

University of the Witwatersrand
School of Human and Community Development
Discipline of Psychology

MASTERS
RESEARCH DISSERTATION

The experience of persons diagnosed with schizophrenia of their first admission to a South African psychiatric hospital ward for acute psychosis.

Masters in Clinical Psychology

Yumna Zobi

Student No. 0211387X

Supervisor: Patrick Connolly

Dissertation submitted in partial fulfilment of the requirements for the Degree of Masters in Clinical Psychology in the Faculty of Humanities at the University of the Witwatersrand.

DECLARATION

A research project submitted in partial fulfilment of the requirements for the degree of Masters in Clinical Psychology in the Faculty of Humanities, University of Witwatersrand, Johannesburg, 11 October 2010.

I, Yumna Zobi, declare that this thesis is my own, original unaided work unless specifically indicated to the contrary in the text. It has not been submitted before for any other degree or examination at this or any other university.

Yumna Zobi

Masters in Clinical Psychology

DEDICATION

To Rowan Hillis

*For the hope you gave, for reaching out and giving, even when you had nothing left to give,
we remember you with love.*

ACKNOWLEDGMENTS

Since I started this project I have really come to appreciate and understand the true meaning of help. Along this insightful journey I have had much valued and treasured assistance and would therefore like to acknowledge and extend my gratitude to the following persons, without whom this dissertation would not have materialised.

- ✓ *To my supervisor, Patrick Connolly. Thank you for your belief in me and my abilities. Your valuable insight, knowledge, and encouragement has helped me push myself beyond my boundaries and strive further.*
- ✓ *To all the participants of Gordonia who took part in this research. Thank you for letting me into your hearts and minds. It is an experience I will never forget.*
- ✓ *To Beryl Allen, for your willingness to always help, for your support, for your unyielding spirit in fighting for those who cannot fight for themselves. You are an inspiration to me, and you will always have a place in my heart.*
- ✓ *To my MA Clin Class of 2010, you know who you are, for supporting me throughout the year and for understanding when all others could not.*
- ✓ *To my mother Fatima, for your unconditional love and support throughout this journey of study and change. Thank you for all you do for me. I am extremely blessed to call you my mother.*
- ✓ *To my brother- in-law Abdullah, for trying, for fighting, for never giving up.*
- ✓ *To my family, for their encouragement, praise and thoughts. To my sister Ra'eesa, Thanks for always being willing to lend an ear.*
- ✓ *To Dr. Sharmane Mattinson, for your support throughout the years. You are a very special person and I thank you deeply for all you have done.*
- ✓ *To my mother in law, Sharon. Thank you for all your support and for lending a hand when no one else could.*
- ✓ *Lastly, to my best friend, partner and husband, Muhammad. I cannot begin to thank you for all the support, love, encouragement and understanding that you have shown throughout this difficult year. Thank you for always believing in me and remaining positive when I could not.*

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CHAPTER 1: INTRODUCTION

Schizophrenia has been described as one of the most severe mental illnesses. The current rate of schizophrenia is estimated at 1% of the population globally (Torrey, 2001). The term schizophrenia is extremely complex and difficult to define. Research has shown that schizophrenia is not a stable construct and that there has been a change in the perception of schizophrenia over time (Torrey, 2001). The term schizophrenia is one which has been extensively debated among theorists. In this study, the term schizophrenia will be defined according to the Diagnostic and Statistical Manual of Mental Disorders. The DSM-IV-TR define schizophrenia as “a disorder that lasts for at least 6 months and includes at least 1 month of active-phase symptoms (i.e., two [or more] of the following: delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behaviour, [negative symptoms”] (American Psychiatric Association, 2000, p. 298).

First time admission to a psychiatric hospital has been reported to be extremely traumatic for people (McGorrey, Chanen, McCarthy, Van Riel, McKenzie & Singh, 1991; Morrison, Frame, & Larkin, 2003). Patients who have a distressing first experience of admission to a psychiatric ward are less likely to remain treatment compliant in the future (Stein, 1996). If a person with schizophrenia refuses mental health care, the chance of relapse significantly increases (Schlebusch, & Luiz, 1985) and has implications on how the system responds to them in the future. This will also have an impact on the individual’s long term well being. Furthermore, it plays a role in alienating them from the mental health services. Consequently there is a need for research looking at users’ experiences of first time admissions to a psychiatric hospital for acute psychosis. This will help to enable health care professionals understand patients’ first time experiences of the psychiatric hospital, to identify the most distressing aspects of the experiences, and further develop better intervention strategies to lessen the distressing experiences and ensure more successful first time admissions.

1.1 Research aim

The study aims to explore the experiences of persons diagnosed with schizophrenia of their first admission for acute psychosis to a South African psychiatric ward.

1.2 Research Rationale

“Despite the extensive historical literature on asylums, few studies explore patients’ perceptions of psychiatric hospitalization, particularly what patients themselves thought about the facilities...” (De le Cour, 1997, p. 131). The attitude toward hospitalization, held by those diagnosed with schizophrenia, is an area of research that has been relatively ignored (Drake & Wallach, 1988). In many studies conducted on hospitalisation, the patients’ attitudes and perceptions are relatively neglected. The majority of studies tend to focus on staff members’ perceptions of hospitalisation, leaving out the patients’ perceptions completely (Rossberg & Friis, 2004). In a study carried out by Rossberg & Friis, (2004) regarding the perceptions of a psychiatric ward environment by both staff and patient, they concluded that the staff members’ views on treatment and hospitalisation were more favourable than those of the patients.

According to the majority of the studies conducted on trauma and psychiatric hospitals, there is a consensus that patients often have negative experiences, specifically during their first admission to a psychiatric hospital. To date, there is a paucity of existing studies which focus on the traumatic effects of acute psychosis and admissions. McGorrey, et al. (1991) was among the first to suggest that the experience of a psychiatric hospital might be a direct cause of PTSD within psychosis. This negative experience of first time admissions can have a profound impact on the treatment. In a study conducted by Day, Bentall, Roberts, Randall and Power (2005), focusing on patient attitude toward antipsychotic medication, it was concluded that “The quality of relationships with clinicians during acute admission appears to be an important determinant of patients ‘attitudes’ toward treatment and adherence to medication. Enhancing such relationships may yield important clinical benefits” (p.717). Negative experiences during first time admission could have a profound impact on patients’ perceptions of mental health care, further increasing the risk of relapse.

The studies looking at first time admission to a psychiatric hospital are mostly quantitative studies and do not focus on the people with acute psychosis. Research into patients’ perceptions of disease and other mental disorders, such as depression, has helped health care professionals to understand and improve existing treatment programmes (Torrey, 2001). Magliano, Fiorillo, Malangone, Del Vecchio and Maj, (2008) did a study in Italy focusing on patients’ perceptions of schizophrenia. Results derived from this study indicated that 56% of

participants, out of a total of 241, felt that it was difficult for a person with schizophrenia to get married or live with a partner. Magliano, et al, (2008) suggested that an intervention to address this issue should be “aimed at increasing patients’ self-esteem and interpersonal skills which are clearly needed to support them in the achievement of these emotional goals” (p. 799). This research was the first to be carried out in Italy and has led to the study’s results being used to help develop intervention programs at clinics.

This exploratory study into the perceptions of psychiatric hospitals among persons with schizophrenia is important as hardly any research has been done in the field, specifically within a South African context. Being able to explore the perceptions of psychiatric hospitals by people with schizophrenia would give some insight into the difficulties they face. This might also enable health care professionals to develop further interventions to support and help people with schizophrenia on their first encounter within a psychiatric hospital. For example, receiving appropriate treatment in the acute psychotic stage might prevent deterioration and possible secondary syndromes, like depression and PTSD (Birchwood, et. al., 1998 as cited in Morisson, Frame & Larkin, 2003).

“Taking the patient’s phenomenology into account may explain how a variety of risk factors and supports are idiosyncratically perceived and weighed to arrive at their meaning for the given patient” (Drake & Wallach, 1988, p. 29). Examining patients’ perceptions regarding first admission to a psychiatric hospital has the potential to open up new avenues for research within the field and might serve in creating intervention programmes designed to assist with psycho-social interventions during the admission procedures. According to Magliano, Marasco, Fiorillo, & Maj (2006) the common opinion is that schizophrenia is seen as ‘different’ from other psychological disorders and implies a higher level of discrimination by affected people. This results in stigmatization, delays in access to appropriate treatments, and obstacles to being able to achieve life goals.

“In the aftermath of apartheid, South Africa has inherited a fragmented, under-resourced and inequitable public sector mental health service” (Lund & Flisher, 2006, p. 587). Lund and Flisher (2006), state that general psychiatric hospitals in South Africa lack the resources to cater for the needs of people with psychiatric conditions. This lack of resource is reflected in a range of areas; from the number of psychiatric beds available to medication and the staff needed to maintain the operational needs of the psychiatric facility. Since this study focuses

on a South African context, it will be useful to explore the particular challenges faced by South African hospitals and what effect these challenges have on patients' first admission to a psychiatric hospital for acute psychosis.

CHAPTER 2: Literature Review

In this literature review, a brief history of how the term ‘schizophrenia’ emerged will be discussed, as well as a definition of the term acute psychosis and schizophrenia. The main emphasis of the literature will be on psychiatric treatment, with a focus on psychiatric hospitals in particular, and their impact on the wellbeing of persons experiencing first time admissions for acute psychosis. Another key theme within the literature is the experience of trauma and distress due to first time admissions to a psychiatric hospital.

In 1896, Kraepelin isolated a group of psychoses which included morbid states that tended towards progressive deterioration. He termed this ‘dementia praecox’. Kraepelin argued that this ‘dementia praecox’ had the same aetiology and deteriorating course (Boyle, 1990; Vetter, 1968). In 1911, Eugene Bleuler, a critic of Kraepelin’s assumptions on the prognosis of dementia praecox, introduced the term ‘schizophrenia’. Bleuler described schizophrenia as a “splitting” of psychic functions (Boyle, 1990; Rochester & Martin, 1977). Bleuler argued that the disturbances present in someone with schizophrenia “could come to a standstill at any stage and that some of the symptoms could clear up to a large extent or altogether” (Vetter, 1968, p.3). It is still widely debated by some in the medical profession whether schizophrenia necessarily has a negative progressive deterioration; whereas others take a more optimistic view of the prognosis (Warner, 1994).

2.1 Defining psychosis and schizophrenia

Historically, the term psychosis has had many definitions. However, none has received universal acceptance (American Psychiatric Association, 2000). The Oxford English Dictionary defines the term psychosis as “a severe mental disorder in which thought and emotions are so impaired that contact is lost with external reality” (p. 942). The Greek word, psyche, means the human soul, mind or life and the suffix “osis” denotes a process, condition or pathological state. Historically, the broadest definition of psychosis has referred to failure to meet the demands of everyday life, with the narrowest definition restricted to delusions and hallucinations, with the absence of insight. According to the APA, (2000) psychosis in schizophrenia refers “to delusions, any prominent hallucinations, disorganized speech, or disorganized or catatonic behaviour” (p. 297). At this point, it is important to make a distinction between acute psychosis and schizophrenia. Acute psychosis implies it is the first time that a person is experiencing psychotic symptoms; furthermore, it implies that the

symptoms have been present for a short period of time. With regard to schizophrenia, on the other hand, the symptoms have been present for one month (APA, 2000).

According to the Diagnostic and Statistical Manual of Mental Disorders IV, schizophrenia is a disorder that lasts for at least 6 months and includes at least one month of active-phase symptoms; (i.e., two [or more] of the following symptoms need to be present. These include delusions (persecutory or referential), disorganised speech, disorganised behaviour, catatonic motor behaviour and negative symptoms [flat affect, alogia or avolition] (APA, 2000)

The DSM IV-TR has aimed to further differentiate the types of schizophrenia by including subtypes. There are 5 subtypes of schizophrenia, and each subtype depends exclusively on the symptoms of the illness. The first is the paranoid type which includes persecutory or grandiose content hallucinations. The second is the disorganized type which is predominantly disorganized speech and disorganized behaviour. The third is the catatonic type which includes behavioural disturbances, such as rigidity stupor and mutism. The fourth is the undifferentiated type where symptoms are mixed. The last is the residual type where the person suffers at least one episode of schizophrenia and displays only negative symptoms, without the presence of prominent positive symptoms (APA, 2000).

Despite these subtypes of schizophrenia seeming to assist in differentiating the types of schizophrenia, Torrey (2001) questions the need for them by stating that the “validity and utility of these subtypes are very questionable despite their widespread usage” (p. 93). Few people diagnosed with schizophrenia fall clearly into one of these subtypes, and many have a mixture of symptoms. Some people with schizophrenia often show a shift in these symptoms over time, moving from one subtype to another. “For these reasons there has been an increasing tendency among psychiatrists in recent years to diagnose most patients as having the undifferentiated type, which simply means that their symptoms are mixed, and to rely less on the traditional four-part division”(Torrey, 2001 p. 93).

Since the concept of schizophrenia continues to be debated, the diagnosis can be unclear in a person’s initial contact with psychiatric hospitals. For this reason, the term psychosis will be used, as the study focuses on perceptions of psychiatric hospitals during acute psychosis.

2.2 Treatment

“The study of the history of the treatment of schizophrenia shows that these patients have been brutalized for as long as we have written records” (Gralnick, 1983, p.121). Gralnick (1983), states that terror and intimidation were used as important treatment techniques and were seen as a way of shocking people into rationality. Some of the techniques used include “immersing people in wells, throwing people from great heights into bodies of water, and submerging people under water in coffin-like boxes until air bubbles ceased to rise” (Gralnick, 1983, p. 121).

Nowadays, there is a vast shift from these brutal methods and there are numerous treatment options available to help control the symptoms of schizophrenia, such as psychosocial treatments. These treatments are aimed at preventing the event of relapse and also to improve social skills within the person (Tsung, 1982). Some of the most common forms of psychosocial therapy are cognitive behaviour therapy, psychotherapy and family therapy. “Multiple family group therapy is an evidence-based intervention for treating persons with severe mental illness, particularly schizophrenia, and their family integrates psycho-education and behavioural family therapy in a multiple-family group format” (Stuart & Schlosser, 2009, p. 435). This type of intervention is highly effective in reducing family members’ expressed emotion, which in turn reduces patients’ relapse rates (Penn & Mueser, 1996). However, the most effective and mainstream method of treatment remains medication (Torrey, 2001).

2.2.1 Medication

“Psychopharmacologic drugs are useful and have made a major contribution to the treatment of the schizophrenic disorder” (Gralnick, 1983, p. 123). The most common medication used for the symptoms of schizophrenia is anti-psychotics. These medications can make symptoms milder, shorten the course of an episode and further increase the time between psychotic episodes. According to the World Health Organization in an article entitled Schizophrenia and public health the “findings from a large number of clinical trials indicates a substantial improvement within 6-14 weeks in 75% of patients with acute symptoms of schizophrenia” (WHO, 1998, p.17).

These drugs are not perfect tools and should be used with psychotherapy for optimal results. Relapse rates of persons with schizophrenia taking antipsychotic medication and psychotherapy is between 10 and 15%. This compares with the very high risk of relapse in patients not taking medication, which is as high as 70% (Perkins, 2002).

Antipsychotic medication does not cure schizophrenia but has helped to improve psychopathology, reduce relapse, improve functioning and keep people with schizophrenia out of hospital. However, non-adherence to medication among people with schizophrenia has been estimated at approximately 50% (Gilmer, Dolder, Larco, Folsom, Lindamer, Garcia & Jeste, 2004). A possible reason for the non-adherence to medication could be due to the side effects of the antipsychotic medication. These side effects are called extra pyramidal signs (EPS). Some of the common side effects of these drugs are involuntary muscle movement, sedation, dry mouth, blurred vision, acute dystonic reaction (stiffening of the muscles) and weight gain (Gianfrancesco, Rajagopalan, Sajatovic & Wang, 2006).

These extra pyramidal signs are common in conventional antipsychotic drugs which are now being replaced by modern “atypical” antipsychotics. These modern antipsychotic drugs have a lower risk of some of the extra pyramidal symptoms and improve cognitive functioning (Garner, Baldessarini & Waraich, 2005). The antipsychotic medication helps reduce positive symptoms and usually allows the patient to function more effectively and appropriately. This in turn has a positive effect on the person’s satisfaction regarding treatment.

Numerous studies conclude that despite these modern antipsychotic medications, non-adherence to either type of antipsychotic medication is extremely high (Fenton, Blyler & Heinssen, 1997; Torrey, 2000). Non-adherence to antipsychotic medication has been associated with a greater number of psychiatric hospitalisations (Gilmer, et. al. 2004).

2.2.2 ECT

Electroconvulsive therapy (ECT) involves the initiation of a seizure for therapeutic purposes by administering a variable frequency electrical stimulus shock to the scalp. The effects of ECT of people diagnosed with schizophrenia are still unclear (Tharyan & Adams, 2005). Although ECT was originally introduced as a treatment for schizophrenia, it soon became apparent that it was more successful in treating major depressive illnesses. “With the advent

of neuroleptic medication for schizophrenia, ECT became less frequently used” (Dodwell & Goldberg, 1989, p. 635). In the majority of the studies, patients described coercive ECT being the most disturbing and frightening experience (Breggin, 1964; Iversen, et al., 2002). In a study conducted by Malcom, (1989) fifty-five patients stated that they found the treatment frightening. While more than half of the patients reported negative effects from the ECT, a few reported “pleasant aspects to the treatment, such as drifting off to sleep or amnesia, which made them forget their worries” (Malcom, 1989, p. 162).

2.2.3 Psychiatric hospitals

Hospitalization is an important environment for the treatment of people who are severely psychotic (Rossberg & Friis, 2004). According to Torrey (2001), after a person is diagnosed with schizophrenia, there is a need for them to be initially hospitalised. The main reason is that “it enables mental health professionals to observe the patient in a controlled setting” (Torrey, 2001, p. 185). This is vital because medication can be altered, and nurses are present to monitor the side effects and determine the correct dosage for the patient. When one usually thinks of hospitalization, it is generally with the idea that the patient’s entry into a hospital is one of choice. However, this may not always be the case as some people with mental illnesses may be forced into treatment by police, judges or family members (Pescosolido, Gardner & Lubell, 1998).

2.2.3.1 Historical critique of the psychiatric hospital

The psychiatric hospital was established in the interest of the capitalist state. Many argue that it was established for reasons other than the interests of the individual person. During the 18th century, also coined the Asylum era, mentally ill people were referred to as ‘lunatics’ and were forcibly removed from society and locked away. It was the first time that mental illness was seen as a disease of the mind and not as a possession by demons. During this century, one of the first asylums in London, the Bethlehem Royal Hospital, was opened and later became known as the infamous ‘Bedlam’. These types of institutions were like prisons with extremely neglectful conditions (Millon, 2000). Arieti (1979) argues that hospitals might have been a place to confine mentally ill people in the past. Nowadays, however, people have to give consent to be hospitalised. Only in extreme cases where the person is seen to be a danger to him/her self or society, are they forced to be hospitalised. That is for a short period of time until the patient is contained (Arieti, 1979).

Foucault (1977) describes psychiatric hospitals as a form of panopticon. The panopticon simply refers to the method of surveillance where power is exercised over people in order to try and normalise their behaviour. This concept has the potential to shed light on this study since the majority of schizophrenic patients are constantly being hospitalised as they experience highly disordered thought processes. They are constantly being watched by mental health professionals. From a Foucauldian perspective, this constant process of hospitalisation and surveillance would be to try and normalise the inappropriate disorganised thought. Foucault (1977) claims that psychiatric hospitals, like prisons and asylums not only house the madman but actually create the madman. The reason is that people in psychiatric hospitals are stripped of all their rights. They are treated as madmen and are at all times instructed when it is permissible to eat, drink, sleep, bath, who is able to come visit them and at what time. This type of treatment does not allow them any freedom or voice to decide what might be best for them. Since the person is robbed of all his rights, he becomes a madman. Szasz (1970) argues that these patients are imprisoned against their free will, and considers it a crime against humanity.

While this view does appear to be extreme, it is also important to acknowledge the importance of surveillance and why it is necessary. While it is acknowledged that the method of surveillance does appear to be a method of power or control over the patients, it is also important to acknowledge that the power yielded over the psychiatric patient is done in order to protect them. “A few patients, for example, consistently refuse any type of treatment and will always walk away from an open-door establishment” (Warner 1994, p. 273). By not complying with treatment, there is the risk of their becoming violent towards themselves or towards members of the public. Warner (1994) argues that an attempt to treat such patients in a community setting would most likely fail and therefore have to be hospitalised and constantly monitored to ensure they receive treatment.

Goffman (1961), who based his research on the asylum where he spent a considerable amount of time observing patients, takes a similar view to that of Foucault (1977) stating that “Mental patients are persons who caused the kind of trouble on the outside which led someone physically, if not socially, close to them to take psychiatric action against them” (Goffman, 1961, p. 268). The official objective is to reform the mentally ill patient in the direction of some ideal standard (Goffman, 1961).

Goffman (1961) asserts that inmates in the psychiatric hospital are not only humiliated but also have their roles dispossessed. During the first admission “the most significant of these possessions is not physical at all, one’s full name; whatever one is thereafter called, loss of one’s name can be a great curtailment of the self” (Goffman, 1961, p. 27- 28). This basically means that any role the inmate had before coming into the psychiatric hospital is abolished. The inmate is allowed no contact with the outside world; this can be seen as a way of punishing the inmate for his incorrect behaviour. These psychological effects are part of the process and depending on the nature of the effect can be either direct or indirect. An example provided by Goffman (1961) which illustrates this, is his reference to patients who have witnessed physical assault and find themselves unable to take any action. In this example, assault is referred to by Goffman (1961) as shock therapy and the resultant psychological and physical effects, as they not only witness it, but have the physical experience of shock therapy as well.

The psychiatric hospital can be viewed as a prison as Goffman (1961) and Foucault (1977) clearly point out, however it is important to acknowledge that the psychiatric hospital serves many functions that benefit the patients. Firstly, it provides care for chronically disturbed individuals. Secondly, it provides respite from pressures for patients (Dingman 1974; Stewart 1975 as cited in Bachrach, 1976). It further provides a place for escape for the patient from the society in which behaviour is friction producing (Polak and Jones 1973 as cited in Bachrach, 1976). Arieti (1979) points out psychiatric hospitals provide many needs which family members cannot. Many people diagnosed with schizophrenia do not keep on taking the medication, which subsequently puts them at risk of relapse. The symptoms which the medication helps to control may return. For instance, symptoms of paranoia and hallucinations might return, causing a heightened feeling of paranoia in the person or a feeling that others are out to harm him. He might have auditory hallucinations where he hears voices instructing him to harm himself or others. For this reason, psychiatric hospitals will help protect the person from himself and others and will also help with the adherence to the medication (Arieti, 1979).

2.4 Contemporary Challenges in South Africa

According to the department of health (2005) in a paper entitled ‘Disease control priorities related to mental, neurological, development and substance abuse disorders’ the South

African public health sector serves between 75 and 80% of the population. The funding for this sector is achieved through national and provincial budgets and is mainly sustained through government funding. Furthermore, the distribution of highly skilled health care personnel is greater in the private and urban areas, and less so in the public and rural areas. The introduction of community service for health care professional has been implemented to help alleviate this (Department of Health, 2005).

Another issue facing South African hospitals is the working environment of under staffing and attrition which can lead to reduced job satisfaction. Because of the shortage of mental health practitioners in South African hospitals, the work load of existing staff members has increased. This increase can raise the level of stress, fatigue and emotional exhaustion, all of which compromise both the quality and safety of care. Staff members might have to work unpaid overtime to complete their work load. They are probably faced with less flexibility in taking leave or participating in staff development and training activities (Gerin, Green, & Pearson, 2006). The day to day work in a psychiatric setting can be pressurised, which could lead to self protective defences such as reductive labelling, them and us blaming, and emotional detachment (Hardcastle, Kennard, Grandison, & Fagin, 2007).

Another factor affecting hospitalisation and patients includes whether patients should be forced to be hospitalised against their will. Involuntary or coercive treatment can be defined as treatment imposed on the patient against his/her will. Coercive treatment of persons with mental illnesses is a controversial topic (Lidz, Mulvey, Hoge, Kirsch, Monahan, Eisenberg, Gardner & Loren, 1998). The main debate on this issue is whether an infringement and deprivation of liberty can really be justified in order to help a patient into a rational state of being or whether it is merely a means of social control for those who display deviant behaviour (Kaltiala-Heino, Korkeila, Tuohimaki, Tuori & Lehtinen, 2000).

Critics of involuntary commitment argue that it does more harm than good. It causes patients to mistrust mental health professionals, as well as caregivers which then cause them to become alienated. Coercion may further reduce adherence to treatment, such as taking prescribed medication. In a study conducted in New Zealand by McKenna, Simpson, & Laidlaw (1999) which focused on patient perception of coercion on admission to acute psychiatric services, it was found that “those admitted to hospital under the legislation feel

loss of autonomy and are more likely than voluntary admissions to perceive hospitalization as coercive” (p. 150).

On the other hand, many mental health professionals argue that the use of coercion is sometimes necessary and important to ensure patients receive the proper care. They further argue that involuntary treatment is necessary when patients are too ill to understand that they might need it, and when the patient might attempt to harm him / herself or others (Lidz, et. al., 1998). Traditionally, mental patients were denied the right to discharge themselves from a mental hospital. In this present age of informed consent, however, patients are able to refuse hospital treatment (RHT), despite staff recommendations, on the basis that they have insight and good judgement (Schlebusch, & Luiz, 1985). However, not all mentally ill patients have insight and good judgement. Even though it is internationally recognized that the majority of mental health care users should be treated voluntarily, under circumstances where the patients might cause significant distress and be a potential danger to themselves or others, they might be forced against their will (Mental Health Care Act, 2002). “In accordance with this MHCA, a mental health care user may be treated involuntarily at a health establishment on an inpatient basis under very specific regulations which serve to protect the users’ rights as much as possible” (Moosa, & Jeenah, 2008, p. 109).

There is a huge debate amongst theorists as to whether psychiatric hospitals provide a positive rehabilitation place for the mentally ill patient or whether they create further harm to the rehabilitation and readjustment process (Arieti, 1979; Warner, 1994; Wing & Brown, 1970).

2.5 The Burden of Schizophrenia

“The chronic course and debilitating effects of schizophrenia combine to create a disease which imposes very considerable clinical, social and economic consequences on individuals and societies throughout the world, resulting in it being a leading contributor to global and regional levels of disability and the overall disease burden”(Chishold, Gureje, Saldivia, Caldero, Wickremasinghe, Mendis, Ayuso-Mateos & Saxena, 2008, p. 542). According to the World Health Organization (2006), in an article entitled the disease control priorities related to mental, neurological developmental and substance abuse disorder, schizophrenia affects 24 million people worldwide. This is attributed to the condition being associated with

early onset, long duration and severe disability. According to Torrey (2004), the cost of schizophrenia and other serious mental illnesses in the United States is \$41 billion annually.

This burden does not solely reside with the state as it also affects family members as well as the individual person. Research studies have documented that up to 83% of family members and friends of people diagnosed with schizophrenia experience financial, emotional and practical burdens (Magliano, et al, 2006). Some of the common complaints involve reports of time lost from work, non reimbursement by medical aids and other patient expenses, as well as limited time for socializing, leisure, and an increase in psychological distress and stigmatization (Perlick, Rosenheck, Kaczynski, Canive, & Lieberman, 2006). Family member accounts indicate a profound sense of loss of the person with schizophrenia; a loss of the person he/she was before the illness. There is also strong tension among family members who have to distance themselves from the person with schizophrenia because of the all the chaos and distress it creates, and further more to accept the relationship that has been changed by the disorder. They try to hold onto the lingering desire and hope that the person who they knew before the diagnosis will return. “As a consequence of this social disability, family members feel at an increasing emotional distance from their loved one...” (Marinelli & Orto, 1999, p. 223).

The burden has a significant impact on the life of the person affected by schizophrenia. Firstly, the disease affects the person’s thinking, cognition and ability to communicate. Furthermore, the person has to face a host of social and life related issues, which can include criminalization, poverty, social isolation, lack of resources and stigma (Award & Voruganti, 1999). The first person account is pervaded by a loss of interpersonal relationships, loneliness and social isolation (Marinelli, & Orto, 1999). Furthermore, research has indicated that many people with schizophrenia experience homelessness. In a study conducted by Herman, Susser, Jandorf, Lavelle, & Bromet, (1998) they found that 15% of patients (sample size of 237) has experienced at least one episode of homelessness before or within 24 months of their initial psychiatric admission.

2.6 Impact of distress/trauma

First time experiences of a sudden closed environment with other people who are disturbed could be extremely traumatic (McGorrey, 1991; Priebe, Borker & Gunkel, 1998). In a study

conducted by Priebe, et al. (1998), who examined involuntary admission and PTSD symptoms in schizophrenic patients, they found that 51% (sample size of 105) of participants met the criteria of PTSD precipitating treatment experiences. Another study conducted by Morrisson, Bowe, Larkin and Nothard (1999) yielded similar results. However, a smaller sample size was used (34) and it was found that 44% of participants met the criteria of PTSD in relation to psychiatric admission.

Compulsory psychiatric hospitalization, especially during an acute psychotic episode, has been suggested as being extremely traumatic. In a study conducted by Beattie, Shannon, Kavanagh and Mullhollan, (2009) 66% of participants (sample size of 31) said their first psychiatric admission was most distressing. To date, there is a lack of existing studies focusing on the traumatic effects of acute psychosis and admissions. McGorrey, et. al. (1991) were among the first to suggest that the experience of a psychiatric hospital might be a direct cause of PTSD within psychosis. The main finding of the study indicated that the prevalence of PTSD was 46% at 3 months and 36% at 11 months. A second study which also focused on the experience of psychiatric hospitals being a cause of PTSD within psychosis was conducted by Jackson, Knott, Skeate and Birchwood (2004). The study found that approximately one third of patients developed PTSD. However, this study along with McGorrey, et al. (1991) and Prieb et al. (1998) found no relationship between PTSD and involuntary hospitalisation. Jackson et al. (2004) concluded that “patients’ appraisals of potentially traumatic events and their coping styles may mediate the traumatic impact of a first episode of psychosis” (p. 327).

A recent study by Beattie, Shonnon, Kavanagh and Mullhollan (2009) looked at the predictors of PTSD symptoms in response to psychosis and psychiatric admissions. They found that 45% of the sample had moderate symptoms of PTSD and 45% of the sample had moderate symptoms of PTSD in relation to psychosis and admission to hospital. The majority of the participants identified first admission to a psychiatric hospital and positive symptoms as the most distressing aspect of psychosis and admissions.

2.7 Stigmatization

“Schizophrenia is to psychiatry what cancer is to medicine: a sentence as well as a diagnosis”. (Hall, Andrews and Goldstein as cited in Torrey 2001).

The word stigma can be classified as “a special kind of relationship between attribute and stereotype...” (Goffman, 1963, p. 13). Schizophrenia is a mental illness that has been greatly neglected, as Torrey (2001) points out; that the stigma is attached to the disease is regarded as the primary reasons for this neglect. Fear is a very important aspect of stigmatization, as people automatically fear that those diagnosed with schizophrenia are all violent. Stigmatization makes it harder for the schizophrenic to come to terms with their illness and hinders them from seeking necessary treatment (Crisp, Gelder, Goddard, & Meltzer, 2005). As Tsung (1982) states that the word schizophrenia is not properly understood and is “commonly misused in our daily conversation, and means different things to different people” (Tsuang, 1982, p. 11). Any type of mental disorder or simply a nervous breakdown is referred to as being ‘schizophrenic’. “The extent of the stigma and discrimination is such that schizophrenics might as well be described as the final taboo” (Howe, 1991, p. 50 -51). As Laing (1969) states that “the mad things said and done by the schizophrenic will remain essentially a closed book if one does not understand their existential context” (p. 17). Since the stigma against mental illnesses and psychiatric admissions is prevalent, it is important to understand what the stigma is as well the different types of stigmas.

The stigma placed on people with mental disorders plays a crucial role in the way in which the patient not only accepts their diagnosis, but also how they perceive themselves, as stated by Goffman (1963) in his seminal work on stigmatization. “Those who have dealings with him fail to accord him the respect and regard which the uncontaminated aspects of his social identity have led them to anticipate extending, and have led him to anticipate receiving” (19).

Stigmatization affects not only the schizophrenic but all people with mental illnesses, and in different ways. According to Deacon, Stephney, and Prosalendis, (2005), there is a need to understand stigmatization as a social process and not as an individual attribute. They make reference to two types of stigma, namely stigma by association and secondary stigma. Stigma by association involves an internal process of stigmatization; this involves the process of self stigmatization and perceived stigmatization. These are responses to stigmatization rather than a ‘type’ of stigma. Ostman and Kjellin (2002) conducted a study looking at stigmatization by association. They found that majority of family caregivers experienced stigmatization by association. “A relatively high proportion of relatives

considered that the patient's mental illness had affected the possibilities of having company of their own or had influenced relations with others, and had also led to mental health problems in the relatives themselves" (Ostman & Kjellin, 2002, p. 496). Self stigmatization involves the acceptance of some negative social judgment whereas perceived stigmatization is what those with mental illnesses expect other people to have of them regarding their disease or disorder (Deacon, et al. 2005).

2.7.1 Responses to Stigmatization

Stein (1996) further explains that self stigmatization involves accepting the negative judgments of society. This process can be psychologically damaging as it reduces self-esteem which affects the recovery process. If the person labels him/herself as mentally ill and internalizes the stigma it will result in expectation of stigmatization from others (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002). The stigma society places on people with mental illnesses affects the person by trying to change them, trying to normalize them in an attempt to remove society's blemish which is imprinted on them. People internalize what it means to be institutionalized. "The simplest sociological view of the person and his self is that he is to himself what his place in an organization defines him to be (Goffman, 1961, p. 280)".

Magliano et.al, (2008) conducted a study in Italy whereby they looked at how people living with schizophrenia perceived their own disorder. They used the Users' Opinions Questionnaire (UOQ) which is a self-report questionnaire which explores respondents' opinion about the usefulness of drugs, affective problems, social distance, the right to be informed, recognizability and social equality. Magliano et al. (2008) found that "stigma and feelings of unpredictability are largely shared by patients. These views are likely to negatively influence patients' social participation and achievement of life goals" (Magnolia et al. 2008, p.795). Mentally ill people who are educated and have insight into their illness are said to reduce the stigmatization they would encounter. However, insight may also sensitize a person's to stigma reactions (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002).

In reality, people living with schizophrenia constantly face being stigmatized. This form of stigmatization is referred to as secondary stigmatization. Deacon, et al. (2005) explain that

the process of secondary stigmatization involves instrumental and symbolic stigmatization relating to different causes, such as discrimination and moral judgments, which emanate from society. An example of this could be the lack of research that has been conducted on the experience of stigmatization on people with severe mental illnesses. Wahl (1999) stated that a possible reason for this could be because people with schizophrenia are unable to describe their experiences accurately and so are neglected. However, Wahl (1999) further argues that to completely understand how stigmatization affects people with mental illness, one has to interview the people themselves to get their subjective experiences. This neglect of research “may itself be a reflection of the stigmatization and devaluation of those with psychiatric disorders (Wahl, 1999, p. 468). A possible reason for the stigmatization attached to mental disorders such as schizophrenia could be due the media’s portrayal of mental illnesses.

2.7.2 Media

The media plays an influential role in its reporting on mental illnesses to the public. Wahl (1992) conducted a systematic review of more than 40 years of published research on images of mental illnesses in the media. His review extended across popular magazine, media channels including television and movies. His findings were that Media depictions of mental illnesses are often inaccurate, obscure and contradictory. They depict characters with mental illnesses as killers and villains (Wahl, 1997). This inaccurate portrayal of mental illness adds to the misinformation. “The public’s knowledge of mental illness comes from sources closer to home, sources to which we are all exposed on a daily basis – namely, the mass media” (Wahl, 1997, p. 3). A more recent study conducted in 2004 by Sout, Villegas and Jennings corroborates Wahl’s, (1992) findings.

An example of how the media in South Africa depicts stigma in schizophrenia can be illustrated by a newspaper article by the South African Publication Association, SAPA (2004) entitled “Mental patient allegedly slit pensioner’s throat”. The article was about a woman who was diagnosed with schizophrenia and who slit another woman’s throat. In this incident the media made huge generalizations that all people with schizophrenia are violent and killers. “It should be noted that most people with schizophrenia are not more dangerous to others than those in the general population” (American Psychiatric Association, 2003, p. 304). It is very rare for people diagnosed with schizophrenia to become violent unless they are not taking their medication, or else are having a psychotic episode and believe that they

are in danger (Torrey, 2000). No mention of this was made in the article to alert the public that not all people with schizophrenia are violent.

Another article by SAPA (2005) entitled “Cresta stabber attacks inmate” also assumes a negative violent aspect to all mental illnesses. The article mentions that she was schizophrenic but did not even try to explain the exact nature of her mental illness and educate the public in understanding what would drive someone to commit such a violent act. The fact that the article referred to the young woman knowing she had a mental illness as the Cresta stabber and also that they published her name in the newspaper is an indication of how the media portray mental illnesses. The media should have been more respectful and sensitive to vulnerable members of society. As Wahl (1997) argues that the media is not empathetic and takes advantage of a vulnerable section of society. Wahl (1999) conducted a study where he interviewed people with severe mental illnesses to explore their perceptions and experiences of stigmatization. He found that most of the participants claimed that negative remarks and negative portrayal were extremely hurtful. The “results suggest that they are sensitive to such remarks, which serve as constant reminders of the low esteem in which they are held” (Wahl, 1999, p. 475).

Torrey, (2001) has a more optimistic view and claims that the media portrayal of mental illness specifically schizophrenia was not as negative as portrayed. Films such as *One Flew over the Cuckoo’s Nest* and *A Beautiful Mind* have managed to provide a more accurate and realistic account of schizophrenia and mental illnesses. In the film ‘*One Flew over the Cuckoo’s Nest*’, inmates were portrayed as normal human beings with normal problems and not as insane. Despite Torrey’s (2001) optimistic view of mental illness in the media, he does acknowledge that some movies do depict mental illness in a negative light.

This depiction of mental illness in the media adds to the misinformation and the stigmatization attached to mental illnesses. According to Goffman (1963), if a family member is diagnosed with a mental illness not only do they become stigmatized, but the rest of the family runs the same risk of stigmatization as well. In one of his case studies he states that when one parent was hospitalized, the other parent tried to conceal it by telling the children that the father was in hospital for a physical problem instead of a mental one. The wife explained that she did so to protect her child saying that;

“I live in horror – a perfect horror – that some people will make a crack about it to Jim” (her child) (Goffman, 1963, p.72).

This quote depicts the stigma associated with people who are institutionalised.

2.8 First person account of hospitalization

Being committed to a psychiatric hospital has huge implications on the person as “patients must make sense of why they are in the hospital, and what it says about who they are” (Lally, 1989, p.253). Patients have to combine their previously held perceptions of self with new definitions of what it means to be hospitalised. In psychiatric hospitals, patients have to face seclusion, forced medication and forced restraint. Also, existing beliefs of psychiatric hospitalisation housing crazy people play into the identity of self. As one patient with schizophrenia who was admitted to a psychiatric hospital stated:

“Like I had always looked down on mental institutions, like when I was in high school there was a guy who was 3 years ahead of me and he wound up in a hospital. And I would always look down on him, for just being in here, in a place like this. Then when I got here, it was like my life had ended” (Lally, 1989, p.159).

In a study carried by Dinos, Stevens, Serfaty, Weich and King (2004), they argue that the stigma of mental illnesses, specifically schizophrenia, has a huge implication as to whether a person will seek treatment. As they noted from a patient’s statement:

“I regret not going to the hospital. I listened to too many people and I suddenly thought I am going to be labelled a loony. I wasn't aware obviously because it hadn't happened to me before so I was...yes it did stop me from going there” (Dinos, et. al., 2004, p.178).

Lally (1989) also found that first admission to a psychiatric hospital was the most traumatic amongst patients’ subjective perceptions. The findings of this study are further supported by McGorrey, et al, 1991; Morrison, et al, 2003; Priebe, et al, 1998. In a study done by Mueser, Rosenberg, & Wolfe (2009), they found that the most distressing treatment experience reported by half of the participants involved involuntary hospitalisation and being physically restrained. Below are some experiences of people who had been restrained during their admission to a psychiatric ward.

“The first time it happened I was in this hospital i’d got transferred to. I was really frightened. I went to leave my room and the beepers went off and six nurses jumped on me... If someone had sat down and talked to me and explained what was going to happen it would probably have been different. I’d rather know it [being restrained] was a possibility so I could explain to myself how it was going to make me feel” (Ockwell, as cited in Hardcastle, et al, 2007, p. 49).

“It was years ago and I still remember it like yesterday. The first time was very traumatic...I’d never been in a psychiatric hospital before, I refused medication and I was held down and injected by six staff. What I feel really strongly about is that no one gave me a choice... They might have said to me you need medication, but no one said if you don’t take the medication we will have to force you to have an injection. If someone had talked to me instead of leaving me on my own in a room, and explained what my choices were...There would have been no need to hold me down and inject me which I interpreted as a physical assault...added to the trauma that I’d already experienced in my home, being yanked out to an ambulance,...it was a very nasty experience” (Ockwell, as cited in Hardcastle, et al, 2007, p. 49).

These accounts raise issues of re-traumatisation for persons who have already in the past been victims of traumatic experiences which are likely to reinforce feelings of worthlessness and violation (Hardcastle, et. al, 2007). As one patient stated

“At the time I accepted it. When you are that low you don’t think you deserve to be treated like a human being. I felt violated” (p.49).

According to Hardcastle, et al, (2007) in an acute psychiatric wards the majority of people had damaging experiences, and by being restrained reinforces the damage and traumatic experiences. In a study carried out by Lampshire, (2009), he noted persons with psychosis first account of mental health professionals. One participant stated that:

I sat in front of the psychiatrist and we spoke of private, personal things with no introduction. I was twelve, he was a hundred. He asked me embarrassing questions about sex and boys, trying to extract answers that I didn’t want my parents to know about: I knew that everything I said to him would be repeated to my parents so I lied profusely” (Lampshire, 2009, p.180).

In a study conducted by Schulze and Angermeyer (2003), they noticed that patients who were hospitalised felt stigmatised by psychiatric hospitals. They found that participants expressed that psychiatric hospitals used a standard treatment for all patients with mental problems. As one participant stated;

“And when you get to the hospital, the first thing is sedation. Nobody is talking to you. You have no idea what is going on. And then all patients get the same drug, no matter what’s the history of their problem, and it’s only after a few days that a patient is asked what is actually wrong with him”
Participant E. (Schulze & Angermeyer, 2003, p. 304).

In the majority of these research studies, it is evident that people diagnosed with psychotic disorders can experience symptoms of PTSD. These symptoms could be accounted for as a result of traumatic experiences encountered during hospitalization, specifically during first admission to a psychiatric facility (McGorrey, et al, 1991; Morrison, et al, 2003; Priebe, et al, 1998).

Looking through extensive research, and to the researcher’s knowledge, there is no qualitative study specifically looking at first person accounts of acute psychosis on first time admissions to a hospital.

Research into first person experiences of diseases and other mental diseases such as depression has helped understand and improve existing treatment programmes (Torrey, 2001). Magliano et al., (2008) did a study in Italy focusing on patients’ perceptions of schizophrenia. This research was the first to be carried out in Italy and has led to the study’s results being used to help develop intervention programs at clinics. Research exploring the experience of first time admission to a psychiatric hospital of persons with schizophrenia might also help to develop interventions programmes to help ease first time admissions to a psychiatric hospital for acute psychosis.

Another illustration of how patients’ perceptions of their own disorder can help develop intervention programmes can be seen in a study conducted by Haan, Peters, Dingeman, Wouters and Linszen (2002) which focused on the attitudes of patients toward the first psychotic episode and the start of treatment. The findings of the study suggested that “Nearly 43 percent of patients gave suggestions regarding earlier treatment. Most of them (14 patients, 25% of the total group) thought they themselves were responsible for the treatment delay. Five patients (9%) thought more information and publicity about prodromes of psychosis and treatment options would help get treatment started earlier. Five patients (9%) thought professionals should ask more in-depth questions” (p.435). Each of these findings

could be used to help create intervention programmes that would help eliminate the stigma of psychotic disorders as well as help develop early intervention programmes.

The recognition of the value of talking to patients on their perspectives on schizophrenia is, in itself, empowering to the patient. The subjective accounts of people with schizophrenia also encourage empathy and reflection in health care providers (Stanton & David, 2000). “Taking the patient’s phenomenology into account may explain how a variety of risk factors and supports are idiosyncratically perceived and weighed to arrive at their meaning for the given patient” (Drake & Wallach, 1988, p. 29).

2.9 Research Question

What are the experiences of first time admissions to a South African psychiatric hospital ward amongst persons diagnosed with schizophrenia?

CHAPTER 3: METHODOLOGY

3.1 Research design

Since this project aimed to explore the experience of people with schizophrenia about their first admission to a psychiatric hospital, the most obvious method was to draw on qualitative methods. Qualitative research focuses on “meaning through the eliciting and describing of stories of the experiences of everyday life that embody the phenomena of interest and the understanding of these experiences through analysis and interpretation of the meanings that are both explicit and implicit in them” (McKay, 2008, 255). Bryman (2004) highlighted that the qualitative approach emphasizes the ways in which people interpret their social worlds. By using a qualitative approach this study allowed for an exploration into the perceptions of first time admissions to psychiatric hospital amongst South African persons with schizophrenia. “Exploratory studies are used to make preliminary investigations into relatively unknown areas of research” (Terre Blanche & Durheim, 1999, p. 39). This research drew on an interpretive phenomenological paradigm as the main aim was to understand participants’ subjective experiences. “Interpretive methodologies focus primarily on understanding and accounting for the meaning of human experiences and actions” (Fossey, Harvey, McDermott, & Davidson, 2002, p. 720).

This study was a cross-sectional study, as opposed to a longitudinal study, as participants with schizophrenia were interviewed only once and not over a period of time. A cross-sectional approach was preferred as this study aimed to look at participants’ experiences of first time admissions to a psychiatric hospital, rather than comparing their experiences over a period of time. It also allowed for some comparison of experiences across cases, to allow not only commonalities, but also differences to be observed. “Methods that consider schizophrenics “from the inside” represent important tools in advancing our understanding of help seeking and illness experience in subjectively nuanced ways” (Judge, Estroff, Perkins & Penn, 2008, p.99). This qualitative approach allowed for the incorporation of special interpretation into the research.

3.2 Sampling Method

Non-probability sampling methods were used in this study as it was the most appropriate method of convenience (Gobo, 2004). The type of non-probability sampling best suited for this type of sample is purposive sampling. Purposive sampling “consists of detecting cases

within extreme situations as for certain characteristics or cases within a wide range of situations in order to maximize variation....”(Gobo, 2004, p. 448). Participants were chosen on the criteria that they were formally diagnosed with schizophrenia and that they were no longer actively psychotic at the time of the interview. This was accomplished by the researcher who enquired which members of the half way house were diagnosed with schizophrenia. No other criteria such as age, gender or race were employed in acquiring the sample. The reason for not including any other criteria was that schizophrenia is a rare disorder and including the above criteria would have made it challenging to obtain a sample.

Viva Youth College had initially been chosen for the samples as it is a half-way house which specialises in people diagnosed with biochemical imbalances, such as schizophrenia and bipolar disorder. However, at the time of the study there were no residents with schizophrenia at the half-way house. Consequently, the researcher then approached the Central Gauteng Mental Health Society (CGHMS) and interviewed participants from their half way house, Gordonia. The staff members at Gordonia approached the residents that they felt would be suitable to participate in the research. The suitability of each participant was based a diagnosis of schizophrenia, mental stability and previous psychiatric admissions. At the time of the research, Gordonia had 80 residents with mental illnesses living there.

3.3 Participants

As this was a qualitative study, the proposed sample size was between 6 and 8 participants. Interviewing participants until saturation would have been ideal. However, given the time-limited nature of the study only 7 participants were interviewed. Another reason for only including 7 participants was that people with schizophrenia form part of a relatively small population and access to participants with schizophrenia could have been difficult. Secondly, since this study was conducted with a sensitive population, in order to minimize the impact on people with schizophrenia, only a small sample size was used. Seven participants who lived at Gordonia were interviewed. They were all Caucasian and between the ages of 24 and 54. Five of the participants were males and two were females. All participants were South African citizens and had had more than two admissions to a psychiatric hospital.

3.4 Data collection: semi-structured individual interviews

Since this study aimed at exploring perceptions of people with schizophrenia on first time admissions into psychiatric hospitals, the best method for gaining information was by conducting semi-structured in-depth interviews. In-depth interviews took the form of a conversation with a clear purpose which was to “learn about the participant’s perspective and experiences” (Greenstein, Roberts & Sitas, 2003, p. 57). According to Legard, Keegan and Ward (2003) in-depth interviews allow for greater flexibility as they make it possible for the interviewer to clarify the participants’ responses by probing. Researchers are also able to use an observational method to observe whether what the participant is saying is in congruence with their facial and body language (Greenstein et al, 2003).

Semi-structured interviews were guided by specific issues. However, there was no specific order in which the topics were covered. “This format makes data collection more systematic than in unstructured interview while allowing the interview to be flexible and somewhat conversational” (Whitely, 2001, p.323). Some of the main benefits of using semi-structured interviews are that it is directed towards studying natural everyday events, it allows for flexibility and openness of information gathered. Semi-structured interviews are not strictly standardised and therefore allow for adjustment and correction of the study as required (Gobo, 2004).

Each interview conducted consisted of open ended questions. A semi-structured interview was extremely useful as the researcher was able to gain rich and in-depth information. Types of questions included in the interview schedule ranged from general questions such as ‘When were you first admitted to a psychiatric hospital?’ The main reason behind asking such basic questions so early on in the interview process was to be able to create a rapport with the participant before delving into more sensitive questions. Other questions such as, “Can you tell me a bit about your first experience of being in a psychiatric hospital?” “Did you think you required psychiatric treatment”? (Refer to appendix H). Some of these questions were adapted from a quantitative study using closed ended questions conducted by Haan, et al, (2002) which looked at the attitudes of patients toward the first psychotic episode and the start of treatment. Other questions were derived by looking at the relevant literature in the field. It is important to note that because of the sensitive nature of this study, the researcher

did not probe any of the participants' responses. Instead the researcher replied with containing reflections.

3.5 Procedure

The first step in the procedure entailed getting consent to conduct the research from the University of Witwatersrand ethics committee. Once ethical clearance had been granted by the university, the next step was to approach the director of the half way house to give consent to approach and to invite the caregivers to participate in the study. Once that permission was granted, the potential participants were approached. Information sheets were given to all potential participants. Each participant who agreed to partake in the study was handed consent forms. Each participant gave consent by signing the form before the interview was carried out. All participants were made aware that participation was entirely voluntary and that, as far as possible, all the information gathered would be kept confidential. Refer to Appendix H.

Participants were all briefed on the aims of the research as well as the procedure. All the interviews were conducted at the half-way house at a suitable time for the participants (Gobo, 2004). The in-depth interviews were conducted individually.. The length of each interview varied from 20 minutes to 45 minutes.

3.6 Ethical Considerations

Due to the number of ethical issues this research topic might raise, all ethical concerns were taken into account before conducting any research.

All research concerned with human beings can pose ethical dilemmas. Schizophrenics are people who suffer from mental disorders due to symptoms of delusions/hallucinations (Torrey, 2001). These symptoms can trigger negative reactions in individuals due to high levels of stress, or simply due to the recurrence of their disorder. When this type of situation arises, there is a risk that the person's health could be affected which could worsen the person's situation. It is important that all aspects of vulnerability of the vulnerable population in society are taken into consideration before conducting research on them. "It is important to emphasize that the issue of not harming people is of particular concern when we investigate

certain more 'vulnerable' groups in society. Some 'populations' in society are more at risk as far as science is concerned" (Babbie & Mouton, 2001, p. 523).

The following ethical considerations were of vital consideration before conducting this project.

Firstly, ethics clearance was obtained through the University of Witwatersrand. Secondly, since this research was being conducted at a half way house as well as two support groups, permission was needed from the Institute. The director of the half way house, as well as the directors of the support groups, gave written permission to conduct research at their premises as well as given consent to interviewing volunteer participants. (Refer to Appendices C, E and F)

Approval from every voluntary participant was gained through consent forms. (Refer to Appendix G). All participants were briefed on the research being carried out. It was clearly stated that participation was completely voluntary and that if they chose to participate they could freely withdraw from the study at any time during the interview process (Willig & Stainton-Rodgers, 2008). Also participants were made aware that the information gathered is solely for research purposes and that no aspect of their identities would be revealed at any stage in the research project. Since this research dealt with a particularly sensitive issue it was only logical to ensure that all participants had access to free counselling. It was discussed with members of staff at the half-way house, who already have existing structures of containment, to develop a coherent plan should any participants experience any negative effects from participating. None of the participants required containment after the individual interviews. Staff members at the half way house agreed to check up on all residents who participated in the study and to provide containment should any residents encounter any negative effects from participating in the study. Additionally, participants were also given access to a clinical psychologist at TARA hospital, Psychology department who agreed to provide free counselling to any participant who encountered any negative effect due to partaking in the study.

Lastly, it was important to note to all participants that all attempts would be taken to ensure confidentiality. Since this study made use of direct quotes of participants, the participants were made aware that the research would ensure that all identification information would be

removed from the quote in order to protect the participant's identity. Pseudonyms have been used to help protect participants' identities.

3.7 Data analysis: Thematic content analysis

Due to the nature of this study, the researcher gained large volumes of information from the in-depth, semi-structured interviews. The way the researcher overcame this challenge of sorting so much information was to place the data into relevant themes (Legard et al, 2003). This method of data analysis is termed thematic content analysis. Thematic content analysis "entails the systematic examination of forms of communication in order to identify patterns emerging from the data" (Greenstein, et al. p. 66). This method helped code the information gathered into more manageable components.

The first step was to transcribe the interviews. This involved transcribing each interview into a written format on the computer. The second step was coding the data. "This entails marking different sections of the data as being instances of, or relevant to, one or more of your themes" (Terre Blanch & Durheim, 1999, p. 143). The third step involved the researcher immersing and familiarising herself with the data. The next step involved reducing the amount of data. "This refers to the process of manipulating, integrating, transforming and highlighting the data while they are being presented"(Sarantakos, 1998, p. 315). This helped to focus the data collection as it included careful reading of the material and identifying the main themes.

The following step involved data organisation. "This is the process of assembling information around certain themes and points, categorising information in more specific terms and presenting the results in some form" (Sarantakos, 1998, p. 316). As Legard, et al. (2003) state that this would help create structure and make the analysis process easier. The themes also helped to illustrate any similarities or differences that might be evident in the participants' perceptions. Legard, et al. (2003) further pointed out themes which would also help in identifying any gaps within the literature review as well as in the research being conducted. The final step was to interpret the data. This step involved making decisions and drawing conclusions. It also involved identifying patterns and finding regularities in the data.

It is important to note, some of the limitations of thematic content analysis which include the fact that it could be extremely time consuming if not carried out correctly. Furthermore, one had to be aware of the context in which the research was conducted as thematic content analyses often disregard the context (Legard, et al. 2003). As this study is an exploratory study, no generalisations can be made as the data provides a subjective experience of participants interviewed and will, in no way, be a reflection of the experience of all people diagnosed with Schizophrenia. Another limitation is that the researcher is the one who ultimately shapes the material of the research from a subjective perspective.

Chapter 4: Results

In order to make sense of the data, this section has been divided into main themes which have been partly derived from the literature review (reified in the data) and partly driven by the data itself. It should be noted that within these overarching themes, sub-themes exist. It is also important to note that due to the large amount of data collected, only sections of the data that the researcher felt were most appropriate and that contributed significantly in establishing the objectives of this research were used. Direct quotes from the transcribed data have therefore been presented in order to substantiate and represent the themes and general findings which emerged from the analysis of the data. The main themes and sub themes are listed below.

4.1 Treatment

- 4.1.1 Medication
- 4.1.2 Needles
- 4.1.3 Occupational therapy
- 4.1.4 ECT

4.2 Perceptions of hospitalisation

- 4.2.1 Preconceived ideas and attitudes
- 4.2.2 Attitudes after hospitalisation

4.3 Incarceration

- 4.3.1 Isolation
- 4.3.2 Containing

4.4 Diagnosis of Schizophrenia

4.5 Stigmatization

- 4.5.1.1 Work place

4.6 Police / Law enforcement

4.7 Social Interactions during hospitalisation

- 4.7.1 Other Patients
- 4.7.2 Staff Members
- 4.7.3 Family Members

4.1. Theme 1: Treatment

In this theme, treatment is associated with the experiences of medication, needles, occupational therapy and electroconvulsive therapy (ECT). One of the key sub themes which emerged through the interview process was the role of medication. The majority of the participants questioned the role of medication and highlighted the negative experiences they

attributed to medication. The next few quotes illustrate participants' experiences of medication.

4.1.1 Medication

"The medication they gave me at Tara. I was so restless I couldn't sit still. I didn't know whether to lie down, whether to sit, whether to stand, to walk. I was just walking all over the place. I think it was Haloperidol, I'm not sure. They put me on that drug and I couldn't have a moments peace I was just up and up all the time, I couldn't relax and they took it off me eventually when I got here and then I started calming down" (Participant R).

"I think that was what actually made it bad for me, is the side effects from my medication but further the place wasn't that bad and the people were ok. It was the medication and the side effects of it. I suppose not taking that type of medication before and all of a sudden into your body it feels very odd... very irritable, I was very irritable, uh uncomfortable and that. Apparently they were trying to sedate me. I was actually feeling the quite opposite" (Participant G).

"Well they gave me a lot of medication and my head was going like this, I don't know if they gave me the wrong stuff, it was going like this and I didn't want to go and eat down there with all the other people because they're not well. I couldn't enjoy my meal, they were eating badly" (Participant P).

All participants appeared to experience negative side effects of the medication during their first psychiatric admission, as well as seemingly attributed a variety of bad experiences to the medication. It appears that participant P and BR both question whether they were given the correct medication. Participant P questions the role that medication plays. Some participants also commented on their experience of being injected with medication.

4.1.2 Needles

Half of the participants interviewed commented on their experience of needles, and their first experience of injection in a hospital context, which was usually described as coerced. For most of these participants, these experiences with needles were often described as fearful, painful, confusing or traumatising in some way.

"because I knew they wanted to bend my mind and change what I believed in and uh I went in this room and some guy with the glasses on walked around with an injection needle and said, come let me inject you" (Participant Br).

"Yes and when they come with needles and medication and they injected me, I was very scared of needles because at Town Hill they got into muscle, do you know how sore that is?" (Participant P).

I was in a research ward for almost 5 years you know experimenting different kinds of tablets and injections there could be used on people outside and in the hospital as well. It did affect me then (Participant PU).

Not all participants commented on their experiences of needles. However, participants who did express their experiences appeared to describe themselves as extremely frightened at the time. For participant BR it seems as though she viewed the injections as a method of as a way “to bend my mind”. For participant P, the physical pain associated with injections caused her great fear. Participant PU seemed to view the injections and medication as a research experiment instead of receiving treatment; as for participant BR, the first experience of coerced injection seems couched in a delusional or paranoid understanding of the purpose of the injection that is persecutory in nature. Overall it appears that all the participant’s descriptions are of passivity and victimisation. They appear to ascribe no agency to themselves in these situations.

4.1.3 *Occupation therapy*

Three out of the seven participants commented on their experience of occupational therapy. All participants made very general positive comments on the role of occupational therapy.

“But what I liked about it was the uh um, what do you call it again, Occupational Therapy. We did nice things. The Occupational Therapy was nice. It was soothing and helpful to do the Occupational Therapy and we did nice things and I brought nice things home” (Participant O).

All the participants who spoke about occupational therapy described it as nice and soothing. It also seemed to be experienced as one of the more positive aspects of the hospital.

4.1.4 *ECT*

Since a few of the participants were older, it was expected that some would have an experience of ECT, however only one participant mentioned it.

“Um, if you went according to the rules you could have a normal life but if you do anything wrong you will be severely punished you know. I had a lot of shock treatment and a lot of lumbar punctures” (Participant PU).

From participant PU’s perception it appears as though ECT was used as a method of punishment rather than a method of treatment, and is experienced as a means of authoritarian control. For this participant it also appears as though other medical treatments, such as a lumbar puncture, were used as a method of punishment, not treatment.

4.2. Theme 2: Perceptions of psychiatric hospitalisation

4.2.1. Preconceived ideas and Attitudes

The majority of the participants interviewed reported that they had negative preconceived ideas of hospitalisation before being admitted to a psychiatric hospital for the first time. The following quotes are illustrative of this.

“I thought they were places where you were strapped up and kept in a cell and drugged and they did lot so what do they call it, you know when they do something to your head...umm shock treatment and that type of thing” (Participant R).

“Hospitals. Maybe well it was something that takes over your life you know, it’s something strange like you don’t have the freedom to do what you want to do” (Participant BL).

“I had a bad view of them because the name Sterk, I wasn’t at Sterkfontein ever, but the name Sterkfontein conjures up for me um Sterk in badness, strong in badness and it’s a place where it’s not too kosher. Because I thought this is the worst that can ever happen to a person” (Participant O).

“You know just what I saw in the movies people in big glasses with big injection needles you know. And uh it never really occurred to me that I would go there one day, you know what I’m saying and then I landed up there” (Participant BR).

It is apparent that the participant’s perceptions of psychiatric hospitals were all extremely negative before their first admission. For Participant R, psychiatric hospitals seemed to be a place of torture where a person did not have any say about what happened to them. For BL, it was a place where your freedom was taken away. Participant BR’s perception of hospitalisation seemed to be based on films and media reports.

4.2.2 Attitudes after hospitalisation

Some of the participants also described how their preconceived attitudes towards psychiatric hospitalisation changed after their first hospitalised experience.

“I’m petrified to go to hospitals, I’m petrified. A lot of my friends have died there” (Participant P).

“Terrible. It’s like a hell hole you know. I don’t know what happened, my spirit left me, my mind left me, I was a Zombie. That was one of my worst experiences in my life” (Participant Br).

For participant P, it appeared as though her experiences of being hospitalised and having friends who had died while hospitalised, have really scared her. Both quotes seem to imply that the hospital setting became linked to a fear of dying. Some participants stated that their perception after being hospitalised had changed, becoming more positive.

“But my experience in the hospital was not what I had imagined. It was quite pleasant. Well the fact that I had a roof over my head because I didn’t, I had been on the street for seven years, on and off. Ja, you had three main meals, and you had tea time and you had another tea time, supper time and then after supper you would come back to the ward, and then you’d take your meds and then you would have a few sandwiches to eat before you went to bed” (Participant R).

“Also the food was nice” (Participant O).

“You get coffee there and had nice lunches, and stuff so it was alright You know” (Participant B).

“Until I got used to it and then it wasn’t so bad, it was a nice place though you know. They take care of you, keep you clean and they make sure that you are clean all the time and that you eat well” (Participant PU).

It was interesting to note that all the participants interviewed said that there was one common positive aspect of being hospitalised. This was the food. Some participants spoke about the regularity, structure, and hygiene that the hospital provided them, as well as the experience of being cared for.

4.3. Theme 3: Incarceration

4.3.1 Isolation

While no direct question about incarceration and isolation were asked, it was evident from participant’s statements that they all appeared to have some experience of social isolation in their first hospitalisation experience.

“Ja, the closed wards. You can’t go out, there’s nothing around you, and you feel isolated from everything. Um you know you can’t actually see your friends that you used to have, not nuts about that...Ja, you actually lose contact with everyone you used to know, you know when you’re in there. When you actually get released or discharged or whatever, then you’ve got to start all over again, you’ve got to make new friends usually”. (Participant G).

“Um. The first time I got there I was very afraid. They [my family] were asked to stop and sort of back off and leave me until I was stable and whatever” (Participant PU).

“But I was lonely because no-one, none of the ladies spoke to me....”
(Participant O).

These participants all described being isolated from society while being hospitalised, finding it difficult to socialise while in hospital, and in some cases some damage being done to existing social relationships through the hospitalisation, particularly family. One participant described losing all her existing friendships in her first hospitalisation.

For participant O being isolated from family members and friends and being in a new environment, was quite lonely for her.

4.3.2 Containment

The hospital was also described as a positive, containing environment. Below is a quote illustrative of this.

“And also there was a library I used to like. I used to visit the library and browse around and also there was a nice big garden. I used to go right down to the bottom of the garden where there was a wall broken down as if they let people escape if they want to, I don’t know but I used to sit there by myself and just sit there and walk in the garden and sit in the garden. The garden was very special” (Participant O).

For Participant O, the hospital garden and library seemed to provide some containment and comfort to her. Other participants stated that it provided a containing environment for them in different ways.

“Well the fact that I had a roof over my head because I didn’t, I had been on the street for seven years, on and off...living in a ward and you felt safe and secure and you could walk around the gardens and it was fine you know”.

“Get cleaned up, get changed and go to breakfast or wait for breakfast or wait for the time for breakfast, go to breakfast, come back, take your morning meds then wait around until tea time and just uh on weekends you could do whatever you wanted, you know go out to around the fields or whatever but during the week you would have to attend OT. At lunchtime you would go to lunch and come back and they’d let you sleep for a while if I remember until afternoon and then you’d sit outside in the corridor where you had chairs and benches, JA you used to sit there. You weren’t allowed to lie on your bed, you know” (Participant R).

“I was in an open ward and there was big ground there and met nice people there” (Participant Br).

For R the structure and routine provided by the psychiatric hospital seemed to provide him with the safety and security. The routine of knowing that he would have meal times, a place to sleep and the necessary treatment provided him with a great sense of relief and safety. It is also interesting to note that for participant Br being admitted to a psychiatric hospital provided him with social interactions with the other patients.

4.4. Theme 4: Diagnosis

Being formally diagnosed with a mental disorder, such as schizophrenia, can be very traumatic. Below is a quote illustrating how participant PU describes his life prior to being hospitalised and diagnosed with schizophrenia.

“No I was normal. I was a Boxer, a Tradesman, I was a soccer player. I lived a healthy good life. I was an athlete and then I had an accident and I ended up dead and I was brought back to life you know. And ever since that time I have never been the same again. I mean sickly sort of” (Participant PU).

For participant PU it was evident that being hospitalised and diagnosed with schizophrenia had caused him a great sense of loss. He was now unable to do a lot of the things that he had been able to do in the past, such as being a boxer, tradesman and soccer player. For him, having a mental illness has robbed him of his vocation and social identity. Another participant stated:

“Like I once I went to the hospital and the doctor said to someone on the phone that I’m a known schizophrenic and that, he was probably explaining to the hospital staff that I’ve got a mental illness. When I was in hospital another time a Psychiatrist and a Psychologist wrote a report that I had mental illness and I thought that this is all rubbish and you know it made me feel more persecuted, I thought you know ja, well you know it definitely made me feel all angry and that you know” (Participant G).

“I didn’t know what it [schizophrenia] was so I brushed it aside, I didn’t accept it. I didn’t know, I read the letter later and I didn’t know what the letter meant, what it meant but I just brushed it aside and ignored it and decided to carry on my life as usual when I got out of Tara .But I couldn’t live as usual because I had been boarded from teaching and that was the love of my life” (Participant O). “I also want to tell you I lost my children because my first husband, I’ve had two husbands, I’ve been married and divorced twice, and I had three children from my first marriage and one from my second and the three children my husband went to the Welfare and said that she’s a nutty,

she doesn't know what she's doing, um she needs a lot of rest and the children had to suffer. I had to put them in bed at 6 o'clock but they were 4 and 2 but that's not right actually, so the Welfare took them away from me" (Participant O).

For Participant O, after being admitted to a psychiatric hospital, it was difficult for her to return to her normal life, primarily work and family. Having been admitted to a psychiatric hospital and being diagnosed with a mental illness was not easy to ignore as it affected her life prior to the hospitalisation. O was seen as unfit and unable to teach, she was unable to take care of her children and the welfare had removed the children from her custody.

"Well I thought they were in the same boat as me and I said to myself, well can I be in this bad position, how did I get here. You know. How am I going to get out of this, what's going to happen next, I didn't know. Mm. And even today I say how am I going to get out of here [halfway house] because I don't want to die here. What am I going to do? You know I used to do aircraft maintenance, Ja before I got sick. And um I used to enjoy it, I had my own life and Ja, I enjoyed my life to an extent. Much more than I do now. Then there was no work. Then I was on the street and I lost my flat, lost my car. I used to write maintenance manuals for Armscor I was quite proficient at it. They always seemed to like my work" (Participant R).

For participant R, diagnosis was described as having lost him his career. For all the participants, it appeared as though their initial diagnosis of schizophrenia caused them great loss. Many described it as a label which they were unable to shake off.

4.5. Theme 5: Stigmatization

While there was no direct question regarding stigmatization, it became apparent that each participant spoke about the stigma that became attached to their first hospitalisation experience. As one participant described how he perceived people in psychiatric hospitals.

"Well I thought to myself that I thought that they are really crazy or something's wrong with them, I really didn't believe that there was anything wrong with me. I didn't want to believe that here is anything wrong with me. No-one really explained to me what mental illnesses are. I think that my parents have a stigma, that I'm crazy or something" (Participant G).

For Participant G, being admitted to a psychiatric hospital and coming to terms with his mental illness was extremely difficult as he felt there was a stigma attached to mental illness. It appeared easier for G to deny his mental illness rather than face the stigma that he and his family had attached to mental illnesses.

Another participant stated;

“Once you come from there, life outside is never the same? People seem to reject us because they know we have that psychiatric problem. I umm once people know that you have a mental illness you’re sort of hostile heh, by society outside you know especially if you’ve been locked up like me” (Participant PU).

“I’m embarrassed about mental illness and I’ve got both illnesses. Schizophrenia and Bipolar. To have a mental illness is not pleasant. I’m very scared. People with mental illness, I don’t want to run them down but people act different at different times, you never know when they’re going to spark off” (Participant P).

What seemed to be common among all participants’ points of view is that a stigma was present in any talk about mental illnesses. For Participant PU, the consequence of being admitted to psychiatric hospital was that society placed a stigma on you. PU appeared to be quite hopeless about this stigma attached to people who were hospitalised; this was made apparent as she stated “Once you come from there, life outside is never the same”. Participant P acknowledged that she has a mental illness, however it seems apparent that she self stigmatises herself and other people with mental illnesses as dangerous and unpredictable.

4.5.1 Workplace

For most participants, it appeared that after the first admission to a psychiatric hospital and being diagnosed with schizophrenia their lives were no longer the same. One participant stated how difficult it was for her to find a job after being hospitalised with a mental illness.

“Also I was boarded, I used to be a teacher of Grade 2 and Standard 1 and the headmaster got me boarded because I went to Tara, till I but two years later I got unboarded, I went back so I can still teach but it’s too much for me. It’s impossible I can’t cope. So I really suffered and then I remember I worked at one stage, I worked at all the menial jobs in the bank, West bank in Braamfontein in that big building” (Participant O).

“Um once people know that you have a mental illness you’re seen as sort of hostile heh, by society outside you know especially if you’ve been locked up like me. It is difficult like to get jobs. I have had many good jobs outside here but once they find out that I take tablets and what, the next thing the employment shrinks all of a sudden and there’s no more work. They think that we’re not all there in our heads and we’re going to damage their properties and whatever and yet when we finished they all wanted to come and apologise and be nice” (Participant PU).

4.6. Theme 6: Police / Law enforcement

It was apparent that most of the participants had some encounter with the law enforcement during their first psychiatric admission. For the majority of participants it appears that their encounter with law was against their will.

“So there they called the police and they came and saw the damage to the house and they saw this and they said no, there must be something wrong with this guy” (Participant R).

“The courts. Ja. You have to be diagnosed by the doctor and then the doctor thinks you need a rest or something then you go to the court and they will send you” (Participant PU).

“No that’s trauma hey, that’s a big mission. I’ve been in the back of police vans and put in jail all over the place, Ja I’ve been attacking people. Not really attacking people, once people got me in their grip I don’t attack them but I’ve been attacking people in the streets and that, well paranoid you know. I’ve sworn people and I got hit you know and then one day somebody swore me and I hit him you know. They could have killed me you know, my life’s in danger (inaudible) because you’re in crowds of people you know and any time early morning hours in the street, because I always land up in the street you know. Well it’s terrible. You first have to have the injection and go to see people in offices together to get signatures. It’s still against your will, although you’re sick you know it’s still fully against your will” (Participant Br).

Participant Br’s encounter with law seemed to be traumatic for him. He emphasised that the entire hospitalisation admission was against his will. He described how he was forced to have injections and to see people to get signatures. While Br acknowledged that he was sick, he still seemed to emphasise that it did not make the process of being forced to be admitted any easier.

4.7. Theme 7: Social Interaction during hospitalisation

4.7.1. Other Patients

Some of the participants stated that they had a good relationship with other patients in the ward. The majority of these participants interviewed stated that one of the most positive experiences of being hospitalised was that they made friends with other patients in the hospital.

“I had one or two friends there. Um, the odd girl, they weren’t girl friends they were just friends that I met there and one or two guys that I met there. I wasn’t really outgoing at that stage you know” (Participant R).

“Well in Tara I think it was the fact that you could mix with girls, boys and girls were allowed to mix with each other and um I had a nice friend in Tara, another guy who was my age, and that’s about all. Uh well I got along quite well with the other people there I didn’t really have fights or arguments. I got along well with everyone basically” (Participant G).

“Um, you meet friends and they sort of put you on the right track and help you. Others never go home, they stay there and they become like your family in the end there you know. You know them very well. White and Black and Indian and Coloured all stick together. I had a very good Indian friend there, and he was there, he’s there for the rest of his life” (Participant PU).

For participant G, making friends and not getting into any fights was important for him. For Participant PU making friends at the hospital helped her with her recovery as they were felt to become like her family. It provided her with social opportunities, and experiences of racial integration which appeared to have been positively experienced. More than half of the participants stated that they had a negative experience of other patients in the wards. These participants experienced other patients in the ward as being extremely frightening. They all reported having witnessed violence and feared that the same would happen to them.

“Well, the people used to drive me crazy there because they weren’t well and they used to do silly things and there was this girl who was locked up in one of the cells and she would scream. I was very scared. Yes. It’s a hard life in these hospitals. They lock us up” (Participant P).

“The fighting in the hospitals. I’m very scared. People with mental illness, I don’t want to run them down but people act different at different times, you never know when they’re going to spark off. I was only there for four days but this girl Ingrid was cutting her wrist with glass and my other friend ***, her name’s *****, she said come I’m going for a walk so we went for a walk to this other ward, big wards, big, big, big and there were lots of people and it’s very sad. We went to this ward and we were sitting and chatting and what what what. In the evening this other girl started kissing her and she said you, if you report me I’ll slit your throat” (Participant P).

“No, I saw somebody just attacking someone and thrown on the floor and kicked him in his head a long time and saw the blood. Ja you know you want to help the guy but you know there’s backup for the other guy so you just stay out of it. I don’t know if it’s your soul that leaves you or your spirit that leaves you, it’s just a brain, but it’s nothing else. Nothing else, no feeling no nothing, just pain” (Participant Br).

“Yes because it was such a terrible shock and I remember seeing a man swinging a belt or a chain or something, I can’t remember, in the garden and going crazy and I was scared” (Participant O).

Each of these participants appeared to be afraid of other participants, particularly because of witnessing or experiencing acts of violence, intimidation, and feeling ‘ganged up’ on. For Participant P, her fear was that patients were unpredictable and that they were able to turn on you at any time without any warning. She also described the difficulty of being exposed to other patient’s profound stress for long periods of time. For Participant BR, it was the difficulty in watching someone else getting beaten up, and not being able to do anything as he was fearful that someone else would attack him. For Participant O, seeing people doing strange things was a great shock for her which made her scared to interact with them.

4.7.2 Staff members

Some participants seemed to have rather mixed feelings of the staff members at the psychiatric hospitals. This is illustrative in the following quotes.

“Well some nurses I didn’t get along with but I mean it’s only because I didn’t want to be in that position. But it was better than where I was before and it was just difficult trying to get used to the environment as well even though I was better off than where I was before. I got along with them. A lot of things they said about me was wrong but it was their perception I suppose because I read my file” (Participant R).

“And the staff there , it’s difficult to make, you know as a need there, for a person to take a hat trick you need, especially when you just come right, and you’re in the environment , in the hospital, you can’t blame the staff but you need that support. There’s somebody from the outside world, you look up to him and you just need some comfort from them and you’re still a person, that’s what you need from them and you do get it, you do get it but they tend to keep to themselves, the staff talk to the staff and the patients to the patient you understand” (Participant Br).

From the responses above of participants on their relationship with staff members, it seemed as though most of them express an ambivalent relationship with the staff. For example, participant R stated that his relationship with staff members was not great. However, he also suggested that it might have been because he was unhappy to be there and not necessarily because of the nurses. He also seemed to be suggesting that staff members had an inaccurate perception of him but he seemed to express tolerance for this. For Participant Br, it appeared as though he acknowledged the important role the staff members played in his healing. A part of him seemed to suggest that he respected them. This was made evident when he stated that “you look up to them” while another part of him suggested that that he did not feel they gave him exactly what he needed and in some sense viewed them as withholding. This was made evident when he stated “they tend to keep to themselves”. This is in contrast to other

participants who expressed a more negative experience with regard to their interactions with staff members.

“If you’re rebellious you’ll be beaten and whatever, whatever goes around there. They hit you and kick you, or give you tablets you won’t know what you are doing and you collapse, and they’ll beat you” (Participant PU).

“And they bath you and they shower you, it’s embarrassing. Like I had with me at Town Hill and I asked him please to get me something I need to urinate. They didn’t come so I just weed on the floor. I didn’t have an option and they gave me a little thick mattress like that to sleep on the floor. “I just hear my voice and I say, please, please come and help me. They were laughing at me. And when the girls fight, I don’t like that heh” (Participant P).

For participant PU, not conforming to the rules within the hospital would result in negative consequences such as being forced to take medication you unsure of, as well as being beaten. For participant P, the nurses are described as being in a position of power which they are regularly abuse.

4.7.3 Family Members

A few participants stated that they did not have a good relationship with family members during their initial hospitalisation.

“I was angry with them a little bit or a bit much, I thought you know how they could put me here and all that. I had a lot of regrets in me with me towards them and for putting me in rehab and all that stuff” (Participant G).

It appeared as though G held his parents responsible for admitting him to a psychiatric hospital, and felt very much betrayed. Another participant relayed her experience of being abandoned by all her family members after she was diagnosed with a mental illness.

“I was staying in a Mission because my parents paid for me to stay there because they couldn’t afford to take me with them to live in Spain and my brothers couldn’t take me because they had small children and there was no place for me so I was in Missions. I don’t know if you know what Missions are, like a settlement. It’s a dreadful place. It’s places where families um where families who don’t want their families with them because usually they are alcoholics, hobos who come in from the street. Alcoholics steal your clothes and your things. I had to keep my clothes locked up” (Participant O).

“Well my mom’s retired now, she’s in Greece, she’s 70 years old now and I’ve got a few brothers, half brothers who are around who don’t come and visit me. I’ve got one brother who comes but he wants things from me and I can’t help him you know because he’s also virtually on the street so he comes

here and has a meal now and again and comes some time on the weekend and I give him what I can. It's difficult not having any support, family support” (Participant R).

For these participants their experience of having a mental illness and being admitted to a psychiatric hospital resulted in them being abandoned by their family members. For Participant O, the experience of having a mental illness resulted in her being isolated from all members of her family and being discarded with people she describes as ‘alcoholics’ and ‘hobo’s’. For Participant R, his diagnosis and hospitalisation also resulted in his family members not having any contact with him.

Chapter 5: Discussion section

The main aim of this project was to explore the experiences of people diagnosed with schizophrenia of their first admission for severe psychosis to a South African psychiatric ward. The main themes which emerged from the data collection were treatment, preconceived ideas of hospitalisation, incarceration, diagnosis of schizophrenia, stigmatization, law enforcement and social interactions during initial hospitalisation.

The first theme is treatment. Under this theme, various subthemes emerged, namely, medication, needles, occupational therapy and ECT. All the participants expressed extreme dislike of taking medication for the first time, referring either to side effects, or attributing a range of bad experiences to the medication. It is estimated that 50% of individuals with schizophrenia do not adhere to taking their medication, due to the extra pyramidal signs and terrible side effects, a finding also reflected in a study conducted by Gilmer, Dolder, Larco, Folsom, Lindamer, Garcia & Jeste, 2004). The following quote is illustrative of this;

“The medication they gave me at Tara. I was so **restless I couldn’t sit still**. I didn’t know whether to lie down, whether to sit, whether to stand, to walk. I **was just walking all over the place**. I think it was Haloperidol, I’m not sure. They put me on that drug and I **couldn’t have a moments peace** I was just up and up all the time, **I couldn’t relax** and they took it off me eventually when I got here and then I started calming down” (Participant R).

In the case of these participants, it seems possible that they may be attributing a wide range of unpleasant experiences to the medication, which could be a mis- or over-attribution of the effects of the medication when these could possibly be attributable to either the illness, or predictable responses to unpleasant environmental or physical stimuli. This misattribution could be related to overall poor insight of their disorder (Day, Bentall, Roberts, Randall, Power, 2005). However, it also seems possible that while the experiences that the participants responded to are not directly attributable to the medication, the altered state of consciousness (induced by the medication) through which these stimuli are experienced, might go some way in explaining these participants’ statements.

It also became apparent that none of the participants mentioned any positive effects resulting from the use of the medication, for example symptom reduction. A possible reason for this could be that patients were not attributing their later improved psychological state to the medication. Both these points relate to attribution patients made from their behaviour or experience, to the medication.

Under the next subtheme relating to injections, or ‘needles’, half of the participants interviewed commented on their experiences of injection needles. For most of these participants, needles evoked a great fear in them, and their first experience of receiving forced injections was often vividly recalled by participants. For one of the participants it seemed that the fear expressed was due to the physical pain associated with being injected.

“Yes and when they come with **needles** and medication and **they injected me**, I was **very scared of needles** because at Town Hill they **got into the muscle**, **do you know how sore that is**” (Participant P).

For another participant the fear seemed to be more psychological than physical.

“because **I knew they wanted to bend my mind and change what I believed in** and uh I went in this room and some guy with the glasses on walked around with an injection needle and said, come let me inject you” (Participant Br).

For participant Br, the fear was psychological and the injections served as a method of changing her existing beliefs. The fear of the psychological control that the needles (medication) represented for participant Br could be understood in terms of the coercive nature of the experience. Participants Br’s initial psychiatric admission was involuntary. Being committed to a psychiatric hospital and being coerced into received injections can cause patients to distrust mental health professionals (McKenna, Simpson & Laidlaw, 1999). Furthermore, the invasive nature of involuntary needle injection (the patient’s body is involuntarily penetrated) seems to have been described far more ‘delusionally’ than other treatment experiences. It seems likely that the extent of psychotic distortion of thought is more severe at these times and is possibly directly caused by the intense feelings of fear and victimisation at these times. Patients’ appraisal of a traumatic event and the coping styles that they had at the time may mediate the traumatic impact of a first episode of psychosis (Jackson, Knott, Skeate and Birchwood, 2004).

The next subtheme which emerged was ECT. Since a few of the participants were much older it was expected that some would have had an experience of ECT, however only one participant mentioned it.

“Um, if you went according to the rules you could have a normal life but **if you do anything wrong you will be severely punished** you know. I had a lot of **shock treatment** and a lot of **lumbar punctures**” (Participant PU).

From participant PU's perception, it appears as though ECT was used as a method of punishment rather than a method of treatment. Goffman (1961) and Foucault (1977) state that the official objective of the psychiatric hospitals is to reform the mentally ill patient in the direction of some ideal standard. In other words, if the patient conforms to the norms, he will be released, if not he will be punished until he does conform and his behaviour is normalised (Goffman, 1961). Therefore, Goffman (1961) and Foucault's (1977) notion of power within the institution, offers support for viewing such a statement as an accurate reflection of the social forces at work during his first hospitalisation. However, it is also important to note that people who have schizophrenia usually have quite a low insight, which means that it is possible that this participant was unaware of the actual reason for the ECT, and attributed it to punishment instead of treatment. It is also possible that the coerced nature of the treatment, the ECT and the lumbar puncture evoked a great fear in this particular participant and may explain why he viewed it as persecutory, and hence a punishment instead of a treatment. As discussed in the literature many studies describe coercive as ECT being the most disturbing and frightening for patients (Breggin, 1964; Iversen, Hoyer, Sexton, Gronli, 2002).

Only three out of the seven participants commented on their experience of occupational therapy. All participants described occupational therapy as 'nice'. It is possible that OT might have served many positive functions for participants such as helping them to gain social skills by socialising, doing tasks which could lead to economic benefits, inspire them with hope and decrease some of the negative symptoms (Chugg & Craik, 2002).

The next theme that will be discussed is the perceptions of hospitalisation. This theme has two subthemes, namely preconceived ideas and attitudes and attitudes after hospitalisation. Due to the vast amount of literature on the negative portrayal of mental illness in the media (Stout, Villegas and Jennings, 2004; Wahl, 1992, 1997, 1999;), it was expected that some participants would have a negative perspective drawn from the media's depiction of mental illness, specifically schizophrenia. The results concur with those of previous studies. For these participants, psychiatric hospitals seem to be a place of torture where a person does not have any say about what happens to them. Below are quotes which illustrate this.

"I thought they were places where you were **strapped up** and **kept in a cell** and **drugged** and they did lot so what do they call it, you know when they do something to your head...umm **shock treatment and that type of thing...**"
(Participant R).

“You know just what I saw in the movies people in big glasses with big injection needles you know...” (Participant BR).

As discussed earlier in the literature the public’s knowledge of mental illness comes from sources to which they exposed on a daily basis, namely the mass media. These reports are often inaccurate, obscure and contradictory (Stout, et. al., 2004; Wahl, 1992; 1997; 19997). The majority of the participants interviewed reported that they had negative preconceived ideas of hospitalisation before being admitted to a psychiatric hospital.

In previous studies, they found that between 44% (sample size of 34) and 51% (sample size of 105) of participants met the criteria for PTSD after initial admission to a psychiatric hospital. (Priebe, et.al, 1998; Morrison, et. al., 1999). Some participants did experience their first admission as extremely traumatic. One participant highlighted just how traumatic it was for her. She described it as

“Terrible. It’s like a hell hole you know. I don’t know what happened, my spirit left me, my mind left me, I was a Zombie. That was one of my worst experiences in my life” (Participant Br).

Participants Br’s experience (as well as those reported by three of the other seven participants) seems to be in line with findings of other studies conducted where first time admission to a psychiatric hospital has been reported as being extremely traumatic for people (McGorrey, et. al, 1991; Morrison, et. al, 2003).

One participant in particular reported experiencing their first hospital admission as pleasant.

“But my experience in the hospital was not what I had imagined. It was quite pleasant. Well the fact that I had a roof over my head because I didn’t, I had been on the street for seven years, on and off. Ja, you had three main meals, and you had tea time...” (Participant R).

“Until I got used to it and then it wasn’t so bad, it was a nice place though you know. They take care of you, keep you clean and they make sure that you are clean all the time and that you eat well” (Participant PU).

For Participant R, his first psychiatric admission was described as quite pleasant, mostly because he was no longer living a life on the street, and had safety and shelter. Participant PU describes positive caring experiences and her basic needs being met by others. Given that

most of the research studies conducted on the subject indicate that patients' first admission at a psychiatric hospital are the most traumatic (McGorrey, et. al, 1991; Morisson, et. al. 2003), this finding may need some attention.

As with participant R, it is possible that for some, the hospital environment might provide benefits and meet basic needs which were not present in the participant's life before hospitalisation. However, this last participant also suggests that it 'took getting used to' – it might be that some of the trauma of first hospitalisation could be related to the unfamiliarity of the environment. Furthermore, as in the case of 'medication' above, it is possible that the horrific nature of the first hospital experience might be misattributed to the hospital environment, where, in fact, it could be the participant's own terrifying psychotic state which might be a central traumatogenic factor in the experience. Moreover, these statements are being made in hindsight, many years after the initial hospitalisation, and it is possible that attitudes towards the original experiences might have undergone change in time. Lastly, participants' understandable need to avoid traumatogenic memories in their descriptions of their experiences were of concern to the researcher, who did not probe, question or contradict such descriptions so as not to 'insist' that the patient reflect on painful memories. However, it cannot be ignored that a number of patients may well find aspects of the first hospitalisation experience to be positive and rewarding.

Two of the participants expressed how they felt contained in the hospital.

"And also there was **a library I used to like...**"**"The garden was very special"**
(Participant O).

"Well the fact that **I had a roof over my head** because I didn't, I had been on the street for seven years, on and off...**living in a ward and you felt safe and secure and you could walk around the gardens and it was fine** you know"
(Participant R).

Foucault (1977) stated that the life of the mental patient is inherently regulated; patients are instructed when it is permissible to eat, drink, sleep, bath, who is able to come visit them and at what time. Participant R did acknowledge some of the restrictions of being in the hospital. This was evident when he stated "You weren't allowed to lie on your bed, you know", however, this did not appear to cause him great distress. In fact, he viewed the hospital as a safe, containing environment where all his basic needs such as eating, sleeping bathing were met. A possible reason for this could be that before hospitalisation he lived on the streets,

which he states was much more difficult and unstructured. The routine of knowing that he would have meals, a place to sleep and the necessary treatment provided him with a great sense of relief and safety. It is also interesting to note that for participant Br being admitted to a psychiatric hospital was not an isolating experience for him, but instead provided him with social interaction. Homelessness among persons with severe mental disorder is both common and distressing. In a study conducted by Herman, Susser, Jandorf, Lavelle, and Bromet (1998) they found that 15 percent of patients (sample size of 237) hospitalised at 10 of the 12 inpatient facilities in east Long Island, New York, had experienced at least one episode of homelessness before or within 24 months of their initial psychiatric admission. For this participant, being homeless made him feel extremely isolated and hospitalisation provided an occasional refuge, and in part, some social reintegration and support (Herman, et .al, 1998).

For the majority of the participants, their first admission to a psychiatric hospital resulted in them being abandoned by their family members. The initial lack of contact with family members during the first hospital admission is normally a requirement from the psychiatric hospital usually to reduce the high expressed emotion of family members (Penn & Mueser, 1996). However, it is possible that this has long standing consequences, as it appears that after the first hospitalisation, along with a diagnosis of schizophrenia, family members did not play a supportive role. Evidence from many studies have documented up to 83% of family members of people diagnosed with schizophrenia experience financial, emotional and practical burdens (Magliano, Marasco, Fiorillo, & Maj, 2006). Some of the common complaints of burdens involve reports of time lost from work, non-reimbursement by medical aids and other patient expenses, as well as limited time for socializing, leisure and an increase in psychological distress and stigmatization (Perlick, Rosenheck, Kaczynski, Canive, & Lieberman, 2006). Another possible reason for the lack of contact from family members could be attributed to experience of stigmatization, not only by the person with the mental illness but the fact that the rest of the family also runs the same risk of being stigmatized as well (Goffman, 1961). In a study conducted by Ostman & Kjellin (2002), they found that majority of family caregivers of people with mental illnesses experienced stigmatization by association. “A relatively high proportion of relatives considered that the patient’s mental illness had affected the possibilities of having company of their own or had influenced relations with others, and had also led to mental health problems in the relatives themselves” (Ostman & Kjellin, 2002, p. 496).

It was evident from participants' statements that majority of them appeared to have had some experience of isolation during their first hospitalisation. People diagnosed with schizophrenia are frequently hospitalised and this causes them to face a host of social and life related issues such as social isolation and stigmatization (Award & Voruganti, 1999). While some participants experienced their hospitalisation as destroying relationships and resulting in isolation, it was interesting to note that others experienced it as containing. Participants, who experienced it as isolating, seemed to highlight the loss of contact with society. One participant expressed how difficult it was for him to be in a closed ward, where he felt alone, as he was surrounded by strangers as he was not allowed any contact with his family and friends. The quote below is illustrative of this.

"You can't go out, there's nothing around you, and you feel isolated from everything...When you actually get released or discharged or whatever, then you've got to start all over again, you've got to make new friends usually". (Participant G).

"Um. The first time I got there I was very afraid. They [my family] were asked to stop and sort of back off and leave me until I was stable and whatever" (Participant PU).

These participants both describe being isolated from society while being hospitalised, and in some cases the damage done to their previous social relationships through the hospitalisation. This disruption of social relationships may represent a major stressor or trauma, indirectly resulting from psychiatric hospitalisation, and feelings of isolation and loss may form part of the overwhelming impact this experience has for these participants and others. This is in line with the literature which states that the most common experience by people with schizophrenia, specifically during their first admission to a psychiatric hospital, is a sense of pervading loss of interpersonal relationships, loneliness and social isolation (Marinelli, & Orto, 1999).

The second quote above does indicate that the hospital plays a role in managing the familial relationships through the experience. In this instance it seems that the intervention was to reduce the family's involvement, which might be detrimental to the patient's wellbeing. A reason for the hospital restricting family members contact could be that during a time of crisis family members usually express a high rate of emotion. By reducing family members' expressed emotion this in turn reduces patients' relapse rates (Penn & Mueser, 1996). It also important to recognise that family member's accounts are also pervaded by a profound sense of loss of a loved one with schizophrenia. There is a strong tension among family members

who have to distance themselves from the person with schizophrenia because of all the chaos and distress it creates, and furthermore to accept the relationship that has been changed by the disorder, or else hold onto the lingering desire and hope that the person whom they knew before the diagnosis will return. This conflict and sense of loss of the person prior to the illness may cause them to further distance themselves from loved ones (Marinelli, & Orto, 1999).

Participants stated that the most positive experiences of being hospitalised were that they made friends with other patients. Some participants described the hospital and other patients as a social opportunity where other patients were described as ‘family’. They also described experiences of racial integration which appeared to have been positive. One participant described the friends that she made at the hospital as her family.

“Um, you **meet friends and they sort of put you on the right track and help you.** Others never go home, they stay there and they **become like your family** in the end there you know. You know them very well. **White and Black and Indian and Coloured all stick together.** I had a very good Indian friend there, and he was there, he’s there for the rest of his life” (Participant PU).

For these participants, other patients seemed to help fill the isolation they felt from their family members and friends. They also appear to feel a sense of cohesion with patients, providing them with support to help them through their hospital stay. Participants who were fearful of other participants all reported having witnessed violence within the hospital by other patients and feared that the same would happen to them. Each of these participants appeared to be afraid of other participants.

Based on the literature, it was expected that first time experiences of a sudden closed environment with other individuals who are disturbed could be extremely traumatic (McGorrey, 1991; Priebe, et.al., 1998). More than half of the participants described how difficult it was for them to be in the ward because of the crazy things other patients would do.

“...I saw somebody just attacking someone and **thrown on the floor and kicked him in his head a long time and saw the blood.** Ja you know you want to help the guy but you know there’s backup for the other guy so you just stay out of it...” (Participant Br).

Goffman (1961) states that during the first admission one of the most distressing effects are the psychological and physical effects experienced in the hospital. An example of a psychological effect provided by Goffman (1961) which is illustrated in the above quote is his reference to patients who have witnessed physical assault and find themselves unable to take any action. The experiences encountered during first time hospitalisation, specifically witnessing any direct or indirect violence (physical or psychological), could be attributed to the high rates of PTSD diagnosed in people with schizophrenia's first time admission to hospital. If the admission is involuntary, this could exacerbate the symptoms of PTSD (McGorrey, et al, 1991; Morrison, et al, 2003; Priebe, et al, 1998).

For many participants, their first hospital admission was also when they were given their first formal diagnosis of Schizophrenia. Being formally diagnosed with a mental disorder such as schizophrenia can be a very traumatic experience (McGorrey, 1991). The results indicate that majority of participant's experienced serious vocational and social losses which they ascribed to being given this diagnosis. Participants all spoke about their life prior to hospitalisation, emphasising that they were 'normal' and lived a 'normal life'. The following are quotes illustrative of this.

"I didn't know what it [schizophrenia] was so I brushed it aside, I didn't accept it. I didn't know, I read the letter later and I didn't know what the letter meant,... but I just brushed it aside and ignored it and decided to carry on my life as usual..." (Participant O).

For Participant O, after being admitted to a psychiatric hospital, it was difficult for her to return to her normal life. Having been admitted to a psychiatric hospital and being diagnosed with a mental illness, it was not as easy to ignore as it affected her life prior to the hospitalisation. O was seen as unfit and unable to teach. She was unable to take care of her children and the welfare removed the children from her custody.

While there was no direct question regarding stigmatization, it became apparent that each participant spoke about the stigma attached, not only to being diagnosed, but to being hospitalised itself (Marinelli, & Orto, 1999; Wahl, 1999). One participant described how he perceived people in psychiatric hospitals.

"Well I thought to myself that I thought that they are really crazy or something's wrong with them, I really didn't believe that there was anything wrong with me. I didn't want to believe that here is anything wrong with me. No-one really explained to me what mental illnesses are. I think that my parents have a stigma, that I'm crazy or something" (Participant G).

For Participant G, being admitted to a psychiatric hospital for the first time and coming to terms with his mental illness was extremely difficult as he felt there was a stigma attached to mental illness. It appeared easier for G to deny his mental illness, rather than facing the stigmatization that he and his family had attached to mental illnesses. Other participants stated;

“Once you come from there, life outside is never the same? People seem to reject us because they know we have that psychiatric problem. I umm once people know that you have a mental illness you’re sort of hostile heh, by society outside you know especially if you’ve been locked up like me” (Participant PU).

“I’m embarrassed about mental illness and I’ve got both illnesses. Schizophrenia and Bipolar. To have a mental illness is not pleasant. I’m very scared. People with mental illness, I don’t want to run them down but people act different at different times, you never know when they’re going to spark off” (Participant P).

All participants mentioned stigmatization when talking about their own experiences. For the majority of participants being admitted to psychiatric hospital and having a diagnosis of schizophrenia results in a stigma being placed on them by society. Participants internalise the stigmatization and in turn, self stigmatise themselves (Stein, 1996). PU appears to be quite hopeless about this stigma attached to people who were hospitalised; this is made apparent as she states “Once you come from there, life outside is never the same”. This basically means that any role the inmate had before coming into the psychiatric hospital is lost (Goffman, 1961). It appears as though participant P did not identify with any of the other patients and seemed to view them as being as being mentally ill, and not themselves. P appears to have a stigma attached to people with mental illness as she perceives them to be out of control or potentially violent. This is in line with many studies which state that the most common type of stigma attached to people with severe mental illnesses are that that they are all violent and unpredictable (Deacon, Stephney, and Prosalendis, 2005).

It was apparent that most of the participants had some encounter with law enforcement during their first psychiatric admission. For the majority of participants it appears that their encounter with the law was against their will. Many people diagnosed with schizophrenia are usually forced into treatment by police, judges or family members (Pescosolido, Gardner & Lubell, 1998).

The experience of coercion on admission to acute psychiatric hospital increases risk of experiencing trauma. In a study conducted in New Zealand by McKenna, Simpson, and Laidlaw (1999) which focused on patient perception of coercion on admission to acute psychiatric services, it was found that “those admitted to hospital under the legislation feel loss of autonomy and are more likely than voluntary admissions to perceive hospitalization as coercive” (p. 150). Coercion may further reduce adherence to treatment, such as taking prescribed medication (Laidlaw, 1999).

Under the next subtheme, staff members, the results suggest that participants seemed to have an ambivalent relationship with staff members at the hospital. For example, some participants suggested that their relationship with staff members was not great; however, they also so suggested that it may have been because they were unhappy to be there and not necessarily because of the nurses. The results also appear to be suggesting that some participants felt that staff members had an inaccurate perception of them.

“...you can’t blame the staff but you need that support. There’s somebody from the outside world, **you look up to him** and you **just need some comfort** from them and **you’re still a person**, that’s what you need from them and you do get it, you do get it but **they tend to keep to themselves**, the staff talk to the staff and the patients to the patient you understand” (Participant Br).

For Participant Br, it appears as though he acknowledges the important role the staff members played in his healing. A part of him seems to suggest that he respects them, this is made evident when he states that “you look up to them” while another part of him suggests that that he does not feel they give him exactly what he needs and in some sense view them as withholding. This is made evident when he stated “they tend to keep to themselves”. This finding can be understood as echoing that of a study conducted by Moyle, (2003) where she explored the nurse – patient relationship. She found that the therapeutic relationship did not come instinctively to mental health nurses. Furthermore, there was a dichotomy between the distant relationship provided by the nurses and the close relationship expected by patients. It seems that patient’s relationship and feelings towards nurses is an important curative agent (Moyle, 2003).

Other participants retained a more negative experience with regard to their interactions with staff members.

“If you’re rebellious you’ll be beaten and whatever, whatever goes around there. **They hit you and kick you, or give you tablets** you won’t know what you are doing and you collapse, and they’ll beat you” (Participant PU).

“And they **bath you and they shower you, it’s embarrassing.** Like ... at Town Hill and I asked him please to get me something I need to urinate. **They didn’t come so I just weed on the floor.** I didn’t have an option and they gave me a little thick mattress like that to sleep on the floor. “I just hear my voice and I say, **please, please come and help me. They were laughing at me...**” (Participant P).

Foucault (1977) states that psychiatric hospitals along with mental health professionals exercise their power over people with mental illnesses in order to try to normalise their behaviour. Given South African hospitals’ shortage of mental health practitioners it is also possible that these staff members have an increasing workload which increases their levels of stress, fatigues and emotional exhaustion all of which compromise both quality and safety of care (Gerin, Green & Pearson, 2006). The day-to-day work in a psychiatric setting is so pressurised that it can lead mental health care staff to use self protective defences such as emotional detachment, reductive labelling and retreating to things such as administrative work (Hardcastle, Kennard, Grandison, & Fagin, 2007). The impact of this emotional detachment can contribute to patients feeling misunderstood, stigmatised and isolated.

Chapter 6: Conclusion

The experience of persons diagnosed with schizophrenia of their first admission to a psychiatric hospital is an under researched field within psychology, specifically within a South African context. The predominant themes used to summarise the data in the analysis were: treatment, preconceived ideas of hospitalisation, incarceration, diagnosis of schizophrenia, stigma, law enforcement and social interactions during initial hospitalisation. Using these themes, this study aimed to explore the experience of persons diagnosed with schizophrenia of their first admission to a psychiatric hospital.

It was found that, in general, first time admission to a psychiatric hospital for acute psychosis has a serious and detrimental effect on the perceived wellbeing of patients. The findings clearly reveal that a number of traumatogenic experiences were described by participants. Participants' experience of involuntary hospitalisation, and treatment methods such as ECT and injections proved to be extremely frightening for the majority of the participants. The findings also reveal that other experiences were quite distressing. The experience of isolation from family members and friends created a huge sense of loss for participants. One of the findings of this study is that all participants expressed minimal to no contact with family members after their diagnosis and admission to a psychiatric hospital. Family members can play a vital role in helping to support a person with a mental illness. A closer look at family members interaction with patients during first admission to a psychiatric hospital would be beneficial, as well as research into the nature of interventions in this regard, taking place in South African hospitals.

Another distressing experience of the participants were the violence witnessed by other patients as well as the detachment of staff members experienced within the psychiatric hospital, particularly during the first admission was extremely traumatising for participants. Nurse-patients interaction is an important field of study that should be explored further.

Another finding has to do with the stigma attached to mental illnesses. In the findings it was evident that some participants stigmatised themselves after their first admission to a psychiatric hospital. This stigma hinders the person with schizophrenia from accepting their diagnosis and from adhering to treatment.

6.1 Limitations

A significant amount of data was generated by the semi-structured and in-depth interviews. However, one of the limitations confronted by this project was the extremely time consuming process of interviewing participants who seem to deviate off topic as a result of the semi-structured interviews. Some participants spoke completely off topic and it was difficult to steer them in the correct direction. Maybe a slightly more structured interview process would have eliminated this problem.

Furthermore, it is acknowledged that the participants may not have provided completely honest and accurate accounts pertaining to the sensitive nature of the first time admission to a psychiatric hospital. It is also possible that participants experienced the researcher as a stranger and found it difficult to disclose sensitive information on the first meeting. It is possible that the level of disclosure from participants would have been more if the participants had met with the researcher on more occasions. It is also possible that the level of disclosure from participants were limited due to the researcher not probing any participants, out of concern of any negative effects that it may have on the participants. It is possible that if the researcher were more investigative rather than containing in orientation, more information could have been obtained from the participants.

While the researcher did ask about first time experiences about psychiatric hospitals, some participants still spoke about their overall hospital experience and not just their first admission. It is possible that the first hospital admission was such a long time ago that participants may have conflated memories and their current memory of their first admission is coloured by their subsequent hospitalisations.

Even though one of the strengths of working with a small sample when conducting qualitative research is the rich detail that it provides (Durheim, 2006), the limitation of this method is that it limits the generalisation of the findings. Due to the research only being conducted with seven participants, the findings cannot be taken as a general representation of all persons with schizophrenia of their first admission to a psychiatric hospital.

Another limitation that needs to be taken into account is the researchers own subjectivity and biases. It is important to indicate that the researcher's interest in this topic was driven by her own experiences of having a family member diagnosed with schizophrenia. The researcher

was aware of her own bias, which was anticipating that participants would have a negative experience of their first psychiatric admission, an agenda in the research towards seeking improvement in the hospital intervention. It is conceivable that this preconception and agenda may have affected the research process, either during data gathering, analysis or discussion. At the same time, the researcher was aware of these biases, and was open to positive statements that participants experienced and has included it in the results and discussion sections.

6.2 Recommendations

Since all the participants expressed distress that they have minimal to no contact with their family members, it is recommended that more research be conducted that examines the specific activities and outcomes of family intervention programmes at psychiatric hospitals. This will in turn help to create intervention programmes that may help support family members and patients.

From the findings it appears that participants have strong emotional needs from the nursing staff during their hospitalisation. It is clear that the nurse-patient relationship appears to be a complicated one and that the majority of the participants view the nursing staff as being detached. This presents with an opportunity to enhance the experience for patients during their hospitalisation period. Research focusing on the nurse-patient relationship will help to explore the dynamics of the relationship which will in turn help to identify potential training initiatives to help nursing staff members better manage their relationship with patients.

The use of injections specifically used as a coercive method appears to be one of the most traumatising experiences for participant during their first admission to a psychiatric hospital. It is recommended that research be conducted on how patients are prepared for injections during hospitalisation and whether any formal procedure has been put in place for coercive treatment methods.

Since many participants felt self- stigmatized, it is recommended that further research be conducted exploring the factors that cause patients to self stigmatize. This will help create further intervention programmes to help reduce patient self stigmatization.

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Appendix A: Medical Ethics Clearance Form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mrs Yumna Zobi

CLEARANCE CERTIFICATE

M10436

PROJECT

The Experience of Persons Diagnosed with
Schizophrenia of Their First Admission to a
South African Psychiatric Hospital Ward for
Acute Psychosis

INVESTIGATORS

Mrs Yumna Zobi.

DEPARTMENT

Department of Psychology

DATE CONSIDERED

30/04/2010

DECISION OF THE COMMITTEE*

Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 25/05/2010

CHAIRPERSON


(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Mr P Connolly

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Appendix B: Information page for half-way house



School of Human and Community Development

*Private Bag 3, Wits 2050, Johannesburg, South Africa
Tel: (011) 717-4500 Fax: (011) 717-4559*

Dear _____

My name is Yumna Zobi, and I am currently enrolled as a Masters student in Clinical psychology at the University of Witwatersrand. It is required that I conduct research for the purposes of obtaining my degree. This research will explore the experience of persons diagnosed with schizophrenia in South Africa of their first admission to a psychiatric hospital for acute psychosis. I would like to invite the residents at your half-way house with schizophrenia to participate in this research. The interview process will take place individually with each participant for approximately one hour.

Kindly note, that participation in this study is entirely voluntary. Please note that participants that wish to participate also have the right to withdraw from the interview as well as to not answer any question that they feel uncomfortable with. Confidentiality will be maintained as far as possible. In the case that any participant has any negative effects due to partaking in this study, they will have access to existing counselling that will be free of charge by the staff members of the half way house / support group. Additionally participants who experience any negative effects from partaking in the study are welcome to contact the support group for Schizophrenia and Bipolar Disorder Alliance on (011) 463 9901 or the South African Depression and Anxiety Group (SADAG) on the toll free number 0800 567 567 for free counselling and debriefing.

Should you request feedback on the research finding, this will be made available to you. Should you choose to participate in this study kindly complete the attached consent form. If

any queries or questions of any kind arise with regards to this research project please feel free to contact me or my supervisor without hesitation.

The Human Research Ethics Committee

The research office: 011 717 1234

Yumna Zobi
(Student)
Email address: Yumna.Zobi@wits.ac.za
Or Cell: 072 097 8887

Patrick Connolly
(Supervisor)
Counselling Psychologist
Email address: Patrick.Connolly@wits.ac.za
Office: 011 717 4547

Yours sincerely
Yumna Zobi

Appendix C: Consent letter from Schizophrenia and bipolar Disorders Alliance (SABDA)



SABDA

Schizophrenia and Bipolar Disorders Alliance
(NPO No. 003-907)

Tel: (011) 463 9901 Fax: (011) 507 5024 e-mail: norma@supportsabda.co.za
Website: www.supportsabda.co.za Postal Address: 72 Mackay Ave, Blairgowrie 2194

Ms Yumna Zobi
Department of Psychology
Witwatersrand University
Johannesburg.
4th February 2010

Dear Yumna,
We are delighted to be of help with the research for your Masters degree and would like to offer you the use of our facility at Tara Hospital. Both Beryl Allen and the committee members of SABDA would like to wish you every success with your research studies.

Sincerely,

S.M. Lahoud
Committee member SABDA

Committee: Norma van Ginkel (Director), Alana Watson (Chairperson)
Sheila Lahoud (SABDA House), Charmion Gibson, Marina Berg, Cecily van Niekerk, Eve Swart

Appendix D: Consent letter from Central Gauteng Mental Health Society



12 February 2010

To: Ms Yumna Zobi
Department of Psychology
Witwatersrand University
Johannesburg

RE: CENTRAL GAUTENG MENTAL HEALTH SOCIETY

With this letter Central Gauteng Mental Health Society (CGMHS) offer our commitment to assist Ms Yumna Zobi in which ever way we can with her Masters Degree research in Psychology.

Central Gauteng Mental Health Society is a non-profit organization providing services to persons affected by mental illness, intellectual disability and those experiencing life crises.

We wish Ms Zobi all the success in her studies and future in working in the mental health field.

For any information, please don't hesitate to contact us.

Kind regards,

A handwritten signature in black ink, appearing to read "Shanbangu".

Mrs Fundiswa Shanbangu
Acting Director: Central Gauteng Mental Health Society
Tel: (011) 614 9890 Fax: (011) 614 5503 E-mail: admin@witsmhs.co.za

Central Gauteng Mental Health Society, PO Box 10443, Johannesburg 2000
Tel: +27 11 614 9890 Fax: +27 11 614 9890 E-mail: admin@witsmhs.co.za www.witsmhs.co.za
Johannesburg Central +27 11 614 9890 Ekurhuleni +27 11 909 0152 West Rand +27 11 984 4038 Gordonia +27 11 814 6855 Tshepong +27 11 909 3255

Appendix E: Subject Information Sheet



School of Human and Community Development

Private Bag 3, Wits 2050, Johannesburg, South Africa

Tel: (011) 717-4500 Fax: (011) 717-4559

Dear Prospective Participant

My name is Yumna Zobi, and I am conducting research for the purposes of obtaining a Masters in clinical psychology degree at the University of the Witwatersrand. My area of focus is exploring the experience of persons diagnosed with schizophrenia in South Africa of their first admission to a psychiatric hospital for acute psychosis. I would like to invite you to partake in this study. I am interested in your views on this topic and would value your input.

Participating in this research will entail a one hour interview by myself which will consist of open ended questions that focus on your first admission to a psychiatric hospital. With your permission the interview will be tape recorded. Confidentiality will be maintained as far as possible. Confidentiality will be maintained by not including participants names within the report, pseudonyms will be used instead. In other words, any information or responses during the interview will only be seen by me and my supervisor. Information will be used strictly for research purposes. Participation in this study is voluntary; a choice to participate will have no negative consequences. Please note that should you choose to participate, you may decline to answer any questions. Also, you may withdraw from the study at any time. Please note that if participating in this study evokes any distress, free counselling will be provided to you by the staff members of the half way house or support group. Additionally participants who experience any negative effects from partaking in the study are welcome to contact the support group for Schizophrenia and Bipolar Disorder Alliance on (011) 463 9901 or the South African Depression and Anxiety Group (SADAG) on the toll free number 0800 567 567 for free counselling and debriefing.

Results of this study will be used in the final research project. If you would like to obtain the results of this study, feel free to contact me. Kindly note no risk or benefit is anticipated for

participating in this study. Consent for participation as well as recording will be obtained before participation in the study. Should you choose to participate in this study kindly complete the attached consent form.

If any queries or questions of any kind arise with regards to this research project please feel free to contact me or my supervisor without hesitation.

The Human Research Ethics Committee

The research office: 011 717 1234

Yumna Zobi (student)

Email address: Yumna.Zobi@wits.ac.za

Or Cell: 072 097 8887

Patrick Connolly (supervisor)

Email address: Patrick.Connolly@wits.ac.za

Office: 011 717 4547

Appendix F: Consent Form (Interview)

CONSENT FORM TO PARTICIPATE – FOR PARTICIPANTS

I give consent to being interviewed by Yumna Zobi for her study on the experience of persons diagnosed with schizophrenia in South Africa of their first admission to a psychiatric hospital for acute psychosis.

I am aware that:

- My participation in this study is voluntary.
- I may refuse to answer any questions I would prefer not to.
- I may withdraw from the interview process at any point without any negative consequences.
- As far as possible all information I provide will be kept confidential.
- No expected risk or benefit is involved in partaking in this research study.
- However, should any negative effects arise due to partaking in this study I will have access to free counselling from a qualified psychologist at the Tara psychology department.
- Direct usage of quotes during the interview may be used in the research report

Signed: _____

Date: _____

Appendix G: Consent Form (Recording)

CONSENT FORM FOR RECORDING INFORMATION

I give permission for this interview to be recorded. I understand that the content of this interview will be used entirely for research purposes and that my identity will be protected.

I am aware that

- The use of a tape recorder will be used to record the interview session.
- Access to these tapes will be restricted to the researcher and her supervisor.
- The tapes will be kept in a safe location at the University of Witwatersrand.
- Direct quotes that I give during the interview may be used in the research report.
- I am aware that recorded tapes of the interview will be kept strictly for research purposes.
- I am aware that recorded tapes will be kept for 2 years after publication or for 6 years if not published.

Signed: _____

Date: _____

Appendix H– Interview Schedule

SEMI-STRUCTURED INTERVIEW QUESTIONS FOR PARTICIPANTS

1. When were you first admitted to a psychiatric hospital?
2. Prior to your first encounter with a psychiatric hospital, what was your perception of psychiatric hospitals?
3. Can you tell me a bit about your first experience of being in a psychiatric hospital?
What were the aspects that stick out the most for you?
What were some of the positive aspects of being hospitalised?
What were some of the negative aspects of being hospitalised?
What were your relationships with mental health staff like? (nurses, doctors, psychiatrists, psychologists?
What were your relationships with other patients like?
4. Did you think that you required psychiatric treatment? *¹
5. Did you initiate your first hospital admission or did someone else initiate it?
6. Did others contribute to you getting psychiatric treatment?
7. If you ever fell ill again, would you want to be hospitalised? (Why/Why not)

¹ * These questions were adapted from the research conducted by: Haan, L.D., Peters, B Dingemans, P., Wouters, L., & Linszen, D. (2002). Attitudes of patients Toward the First Psychotic Episode and the Start of Treatment. *Schizophrenia Bulletin*, 28 (3): 431-442