted repeatedly. The participants reported that while some suicide attempts were linked to commanding voices/hallucinations and delusions, others were linked to depression. As stated in literature, a patient may feel hopeless, worthless, and see no reason to live during a depressive episode, thus attempting suicide (American Psychiatric Association, 2000). Tarrier et al., (2007) conducted a study on psychosis-related suicide, they found that patients who had attempted suicide due to their psychotic illness, gave reasons including depression, hopelessness, frustration and response to auditory hallucinations. Participants of the current study gave similar reasons for their suicide attempts.

According to Tarrier et al., (2007) a statistically non-significant but important association between PTSD and suicidality was that 58% of those who met PTSD criteria were suicidal. Results suggestive of an association between suicidality and PTSD were not indicated in the current study. Tarrier et al., (2007) found no significant associations between suicidal ideation and loss, change and disruption to life, reduction in hopes and aspirations, experience of physical harm or violence, the experience of stigma or social exclusion, symptoms of depression, DUP and duration of hospitalisation. However, a significant association between suicidal ideation and the experience of prior trauma was noted, although this was not related to the severity of the trauma (Tarrier et al., 2007). Further research into factors significantly related to suicide in patients with Bipolar I Disorder with psychotic features, taking trauma into account, is indicated for the South African context.

6.6.9 Dual diagnosis

Comorbid psychiatric conditions such as Bipolar Disorder and Substance Use Disorder are associated to a poorer prognosis (Miklowitz, 2012). In the current study, just above 45.7% (n=16) of the patients were exclusively diagnosed with Bipolar I Disorder with psychotic features, while the remaining 54.3% (n=19) had additional diagnoses. The most common dual diagnosis was substance abuse, followed by HIV, then followed by a combination of HIV and substance abuse. The age group 20-29 had the highest number of patients with substance abuse, HIV, and a combination of these two. In terms of gender, 15 (60%) of the females did not have a dual-diagnosis, while a majority (n=9, 90%) of the males had a dual-diagnosis of substance abuse. Additionally, sixty percent (n=6) of male participants relapsed in relation to substance abuse, in contrast, four percent (n=1) female participant relapsed in relation to the same.

The coexisting substance abuse within the population of the current study further compromised their prognosis. Although some participants confirmed that they had received psychoeducation from their HCPs on what life style changes they needed to adopt, particularly in relation to substance intake, they struggled to adhere to the HCPs' recommendations. Rather, they found reasons to justify their continued use of substances. Some reasons were linked to denial, as they struggled to accept the diagnosis and therefore struggled to stop doing certain things or engaging in activities that were said to exacerbate what they believed they may not have. It also surfaced that patients may be confused by factors linked to what led to the onset of their illness. They may look for causal factors as opposed to appropriately understand predisposing and precipitating factors. It was observed that it was difficult for them to develop insight when they struggled to fully grasp all the critical factors related to their diagnosis.

6.6.10 Insight

Crucial processes improving a patients' prognosis include firstly receiving the correct diagnosis, gaining knowledge of it and then accepting it. Russell and Browne (2005) found that many participants with Bipolar Disorder had initially received an incorrect diagnosis and the subsequent mistreatment with incorrect medication, which had serious implications for their

quality of life. In that study, depression and anxiety were among the most common misdiagnoses (Russell &Browne, 2005). It surfaced in the current study that some patients had also been initially incorrectly diagnosed. Following correction of the error, some of those patients found it easier to retain the previously accepted diagnosis of depression. Even after being diagnosed with Bipolar Disorder, they would deny it and state that they had depression. It should be noted that the overlap in symptoms within psychiatric conditions creates a complex picture, one which may be understandably difficulty for patients and family members to comprehend.

Literature suggests that some patients who initially received an incorrect diagnosis find the correct diagnosis of Bipolar Disorder a relief. However, for many patients, the diagnosis of Bipolar Disorder is shocking, and there may be a period of denial in which the diagnosis is not accepted (Russell &Browne, 2005). Similar emotional responses were communicated by some of the participants of the current study. While some patients reported an initial sense of relief following diagnosis, as their negative life experiences could be understood as actual illness and provide a sense of validation. Others reported receiving the diagnosis as shocking and significantly disturbing, as they associated it with uncontrollable "madness" that compromised their identity.

The participants stated that Bipolar and its symptoms were generally unknown prior to their personal diagnosis. Although many patients were able to name their diagnosis of Bipolar Disorder, they demonstrated poor insight on other factors regarding the condition. The patients generally struggled to demonstrate good insight, although a few displayed fair insight. Fair insight meant that the participants could name their diagnosis correctly, they could identify some of their symptoms accurately, and they knew that they had to take medical treatment. However, they could not accurately identify all their symptoms and they struggled to accept the chronic nature of the illness, together with the importance of lifelong adherence to a wholistic treatment approach.

Participants spoke of a strong desire to have normal lives, they believed the main way for them to achieve this would be getting cured. Apart from discovering a cure for Bipolar Disorder, some felt there was no further help that could be provided. For some the denial was so strong, they were convinced they would be cured by the treatment they were taking at the time,

contradictory to the chronic nature of Bipolar Disorder and its treatment. Russell and Browne (2005) discuss a variety of factors through which patients who have learnt about and developed good insight into Bipolar Disorder are able to recognize when they need to intervene with strategies to prevent episodes of illness. They identified the different mediums through which learning may take place, including books, health care professionals, mental health organizations, seminars, support groups, internet and talking with other people with the condition. What follows is a process of patients learning about their own individual responses and how best to recognize their individual trigger and warning signs, such as stress, sleep deprivation, fatigue, jet lag, hormonal fluctuations, change of seasons, all night partying and recreational drugs (Russell & Browne, 2005).

In the current study it surfaced that 48.6% (n=17) of patients had no insight about their illness, while 51.4 % (n=18) demonstrated fair insight levels. No insight was rated as 0, fair insight as 1, and good insight as 2. The mean for insight was found to be 0.51 with a standard deviation of 0.51, placing the participants between poor and fair insight levels. This resulted in an inability to pick up results what would be comparable to studies where participants with good insight were present, affecting results that may have significantly contributed to understanding adherence and other insight related components for the current study. Six of the seven interviewed family members knew that the patients were diagnosed with a form of psychiatric illness. However, only three of them could correctly name the Bipolar Disorder diagnosis. There was marked inconsistency regarding family members' understanding of Bipolar Disorder. While some reported that they had never been psycho-educated by the treating health care professionals, others stated that they got information on Bipolar Disorder from the internet (google), while one had no information at all.

What some family members raised as further problematic, was frustration with the lack of opportunities for them to discuss some of their questions with health care professionals. It appeared that some participants were not properly psycho-educated about Bipolar Disorder. Although doctors and other health care professional may attempt to psycho-educate the patients and family members, some may continue to struggle with gaining understanding or improving insight. Shaw et al., (2002) investigated the role of insight with the hypothesis that more 'insightful' individuals seemed less protected by denial from the reality of their illness. They found that insight was not associated with the PP/PTSD group and concluded that the negative

findings might, amongst other factors, reflect the complexity of the concept of insight. On their clinical impressions, they reported that some participants could not tolerate too much insight into their illness. Their findings confirmed this as there was an indication that positive insight, whereby the participants' awareness of personal change due to illness, was associated with more distress, intrusions and more avoidant behaviour (Shaw et al., 2002). Although insight in relation to PP/PTSD could not be directly measured in the current study, distress and PP/PTSD symptoms related to the participants awareness of implications of the Bipolar I Disorder with psychotic features was noted.

It surfaced from the current study that processes that HCPs undergo to reach a specific psychiatric diagnosis may contribute to how well patients and family members understand and accept the diagnosis. It is important to acknowledge that HCPs may not know from the initial presentation of the patient what the final psychiatric diagnosis will be, as investigations, collateral and observation form part of the process they must follow to reach a diagnosis. The strong emotions aroused within patients and family members throughout the diagnosis and treatment processes may further influence the extent to which insight is gained. Through psychoeducation from treating professionals and other information sources, some of the patients and their family members were able to gain some insight into the illness. As they grew in understanding what having such a diagnosis meant, they appeared to vacillate between denial and acceptance of the diagnosis.

Most people have a mixture of little and wrong information about mental illnesses, alongside wary and cautious attitudes about mentally ill people. Therefore, they are often slow to recognize developing mental health problems in themselves, in family members or in friends, and are reluctant to seek help for fear of the consequences (Thornicroft, Rose & Kassam, 2007). This fear may be linked to stigma.

6.6.11 Stigma

The lack of a sense of belonging stemming from stigma was one of the concerns raised by the participants. Burns (2011) argues that the South African government has failed to carry out

their obligations and responsibilities as signatories of the (CRPD), stating that the rights of individuals with disabilities are regularly violated, and that they remain stigmatized and isolated. This was confirmed by the participants of the current study.

Some participants of the current study reported indirect stigmatization, whereby their peers would make negative comments about mental illness, or make fun of people with mental illness, without directly mocking them. While some patients had disclosed their condition, most had not disclosed to avoid direct stigmatization. In addition to concerns about possibly being directly mocked, some participants raised concerns regarding how stigma could potentially influence their possibilities of obtaining future employment. While on one hand, some patients struggled with decreased functioning directly affecting certain employment functions, others worried that they may be discriminated in future because of their diagnosis.

According to WHO (2015), when societies value recovery-oriented psychosocial interventions for individuals with mental illness and their family members/caregivers, social inclusion is improved, while disability and human rights violations are reduced. Rummel-Kluge et al., (2008) argue that issues of stigma may contribute negatively to adherence, as their findings indicated that 68% patients feel embarrassed about having to take the prescribed medication on a daily basis. They added that stigma may contribute in the perpetuation of trauma symptoms (Rummel-Kluge et al., 2008). This suggests that stigma may affect several components of patients' wellbeing, of which, the participants of the current study confirmed. This strengthens the argument that community-based interventions, aimed at reducing stigma, involving all relevant stakeholders, are a pivotal part in addressing patient wholistic wellbeing.

6.6.12 Treatment

Although research has shown that treatment of Bipolar I Disorder is most effective when pharmacotherapy is combined with psychosocial interventions such as supportive therapy, psychoeducation, cognitive behavioural therapy (CBT), group therapy, family therapy and even social media/network or other technological advances (Garety, Fowler, Freeman, Bebbington, & Dunn, 2008; Chisholm, 2005; Cornutiu, 2013; Saunder & Geddes, 2016; bin Jabal et al., 2018), the availability and application of such evidence-based treatment approaches is absent in other contexts. For the current study, pharmacotherapy, psychoeducation and

individual psychotherapy were used in combination for some participants, however, it was not routinely applied practice for all participants. CBT, group therapy, family therapy and the use of technology were absent as treatment modalities in this context.

All patients in the current study were on psychiatric medication and stable at the time of data collection, however, there were substantial discrepancies in the complementary treatment approaches they received. A total of 60% (n=21) of patients had a history of receiving psychological intervention in the form of individual supportive psychotherapy, with the remaining 40% having had none. Within the 60%, only 17.1% (n=6) were in therapy during the research data collection phase, while others had previous brief in-patient or out-patient therapy. In addition to psychosocial interventions empowering the patient, they are aimed at empowering his/her support structure in understanding the illness and its management, improving patient-family relationships, and harmonising the patient's primary group (Cornutiu, 2013; Saunder & Geddes, 2016; bin Jabal et al., 2018). While some families benefit from full structured family interventions, others require brief needs-led caregiver-focused interventions (Cohen et al., 2008; Roddy, Onwumere & Kuipers, 2015). It has been shown that treatment manuals drawing on the CBT approach are effective in reducing relapse rates, reducing the impact of negative caregiving and reducing high levels of expressed emotions (Onwureme et al., 2009). However, a stark lack such interventions was noted by the patients and their family members participating in the current study.

Areas that may be addressed through CBT include changes in self and other perception, cognitive biases, individual sensitivity in interpretation of future life experiences, and other cognitive factors increasing psychological vulnerability (Tarrier et al., 2007). Both patients and family members in the current study presented evidence of such cognitive biases, and their psychological vulnerability was pulpable. This suggests that they may benefit from such interventions. Literature shows that caregivers of people with psychotic illnesses can experience significant distress as part of their role. Additionally, online resources such as mental health websites have been identified as helpfulness sources information about psychosis and coping strategies (Roddy, Onwumere & Kuipers, 2015). Family members of the current study concurred with this finding, expressing appreciation for access to online mental health resources. It is the argument of the current thesis that more interventions including caregivers within the South African mental health context are needed. It is acknowledged that in contexts

with limited resources, meeting caregiver needs is not easily identified as being the primary responsibility of clinical services. However, over time, successful inclusion of family members would possibly reduce the burden on the health care system.

Careful consideration is needed in advancing economically feasible interventions. The cost of evidence-based interventions compared with the cost of hospitalisation and prolonged in-patient care need to be clearly articulated (Miklowitz, George, et al., 2003; Rea et al., 2003; Morris, Miklowitz & Waxmonsky, 2007). The 'Stay Well Plan', may be cost effective with health-care professionals only facilitating a programme where the patients lead as experts in their own lives, actively involving their family members and friends and taking into account individual circumstances that are suitable to the participants' social, economic and cultural contexts (Russell, 2008; Harrop et al., 2015). This approach could include the use of technologies to monitor mood and other related variables such as activity levels and sleep patterns. The integration of self-monitoring with clinical care has the potential of enhancing joint clinical decision-making and earlier identification of and intervention for relapse (Saunder & Geddes, 2016; Russell &Browne, 2005).

Participants in the current study expressed a strong desire to improve personal control over their lives, identifying the lack of control as an area of great concern. Treatment approaches such as the stay well plan allow the patient to regain their sense of control. Although none of the participants identified a technological tool that they were using for self-monitoring, the usefulness of such strategies can be further investigated, given increased access to smart phones and applications that may be downloaded. It is said that taking control leads to patients becoming less anxious/fearful of the illness. Further, staying well involves participants being mindful of their illness, being aware of themselves and how they are responding to their physical, mental, emotional, social and physical environment, together with being able to observe minor changes in these areas (Russell & Browne, 2005). Being mindful of and implementing staying well differs from preoccupation with the negative cognitions, thus it may be particularly beneficial for patients. In addition to medication, psychosocial interventions are highly recommended to equip patients with psychotic disorders with effective skills that improve their subjective quality of life and independent functioning (Tsang, Fung, & Corrigan, 2006).

Apart from interventions offered by HCPs, alternative treatment approaches were explored by some participants in line with their belief systems. As noted in literature, not all individuals who experience the first episode of psychosis are immediately brought to mental health care facilities. In the South African context, it has been found that some patients first consult traditional healers before turning to formal psychiatric institutions for treatment (Burns, 2011). Results of the current study indicated that some participants had sought help from traditional healers and spiritual leaders in churches. However, a majority of those interviewed expressed preference for western medical treatment as opposed to alternative approaches such as traditional healers. They stated that they relied on the scientific proof and trusted the medical approach, rejecting treatment without 'scientific evidence'. Those who used spiritual approaches reported that their faith in God was combined with a belief in the efficacy of medical psychiatric treatment. They found non-judgemental prayers and support from their churches beneficial. It is the argument of the current thesis that treatment approaches may be most efficient if tailor made for the individuals involved, taking into careful consideration their unique circumstances, attitudes and beliefs.

6.7 Limitations of the study

The following hampering methodological factors have been considered as limitations:

Firstly, there were limitations with regards to the sample. Similar to other studies with a small sample sizes, limits to the generalisability of the quantitative findings is acknowledged. The small sample size restricted the application of more generalisable statistical procedures as well as the interpretation of the quantitative results obtained. Furthermore, the participants comprised of individuals accessing CHBAH health care facilities in Gauteng. This further compounded on the limited generalisability, as the participants' perceptions within the context of their socio-economic, cultural and educational backgrounds among other factors, were considered.

There is a likelihood that the sample did not include a complete representation of both adherent and non-adherent individuals. Particularly those individuals who were more likely to fail to

meet the research inclusion criteria as a result of their instability/poor health linked to treatment non-adherence. It is also possible that non-adherent individuals were likely to refuse participation in the study.

Therefore, several potential sources of bias in sample selection may affect the generalisability of the study results, including the use of patient files and information from treating Health Care Professionals in the process of identifying potential participants. It is unknown which of the excluded participants were more or less likely to be non-adherent or present with PTSD and the associated factors. It may be speculated that the recently hospitalised participants, and those receiving continuous treatment from a tertiary hospital setting, may have been more likely to fulfil non-adherence criteria as compared to those receiving treatment from their local clinics.

Secondly, the researchers' subjectivity was considered as a limitation that may have influenced the data, its analysis and interpretation. As previously outlined, through applying the interpretive research approach, the researcher was mindful of possible bias, and directed effort in accommodating the subjective nature of the responses, giving priority to the discovery and understanding of the participants' experiences (Fossey et al., 2002). Furthermore, the researcher was open and receptive to feedback from her supervisor and colleagues which assisted in communicating the findings as accurately as possible, fully employing inside-outside legitimation as recommended by Onwuegbuzie and Johnson (2006).

The third important limitation considered was the use of predetermined assessment tools and its shortfalls. Multiple assessment tools were primarily administered in English. This may have affected the responses of those participants who did not use English as a first language or had varied competencies in English. However, participants could request clarity on some questions in isiZulu, which enable them to better understand and answer questions more appropriately.

The assessment tools were administered only once on each participant. It is important to acknowledge that assessment results may vary over time or on different occasions within the same individual, such variance was not accounted for in the current study. Moreover, a self-report measure of PTSD was employed. This tool is limited by the subjective as opposed to a more objective report on the participants' perception of experienced symptoms.

Notwithstanding that psychiatry and psychology takes interest on the patients' report of experienced symptoms.

The DAI, which was employed to explore the participants' attitudes towards their treatment together with their perceptions and experiences, was found to be inaccurate in the results that surfaced. Participants knew how to respond to give the impression of adherence to treatment, even when they were non-adherent. This highlighted the disadvantage of subjective information sourced from participants, pointing to a need for re-evaluating the reliability and validity of the DAI on the identified population, as well as a need to employ more reliable tools for future research. To address research questions targeting adherence, classification through clinical indicators sourced from clinical records, the general information questionnaire, and collateral information from treating health care professionals and family members was employed. However, weak statistical power remained a hinderance.

Lastly, other factors that may have influenced research findings and may need further probing include the impact of comorbidity with other psychiatric or other medical conditions and the impact of the lack of differentiation between non-adherent and partially adherent, as well as in mood congruent and mood incongruent psychotic features. Likewise, the extent to which other practical problems, such as access to adequate medication at the pharmacy, may have influenced patients who were not well enough to participate, is unknown.

Although the current study has the above-mentioned limitations, useful information has been generated, together with considerable agreement in findings when comparing to other studies within the current subject matter. The use of mixed-methods was a relative strength of the study in that the researcher had the opportunity to choose a suitable combination of methods and procedures that yielded fruitful information in answering her research questions. Through fitting together insights provided by both qualitative and quantitative research, the two paradigms contributed in advancing knowledge in the subject of the current study.

7. CHAPTER SEVEN: CONCLUSIONS AND RECOMMENDATIONS

7.1 Conclusions

In commencing the study into Post-Psychosis Trauma in adherent and non-adherent patients diagnosed with Bipolar I Disorder with psychotic features and their family members, a major gap identified through an extensive review of literature was that within previous research, the two broad areas, i.e., Post-Psychosis Trauma and adherence were largely investigated in isolation. Additionally, there were limited studies investigating Post-Psychosis trauma in individuals diagnosed with Bipolar I Disorder and their family members.

Literature indicates that studies that have looked into non-adherence and Bipolar I Disorder have identified identifying variables such as demographic characteristics (e.g., gender, age, socio-economic status, education, stigma and accessible support structures), clinical characteristics (e.g., insight, dual diagnosis, childhood psychopathology, psychotic symptoms at baseline, and depressive phenomenology) and treatment (e.g., medication and its side effects, combining psychosocial and pharmacological interventions), as critical variables in understanding adherence behavior within this population (Carlson et al., 2012; Bromet et al., 2005; Fisher & Hosang, 2010; Castanho de Almeida Rocca et al., 2008).

In the area of Post-Psychosis Trauma, studies have identified that psychosis may be experienced as traumatic and followed by PPT symptoms, and that the psychological threat may manifest as threat to self-worth, shame, guilt, abandonment or helplessness (Gliko, 2004; Steel et al., 2005; Tarrier et al., 2007). These studies rarely assessed specific relationships between PPT and adherence and they did not clearly identify which of the ‘high risk’ groups would present with Post-Psychosis Trauma symptoms.

This sparked an interest to firstly investigate the presence or absence of PPT in the selected population from CHBAH, and to compare PPT occurrence in the adherent and the non-adherent groups. It was not surprising that a higher number of patients presented with PPT symptoms meeting criteria for Post-Psychosis PTSD as opposed to those who did not, which was similar to information in existing literature (Jeffries, 1977; Lundy, 1992; Gliko, 2004; Steel et al.,

2005; Tarrier et al., 2007). It was however interesting to note that PPT was present within family members as well, and that regardless of their adherence or non-adherence status, both patients and their family members were found to experience PPT. Additionally, it was found that avoidance of possibly re-experiencing the trauma of psychosis became a driving force towards adherence for some participants.

Certain family members and patients confirmed that they experienced PTSD symptoms in relation to exposure to a psychotic episode and diagnosis with a psychiatric disorder for a duration of more than one month, presenting with clinically significant distress/impairment. The family members denied physiological effects of substances or other medical conditions. However, exclusion of substances and other psychiatric and medical conditions was more difficult with patients having dual diagnosis. This study and other research specifically investigating psychosis-related and hospital-related PTSD suggests that therapy protocols for PTSD with people with a diagnosis of psychosis, should recognize the traumatic nature of symptoms and treatment (Berry et al., 2015)

Despite the high prevalence PPT, under-detection/diagnosis within the identified population persists (Kilcommons & Morrison, 2005). Participants of the current study reported negative alterations in cognitions and mood associated with the psychotic episode and diagnosis. Persistent negative emotional states including fear, anger, guilt and shame in relation to the psychotic episode experience and the diagnosis played a major role in how the patients perceived themselves and how they were perceived by those around them.

The participants discussed some persistent and exaggerated negative beliefs or expectations of themselves and/or other people. They struggled with a persistent inability to experience positive emotions. They further presented with distorted cognitions about the causes of the onset and consequence of the illness, mainly manifesting in either self-blame or other-blame. This suggest that interventions need to target a variety of areas to achieve wholistic restoration of optimum psycho-social functioning.

Systematic reviews have concluded that combining medication with psychological interventions, specifically CBT and family intervention improves clinical outcome (Garety et al., 2008). However, studies have demonstrated that many mental health care users default both

forms of treatment. It has been suggested that ways of improving compliance and reducing readmission rates include telephone interventions, ensuring adequate social support, home-based adaptation training, rationalising drug regimen, psychosocial interventions, and improving insight (Rummel-Kluge et al., 2008).

It became apparent that within the current sample, most participants lacked good insight into Bipolar I Disorder with psychotic features, which increased the risk of non-adherence. This indicated a particular need for psychoeducation for this group of individuals. However, it could also reflect the impact of the lack of resources in South African mental health care services. In summary, this study suggests that more work and resources need to be directed towards improving mental health care services in SA.

7.2 Recommendations

Having considered the limitations of the current study, improved methodology would be imperative in future research, especially when measuring symptoms of PTSD. It recommended that future research considers a larger sample with a wider variety of population groups. Given the significance of factors such as race, religion, gender and class with the South African context, it is recommended that future research explores the significance of these contextual factors, using sample accessed from other provinces within South Africa, accommodating both the public and private sectors, tertiary and primary health care institutions, as well as urban and rural areas, such that interventions are tailored made with particular focus on relevant issues.

The recommended large sample size will enable the use increase of generalisable statistical procedures, as well as outline generalisable quantitative findings. It would be beneficial for this effort to be aimed at determining the core PP/PTSD predictive factor. Access to generalisable information in this area is more likely to increase the drive towards improving and employing relevant treatment strategies

Given that assessment tools applied in the South African context need to be updated and normed for the population, and that assessment tools available in the official languages would be useful. It is recommended that more studies aimed at developing and validating tools

specific for our context be conducted. It is believed that this will improve the probability of employing more reliable tools for future research, strengthening statistical power in findings.

This study adds to the growing body of research highlighting the distressing nature of psychosis, the likelihood of PPT and implications for the urgent development and implementation of appropriate treatment strategies. This later factor indicates that mental health practitioners need to specifically and routinely assess patients and their family members with a particular interest in reactions to experiences of psychosis and hospital treatment. Similar to recommendations from other studies, it is the argument of this thesis that HCPs need to be empowered such that they can screen for PP/PTSD and employ effective evidence-based treatment strategies (Mueser & Rosenberg, 2008). In addition to empowering HCPs, it is recommended that patients and their family members are educated on PP/PTSD in BMD I with psychotic features, as well as the role of stigma and internalised stigma in perpetuating negative outcomes, this improved awareness may assist improving the efficacy of psychosocial interventions

In conclusion, it is the argument of the current thesis that there are serious implications for clinical intervention arising from this study. Therefore, future research focusing on the application of evidence-based treatment strategies, together with monitoring and appropriate adaptation to attain treatment efficacy within the South African context would be greatly beneficial.

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9. APPENDICES

9.1 Appendix 1a: Participant Information Sheet

Research title: Post-Psychosis Trauma and non-adherence in Bipolar I Disorder with psychotic features: Patients and their families in Gauteng. (Chris Hani Baragwanath Academic Hospital)

Hello

My name is Bongiwe, and I am conducting research for the purposes of obtaining a Doctor of Philosophy degree at the University of the Witwatersrand. My study aims to explore trauma linked to psychosis (loss of touch with reality) and non-adherence (not taking treatment as advised) in patients diagnosed with Bipolar Disorder, who also experienced psychosis and in their family members. This research will help us to understand some of the challenges patients and their families face. I would like to invite you to participate in this study.

Participants should meet the requirements in the table below

Age	Gender	Psychiatric Diagnosis	Participants
18 - 60	Male/Female	Bipolar I Disorder with psychotic features	1 patient and 1 family member who stays with the patient.

Participation in the study will entail filling in some questionnaires which may take you about 1 hour to complete and being interviewed for approximately one hour. Appropriate breaks will be taken during this process. With your permission, I would also like to record the interviews. The tapes and transcripts will not be seen or heard by other people at any time, and will only be processed by myself, and my supervisor.

Participation is voluntary; therefore, no individual may be forced to participate. Also, no person will be advantaged or disadvantaged for choosing to participate or not to participate in the study. All the responses will be kept confidential, and no information that could identify the subjects will be included in the research report. Should you require assistance with transport money, you will be given taxi fare not above R50 that will be calculated according to your

residential area. You may refuse to answer questions you would prefer not to, and you may also choose to withdraw from the study at any point with no consequences to you.

If you choose to participate in the study please fill in your details on the form below, you will be contacted in due course. For further information please contact me on 011 933-9077 or via email: vales777@yahoo.com

You may also report complaints or problems to the research ethics committee administrator on 011 717-1234 and the HREC (Medical) Chair on 011 717-2301. If you need counselling, you may contact Gugulethu Makome, a clinical psychologist in the department of psychiatry, on 011 933-8494.

Kind Regards;

Bongiwe Mahlobo

9.2 Appendix 1b: Consent Form (Participation)

I _____ hereby consent to participating in the study conducted by Bongiwe Mahlobo on trauma after psychosis and non-adherence in patients diagnosed with Bipolar I Disorder with psychotic features and their family members.

I understand that:

1. Participation is voluntary
2. I may refuse to answer any question I would prefer not to
3. I may withdraw from the study at any time
4. No information that may identify me will be included in the research report
5. The collected information will be processed by the researcher, research assistant, and her supervisor

Signed _____

Date _____

9.3 Appendix 1c: Consent Form (Recording)

I _____ hereby consent to the recording of my interview in the study conducted by Bongiwe Mahlobo on trauma after psychosis and non-adherence in patients diagnosed with Bipolar I Disorder with psychotic features and their family members.

I understand that:

6. Participation is voluntary
7. I may refuse to answer any question I would prefer not to
8. I may withdraw from the study at any time
9. No information that may identify me will be included in the research report
10. The recordings and transcripts will be processed by the researcher, research assistant, and her supervisor
11. All recordings will be destroyed after the research process is complete

Signed _____

Date _____

9.4 Appendix 2: Modified Mini Mental State Examination (3MS) (patients only)

S's ID# _____ Nam e: Mr/Mrs/Ms _____ Examiner: _____

Normal__ or DX_____ AGE ___ EDU ___ M F 3MS _____ MMSE ____
yrs. yrs. 100 30

Test date: ____/___/___ Location: _____ (Start: ____: ____) Test Time: ____ SESSION #: ___
yy mm dd hh mm min.

3MS MMSE

5 PLACE & DATE OF BIRTH:
Place: Town _____, State _____
Time: Year _____, Mo. _____, Date _____

3 3 REGISTRATION # ___: (No. Presentations ___)
#1: Shirt ___, Brown ___, Honesty ___
#2: Shoes ___, Black ___, Modesty ___
#3: Socks ___, Blue ___, Charity ___

7 5 MENTAL REVERSAL (Coach fwd. once if needed)
5 to 1 (Can ___ Can't ___ count 1-5)
Accurate 2
1 or 2 errors/misses 1
3 or more errors/misses 0

DLROW (Can ___ Can't ___ spell WORLD)
0 1 2 3 4 5

9 3 FIRST RECALL
Spontaneous recall 3
After "Something to wear" 2
After "SHOES, SHIRT, SOCKS" 1
Still does not know 0

Spontaneous recall 3
After "A color" 2
After "BLUE, BLACK, BROWN" 1
Still does not know 0

Spontaneous recall 3
After "A good personal quality" 2
After "HONESTY, CHARITY, MODESTY" 1
Still does not know 0

15 5 TEMPORAL ORIENTATION
Year Accurate 5
Missed by 1 yr. 4
Missed by 2 - 5 yrs. 2
Missed by > 5 yrs. 0
Month
Accurate or within 5 days 2
Missed by 6 days to 1 mo. 1
Missed by > 1 mo. 0
Date (of the month)
Accurate 3
Missed 1-2 days 2
Missed 3-5 days 1
Missed > 5 days 0
Day (of the week)
Accurate 1
Inaccurate 0
Season (changes ~ 20th of M J S D)
Accurate (within 30 days) 1
Inaccurate 0

5 5 SPATIAL ORIENTATION
State 0 1
County 0 1
City/Town 0 1
Store/Hospital(Clinic)/Home? 0 1

5 2 NAMING (MMSE: Pencil ___, Watch ___)
Forehead ___, Chin ___, Shoulder ___
Elbow ___, Knuckle ___

10 FOUR-LEGGED ANIMALS (30 sec.)

16 SIMILARITIES (Coach with Orange-Banana)
Arm-Leg (Teach if score <2)
Body parts; limbs; extremities 2
Other correct answer 1
Incorrect; tells difference; DK 0
Laughing-Crying
Feelings; emotions 2
Other correct answer 1
Incorrect; tells difference; DK 0
Eating-Sleeping
Essential for life 2
Other correct answer 1
Incorrect; tells difference; DK 0

5 1 REPETITION
"HE WOULD LIKE TO GO HOME." 2
1 or 2 missed/wrong words 1
>= 3 missed/wrong words 0

"NO IFS ___ ANDS ___ OR BUTS ___"

3 1 READ AND OBEY "CLOSE YOUR EYES"
Obeys without prompting 3
Obeys after prompting 2
Reads only 1
Neither reads nor obeys 0

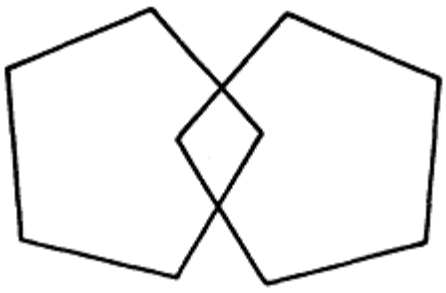
5 1 WRITING (1 minute)
(HE) WOULD LIKE TO GO HOME

10 1 COPYING 2 PENTAGONS (1 minute)
Each Ptgn.:
5 approx. equal sides 4 4
5 but unequal (>2:1) sides 3 3
Other enclosed figure 2 2
2 or more lines 1 1
less than 2 lines 0 0
Intersection:
4 corners 2
Not 4-cornered enclosure 1
No intersection 0

3 3 THREE-STAGE COMMAND (Finish cmds first)
___ TAKE THIS PAPER WITH YOUR L/R HAND
___ FOLD IT IN HALF, AND
___ HAND IT BACK TO ME

9 SECOND RECALL
(SHOES, SHIRT, SOCKS) 0 1 2 3
(BLUE, BLACK, BROWN) 0 1 2 3
(HONESTY, CHARITY, MODESTY) 0 1 2 3

CLOSE YOUR EYES



9.5 Appendix 3: The General Information Questionnaire (patients only)

CONFIDENTIAL

The answers you give to the following questions will be treated strictly confidentially. Please try and answer all questions. If, however, you do not know the answer to any question, you may write 'I do not know'. If you have difficulties answering other questions, you are at liberty to leave them out and proceed to the next one.

1. Date: _____
2. Gender: _____
3. Age: _____
4. Education:

a) What was the last grade you passed at school? _____

b) Did you fail or repeat any grades at school? Yes / No_____

If yes, which ones? _____

c) Did you study further after grade 12? Yes / No

If no, why? _____

_____

d) Please state your college or university qualification _____

5. Are you still studying at present? Yes / No

If yes,

a) Where _____

b) How much further do you intend to study? _____ Years

c) What do you see as your future occupation? _____

6. What is your present occupation? _____
7. Are you happy in your work? Yes / No_____
8. Do you think your illness has affected your performance at work?

Yes /No_____

If yes, how? _____

_____

9. What is your residential area? _____

10. Are you married or in a committed relationship? Yes / No_____

If yes, for how long? _____

11. Do you any children? Yes/ No _____

If yes, how many and how old are they? _____

12. Do you feel you were happy as a child? Yes / No _____

Give reasons _____

_____

13. Did you experience trauma or abuse in your childhood? Yes / No_____

If yes, Please specify (e.g., age, duration...)

_____

_____

_____

14. Did you experience any difficulties during adolescence? Yes / No _____

If yes, please specify _____

_____

15. Have you ever been involved in a serious accident? Yes/No _____

If yes:

a) When was this? _____

b) What kind of accident was it? _____

16. Have you lost people who were very close to you? Yes / No _____

If yes, please specify _____

_____

17. Have you consulted a psychologist for therapy? Yes/No _____

If yes, for how long? _____

18. Do you have a supportive close friend? _____

19. Who are you close and open to within your family? _____

20. Do you have another source of social support? Yes/No _____

If yes, please specify e.g. church, society, etc. _____

_____

21. How do you spend your free time? _____

_____

22. When did you receive the psychiatric illness diagnosis? _____

23. What is the name of that psychiatric illness?_____

If it is more than one, please name the other _____

24. Have you been admitted in a psychiatric ward? Yes/No_____

If yes, how many times? _____

25. When were you last hospitalised in a psychiatric ward?_____

26. How long did you stay in the ward? _____

27. What contributed to your latest relapse, please select/tick one of the following options?

Family problems ☐ Death of a family member or friend ☐

Stopped taking medication ☐ Work related stress ☐

Other (please specify): _____

_____

28. Have you had periods were you stop taking your psychiatric treatment?

Yes/No _____

If yes, can you explain what factors contribute to this? _____

_____

_____

_____

9.6 Appendix 4: Drug Attitude Inventory - 30 (DAI-30) (patients only)

The DAI consists of a questionnaire that is completed by the patient. It includes a series of questions, each with true/false answers, pertaining to various aspects of the patient's perceptions and experiences of treatment.

Name: _____

Date: _____

Question Answer*

1 I don't need to take medication once I feel better T / **F**

2 For me, the good things about medication outweigh the bad **T** / F

3 I feel strange, "doped up", on medication T / **F**

4 Even when I am not in hospital I need medication regularly **T** / F

5 If I take medication, it's only because of pressure from other people T / **F**

6 I am more aware of what I am doing, of what is going on around me, when I am on medication **T** / F

7 Taking medications will do me no harm **T** / F

8 I take medications of my own free choice **T** / F

9 Medications make me feel more relaxed **T** / F

10 I am no different on or off medication T / **F**

11 The unpleasant effects of medication are always present T / **F**

12 Medication makes me feel tired and sluggish T / **F**

13 I take medication only when I feel ill T / **F**

14 Medications are slow-acting poisons T / **F**

15 I get along better with people when I am on medication **T** / F

16 I can't concentrate on anything when I am taking medication T / **F**

17 I know better than the doctors when to stop taking medication T / **F**

18 I feel more normal on medication **T** / F

19 I would rather be ill than taking medication T / **F**

20 It is unnatural for my mind and body to be controlled by medications T / **F**

21 My thoughts are clearer on medication **T** / F

22 I should keep taking medication even if I feel well **T** / F

23 Taking medication will prevent me from having a breakdown **T** / F

24 It is up to the doctor to decide when I should stop taking medication **T** / F

25 Things that I could do easily are much more difficult when I am on medication T / **F**

26 I am happier and feel better when I am taking medications **T** / F

27 I am given medication to control behaviour that other people (not myself) don't like T / **F**

28 I can't relax on medication T / **F**

29 I am in better control of myself when taking medication **T** / F

30 By staying on medications I can prevent myself getting sick **T** / F

If you have any further comments about medication or this questionnaire, please write them below

_____

_____

_____

_____

_____

_____

Answers shown in **bold are scored +1; answers in normal font are scored -1*

Questionnaires given to participants will have no bold answers indicated.

9.7 Appendix 5: Depression Anxiety and Stress Scale (DASS -21):

(*For patients and family members*)

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree, or some of the time

2 Applied to me to a considerable degree, or a good part of time

3 Applied to me very much, or most of the time

---

1. I found it hard to wind down	0	1	2	3
2. I was aware of dryness of my mouth	0	1	2	3
3. I couldn't seem to experience any positive feelings at all	0	1	2	3
4. I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5. I found it difficult to work up the initiative to do things	0	1	2	3
6. I tended to over-react to situations	0	1	2	3
7. I experienced trembling (eg, in the hands)	0	1	2	3
8. I felt that I was using a lot of nervous energy	0	1	2	3
9. I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10. I felt that I had nothing to look forward to	0	1	2	3
11. I found myself getting agitated	0	1	2	3
12. I found it difficult to relax	0	1	2	3
13. I felt down-hearted and blue	0	1	2	3
14. I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3

15. I felt I was close to panic	0	1	2	3
16. I was unable to become enthusiastic about anything	0	1	2	3
17. I felt I wasn't worth much as a person	0	1	2	3
18. I felt that I was rather touchy	0	1	2	3
19. I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increasing, heart missing a bit)	0	1	2	3
20. I felt scared without any good reason	0	1	2	3
21. I felt that life was meaningless	0	1	2	3

9.8 Appendix 6: Positive and Negative Affect Schedule (PANAS) (Family only)

(*For family members only*)

This scale consists of a number of words that describe different feelings and emotions. Read each item and then list the number from the scale below next to each word. **Indicate to what extent you feel this was right now, that is, at the present moment OR indicate the extent you have felt this way over the past week (circle the instruction you followed when taking this measure).**

	1.	2	3	4	5
Very slightly	a little	moderately	quite a bit	extremely	

Or not at all

_____1. Interested

_____2. Distressed

_____3. Excited

_____4. Upset

_____5. Strong

_____6. Guilty

_____ 7. Scared

_____ 8. Hostile

_____ 9. Enthusiastic

_____10. Proud

_____11. Irritable

_____ 12. Alert

_____13. Ashamed

_____14. Inspired

_____15. Nervous

_____16. Determined

_____17. Attentive

_____18. Jittery

_____19. Active

_____20. Afraid

9.9 Appendix 7a: Patient Open-Ended Interview Schedule

1. How long have you had a psychiatric illness?
2. What is the name of your psychiatric illness?

3. What are some of the symptoms you experienced when you became ill?

4. How did you feel when you were first diagnosed?

5. How do you feel about the diagnoses now?

6. Can you describe the last psychotic episode you experienced?
7. How did you feel at the time?
8. Do you find yourself thinking about that day?
9. How do you feel when you think about it?
10. Which of these feelings remain strong for you (shame/guilt/fear/sadness/anger)?
11. How do you make sense of these feelings?
12. Do you understand why you have to take your medication? Please explain what you have been told about the medication and how you made sense of it.
13. Do you tend to visit the psychiatrist/doctor:
a) When you are slightly ill? (Slightly meaning just a little)
b) When you are moderately ill? (Moderately meaning significant illness but you can tolerate it/not too bad)
c) When you are feeling very ill? (Very meaning significant illness that you cannot tolerate/quite bad)
d) When you have an appointment?
Please explain why?
14. When you are prescribed medication, do you tend to:
a) Avoid collecting the medication from pharmacy?
b) Collect the medication from pharmacy and take only one or two tablets?
c) Take the tablets now and then and not follow the instructions fully?
d) Follow the instructions fully?
Please explain why?

15. Do you come back follow up appointments even though you are feeling better?

Please explain why?

16. Do you:

a. follow the doctor's instructions exactly?

b. follow the instructions more or less ?

c. follow the instructions when they make sense to you ?

d. not really follow the instructions ?

Please explain why?

17. Would you rather go for health diets or alternative medicine (e.g. traditional healer) rather than follow the advice of a psychiatrist/doctor?

Please explain why?

18. What other sources of help have you approached regarding the psychiatric condition? E.g. Traditional healer, church, prophet, etc.

Do you remember when you went and what happened there?

19. How has your life changed since the diagnoses?

20. What have you found helpful in recovering and coping with your illness?

21. What have found unhelpful in recovering and coping with your illness?

22. What further help would you like from the hospital?

23. Have you experienced stigma in relation to the illness? Can you explain your experience?

24. What are your future expectations?

9.10 Appendix 7b: Family Member Open-Ended Interview Schedule

1. How long has your family member had a psychiatric illness?
2. What is the name of your family members' psychiatric illness?

3. What were you told about this illness?

4. Who gave you the information?

5. What are some of the symptoms she/he experienced when she/he became ill?

6. How did you feel when she/he was first diagnosed?

7. How do you feel about the diagnoses now?

8. Can you describe the last psychotic episode you witnessed?
9. How did you feel at the time?
10. Do you find yourself thinking about that day?
11. How do you feel when you think about it?
12. Which of these feelings remain strong for you (shame/guilt/fear/sadness/anger)?
13. How do you make sense of these feelings?
14. Do you understand why your family member has to take her medication? What information were you given regarding this?
15. Do you tend to accompany your family member to the psychiatrist/doctor:
(a) When your family member is slightly ill? (Slightly meaning just a little, only minimal symptoms)
b) When your family member is moderately ill? (Moderately meaning significant illness with notable symptoms but you can tolerate it/not too bad)
c) When your family member is feeling very ill? (Very meaning significant illness with notable symptoms that you cannot tolerate / quite bad)
d) Only when your family member has an appointment?
Please specify why?
16. When your family member is prescribed medication, does she/he tend to:
a) Avoid collecting the medication from pharmacy?
b) Collect the medication from pharmacy and take only one or two tablets?

c) Take the tablets now and then and not follow the instructions fully?

d) Follow the instructions fully?

Please specify why?

17. Do you normally accompany your family member for psychiatric consultation?

18. Do you understand the medication instructions?

19. Does your family member go back follow up appointments even though she/he is feeling better?

20. Does your family member:

a) Follow the doctor's instructions exactly?

b) Follow the instructions more or less?

c) Follow the instructions when they make sense to him/her?

d) Not really follow the instructions?

Please specify why?

21. Would you rather go for health diets or alternative medicine (e.g. traditional healer) rather than follow the advice of a psychiatrist/doctor?

Please specify why?

22. What other sources of help have you approached regarding the psychiatric condition? E.g. Traditional healer, church, prophet, etc.

Please specify when you went and what happened.

23. How has your life changed since the diagnoses?

24. What has been helpful in understanding and coping with your family members' illness?

25. What has been unhelpful in understanding and coping with your family members' illness?

26. What further help would you like from the hospital?

27. Have you experienced stigma in relation to the illness? Can you explain your experience?

28. What are your future expectations?

9.11 Appendix 8: PTSD Symptom Scale Interview

The semi-structured interview below was be administered on all the participants

(PSSI; Foa, Riggs, Dancu & Rothbaum, 1993)

Name: _____ Date: _____

Index trauma (describe): **focus will be on the recent psychotic episode**

_____

_____

_____

_____

_____

Ask, "in the past two weeks" (if < 2 weeks since trauma, ask "Since the [trauma]"). Probe all positive responses (e.g., "How often has this been happening?").

_____

0	1	2	3
Not at all	Once per week or less/a little	2 to 4 times per week/somewhat	5 or more times per week/very much

_____

RE-EXPERIENCING (need one): [probe, then quantify]

____ 1. Have you had recurrent or intrusive distressing thoughts or recollections about the trauma?

____ 2. Have you been having recurrent bad dreams or nightmares about the trauma?

____ 3. Have you had the experience of suddenly reliving the trauma, flashbacks of it, acting or feeling as if it were re-occurring?

____ 4. Have you been intensely EMOTIONALLY upset when reminded of the trauma (includes anniversary reactions)?

____ 5. Have you been having intense PHYSICAL reactions (e.g., sweaty, heart palpitations) when reminded of the trauma?

AVOIDANCE (Need three): [probe, then qualify]

____ 6. Have you persistently been making efforts to avoid thoughts or feelings associated with the trauma?

____ 7. Have you persistently been making efforts to avoid activities, situations, or places that remind you of the trauma?

____ 8. Are there any important aspects about the trauma that you still cannot recall?

____ 9. Have you markedly lost interest in free time activities since the trauma?

____10. Have you felt detached or cut off from others around you since the trauma?

____11. Have you felt that your ability to experience the whole range of emotions is impaired (e.g., unable to have loving feelings)?

____12. Have you felt that any future plans or hopes have changed because of the assault (e.g., no career, marriage, children, or long life)?

INCREASED AROUSAL (need two): [probe then quantify]

____13. Have you had persistent difficulty falling or staying asleep?

____14. Have you been continuously irritable or have outbursts of anger?

____15. Have you had persistent difficulty concentrating?

____16. Are you overly alert (e.g., check to see who is around you, etc.) since the trauma?

____17. Have you been jumpier, more easily startled, since the trauma?

9.12 Appendix 9: Ethics clearance certificate

R14/49 Mrs Bongiwe Mahlobo-Mphohle

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M131132

NAME: (Principal Investigator)	Mrs Bongiwe Mahlobo-Mphohle
DEPARTMENT:	Psychology Chris Hani Baragwanath Academic Hospital
PROJECT TITLE:	Post Psychosis Trauma and Non-Adherence in Bipolar Mood Disorder I with Psychotic Features: Patients and their Families in Gauteng. (Chris Hani Baragwanath Academic Hospital)
DATE CONSIDERED:	29/11/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Esther Price
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	26/02/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

9.13 Appendix 10: Hospital letter of approval

GAUTENG PROVINCE
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 04 September 2013

TITLE OF PROJECT: Post-psychosis trauma and non-adherence in bipolar mood disorder I with psychotic features: patients and their families in Gauteng

UNIVERSITY: Witwatersrand

Principal Investigator: Bongiwe Mahlobo-Mphohle

Department: Psychiatry

Supervisor (If relevant): Dr E Price

Permission Head Department (where research conducted): Yes

Date of start of proposed study: September 2013
Date of completion of data collection: December 2016

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

Recommended
(On behalf of the MAC)
Date: 04 September 2013

Approved/Not Approved
Hospital Management
Date: 05/09/13