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Faculty of Health Sciences

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Title: Factors that promote and impede treatment adherence of out-patient mental health care users at a psychiatric hospital in Johannesburg.

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Research Report submitted for the Degree: MPH (SBCC)

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Declaration

I, Savannah Rowse, declare that this research work is my own original work. Any other work done by other people quoted herein has been properly acknowledged in the report. This report is being submitted in partial fulfilment of the requirements for the degree of Master of Public Health, in the field of Social and Behaviour Change Communication, with the University of the Witwatersrand, Johannesburg. It has not been submitted for any other degree or examination at any other university.

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Date: 17/05/2024

Johannesburg

Abstract

Background: Neuropsychiatric disorders are ranked third in the overall burden of disease in South Africa and are chronic disorders. Adherence (and nonadherence) to treatment for severe mental illness is a multifaceted phenomenon that influences and is influenced by multiple factors in one's environment and context. However, due to the magnitude of this burden of disease and policy agendas promoting deinstitutionalization through community-based care, higher levels of services in South Africa are grappling with the revolving door phenomenon.

Aim: To explore factors that promote and impede treatment adherence from the perspectives of mental health care users (MHCUs) in an outpatient department (OPD) Tara Hospital, Johannesburg in 2022/2023.

Setting: Tara Hospital is a public specialized psychiatric hospital situated in Hurlingham, Johannesburg and is classified as tertiary and quaternary hospital due to the level of specialised services provided. MHCUs are referred from other tertiary hospitals in the Johannesburg metropolitan district or referred from the private sector for specialized services.

Methods: An explorative, descriptive, and contextual qualitative research study was conducted over the 2022/2023 period at Tara Hospital's OPD. Purposive convenience sampling was used to recruit 18 participants aged 18-65 and diagnosed with severe mental illness. In-depth interviews (IDIs) using a semi structured interview guide were conducted, transcribed, and then analysed using MAXQDA software.

Results: A thematic analysis was used to highlight the five dominant themes and their sub themes that emerged from the research. The five dominant themes included: experience of mental illness and adherence, experience of Tara OPD, promoters of adherence, barriers to adherence and stigma. MHCU demonstrate rich insight into their experience of their mental

illness, diagnosis, medication, and relapse. Tara OPD is protective factor and positive influence on adherence for its service users. MHCU's engage dynamically with their adherence and use an array of practical strategies that support their adherence as well as emphasizing the positive influence of social and institutional support. The barriers to adherence included substance use, stigma, poor social support, poor routines, and coping strategies. This stresses the dynamic interplay and role of each level of the socio-ecological model.

Conclusion: Adherence to treatment for severe mental illness does not occur in a vacuum of a MHCU simply taking their medication, but there are multiple factors and influences that are important to consider.

Key words: severe mental illness, socio-ecological model, adherence, out-patient

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List of Abbreviations

MI: mental illness

HIV/AIDS: Human Immune Deficiency Virus/Acquired Immune Deficiency Syndrome

MHCU: mental health care user

OPD: out-patient department

SMI: severe mental illness

WHO: World Health Organization

MDT: multi-disciplinary team

HREC: Human Research Ethics Committee

IDI: in-depth interview

1 INTRODUCTION

1.1 Background and Introduction to the study

Mental health equates physical health in the importance of overall well-being in individuals, societies and countries (WHO, 2001). Yet, in South Africa, the gap in treatment consists of 75% of those with a mental illness (MI) not receiving treatment (Lund *et al.*, 2012a). In South Africa, neuropsychiatric disorders place third as a category in the overall burden of disease – after HIV/AIDS and other infectious diseases (Bradshaw, Norman and Schneider, 2007). However, mental health services remain under resourced and overburdened (Burns, 2011).

These issues translate to the global stage as well. Vigo, Thornicroft and Atun (2016) suggest that the global burden of mental illnesses account for 32·4% of years lived with disability (YLDs) and 13·0% of disability-adjusted life-years (DALYs), however the authors suggest that the current methods underestimate these statistics by more than a third. Despite these alarming figures, mental healthcare remains low on political agendas (Vigo, Thornicroft and Atun, 2016) and the challenges remain consistent – poor access to mental healthcare and poor quality of mental healthcare (Kilbourne *et al.*, 2018)

The post-apartheid context prompted major policy revisions for mental health in South Africa, in which the Mental Health Care Act (17 of 2002) was developed (Lund *et al.*, 2012a) and later, the National Mental Health Policy Framework and Strategic Plan 2013–2020 (Meyer, Matlala and Chigome, 2019). Both focused on de-institutionalization, which sought to achieve the integration

of mental healthcare services into the primary health care (PHC) (Meyer, Matlala and Chigome, 2019).

De-institutionalization through community-based care is the goal of mental health services globally (WHO, 2001). However, policy agendas promoting deinstitutionalization has resulted in a cascade of consequences for higher levels of services in South Africa. This being increased pressure for decreased bed capacity in tertiary institutions, results in mental health care users (MHCU's) being discharged prematurely to make space for more acute cases, this leads to increased rates of non-adherence and the MHCU being re-admitted (Botha *et al.*, 2010).This has been deemed the "revolving door" phenomenon in mental health care in South Africa (Botha *et al.*, 2010).

1.2 Statement of the problem

Non-adherence to psychiatric treatment is detrimental to the individual, impacts their family and burdens the healthcare system. Non-adherence to psychiatric treatment can result in grave medical/personal consequences, social circumstances and for the healthcare system; require increased human and financial resources. The revolving door of MHCU's through the OPD and in-patient wards at Tara Hospital is prevalent and increases the burden on Tara. Although there is a growing body of knowledge related to mental health in South Africa, most of this within the primary health care or policy setting (Lund *et al.*, 2012a). This leaves a large literature gap related to adherence in higher levels of care that serve large populations of MHCU's in South Africa. Extending this gap, is the limited focus on adherence studies in this population even though the effects of non-adherence across all socio-ecological subsystems is well documented

(WHO, 2003). Lastly, there is limited up to date published literature from Tara Hospital. This poses a huge problem as it is one of a handful of specialized psychiatric tertiary level hospitals in South Africa and serves a large population of MHCU's living with severe mental illness (SMI).

1.3 Justification

To align with international policy recommendations of integrating mental health services to community-based care, this has become the focus of mental health policy and research in South Africa. Due to this, there is limited research available within the tertiary level context that is grappling with the revolving door patient phenomena and consequences thereof in which the primary health care system could not serve these MHCU's (Lund *et al.*, 2012a) (Botha *et al.*, 2010). Studies related to treatment adherence of outpatient MCHUs are limited within the South African context. The findings of this study will emphasize the complex, multi-faceted nature of adherence (and non-adherence) which requires thoughtful and evidence-based solutions that are context specific. Tara Hospital is an ideal setting for this study to address these gaps as it is struggling with revolving door MHCU's through high non-adherent and readmission rates. The qualitative approach will gain rich insights into factors related to adherence for MHCU's with SMI using services at Tara, with the hope of informing future interventions. In addition, the study seeks to address these gaps from the perspectives of MHCU's through a socio-ecological lens to highlight the dynamic interaction of factors that promote and impede treatment adherence of MHCUs in the out-patient department at Tara Hospital.

1.4 Research question, overall aim, specific objectives

1.4.1 Research Question:

What are the perceptions among mental health care users with severe mental illness of factors that promote and impede treatment adherence in an outpatient department at Tara Hospital, Johannesburg?

1.4.2 Aim:

To explore the perceptions of factors that promote and impede treatment adherence of mental health care users with severe mental illness in an outpatient department Tara Hospital, Johannesburg in 2022/2023.

1.4.3 Specific Objectives:

- To explore the experiences of treatment and adherence of MHCU's with severe mental illness at Tara Hospital's OPD.
- To explore the perceptions of multi-level factors/influences that promote adherence to treatment in MHCU's with severe mental illness that are attending services at Tara Hospital's OPD.
- To explore the perceptions of multi-level factors/influences that impede treatment adherence in MHCU's with severe mental illness that are attending services at Tara Hospital's OPD.

2 LITERATURE REVIEW

Chapter 2 serves to review the relevant literature related to the research question and the study objectives. To establish this literature review, a thorough search into available sources was conducted. This included searching for peer- reviewed journal articles on Google Scholar, World Health Organization Reports and South African official Policies. The evidence presented in this literature review points to the complexities of mental illness, mental health interventions and adherence.

2.1 Overview of mental health and mental illness

The World Health Organization (WHO) defines mental health as "a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community" (WHO, 2018). Furthermore, the WHO categorizes mental disorders as a "combination of abnormal thoughts, perceptions, emotions, behaviour and relationships with others" (WHO, 2018).

The concept around defining mental illnesses that are chronic in nature are difficult to operationalize, thus many authors have concluded with not being able to reach a consensus on a single definition that encapsulates these illnesses. This is due to the complexity of mental illness, authors report that definitions adopted need to include the three dimensions of a definition; diagnosis, disability and duration, but the definitions operationalized need to be context specific (Bachrach, 1988) (Zumstein and Riese, 2020). Severe mental illness (SMI) is defined operationally by the increased length of duration and disability caused and includes a group of

diagnoses that include moderate to severe depression, bipolar disorder, schizophrenia and other psychotic disorders (WHO, 2018). This research will focus on SMI's as it encapsulates the dimensions of this research in this study setting.

2.2 Holistic Approach to Mental Health Promotion and Interventions

As described above, mental health is a critical component to our everyday functioning and thus is inherently embedded within all health promotion efforts. This has been emphasized in several international documents including the Ottawa Charter for Health Promotion (WHO, 1986) and the Social Determinants Of Mental Health (WHO, 2014). Mental health promotion interventions aim to "promote the mental well-being of those who are not at risk, those who are at increased risk, and those who are suffering or recovering from mental health problems" (WHO, 2004).

Mental health interventions have come a long way in moving away from isolating and intrusive practices and towards deinstitutionalization and inclusive community-based care (Mezzina *et al.*, 2019). However, the treatment of SMI is multiplex and requires an array of healthcare professionals to address various aspects. Therefore, the use of a multidisciplinary team (MDT) has been endorsed as the most suitable method of service delivery in mental health care (Soni *et al.*, 1989). As it facilitates multiple skills from various professionals in a coordinated way to provide a holistic service to MHCU's (Soni *et al.*, 1989). This includes psychiatrists, psychiatric nurses, occupational therapists, social workers and psychologists that have been trained in mental health (Mental Health Care Act 17, 2002) . Treatment of SMI does not only require the use of psychotropic medication but needs in-depth psychosocial factors to be addressed to improve the health outcome of these MHCUs (Sibeko *et al.*, 2017). Each profession plays a key role in the

multi-disciplinary team treating a MHCU with SMI. The consultant psychiatrist plays a vital role as they are the lead MDT member due to their comprehensive training and experience, in addition they are responsible for the clinical management of the MHCU and prescribe psychotropic medication (Soni *et al.*, 1989).Psychiatric nurses provide overall care to the MHCU, from ensuring basic activities of daily living are completed to the management and administration of medications as well as crisis management and supporting families (Sobekwa and Arunachallam, 2015). Occupational therapists' primary role is functional rehabilitation of the MHCU to ensure successful reintegration back into meaningful activities of an individual's everyday life. This includes continuous assessment of MHCU's, individual therapy as well as organizing and facilitating group therapy (Simpson *et al.*, 2005). Social workers are critical in ensuring safe and successful discharge from hospital by assessing social context and circumstances through engagement with the family and community (Bland, Drake and Drayton, 2021). Clinical psychologist are involved in providing psychotherapy which entails assessing and treating psychological and behavioural difficulties (Wahass, 2005), this can be done individually, within the family or in groups.

In an outpatient setting, access to a multidisciplinary team is dependent on where a MHCU follows up for their treatment. MHCU's that are down referred to their local clinic are presented with challenges in terms of access to an MDT as many specialized mental health allied team members are not available on a primary health care level (Shilubane and Khoza, 2014).These challenges will be elaborated further on in the conceptual framework.

2.3 Adherence and non-adherence to mental health treatment

According to the WHO, adherence is defined as "the extent to which a person's behaviour—taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care professional" (WHO, 2003). Adherence is not the same as compliance and should not be used interchangeably (Moosa, Jeenah and Kazadi, 2007).

Adherence relates to the therapeutic alliance of the MHCU and healthcare professional and is preferable but compliance refers to conformity of the MHCU to the healthcare workers treatment plan (Moosa, Jeenah and Kazadi, 2007). People with a mental illness show higher rates of non-adherence than those with physical illnesses (Moosa, Jeenah and Kazadi, 2007), due to complex socio-ecological factors.

There is limited up to date research in adherence rates in developing countries and specifically in South Africa (Mokwena and Ndlovu, 2021). Previous research suggests that non-adherence rates in MHCU's in South Africa were as high as 69% (Kazadi, Moosa and Jeenah, 2008).This is an alarming figure yet there is poor prioritization of mental health care services and resource allocation. Many of these concepts will be unpacked and expanded on in the conceptual framework below to describe what is known about adherence (and non-adherence).

The revolving door phenomenon is not unique to the South African mental healthcare system but is rather as a result of the chronic nature of severe mental illness. The revolving door phenomenon is described by chronic mental healthcare users having multiple sequential hospitalizations and discharges (Marsh, Click and Zigler, 1981). In a systematic review, Fonseca

Barbosa and Gama Marques (2023) found that individuals who are younger, single, poor education/unemployed living with a severe mental illness are more likely to develop a revolving door pattern.

2.4 Conceptual framework: Socio-Ecological Model

The long-term nature and functional disability of SMIs brings about many issues of adherence that manifest in many ways. It has been well documented that treatment adherence in MHCU's, particularly with complex mental illnesses, is influenced by a host of socio-ecological factors (Reupert, 2017) (Matlala *et al.*, 2018) and so, highlights the necessity of a holistic treatment approach. To understand these influences and intricacies, the Socio-Ecological Model (SEM) will be used.

The socio-ecological model (SEM), developed by Bronfenbrenner in 1979, explains the interplay between an individual and their environment (Bronfenbrenner, 1979). An individual's behaviour is often linked to influences from their environment and vice versa (Bronfenbrenner, 1979). This is described by an ecological environment consisting of five sub-systems, each of these systems occur within each other starting with the micro-systems at the center and extending out to the meso-systems, exo-systems, macro-systems and the outer-most chrono-systems (Bronfenbrenner, 1979). The SEM recognizes the dynamic interconnected personal and environmental factors that influence behaviour (Reupert, 2017). Thus, a socio-ecological lens will be adopted in this research and will assist in providing a basis to categorize the factors that promote and impede treatment adherence from various environmental influences.

Bronfenbrenner's SEM has been adapted and used widely in health promotion and mental health promotion (Finan and Yap, 2021) (Richard, Gauvin and Raine, 2011). Recent adaptations of the model make use of the terms; intrapersonal, interpersonal, institutional, community and public policy to describe each subsystem, these will be used in this study (McLeroy *et al.*, 1988). See Figure 1 below for a visual representation of this model.

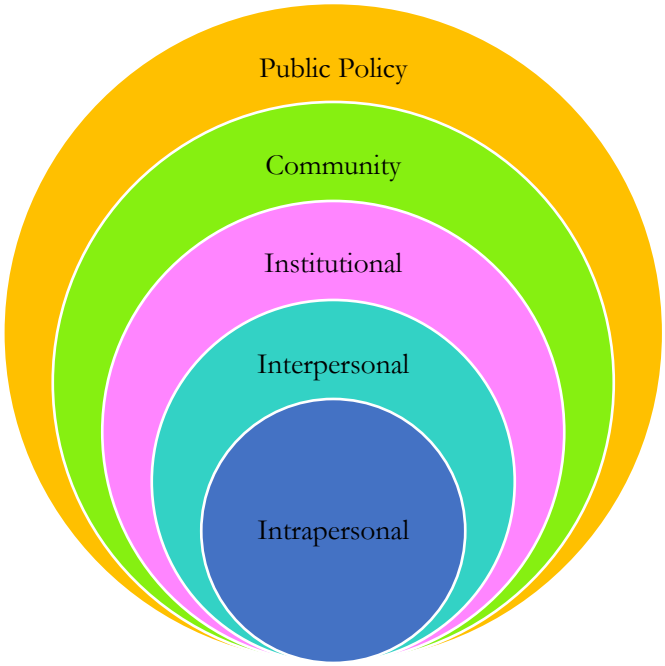

Figure 1: Bronfenbrenner's Socio-Ecological Model (1979) adapted by McLeroy, (1998).

Adherence and non-adherence are multi-faceted with many influential factors, therefore this will be streamlined and unpacked according to the levels of the SEM:

2.4.1 Intrapersonal Factors

Intrapersonal factors are described by the personal characteristics of an individual such as, demographic characteristics, knowledge, attitudes, skills, self-concept, etc. (McLeroy *et al.*, 1988). Health literacy and/ insight is an important facilitator of adherence in MHCUs. It can be defined by the WHO (2013) as cognitive and social skills which influence an individual's

motivation and ability to access, understand and use information to maintain and promote good health. In a latent profile analysis, Degan *et al.*, (2019), found that MHCU's difficulties with health literacy were significantly greater than the health literacy difficulties of other general populations. Copeland *et al.* (2008) concluded that the modifiable factor of insight into the importance of psychotropic medication and psychotherapy was positively related to psychotropic treatment adherence. In assessing the factors associated with relapse in schizophrenia, Kazadi, Moosa and Jeenah (2008) found consistent reasons with the previously mentioned studies, being low insight or health literacy, with the addition of side effects of anti-psychotic medications resulting in increased relapse rates among MHCU's diagnosed with schizophrenia.

2.4.2 Interpersonal Factors

Interpersonal factors of the SEM include a MHCU's direct social network which consist of family, friends, peers and healthcare providers (Salihu, Wilson and King, 2015). A literature review conducted by El-Mallakh and Findlay (2015) revealed that between family and/or clinician support/education, family support interventions showed favourable findings in increasing treatment adherence. The authors further highlight that clinician support or education interventions commonly produced short term results (El-Mallakh and Findlay, 2015). A study conducted in rural Kwa-Zulu Natal regarding the reasons for relapse or defaulting of medication in MHCU's, the authors consolidated the reasons being lack of social support system and poor communication between health care providers (Van Rensburg, Taljaard and Wilson, 2014).

2.4.3 Institutional Factors

Institutional factors are the social institutions with organizational characteristics as well as formal and informal rules of operation (McLeroy *et al.*, 1988) In the context of MHCU's these factors would include health care systems, resources within the health care system. Capacity of psychiatric institutions globally have been reduced over the last few decades, South Africa not being immune to this, with psychiatric bed numbers in tertiary hospitals decreased by 7.7% across the country between 2000-2005 (Lund *et al.*, 2012a). This has been motivated by a many complex considerations, most of which relate back to higher level policies encouraging de-institutionalization. Due to pressure for bed space, the MHCU may be discharged prematurely but they are not yet stabilized or functional enough, resulting in poor adherence and possible re-admission (Botha *et al.*, 2010).

2.4.4 Community Factors

Community factors are described by the relationships between organizations, institutions and informal networks (McLeroy *et al.*, 1988). Stigma is also a well-documented contributor to poor adherence to treatment in MHCU's (Matlala *et al.*, 2018). This is a factor that is prevalent through each level of the SEM (Matlala *et al.*, 2018). In study of communication and adherence in outpatient clinic in South Africa, results found stigma a strong link to non-adherence due to participants perception of society's negative view of psychiatric treatment (Van Rensburg, Taljaard and Wilson, 2014). Tied to this is another re-current factor of health literacy, with improving health literacy being recommended to improve adherence not only on the individual level of the MHCU but also on the community level in addressing stigma and discrimination and so increasing social support (Mokwena and Ndlovu, 2021) (Petersen and Lund, 2011).

2.4.5 Public Policy Factors

Public policy factors are the local, national and international policies related to the care and treatment of MHCU's (McLeroy *et al.*, 1988). Policies during the apartheid era of South Africa restricted health care services according to racial groups, gender, and geographical location (urban versus rural) (Coovadia *et al.*, 2009). These health disparities have had a large consequential impact on the current health care position in South Africa (Coovadia *et al.*, 2009). In addition, the country now faces a quadruple burden of disease consisting communicable diseases, non-communicable diseases (including MIs), diseases of poverty (maternal and child mortality) and injury and violence (Mayosi *et al.*, 2014).

The post-apartheid context prompted major policy revisions for mental health in South Africa, in which the Mental Health Care Act (17 of 2002) was developed (Lund *et al.*, 2012a). This act promoted the human rights of mental health care users (MHCUs) with deinstitionalization through community-based care rather than hospitalization; establishment of mental health review boards and 72-hour observation period of acutely MHCUs before up-referring to a tertiary hospital (Mental Health Care Act No. 17 of 2002). There were several implementation challenges of the Mental Health Care Act (17 of 2002), these included persistent low precedence of mental health, stigma and discrimination, poor integration of both mental health services and intersectoral policy (Lund *et al.*, 2011).

In line with these challenges and alignment to the World Health Organisation's (WHO) recommendations to reduce the burden of mental illness, gave rise to the development of the National Mental Health Policy Framework and Strategic Plan 2013–2020, which sought to achieve the integration mental healthcare services into the primary health care (PHC) embodied in the Mental Health Care Act (17 of 2002) (Meyer, Matlala and Chigome, 2019). However , in 2016 the efforts of these two critical policies were overthrown by the Life Esidimeni tragedy in 2016 where 143 MHCUs died after been transferred to unlicensed facilities (Meyer, Matlala and Chigome, 2019). Since this tragedy, South Africa has refocused and amplified its efforts in ensuring better service delivery for MHCU's.

The focus of mental health policy and research in South Africa is to align with international policy recommendations of integrating mental health services to community-based care. Due to this, there is limited research available within the tertiary level context that is grappling with the revolving door patient phenomena and consequences thereof in which the primary health care system could not serve these MHCU's (Lund *et al.*, 2012a) (Botha *et al.*, 2010). Studies related to treatment adherence of outpatient MCHUs are limited within the South African context. Furthermore, the adherence of MHCU with severe mental illness, whom require complex treatment interventions, is poorly studied and is recommended focus area of policy implementation (Lund *et al.*, 2012a). Lund *et al.* (2012) highlighted a need to shift the research focus mental health from the burden and status of mental health services to intervention studies, however over the last decade there has been poor strides in achieving this.

It can be seen from the review of the evidence that the burden of mental illness deeply affects not only the individual MHCU but cascades into all levels of the SEM. This results in poor policy implementation and healthcare systems that further fails the MHCU.

3 METHODOLOGY

Chapter 3 serves to describe the methodology that was undertaken by the researcher to answer the research question. This chapter will describe the study design, the setting and context of the study, the study population and sample, the pilot study, the data management, and analysis procedures and lastly the ethical considerations that the study upheld.

3.1 Study design

Selecting the suitable study design to answer the one's research questions is one of the most important steps in the research process (Doyle *et al.*, 2020). A descriptive exploratory qualitative study was conducted over the 2022/2023 period at Tara Hospital's OPD (contextual).

A qualitative approach provided rich insights into mental health treatment adherence (and non-adherence) first-hand from the perspectives of MHCU's, as treatment adherence is complex and multi-faceted. The study design made use of in-depth interviews (IDI's) facilitated by a semi-structured interview guide, which ensured a smooth well-progressed interview and assisted in making sure key points were addressed. The use of IDI's allowed participants to share their experiences related to the research question and this facilitated the analysis of their subjective experiences (Flick, Kardoff and Steinke, 2004), this also enabled deeper interpretations according to the conceptual framework in this study.

Qualitative descriptive design is used to describe the candid subjective experiences and perceptions of participants in relation to the phenomenon under investigation (Doyle *et al.*, 2020). This study aimed to explore the factors that promote and impede treatment adherence specifically from the perspectives of MHCU's.

The aims and objectives of this study are inherently exploratory as the study set out to explore a phenomena poorly captured within the study setting (Hunter, Mccallum and Howes, 2019).

This research was contextual as it focused only on MHCU with SMI accessing services at a specialized outpatient department. Therefore, is important to note that the results are not generalisable to other contexts but are transferable to other specialised psychiatric outpatient departments (Kalu and Bwalya, 2017).

3.2 Study setting and Context

This research project was conducted in the OPD at Tara Hospital. Tara Hospital is a public specialized psychiatric hospital situated in Hurlingham, Johannesburg. The hospital comprises of 141 beds across nine inpatient wards servicing adults, adolescents, and children with mental illness. These wards include three adult biological wards, and specialized wards which include an eating disorder unit, adolescent ward, child ward and an adult psychotherapy unit (Dr. T Madigoe; Dr. S Fernandes, no date). The hospital also has a large adult outpatient department, a child outpatient clinic and neuropsychiatric clinic (Dr. T Madigoe; Dr. S Fernandes, no date). Tara is classified as tertiary and quaternary hospital due to the level of specialised services provided (Dr. T Madigoe; Dr. S Fernandes, no date). Therefore, MHCUs are referred from other tertiary hospitals in the Johannesburg metropolitan district or referred from the private sector for specialized services. Thus, Tara does not have a specific catchment area for inpatients and many MHCUs will reside from all over Gauteng. Upon discharge, depending on the severity of the case and taking the social context into consideration the MHCU will continue as an outpatient at Tara for continued specialized outpatient care or will be down referred to the appropriate level of care. This research targeted these outpatient MHCUs to explore treatment adherence as this setting provides services to individuals with complex and severe mental illnesses that come from

diverse contexts and where high non-adherence rates with subsequent re-admissions have been observed and therefore align with the study population that was required.

3.3 Population

The study population consisted of MHCU's diagnosed with severe mental illness aged 18-65 that were attending mental health services at Tara Hospital's out-patient department in 2022/2023.

3.4 Sample

A purposive and convenience sampling method was used to recruit MHCU's aged 18-65 years old that were attending the OPD at Tara Hospital and were willing to participate in an IDI. Purposive sampling was appropriate to this qualitative research project as it facilitated the careful selection of diverse participants based on their mental health history and this provided rich data (Palinkas *et al.*, 2015) in exploring their experiences of treatment adherence. The selection of participants based on their willingness to participate and level of English proficiency spoke to the ease of access for the participants which is indicative of convenience sampling (Palinkas *et al.*, 2015). A total of 18 MHCU's were sampled for this study.

The following describes the inclusion criteria of participants for this research project:

- Aged 18-65 years old at the time of recruitment.
- Diagnosed with a severe mental illness (moderate to severe depression, bipolar disorder, schizophrenia, and other psychotic disorders).
- Attending Tara OPD services at the time of recruitment.
- MCHU's that can speak English.

Exclusion criteria:

- MHCU's that are actively psychotic, manic, or suicidal.
- MHCU's that I am currently treating or part of the professional team responsible for their care.

3.5 Pilot

The interview guide was piloted with two participants to simulate the planned interviews and to determine if the items made sense to them. A critical evaluation of the flow and phrasing of questions was made, and appropriate modifications were made to the interview guide. Modifications included changing the order of the questions by starting off with introductory questions to establish rapport before asking about adherence. This also included reducing the amount of jargon used and adding words such as "compliance/take treatment" as additions to the term 'adherence'.

3.6 Recruitment of participants

Participants were recruited by the researcher and assisted by clinical staff members (nurses, doctors, psychologists and occupational therapists) in the OPD. Clinical staff members in the OPD were provided with the inclusion and exclusion criteria and asked to flag appropriate candidates for the study during their daily appointments. The researcher organized a brief information session about the research project during the OPD's weekly ward round meeting whereby most clinical staff members are present. In addition to this, the researcher would actively enquire with the clinical staff members if they had any appropriate MCHU's booked for a follow up, this would typically occur on a Tuesday and Wednesday as it is the busiest day in

the OPD. Once flagged, the primary researcher would approach the candidate to explain the study and purpose of it. If the candidate signed informed consent procedures understanding that there were no incentives or reimbursements associated as well as their right to withdraw at any point, then the interview process would be initiated.

3.7 Data collection

The primary researcher was responsible for data collection, this was initiated once ethics clearance and institutional approval was received. Primary data was collected using in-depth interviews (IDI's) conducted with participants in a private room in the OPD or occupational therapy department at Tara Hospital. This was based on space availability on the day of the interview.

Participants were asked to complete a short demographic questionnaire (see Appendix A) prior to the interview, this facilitated appropriate probes during the interview and provided context during the data analysis stage. A semi-structured interview guide (see Appendix B) was used to ensure that the objectives of the study were addressed. The average length of an IDI was 28 minutes.

During and immediately after each IDI, the researcher recorded field notes to capture any important non-verbal information and impressions displayed by participants. After the 18th interview, the researcher felt content with the quantity and quality of the data set for analysis. Dibley (2011) describes this type of data saturation as rich and thick. Rich being the quality and depth of the data and thick being the amount of data.

3.8 Data management

The IDI's were recorded on a voice recording application (app) on the researcher's password protected cell phone. Each IDI was labelled using a standard, systematic filing approach without any identifying information of the participants in the IDI. These recordings were duplicated and transferred to the researcher's password protected computer. Fieldnotes that were recorded were typed out on the researcher's computer then saved and duplicated with the standard filing approach adopted. All data collected during the study will be securely kept, on a password protected laptop and google drive as well as a locked cupboard, for two (2) years if a scientific publication arises from the study and six (6) years if there is no publication. Thereafter it will be destroyed accordingly.

3.9 Data Analysis

For the data analysis process, the primary researcher followed the 7 Stages of Framework Analysis Method according to Gale *et al.*, (2013). This method was appropriate to this study as it provided structure to the data analysis process and is useful for obtaining an in-depth descriptive view of a large set of data (Gale *et al.*, 2013). The 7 Stages of Framework Analysis Method applied to this study is outlined below:

1. Transcription

   The audio files were transcribed verbatim using Otter Software and were double checked for accuracy by a research assistant trained by the primary researcher. The transcripts were labelled with the same standard naming and filing system as the audio files. The primary copy of the transcripts was stored on MAXQDA software.

2. Familiarization with the interviews

The primary researcher re-listened to the recorded interviews and then became familiar with the data set by reading and re-reading all the transcripts prior to initiating coding.

3. Coding

   The data set was labelled with codes deductively according to themes related to the interview guide as set out by the research objectives. Through this process sub-themes emerged from the data set. This took place using MAXQDA software.

4. Developing a working analytical framework

   The primary researcher and her supervisor compared codes and defined categories.

5. Applying a working analytical framework

   Indexing transcripts using categories and codes was then completed. Unique colours and numbers were used for the codes and categories for easy identification.

6. Charting data into the framework matrix

   The categorization of themes and sub-themes built a comprehensive codebook.

7. Interpretation of data

   The data was then interpreted based on the SEM.

3.10 Trustworthiness and credibility

This will describe the strategies that were used to enhance the research quality and rigor of this research project. These strategies were informed by the four criteria described by Guba (1981) to ensure the trustworthiness of a qualitative study and are detailed below:

Credibility:

Credibility aims to ensure that the study results are congruent and trustworthy (Guba and Lincoln, 1985). In this study, the researcher made use of clear well recognized research methods and conducted the data collection as per procedures outlines in the protocol that received ethic's

approval. The researcher, with clinical experience in specialised psychiatric services was able to recognize their position in this research study and understand the study setting and context.

Transferability:

Transferability of this study is ensured by the thick description of the study setting and context as well as the parameters of the study sample and data collection procedures (Guba and Lincoln, 1985)

Dependability

Shenton (2004) reiterates the close connection between credibility and dependability, and therefore to ensure dependability of study a researcher needs to provide an in-depth methodological record and description (Guba and Lincoln, 1985). The purpose of this chapter 3 aims to reassure dependability of this research project.

Confirmability:

Confirmability relates to the steps taken to ensure the results reflects the experiences of the participants and not the biases of the researcher (Guba and Lincoln, 1985). Triangulation was made use of by the research supervisor co-coding and overseeing the thematic analysis during data analysis procedures.

3.11 Ethical considerations

Ethical clearance for this research project was acquired from the University of the Witwatersrand (WITS) Human Research Ethics Committee (HREC) on 29/04/2022 – Certificate number: M220445 (see appendix C).

3.11.1 Institutional Approval

Institutional approval was obtained from Tara's Research Committee (see appendix D).

3.11.2 Consent & Voluntary Participation

All informed consent procedures took place before IDI's were conducted, participants were given a clear descriptive information sheet (see appendix E) using non-specific language as well as a consent sheet for the interview (see appendix F) and audio recording (see appendix G). A clear explanation of the purpose of the research project and right to withdraw at any point during the research process was described to participants prior to each IDI.

3.11.3 Confidentiality

Confidentiality of participants was ensured through the removal of any identifying information of the participants and the researcher complying to the adopted standard, systematic naming and filing approach, including any field notes taken (i.e. P01, P02, etc). The data is only accessible by the researcher and her supervisor. This data will be archived for at least two years after publication and for six years if there is no publication.

3.11.4 Minimising Invasiveness

The researchers interfered with the participants only to the extent that was warranted by the research design. IDI's were scheduled according to the availability of the participant and although the average length of the interview was suggested to the participant, each interview's length was determined by factors related to the participant. Lastly, once IDI's were complete there was no need for contact or follow up with the participant.

3.11.5 Responsibility of Researcher

The researcher conducted the research with due concern for the dignity and welfare of the participants. The research process did not involve any harm to the participants whether socially, economically or physically. A distress protocol (discussed below) was in place at the risk of emotional distress due to retelling of lived experiences of severe mental illness.

3.11.6 Distress Protocol

A distress protocol (see appendix H) was on hand if a participant became uncontained during an IDI. This included a step-wise approach for the researcher to follow of being aware of the participants psychological/emotional state and acknowledging changes in this state. A nurse was on standby in the OPD if required. However, the use of the distress protocol was not required during data collection.

3.11.7 Positionality

I am a 27-year-old white female. English is my first language, and this research was conducted in English. I established rapport with each participant at the start of each interview through appropriate small talk, explanation of the research and allowed room for any questions or concerns. This ensured that each participant was comfortable with the interview process.

I am an occupational therapist employed at Tara Hospital and have worked in the various adult in-patient wards and out-patient department. Thus, the sample and some of the participants were MCHU's whom I've had contact within a clinical capacity prior to the study. To account for the risk for researcher bias, I aimed to observe the highest ethical standards during the entire research process. This was managed in various ways. On days I was conducting interviews, I

would not wear my typical uniform of hospital scrubs to ease power differentials in the room. I openly discussed issues of and accounted for positionality with my supervisor, who assisted in unpacking and understanding these issues as they came up the data collection process. In addition, I made my positionality clear at start of each IDI and reinforced here the purpose of the research study in relation to my master's and not as my capacity as an occupational therapist. For patients that I treated in clinical capacity prior, I would spend time explaining this dual position and allow space for any questions as well as ensure that they understood this and were comfortable to continue with the IDI.

4 Results

This chapter will describe the results from the in-depth interviews. Firstly, the socio-demographic profile of the participants will be presented. A thematic analysis was used to highlight the five dominant themes and their sub themes that emerged from the research. The five dominant themes included: Experience of mental illness and adherence, Experience of Tara OPD, Promoters of Adherence, Barriers to Adherence and Stigma

4.1 Socio-demographic profile of participants

Table 1 below represents the socio-demographic profile of the participants.

Table 1: Socio-demographic characteristics of participants

Name	Age	Gender	Ethnicity	HLOE	Home Language	Current Living Situation	Current Psychiatric Diagnosis	Other Illnesses
P01	54	Female	White	Grade 12	Afrikaans	Living with Partner	Depression, Anxiety	Underactive Thyroid
P02	48	Male	White	Grade 10	Afrikaans	Living Alone	Bipolar Mood Disorder I	High Blood Pressure, Diabetes Mellitus
P03	64	Female	White	Higher Certificate	English	Living Alone	Borderline Personality Disorder (BPD)	Emphyzema
P04	47	Female	White	Diploma	English	Living with Family	Schizoaffective Disorder	Diabetes, High Cholestrol
P05	29	Female	Mixed Race	Grade 12	English	Living with Family	BPD, TLE, ADHD, Bipolar	Asthma, Eczema, Allergic Rhinitis
P06	23	Male	Black	2nd year College	English	Living with Family	Schizophrenia	None reported
P07	57	Male	White	Grade 12	Portugese	Living with Family	Schizophrenia	None reported
P08	54	Male	White	Grade 11	English	Living in a Placement Facility	Bipolar Mood Disorder	High Blood Pressure
P09	33	Female	White	Grade 12	English	Living with Partner	BPD, ADHD, OCPD	None reported
P10	62	Female	White	Diploma	English	Living Alone	Schizophrenia	None reported
P11	52	Female	Black	Diploma	Zulu	Living in a Placement Facility	Schizoaffective Disorder	None reported
P12	45	Female	Mixed Race	Bachelors Degree	English	Living with Family	Schizoaffective Disorder	Hypothyroidism
P13	32	Male	Black	Grade 11	Zulu	Living in a Placement Facility	Schizoaffective Disorder	None reported
P14	36	Female	White	Grade 12	Afrikaans	Living in a Placement Facility	Bipolar Mood Disorder	None reported
P15	45	Female	Black	Masters Degree	English and Xhosa	Living with Family	Schizoaffective Disorder	None reported
P16	42	Male	Black	2nd year LLB	Xhosa	Living with Family	Schizophrenia, Epilepsy	High Blood Pressure
P17	53	Female	White	Grade 12	English	Living in a Placement Facility	Schizoaffective Disorder	None reported
P18	51	Female	Black	Bachelors Degree	Xhosa	Living in a Placement Facility	Schizoaffective Disorder	High Blood Pressure, Thyroid

4.2 Thematic Framework

Figure 2 (below) represents the thematic framework that was used to analysis the dominant themes and subthemes that emerged from the data.

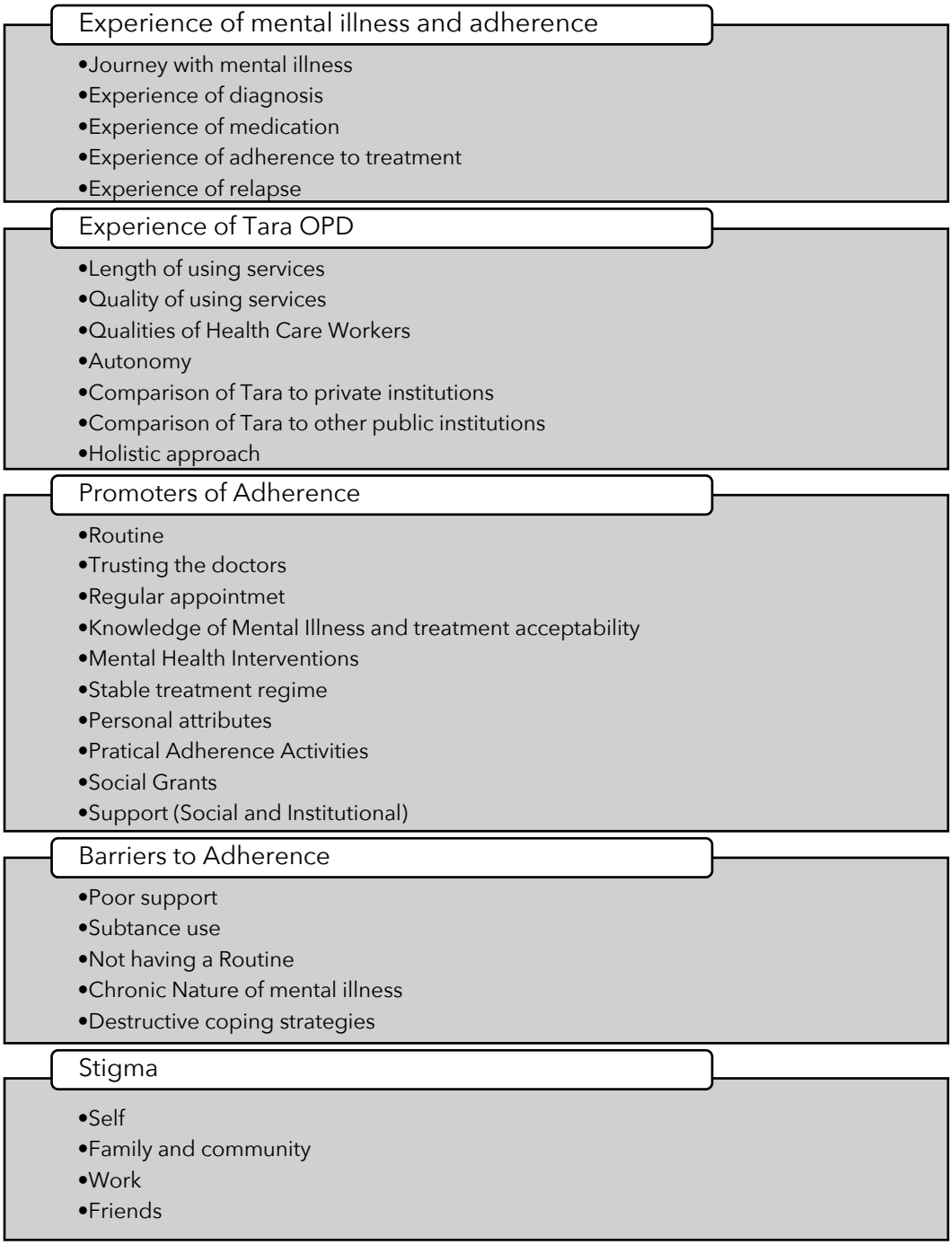

Figure 2: Thematic Analysis

4.3 Experience with mental illness and adherence

Journey with mental illness

A consistent theme in the data shows an expansive journey, a journey that for some participants can span decades in managing mental illness. The data showed that this has not been a linear process but rather an arduous path, with implications in all spheres of the participants lives. Participants described a prominent functional impact of mental illness on an adult as being the loss of employment due to their mental illness. This is shown to be not only because of the symptoms of the mental illness, but the time required to manage the mental illness as well as the stigma associated with mental illness in the workplace.

> *"So I actually did end up losing my job or my income as a result of the treatment and the bipolar." (P04)*

Experience of diagnosis

Participants narrate their experience of their diagnosis through how their diagnosis has changed over time, due to evolution of their symptoms.

> "*When it shifted over to schizoidaffective (sic). I knew that I had to take it seriously. I knew that I had no other source of income. So I couldn't get treatment anywhere else. So I was - I've adhered." (P04)*

Participants were able to reflect easily on whether they felt like a diagnosis aligned with them or not and how this impacted their adherence. For some participants, diagnoses that did not align or feel like they agreed with participants reported struggling with adherence because there was no buy in from their side.

"Um, originally I was diagnosed with both bipolar and generalised anxiety disorder through Akeso. And I didn't like it. I didn't. It didn't resonate. Both my parents had undiagnosed bipolar, but it didn't feel like it resonated with me. So I was - I fought against it.

For one participant, he could reflect that although he did not agree with his diagnosis nor having a mental illness at all, complying to the medication secured him basic needs within a placement facility and that if he didn't take the treatment, he would be homeless.

"The reason I'm taking the treatment is because ... if I don't take the treatment, I'm going to be kicked out and I'm gonna be in the streets again. So let me take the treatment, you get what I'm saying? Only for that reason. Because if I don't take the treatment, they'll be like, "Okay, he's not taking medication. Why are we keeping him here?" (P13)

Contrasting to this, other participants expressed relief in finding out their diagnosis as it provided an explanation to the symptoms they were experiencing.

"...But I got my diagnosis, and I burst into tears from relief. It was this - for the longest time, I've just wanted to name what I'm feeling and what I'm going through." (P09)

Experience of medication

As part of the complicated journey with having mental illness, participants recount their vast experiences with medications and many different types.

"Look, I've been diagnosed since 1990 and I've been taking hundreds and hundreds of pills over the time." P02

Participants that have been MHCU for a long period are able to give detailed insights into not only the different medication itself but how the medications affect them at different dosages. Participants allude to this as being careful dance between the psychiatrist getting it to therapeutic levels and the side effects being tolerable for the MHCU.

“Because if you look at my dosage, on the outside they will say, "Oh, that's just a dosage." But she carefully manoeuvred it and it works perfectly. Even if I go manic, and I take my medication earlier since I feel funny - if I take the dosage, in 10 minutes' time, I'm okay.” (P02)

“Because we're still getting the right cocktail. So feeding through what works helping me sleep, but also sort of working against what's helped me sleep against gaining weight. There's this balancing act and this latest dose I had a "aha" moment about two weeks ago. And it's like, I feel proud of myself and the meds kind of got me to that point of like, "I did that." And I was proud.” (P09)

The biggest hurdle participants expressed in relation to their medication was side effects, these included weight gain, drowsiness, memory difficulties, constipation, and tremors. A dominant theme amongst female participants, was that they reported their greatest side effect being weight gain and how this impacted their self-esteem as well as adherence.

“But the bipolar I battled to accept the illness and therefore adherence was difficult for me. Every time I took that medication, I knew that my body was getting fatter.” (P04)

Another side effect many participants reported on was drowsiness, they elaborated in describing the impact this has on their functionality in terms of contributing to the household, both by being able to work and complete chores. As a result of this impact, one participant reported adjusting her dosages on her own accord.

"No, I can't get up. I'm really tired and I feel dizzy and confused [...] . And what did I eat last night?" She says, "No, you took your medication as normal." I said, "It's a lot. It's making me feel constipated or something." Like I was like, my tummy was upset like, like somebody has stuffed it with blankets upset [..] So my mom said, "No, you can't go on with a dosage like this. You're not going to be able to work and not anytime soon anyway, and we need you to get up as soon as possible and get to work. We need help. We don't have money for groceries at home." (P15)

"Then I had a break down at 36 and that was a huge thing. It took me about a year to come right afterwards. And then it was medication that arrived in my life. And it was lithium. And lithium caused me to shake and I never quite got rid of that." (P10)

Experience of adherence to treatment

Participants' experiences of adherence were intricate and for many influenced by their beliefs of their mental illness. This was particularly evident when participants were asked to explain what adherence or compliance means to them. Participants explained this according to similar definitions such as "sticking to the rules", "guidelines", "as the system has prescribed", "being committed" or "sticking to routine" whilst other participants linked this to their past experiences, beliefs and knowledge towards their mental illness as well as trusting their doctors. This was noted to include predominantly long term MHCU's, who narrate that they are dedicated to their adherence because they believe in the benefits of the treatment, see the value of it, it keeps them stable, and understand the consequences of not taking it.

"Um, when I take it, I believe it will help me with depression and anxiety. But I believe that that that it helps me" (P01)

Participants described other layers to their experience with adherence which included the role of stigma and how their adherence was influenced by other people. Participants emphasized the impact of side effects on their experience of adherence as well as how socio-economic stressors effect their adherence.

"Most of the time I take my medication. But there was a time where I stopped because people believe that your faith is not enough when you take medication. You should be able to be healed. And ... that's one time. And the other time was because the side effects are just too much to manage, especially on my weight." (P18)

Lastly, one participant explained the transition post discharge and adjusting to a new routine as the hospital was very structured took a lot of effort and was a significant influence on her experience of adherence.

> *"...as an outpatient, it's very easy to forget them in the first few weeks. I used to forget the times" (P15)*

Experience with relapse

Participants describe a multifaceted experience with relapse which included non-adherence, failing treatment regimes, socio-economic factors and for some a concluding result of fearing relapse. Participants who had poor adherence despite reported practical measures in place (alarms, medication kept by the kettle) report increased experiences of relapses and conflict with family as a result.

> *"Well, my son gets angry with me because he said, "Yeah, I've seen that movie before, you know? You think you're well, and you stop your meds and then everything's chaos." So I don't intend to stop meds but I do forget sometimes. Genuinely forget. Although I've got them on my kitchen counter. And I've got a thing on my phone to go, "Whizz, whizz." Yeah." (P10)*

Other participants' feelings towards this approach are perceived as poor accountability and met with negative feelings as they believe mental illness is a manageable disease, but people treat it carelessly and keep coming back to hospital.

> *"They just say, "Oh, I've relapsed again." That's all they say. As if it's just nothing, you know, there's nothing wrong with it. They've just relapsed. They have to come to hospital. Yeah, it's something - to them, it's just something that happens and then they have to come to hospital." (P11)*

Non-adherence resulting in relapses were influenced by side-effects as described above as well as the impact of stigma which will be explored below. Participants tell of their relapse experience whilst taking treatment, this boiled down into two large categories failing treatment regimens and socio-economic factors. Participants reported failing treatment regimens or having poor response to the treatment which resulted in relapsing. For one participant, the poor response to treatment resulted in undergoing electro-convulsive therapy.

> *"That's what happened to me when I relapsed on no medication. I was in a depressive state when I was first sent to Ward 6. And in Ward 6, I had to get ECT therapy, because I was not responding to any of the treatment that was administered to me." (P12)*

Socioeconomic factors that participants experience resulted in domino effect leading to a relapse, these factors included familial stress (ill-health of family members, family conflict), financial stress, work-related stressors. All these factors resulted increased experiences of stress and anxiety as well as depression, a few participants report substance-use with over self-medicating and ultimately resulting in a relapse.

> *"The biggest part was financial. […] Because it's a big stress on you, and you don't know which way, and then you get depressed. And then you need to be hospitalised. Then you don't sleep. 2009, I was taking Aquadol which has codeine in, which Dr. (name) said to me it was very bad because it's codeine. It is close enough to opium or something like that. It's a opioid. And then I stopped it. That was to help me sleep." (P12)*

Participants that are long term MHCU express a deep fear of relapse, and this is one of their driving factors for adherence. One participant's recount of a relapse entails how he never wants to be that bad again as he was extremely verbally and physically aggressive. Another participant describes how he has been on a stable treatment regime for years and doesn't want any medication changes as he is terrified of becoming treatment resistant and this facilitates his unwavering adherence.

4.4 Experiences with Tara OPD

Length of using services

A predominant theme showed that the participants in this study have been using OPD services at Tara hospital for a long period of time. For two of the participants this tenure is coming on 36 years of various services at Tara. This provided dynamic insights into participants' experiences with their mental illness, adherence, and Tara as a system itself. Participants recount their journey as a MHCU at Tara has not been linear but rather influenced by periods of non-adherence, the fluctuating nature of psychiatric symptoms, down-referrals to other public institutions or care in the private sector.

> *"Oh my goodness. In terms of - there's a number of years. I'm not able to recall but ... Oh, okay. Um, I have ... I've been - the thing is, since I've been admitted, since I've been first admitted to here to Tara; I have relapsed, like more than once. So like, maybe I'd been an out, an inpatient, and then an outpatient, and an inpatient again, and an outpatient again, and so" (P16)*

Quality of using services

Participants rate the quality of services at Tara highly in terms of care as well as efficiency.

> *"My son said to me he hasn't seen me as good as I have been now. He said, Tara is totally, you know, the best treatment I've had ever. Yeah. I don't know where everything clicked into place. And I started thinking and facing the reality of things" (P10)*

A dominant theme was highlighted through participants experiencing the service being very good in OPD, participants commented on how quick and efficient the entire process is – from getting their file, to vitals, to bloods, to seeing the doctor and lastly the pharmacy.

> *"You get searched at the gate, and then from there on it's just - get your file, do your vitals, see the doctor, get your medication, within an hour. Maximum*

an hour. You've got everything. [..] The service at that pharmacy is better than Dischem." (P02)

Participants linked this to their contrasting experience of other public institutions.

"So obviously, having been there (Alex Clinic), Tara is a massive upgrade." (P05)

This was particularly of note for the participants who had been using the service for a long time, for those who were newer to the Tara OPD system agreed with the efficiency however additionally commented on how it can be daunting and anxiety provoking getting to know all the steps in the process.

"My wait has never been too long. Mostly an in-and-out thing, and sort of getting my medication is also pretty simple. And yeah. Problems are just kind of the communication level and the chaos. I keep referring to chaos, but it's sort of; where do I need to sit for vitals? Where do I need to go for bloods? Who do I communicate through and it's sort of ... Yeah. Duty room, going there, there, there, and there. Three people telling you something different. So with anxiety it does ... Today was absolutely chaotic and I was completely overstimulated and I just wanted to hide." (P09)

Qualities of Healthcare Workers

A strong connection appeared in the data, that participants closely linked their experience of OPD to the qualities of the staff members located in OPD. Staff included admin, nurses, phlebotomist, psychologists, and doctors. These qualities included being friendly, caring, accommodating, good communication skills including listening well and being compassionate.

"It's the tentativeness that the the the tentativeness. It's the the, you know, like if I'm walking "Hello (Name)!" you know that they care. They know. Or at least I think they care. You know what I mean? They make me feel like they care." (P03)

Participants also strongly associated their experience with OPD with their doctor. This was seen to be two-fold, on one hand a strong experience related to consultant psychiatrists and on the other hand a dominant theme related to registrars (doctors training to be psychiatrists). Participants seen by consultant psychiatrists report positive experiences and increased sense of trust with their doctor. This was seen through the qualities and expertise of the psychiatrists. One participant extended this comparison and outweighed the quality of his doctor to the private sector.

*Of note, the following quotes refer to four different consultant psychiatrists:

> *"Touching base with Dr (name) every so often has helped me just keep focused, and feel rest assured that my hand is, my circumstance is, or my health is in the hands of a very qualified, highly respected individual. So, I'm quite happy that I see Dr (name) and I'm quite happy that I go according - I beat according to her drum not to mine. So it's a positive relationship (P04)*

> "*Dr (name)* is an excellent psychiatrist. She helped me out." *(P07)*

> *"People are always willing to help me and they're friendly. Dr (name)is a very good psychiatrist. Okay. Because she listens to me and understand my problems." (P01)*

> *"So now I don't know what you're going to pay privately for this doctor. You're going to pay a lot of money for this doctor privately but luckily I don't have to pay because I'm here. She's also here." (P02)*

In in relation to the registrars, the nature of the training programme means only a 6-month rotation in OPD. Some participants appear ambivalent and familiar to this process:

> *"But the doctors that I see they rotate. Sometimes this one, then the other month, after three months they rotate. After that month - when they, say for instance, I'm coming to see the doctor this month. Maybe they would say it's another doctor and then ... Or I just see by being called by another doctor and I'll be like, "Oh, where's the other one?" I'll ask the doctor when I'm in the office and then she'll let me know that no, the doctor is going to another department of health or hospital." (P13)*

Contrastingly, this has impacted one participant's experience greatly, where he feels nervous about the rotations which he associates to him being stable and has a strong fear of relapse where he is worried a new doctor will change things:

> *"Look, my experience has been relatively well, until five years ago.[..] Five years ago, people started changing, doctors started changing. There used to be like different things all the time. So I've been very happy 'til that point, you know?" (P08)*

Autonomy

Another dominant theme to come up in relation to registrars is participants feeling the lack of autonomy in the management of their mental illness.

> *"It's very frustrating, you know. I want a doctor that knows me and I want a doctor that can sit and ponder my diagnosis, and my medication, and consider it. And say that, "We're not going to do this. We're not going to do that, or ..." Just keep me in the loop. Also, they don't - they just say they're going to do this and do that. And that is very concerning for me, and I must say, I've got a problem with that." (P08)*

Participants report feeling like they must enforce their autonomy due to the lack of engagement around their questions and being dismissed. One participant highlighted that the lack of autonomy makes compliance difficult because then she doesn't know what or why she's taking it:

> *"What was somewhat upsetting, was the lack of engagement, regarding my questions about, like, the links between my other diagnoses and ADHD. Why had I not been diagnosed with ADHD? Like what symptoms overlap with my other diagnoses? And so that was ... yeah, that was quite annoying, frustrating because it meant that I wasn't being given information about why, and what it means, and what the changes, and what the impact might be on my other mental illnesses and what the impact of going on Ritalin will be on my other mental illnesses." (P05)*

Comparison of Tara to Private Institutions

Participants that have experienced psychiatric care in the private sector report that they prefer the service at Tara. Participants feel that care in the private sector is all done in isolation from one another and that the financial burden is too high.

> *"I tried private and it was extremely hard. Obviously, financially, but also because generally private practice is an individual and they have sole power. So there's no oversight, there's no discussion, nothing like that." (P05)*

One participant elaborated further describing a consequence of this is that it allows "too much freedom" between appointments and impacts adherence negatively.

> *"When I'm at Tara, I at least take my medication. When I was in private care I went off my medication because I was feeling sick…It's(Tara) more holistic. Private, they say to you, "Here's your script for six months and we'll see you in six month's time. I only am interested in you if you're sick and at the moment you don't appear sick." Even with that, they see you like every six months for two minutes in their consultation room and that's it. So, here we get all round care." (P04)*

Comparison of Tara to other Public Institutions

In comparison to other public institutions, participants report a preference for Tara. This is influenced by the quality of services described above. Participants report that other psychiatric outpatient services have very high doctor to patient ratios and thus quality and time spent with the health care professionals is compromised, other times resulting in not being seen on the day scheduled for. Overrun pharmacies and long queues were also deterrents for participants accessing services at other public intuitions.

> *"But yeah, it's a lot. So obviously, having been there (Alex), Tara is a massive upgrade. Also, having been to Joburg Gen, which is also - obviously Joburg Gen is a massive hospital, so it's also quite busy. Like the pharmacy is - or was ... shame, a lot. And again, they don't always have medication, and paracetamol isn't going to quite cut it. So that kind of lack of time and focus*

and resources does make it very hard, because you're just kind of being herded into the doctor's office, out of the doctor's office. It's like three minutes. "Are you going to kill yourself? No. Great. Pharmacy." kind of thing." (P05)

"At the other places, you have to sit there for ... you sit there half a day to see the doctor. You sit half a day to get your medication. So not really as smooth as this place. That's why I'm not at Randburg Clinic…And they only see like 20 people. If you're number 21 of everyone you must go and come back the next day." (P02)

Holistic Approach

A common theme related to the Tara experience was the holistic approach of care that participants experienced from services in the OPD. A dominant link that came up was that participants were being treated for other non-communicable diseases such as diabetes and high blood pressure. Participants expressed gratitude for this as it allowed for all their needs to be met at in one place rather than having to access multiple institutions.

"Well, like me personally, if I can speak from my experience, I'm being treated for diabetes and cholesterol as well. I mean, that's just amazing. I would have had to have gone through a GP for that and been under the care of a GP, or at least for that. Dr (name) has given me the medication and she monitors that for me as well." (P04)

Another element to the holistic approach that one participant highlighted was the availability of a multi-disciplinary team at Tara and how it influenced her experience in that it instilled a sense of accountability of the healthcare professionals as they must report back to the team and not work in isolation.

"that's one of the things I like about Tara is that there is that team. So, you don't just have one person who is the ultimate authority on everything going on in this person's head. You have many people with different experience and different levels of qualification, and of course, people see things differently. And so having those discussions, having greater input about possible causes and consequences and interventions, does mean that, I mean as with anything,

oversight is always good. It means that there is more informative decision-making, and people can't just, kind of, decide because that's what they think." (P05)

4.5 Promoters of Adherence

Routine

Participants emphasized the importance of maintaining routine as a promoting factor to adherence. For other participants, this adherence and taking treatment has become an inherent part of their day.

"Yeah, I think like I said, it's just a constant reminder to myself in my mind to like, "Okay, (name), it's breakfast time. After breakfast, take all your meds." you know? And I always look at the meds, like the dosages that I'm supposed to take; how much dosage for what medication. And then I do that and I do the same thing. Like after dinner time, after my dinner, evening meds, dinner time meds, I do the same thing as well." (P16)

For participants living in a placement facility, the supervised and routinized nature of medication administration is a positive influence.

"And that helps. You can't forget because you have to line up for medication and you have to drink your meds. You can't forget about it." (P14)

Participants perceive this as structural support of their adherence. For certain facilities this is extended to ensuring that participants adhere to all appointments and transport is provided whereas.

"Like I said, on my part, the placement makes it very easy for me to take my medication. So my management of this disease is made very easier by the

placement because they make sure I take my medication at the right time in the right quantities, you know?" (P11)

Trusting the Doctors

Trusting the doctors was described by some participants as an inherent positive influence on their adherence. This was seen particularly in participants that have been accessing services for a longer period and that were seeing consultant psychiatrists, whereby they have built a relationship with their doctor and trust their doctor's skills and judgement.

"So I don't know how to explain the medication; she knows what it does. I just have to take it." (P02)

"I beat according to her drum not to mine. So it's a positive relationship." (P04).

Regular Appointments

Regular appointments with specified scripts were described to be a positive influence on adherence. Participants reported that their follow up appointments were not standardized but rather based according to their individual case, for some it was every three weeks, others it was specifically every 28 days and others on a monthly or every second month basis.

"Sort of thinking about it's like, "Hey. Only four weeks of meds." Doing bloods every six months because it's responsible keeping you seeing what your body's doing. There is this care and oversight that is subtle, but reinforced" (P09)

This provided structure and facilitated a feeling of accountability and built trust with the doctor with this instilled sense of individualized care.

"I come to Tara every three weeks [..] I think I was admitted for a long-time last year. For nine months. So she's just worried. She doesn't want anything to happen to me" (P11)

Participants linked this to their contrasting experience in the private sector, where the standardized appointments, sometimes only every 6 months, left them feeling isolated in managing their mental illness with no accountability to anyone.

Knowledge of Mental Illness and Treatment Acceptability

Increased knowledge of mental illness and managing one's mental illness was discussed as a promoting influence on adherence. A few participants described the important role of having knowledge of the treatment and understanding how it worked facilitate a sense of ownership in their adherence. This included participants' emphasis on consistency and routine of taking treatment as well as the negative effect of substance use whilst on treatment. A dominant theme that came up was that treatment acceptability is the main promoting influence for participants. This was compounded through their long journey with mental illness, knowledge of managing their mental illness and as described by the participants "it keeps me stable", "i don't mind taking it - it makes me feel better". Having knowledge and insight into mental illness was further extended to understanding the consequences of non-adherence. For one participant this was the fear of relapse, but more so the fear of readmission. A common thread was drawn between participants that are long term MHCU's, that they highlighted increased knowledge and treatment acceptability.

> *"Yeah. Because - and also, like I understand how the medications work. I feel better because of the medication. If I continue to take medication I'll be feeling better, right? So, I also understand my diagnoses. So … which is why I think that that education about what a person's diagnosis is, and what medication they're on, is so important, because they need to know: Is this a short-term thing, is a long-term thing? What is the purpose of this medication? What is it going to do to my brain? Why does my brain need it? If I go off it, what will the effect be? Having that information makes it a lot easier to make that decision to stay on it." P05*

“It is just easy because you know it's the best thing you have to do; is to take medication. It's not a bad thing. It's there to help you.” p14

“You know, just knowing that it's good. Like my friend said, "It's taking it as if it's your vitamins." But knowing that it's good for me and it will keep me stable, and also that, you know, because I mean, the ramifications of not taking your medications and things like you could lose your job. You could - your relationships become strained because you're doing strange things. I mean, I know that even when I was taking medication, I lost a lot of friends, you know, from this diagnosis, and sometimes not feeling well. But you're compounding that if you're not taking your medication. P18”

“My adherence itself, like actually doing the things doesn't waver because I know the value in it. P05”

Mental Health Interventions

Mental health interventions such occupational therapy and psychology were attributed as a positive influence on managing mental health and adherence. Participants reported that skilled based therapies such as occupational therapy and dialectical behavioural therapy (DBT) enabled the learning of skills such as routine and time management, constructive coping that all contributed to managing their mental illness and facilitated better adherence. Participants reported that interventions such as psychotherapy assisted in navigating emotional components related to adherence such as past experiences and support networks, and overall improving self-awareness in improving management of their mental illness.

"So eventually, I recognised that I really needed some kind of intervention. Medication is obviously very important. But it's not the only thing.OT definitely contributed positively. I think it was a very open and encouraging environment with lots of skills, but like a variety of skills. So like more ... some more creative kinds. Some smaller things that you can do in your daily life, like doing a crossword or a puzzle. And bigger things like planning and routines. And I think what was helpful was also the, like, the kind of neurological education that came with it as well. Because it's not, like, "Do this, it's good for you." It was, "These are things that you can do. This is how you can do them. This is why you can do them. And it's because this is how the brain works. This part of the brain does this thing and when you do that, then it helps the brain do that." [..] psychology has been absolutely amazing. It has been probably one of the most life changing experiences I've ever had." (P05)

Stable Treatment Regime

Reaching a stable treatment regime was described to be an encouraging factor for adherence and participants reported they did not want to risk losing that. This enabled their adherence and, as described above, this was strongly linked to a fear of relapse where they did not want to have to 'start again' by trialling different combinations of medications with close, sometimes invasive (regular bloods drawn), monitoring.

"So I'm very concerned about relapsing, all right? I don't want to relapse. I want to be stable, which I am. I am very stable. [..] So, you know, I know if you stop treatment you relapse and then you become - um, what do they call it? When you can't - when the medication doesn't work. What is it called? Resistant. So I don't want that to happen. So that's what keeps me on the short, long and narrow." (P08)

The sense of stability was a motivating factor to their adherence practices and deepened trust with their doctor.

"At this stage I think I'm happy and comfortable with treatment." (P04)

Personal Attributes

Certain personal attributes were linked to a sense of autonomy, and this contributed to positive influence of adherence and managing one's mental illness. These attributes were described as strong willed, outspoken and being empowered to speak up for oneself.

> *"And then I think being - I think it's partly my personality and also my upbringing that, particularly in terms of my body and my experience, I have been empowered to be vocal and not just accept what authority says." (P05)*

Practical Adherence Activities

Practical adherence activities utilized by participants were the day-to-day activities that facilitated adherence. These included: settings alarms at specific times to take medication, packing pill boxes every week, keeping medication in plain sight as visual reminders i.e. on the kitchen counter. Whilst many report that prepacking medication in pill boxes is helpful other participants reported that their pill burden is very high, so prepacking doesn't work. One participant explains how her local pharmacy assists her with her pill burden and adherence by blister packing her medication for her every month.

> *"Do you know how good that is? Because I used to - always like I'm on my bed, trying to remember, like these medicines, that medicine. I got so blooming deurmekaar, you know? So I was taking my own medicine by myself. Actually, yeah, that's a good thing as well to say. I was taking my own medicine for years and years. And it's such a nice thing that I have my blister pack done. It's a like huge thing as well." (P17)*

Social Grant

Participants report the indirect positive influence of receiving a South African Social Security Agency (SASSA) disability grant as it helps reduce some of the socio-economic effects such as

not being able to work, and this allows them to contribute to the household or ease their financial difficulties which in turn reduce their stress and has a positive influence on their mental health.

Social Support

Participants can reflect on the sources of support they receive in relation to their mental illness. These included multiple levels; from partners, families, friends, and institutions (both Tara and placement facilities).

Participants who report receiving support from their partners narrate this support both in terms of supervision of treatment adherence and general emotional support in managing their mental illness.

> *"My husband is very supportive.[..] He uh, checks every night that I take all my medication" (P01)*

Family support was described by one participant as very important in managing mental illness and avoiding relapse as they live with their family.

> *"You need your family to be able to converse with regarding your issues. It makes a big difference because they understand you better. They know exactly what you're about what your daily routine is... And to be honest, if you're living with family, it makes it so much easier, because they are aware of the situation and they will be able to know when you truly need treatment from the doctors and the hospital." (P12)*

Support from friends was described to be more emotional support and to be a validating experience.

> *"I've got friends and that is like a blessing of note. Yeah.[..] We can talk about stuff, and we can communicate, and we can have laughs, and it's just nice. And I've got quite a few friends which is quite nice, you know? And they support me*

in a way that, you know, you're not alone, you know? We're with you, kind of thing." (P08)

Institutional Support

Participants living in a placement facility describe the institution as a structural support due to the support they receive from the staff, the monitoring and management of their mental illness and the security of their basic needs i.e. food and housing. Tara as an institution was also perceived as a support system to participants.

"it's a lifesaver. Let me just stress that. It (Tara) has saved my life if I didn't have to come here every Tuesday "(P03)

4.6 Barriers to adherence

Poor Social Support

Participants perceived the converse of supportive family or close relationships to be true and reported poor family support reinforced feelings of being alone in their mental health journey. One participant highlighted the key role that families have in helping MHCU's manage their mental illness and attributed this lack of family support to increased readmission and relapse rates when they do not fulfil this role.

"They are at home and sometimes people at home don't go an extra mile in making sure that they manage them, that they manage their disease by taking medication on time, taking medication all the time. So that's why you find some people; they keep relapsing and coming back to hospital, relapsing, going back home, coming back to hospital. That is the reason why they do that because the family does not help them manage their disease. That is by taking their medication on time and at the right quantities." (P11)

Other participants described how the nature of their relationships with their families has shifted during their journey of mental illness and how only over time their family has become supportive.

> *"My family and I had quite some rough times in terms of support. Because my mom thought I was going to be sangoma. And I'm a Christian, so I didn't think I'll be a sangoma. Then she said, "You are a prophet." And it's confused me. And then sometimes they wouldn't talk to me because I was sick and said something to them. So after a while, I learned to live without them, but they're very supportive now." (P18)*

Furthermore in relation to poor support, one participant described having mental illness as a very lonely road as friendships are important but difficult to navigate. This theme was enriched by the experiences of other participants, whereby being friends with other MHCUs is challenging because everyone is managing their own mental illness and is in different phases.

> *"Well now, I get support from others who are residents, you know? And one or two friends or a distant cousin or something like that. So I do get support, but it's very limited. After a while I just had to accept that it's a very lonely road, that I would just walk it on my own and rely on God. And that was it." (P18)*

Another participant reported complicated experiences with a friend (non-MHCU) who would accuse him of stealing on the basis of him being a MHCU, in addition to this would pressure the participant into substance use without understanding the risks to him and ultimately this participant reporting the same lonely road in supporting themselves.

> *"So I didn't have any support from him because he's always - he doesn't respect the fact that I'm not able to smoke cannabis. He doesn't respect it because he - I smoke it with him and ha ha ha, it's going. But I can get sick from it. He doesn't think that smoking cannabis in front of me, I'm going to smoke. He's gonna say, "Sit here and smoke." I'm gonna smoke. And I smoked. So I lost that support, but it was no support system. In the end, I have to support myself, my own mentality. As I said to you, I don't want to go into hospital again." (P02)*

Substance use

Substance use was a major barrier to treatment adherence and contributor to relapse described by participants. Participants could elaborate on their early life experiences of substance use and poor adherence, they linked this to not having a routine and poor care of self-due to the nature of substance use and abuse. Participants reported not being concerned for the management of their mental illness but rather stuck in the cycle of addiction.

> *"Yeah, because I wasn't like, you know, like, I was taking drugs and stuff. So, you know, I was like, a bit funny. But then, you see, I wasn't really taking my medicine properly. Actually, this was when I was about 18, 19. And funnily enough, we knew - I know that when a person is not compliant, they give you an injection. So I was fluanxol for a very long time, as well. Yeah, basically because I was taking drugs. I don't think when people are taking drugs that they are compliant. Nevermind not taking your medicine properly, then you don't remember. "Oh no, I missed a -" This is other people, "I've missed an appointment." and then you got to go back and make another appointment. Yeah." (P17)*

Another participant comments on the recreational use of substances and the impact it has on the efficacy of their medication.

> *"I don't drink, which I can tell you; I'm not supposed to do it. But for some holiday week is our Frenchman's cannabis. I keep on rolling this stuff. And I roll it there. So at one point, I thought, "Let's take a little bit." It's dangerous. It clashes with your medications and you can feel - you can feel it clashing." (P02)*

Chronic Nature Of Mental Illness

The chronic nature of mental illness brings about many complexities and feelings toward adherence.

> *"Factors that make it difficult. What would be those? Probably knowing you're gonna do it for a long term. Like maybe, "Damn, I'm gonna take medication for the rest of my life." Does it make you look cool? Maybe, you know. You know, I'm 32. You know, maybe it comes with age. I'm young. You taking medication, and then maybe it doesn't make you look cool." (P13)*

Participants that have been long term mental health care users narrate a double bind in relation to the chronic nature of mental illness. On one hand, they explain how their journey has made the importance of adherence clear to them and they demonstrate good health literacy and treatment acceptability as previously described. However, on the other hand these participants also express being tired of being in the system, that it has become so repetitive and are just tired – that they value the system but are just tired.

> *"and the - I've just been in the system. I don't necessarily like being in the system. I'm thankful for the system. But I don't want to be poked and I don't want to be watched and I don't want to be seen, you know? Just leave me alone. I want to just carry on with my life, you know? And every time I come here, I've got vitals, and a heart machine, and then blood and - ag man, it's just over and over again. And I'm just getting tired of it, you know? Really. I feel tired, you know?" (P08)*

Similarly, other's feel tired of having to take so many pills for so long and the desire to be 'normal' sometimes creeps in

> *"Yeah and you want to be normal a bit, but you cannot take chances because the medication is balanced in a way that it keeps you stable. If you skip one day, the next day, you run the risk." (P02)*

Destructive Coping Strategies

Participants reflect that during stressful times it's difficult to not fall back into destructive coping strategies such as substance use, self-harm, and increased conflict instigation. This has an indirect impact on the adherence to their medication but rather a direct impact on the ability to carry out suggestions prescribed from other mental health interventions such as occupational therapy and psychotherapy. Participants report the consequences of this detrimental to their overall mental health.

> *"Yeah, so if I'm fighting with someone, like my mom, generally. And then - like the past two weeks, I was working like 14-hour days for 14 days straight, which I think is enough to exhaust anyone but then adding the changing dynamics with my mother and my brother being an asshole. So when those additional things come up, then it's hard to not fall back into those destructive behaviours. Like yesterday, I had a massive fight with my mom and used my nails - because I didn't want to say something she'd regret - and so I kind of dug my nails in. Yeah so I'm looking forward to DBT next week." P05*

Not Having a Routine

As participants stressed the need for routine in addressing adherence, they highlighted that the opposite, of not having a routine, and described it to be a large barrier to adherence. These participants felt that not having a routine and treating adherence haphazardly decreased the efficacy of the treatment. This was compounded by the experiences of other participants where not having a structured routine related to their adherence resulted in often forgetting to take their treatment and missing dosages

4.7 Stigma

Stigma was a prominent theme that came up, often in unassuming and diverse ways.

Self

Participants experience of themselves as a mental health care user perpetuated a sense of 'other' or 'not normal'.

> *"She said, "You're the problem." And you can't speak to people like that. Even normal people out there; you can't speak to them like that. And someone says to you, "You're the problem." then you walk away feeling really just not so lekker." (P08)*

This was found to be multi-layered phenomenon that did not occur unilaterally between mental health care users and those without a psychiatric diagnosis but a complex experience within an individual MHCU.

> *"IN: What would you classify as somebody that's normal?*
>
> *P03: Somebody who hasn't been to Tara! Of course, yes it if you go to Tara then it all those people think you're crazy. You're not right, you're sick, you're mad you belong in a nuthouse. They treat you like that they talk to you like that? It's really not. It's very unpleasant, very, very, very unpleasant." (P03)*

Participants experiences of different diagnoses. Participants descriptions of diagnoses' and particularly those who have had change in diagnoses have elements of stigma embedded in the feelings of different diagnoses. For a participants whose illness has evolved from bipolar mood disorder to schizoaffective reports:

> *"So now my diagnosis is schizoaffective disorder, bipolar type.[..] It just doesn't sound as good as bipolar (laughs). [..]It sounds as if you're some schizo person… it sounds like you may have lost it completely (laughs)." (P18)*

Another participant expressed that she wanted her diagnosis to change from schizophrenia to autism as there is less stigma in the workplace as people with autism are perceived as very smart and successful.

Family and community

Within support systems and communities plays out in many ways. For more religious participants (of various religions) their communities dismissed/diminished their mental health issues to having "weak faith" and that they need to pray more.

> *"I have had people telling me that I don't need to take the medication; I need to pray more.[..] They said to me if you have an illness like this, it's a sign of weak faith and I actually believed those people." (P12)*

Work

Many participants described the impact of their mental illness of their work, embedded in this was stigma. Participants reported feeling the need to hide what appointments or treatments they were attending based on fear of being stigmatized against.

> *"Because I've got an illness. People don't want to give me interviews. Yes. It's that. It's the stigma. The South Africans play too much on the stigma, if that's the stigma, I've talked to people who won't give me an interview, because they call me a patient. And if they don't call me a patient, they say, I have mental illness. They say because I have mental illness, they will not give me an interview and they will not put a mental illness patient on their project. You know?" (P15)*

> *"IN: That stigma that you speak about, how did that play out in your life? P04: Well, I was working at the time. I'm not working anymore. But I was working at the time. It was difficult because my boss didn't know about the*

illness and so I had to take time off every month. I just said to him, "I'm seeing the doctor," and you don't have to disclose what mental - what medical condition - you have but they were aware that I obviously had some kind of medical condition. Obviously, when it got out of hand, they agreed to - well, instead of letting me carry on working because it was a very stressful job, they agreed to incapacitate me. They gave me a lump sum and that was it. So I actually did end up losing my job or my income as a result of the treatment and the bipolar." (P04)

Friends

Forming friendships with non-MHCUs can be wrought with stigma once you disclose to them and then they only perceive you as 'not normal'.

"And it's also difficult, you know, what I've come to realise is you can't be friends with normal people. Because normal people think you're not normal." (P03)

Stigma and Support

Stigma was inversely related to support as explained by participants. The more supportive and open-minded participants immediate support systems i.e. family and friends were, the less the participant felt the impact of stigma against MCHUs from the broader population.

"There is this understanding. So there isn't this need to hide my mental illness. There is this openness of "Oh, I'm going to Tara." "Okay, cool. Just let me know when you're home safe. And don't forget to do this, this and this." But there's this - it's become very casual. So there isn't a pressure, there isn't this, "What are you going to say?" Like this prep for it. It's become very normal. So there isn't a stigma, there isn't a taboo. It's just become ... I think casual is the way of phrasing it because it is part of our lives." (*P09*)

5 DISCUSSION

This study aimed to explore the factors that promote and impede treatment adherence from the perspectives of MHCU's attending services at Tara OPD. The key findings of the study were able to emphasize that a MHCU's experience and journey with their mental illness is complex and the impact manifests in multiple ways. This was highlighted through the intricacies that promote and impede adherence described by participants as well as the multi-faceted role stigma has played in their experience. The Socio-Ecological Model will be used as a conceptual framework to explore these key findings in comparison to other literature. All the results from this study report from an individual level. Since the study sought these factors from the perspectives of MHCU's, it is important to understand how these experiences and factors are influenced at and by multiple levels of the SEM.

5.1 Individual Level (intrapersonal)

The study found that participants who have been MHCU's for a longer time could narrate the high and lows of their experience extensively and express the impact of this on their adherence over the years. A positive outcome of this described by participants is increased treatment acceptability and health literacy of their mental illness. It is well argued that difficulties with treatment acceptability and health literacy contribute to non-adherence and relapse rates (Degan *et al.*, 2019b). However, these results suggest the inverse to a promoting factor for adherence, which supports the findings of (Copeland *et al.*, 2008b). In addition to this, a key finding in this study highlights how the fear of relapse and understanding the consequences to non-adherence positively influenced the experience of adherence for the participants.

Supported by the results of this study, a well-documented theme and impeding factor to adherence for MHCU's is the impact of side effects of medications (Sariah, Outwater and Malima, 2014). Participants feeling a sense of ownership in their treatment was a large determining factor to the experience (either positive or negative) of both their mental illness as well as their experience of Tara OPD.

Participants describe multiple factors and influences that promote adherence which manifest on an intrapersonal level. These include having regular appointments, mental health interventions, stable treatment regime, personal attributes, practical adherence activities (i.e., alarms, prepacking medication, placement of medication in high frequency areas such as the kitchen) and maintaining a routine. In contrast, some of the factors and influences that participants describe to impede adherence which manifest on this level include not having a routine and destructive coping strategies. In an Expert Consensus Guideline Series study conducted by Velligan *et al.*, (2009), the authors recommended a number of psychosocial/programmatic interventions in addressing adherence which are congruent with the findings of this study. These included environmental supports (such as interventions targeting lack of routines and scheduling), more frequent and longer appointments, cognitive behavioural therapy or family focused therapy and medication monitoring.

Velligan et al.(2009) emphasize that the chronic trajectory of mental illness brings about many changes in adherence behaviours which can hinder clinical outcomes. Results from this study concur with this whereby participants acknowledge the negative influence that chronic treatment has on their adherence. Another barrier to adherence from the results is substance use. It is well

known that substance use and abuse is a barrier to adherence and risk factor relapse in MHCU's (Sariah, Outwater and Malima, 2014). Stigma was internalized for many participants, whereby the impact of societal stigma influenced their individual feelings and behaviours (Corrigan *et al.*, 2012). Examples of this included the types of diagnosis as well as the feeling of being 'other'/'not normal' due to having a mental illness and influenced adherence negatively.

5.2 Interpersonal Level

The experience of a MHCU's mental illness, their treatment and adherence and the influence of it on their direct social network cannot be ignored. This includes family, friends, peers and healthcare providers (Salihu, Wilson and King, 2015).

Participants describe the impact of socio-economic factors such as family conflict and stressors on their mental health, in some cases resulting in relapse. This was consistent with stressful life events as a risk factor for relapse among individuals with schizophrenia found by Sariah, Outwater and Malima (2014). In addition to this impact of poor support from family or peers has been attributed to an increased risk of relapse and poor adherence (Sariah, Outwater and Malima, 2014). Gamieldien *et al.* (2022), this agrees with results from this study where participants describe poor support as a barrier to adherence.

Participants describe the indirect positive influence of their monthly social grant as it eases the financial burden on their household. This relates to the findings of Sariah, Outwater and Malima, (2014) where a person with SMI engagement in economic activities is a protective factor for adherence as it boosts their self-esteem and allows them to support their family. Whilst

much of the literature (Sariah, Outwater and Malima, 2014) (Mokwena and Ndlovu, 2021) focuses on the impact of side-effects of medications on adherence within an intrapersonal level, an interesting finding from this qualitative approach stressed the impact of side-effects to medications on the family in terms of functional contributions to the household.

In a systematic review, (Taylor *et al.*, 2009) relay that a positive therapeutic relationship promotes improved clinical outcomes with individuals with SMI. The results from this study align with this and emphasize the level of trust in their doctor as promoting factor to their adherence. This was similar to the results of McCabe *et al.*(2012) where they found that a better therapeutic relationship is associated with better adherence to medication among patients with schizophrenia. Conversely, a poor therapeutic relationship left participants with a feeling of having no agency or autonomy in their treatment.

The chronic nature of SMI's requires increased time to manage the illness which in turn increases the burden on caregivers. It is well documented that the impact of an individual's SMI on their family/caregivers is significant (Rahmani *et al.*, 2015), causing emotional, social and financial ramifications. Substance use, not having routine, destructive coping strategies and poor insight as barriers to treatment adherence are influential at the interpersonal level as these all further increase the burden of the mental illness on the caregivers of the MHCU. Family interventions and support from extended family are recommended to address some of this burden as well as improve medication adherence (Sariah, Outwater and Malima, 2014) (Taylor *et al.*, 2009)

5.3 Institutional Level

On an institutional level, the participants' experience of treatment and adherence at Tara was rated highly in comparison to private and other government institutions. This was closely related to the qualities of the healthcare workers, the high level of support as well as the holistic approach provided by Tara as an institution, which participants perceived as promoting factors for adherence. In relation to the holistic approach, participants felt they could access multiple services at one place. This included mental health interventions such as occupational therapy and psychology, where participants felt that these resources equipped them in managing their mental illness by contributing to intrapersonal factors such as health literacy, various life skills and self-awareness. This relates to the findings of a systematic review conducted by Xia, Zhao and Jayaram (2013), in which they found that brief psychoeducation is a promoting factor for medication compliance in the short-term and reduces relapse rates in the medium term.

Residential-placement facilities are one of the outcomes of deinstitutionalization efforts of MHCUs globally (de Girolamo and Bassi, 2004). Participants from this study living in a placement facility perceived the institutional support as promoting factor for their adherence and wellbeing. This aligns with results from a study by (Hanrahan *et al.*, 2001) whereby residents in community integrated arrangements rated their satisfaction as fairly high as well as a notable decrease in hospital use in the year following the placement.

5.4 Community

Community factors are described by the relationships between organizations, institutions, and informal networks (McLeroy et al., 1988). An unsurprising dominant community factor from the

results was stigma. Stigma was prevalent across all levels of the SEM and participants shared how it showed it multiple forms across different networks including work, family, communities they live in as well as religious groups they belong to. Stigma is a strong barrier to adherence and risk factor to relapse (Mokwena and Ndlovu, 2021) (Gamieldien *et al.*, 2022)(Lund *et al.*, 2012b).

5.5 Public Policy

An important finding from this study is the inadequate community reintegration of participants from a tertiary level hospital, which is highly structured by professionals (including their adherence), back into their home life where themselves and their family are now equally responsible. This finding relates to public policy in terms of policy agendas, namely Mental Health Care Act (17 of 2002) and the previous National Mental Health Policy Framework and Strategic Plan 2013–2020 (National Department of Health, 2013), promoting deinstitutionalization and community-based care. However, in line with the findings from this study, literature confirms the challenges of this policy implementation (Lund *et al.*, 2012b) where primary care services mainly address medication management with no psychosocial rehabilitation for MHCUs. The new National Mental Health Policy Framework and Strategic Plan 2023–2030 (National Department of Health, 2023) that was released in April 2023, acknowledges these gaps and recognizes the importance of mental health in all levels of care and it is with hope that policy implementation for MHCU in South Africa will improve.

6 CONCLUSION AND RECOMMENDATIONS

This final chapter will draw relevant conclusions made from the findings based on each level of the socio-ecological model. Finally, recommendations for future practice, research and service delivery related to the factors that promote and impede treatment adherence for MHCU's in the OPD at Tara Hospital will be suggested.

6.1 Conclusion

This research set out to explore the factors that promote and impede treatment adherence in MHCUs in the OPD at Tara Hospital. This research found that the experiences of mental health care users with SMI are expansive and provide rich insights into their adherence. Most evident was the extensive and varied factors that MHCU use to promote their adherence. This was influenced by multiple levels of the SEM and supports the notion that adherence is more than just taking medication but is a multifaceted phenomenon. In this study, relapse was not synonymous with nonadherence but rather influenced by barriers such as stigma and poor community reintegration as described in higher levels of the SEM.

Within the individual level, several conclusions can be made. Results from this study, show the multiple factors and influences that contribute to promoting their adherence. This was seen through their descriptive increased treatment acceptability and health literacy as well as the emphasis on maintaining a routine. This shed a positive light on adherence in MHCUs and the many practical ways that MHCU engage with their adherence, such as prepacking pills, alarms, environmental cues. A barrier to adherence experienced on this level was managing side effects

of treatment, the chronic nature and non-linear trajectory of SMI and lastly the impact of substances.

Interpersonally, results pointed to the role of socio-economic stressors as a barrier to adherence and risk for relapse. These included poor social support, financial stress, and family conflict. A positive therapeutic relationship, with an emphasis on the high level of trust participants had with their doctor, particularly consultant psychiatrist was a promoting factor to their adherence. Being able to contribute to the household through the aid of a social grant being describe as a positive influence on adherence emphasizes a dynamic interplay of a successful public policy at multiple levels of the SEM.

On an institutional level, Tara OPD is rated highly compared to other government institutions and private facilities and described as a protective factor to adherence due to the level of expertise, care, and efficiency as well as access to multiple psychosocial services. Residential placement facilities further promoted adherence and secured basic needs due to the routinized structure and supervision provided by the placement.

An unsurprising stand-alone barrier to adherence on the community level was the significant impact of stigma. Stigma was prevalent on all levels of the SEM, as participants described self-stigmatizing attitudes and behaviours related to their experiences of having a mental illness as well as their experiences of their family, friends and communities reinforcing stigmatizing beliefs and attitudes in relation to poor social support.

On a public policy level, inadequate community re-integration of MHCU is seen due to the challenges of policy implementation of promoting primary healthcare. This is further seen through the preference of Tara over other government facilities including primary healthcare facilities due to the limited services for psychosocial rehabilitation.

6.2 Limitations and Strengths

Purposively sampling participants that can speak English and conducting the IDI's in English could have potentially introduced some biases. As English proficiency may reflect academic background which could impact one's health literacy as well as affect many health behaviors. Because nonadherence and relapse experience are a sensitive topic to discuss a degree of social desirability could have been introduced where participants may have omitted the depth to these experiences to come across in an approving manner.

Strengths of this study included the rich and thick data that was collected which allowed a deep analysis of the experiences of MHCU's with SMI. The broad sociodemographic profile of the participants also facilitated a vast range of experiences which contributed to the depth of the analysis.

6.3 Recommendations

This study has indicated that Tara Hospital's OPD is overall a protective factor and positive influence on MHCU's adherence. To strengthen this, it is recommended that training and emphasis, particularly for registrar doctors, on the role and importance of fostering a positive therapeutic relationship has on the health outcomes of a MHCU's (Kornhaber *et al.*, 2016).

It is evident from this study that MHCUs with SMI engage dynamically with their adherence and use many practical ways to ensure their adherence which is further facilitated by the support of their family, community, and healthcare providers. Thus, it is recommended to scale up psychosocial services in out-patient settings to improve the health literacy and ownership of health management of MHCUs (Nagesh, Kishore and Raveesh, 2016).

For future research, it is recommended to move away from non-adherence studies and focus on adherence. SMIs are chronic illnesses that have a great impact not only on the MHCU but across levels of the SEM. Thus, it is important that research and interventions shy away from non-adherence focus and move towards a more positive paradigm that focuses on adherence activities and implementation of such.

An emphasis on tailored de-stigmatising interventions related to severe mental illness needs to be addressed to improve community re-integration, engage in economic or community productivity whilst harbouring a healthy sense of self-worth and self-esteem.

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Appendices

Appendix A: Demographic questionnaire

Demographic Questionnaire

Study title: Factors that promote and impede treatment adherence of out-patient mental health care users at Tara Hospital in Johannesburg.

Please answer the following questions by circling the appropriate answer or completing the question:

1. What is your age? _____
2. What is your gender? _____
3. What is your ethnicity?
    - Black
    - White
    - Indian
    - Coloured
    - Other: _____
4. What is your highest level of education? _____
5. What is your home language? _____
6. What is your current living situation?
    - Living alone
    - Living with partner
    - Living with family
    - Living with friends/roommates
    - Living in a placement facility
    - Other:_____
7. What is your current psychiatric diagnosis?
   _____
   _____
   _____
8. Do you have any other illnesses?
   _____
   _____
   _____

Appendix B: Semi-structured Interview Questions

Interview Questions

1. How long have you been an out-patient and attending services at Tara OPD?
2. What services do attend as an out-patient at Tara?
    - Probe: psychiatry(/doctor), psychology, occupational therapy, social work, dietetics
    - What is the focus in each of these services that you attend
    - How have each of these services helped you?
3. What has your experience been of attending services at Tara?
    - What has influenced this experience?
4. How often do attend each of these services?
    - Probe: have you missed any?
5. Can you tell me about your diagnosis?
6. Can you explain your understanding of what it means to adhere/comply to your treatment related to your mental illness?
7. What kind of support do receive in relation to your mental illness and adhering to your treatment?
    - Probe: Who provides this support? How is this support provided?
8. What are some of the important factors that help you adhere to your treatment?
9. What are some of the factors that make it difficult to adhere to your treatment?
10. What would help you adhere to your treatment better?

Appendix C: Ethics Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research and Innovation)

TO:	Ms S Rowse School of Public Health Medical School University E-mail: savannahrowse@gmail.com
CC:	Supervisor: Dr MT Hlungwani <Tintswalo.Hlungwani@wits.ac.za> and <HREC-Medical Research Office@wits.ac.za>
FROM:	Mr Iain Burns Human Research Ethics Committee (Medical) Tel: 011 717 1252 E-mail: Iain.Burns@wits.ac.za
DATE:	2022/06/29
REF:	R14/49
PROTOCOL NO:	**M220445** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)
PROJECT TITLE:	*Factors that promote and impede treatment adherence of out-patient mental health care users at Tara Hospital in Johannesburg*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R49 Ms S Rowse

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M220445

NAME: (Principal Investigator) Ms S Rowse

DEPARTMENT: School of Public Health
Medical School
University

PROJECT TITLE: *Factors that promote and impede treatment adherence of out-patient mental health care users at Tara Hospital in Johannesburg*

DATE CONSIDERED: 2022/04/29

DECISION: Approved unconditionally

CONDITIONS:

NOTE: If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>

SUPERVISOR: Dr MT Hlungwani

APPROVED BY: CB Penny
Dr CB Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL: 2022/06/29

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **April** and therefore reports and re-certification will be due in the month of **April** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator _____ Date _____

Appendix D: Institutional Approval

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
TARA the H. Moross Centre
Private Bag X7
RANDBURG 2125
(011) 535-3096
Yvette.nel@gauteng.gov.za

MEMORANDUM

TO : **DR. F. OTIENO – CEO, TARA HOSPITAL**

FROM : **DR. Y. NEL– CHAIRPERSON TARA RESEARCH COMMITTEE**

DATE : **1 April 2022**

SUBJECT : REQUEST FOR APPROVAL FOR SAVANNAH ROWSE,TO CONDUCT A RESEARCH STUDY AT TARA HOSPITAL PENDING ETHICS APPROVAL

- **NHRD REFERENCE NUMBER: GP_202203_065**

1. Purpose

The purpose of the application is to request permission for Savannah Rowse to conduct qualitative prospective research at Tara Hospital, with the study title: ***"Factors that promote and impede treatment adherence of out-patient mental health care users at Tara Hospital in Johannesburg."***

2. Background

The revolving door of MHCU's through the OPD and in-patient wards at Tara Hospital is prevalent and increases the burden on Tara as well the health system at large. Although there is a growing body of knowledge related to mental health in South Africa, most of this within the primary health care or policy setting. This leaves a large literature gap related to adherence in higher levels of care that serve large populations of MHCU's in South Africa. Extending this gap, is the limited focus on adherence studies in this population even though the effects of non-adherence across all socio-ecological subsystems is well documented. Lastly, there is limited up to date published literature from Tara Hospital. This poses a huge problem as it is one of a handful of specialized psychiatric tertiary level hospitals in South Africa and serves a large population of MHCU's living with severe mental illness.

3. Motivation

The qualitative approach will gain rich insights into factors related to adherence for MHCU's with SMI using services at Tara, with the hope of informing future interventions. This study will comprise of Qualitative research, via in person interviews with stable out-patients, with informed consent, on factors that promote and impede treatment adherence in Mental Health Care Users (MHCUs) that are attending service in the out-patient department (OPD) at Tara Hospital.

4. **Financial implications**

   No costs will be incurred by either the institution or the individual participants.

5. **Recommendations**

   In view of the above it is recommended that permission is granted to undertake Qualitative research at Tara Hospital, pending receipt of Ethics approval, with the research study title: ***"Factors that promote and impede treatment adherence of out-patient mental health care users at Tara Hospital in Johannesburg."***

Proposer

Dr. Y. Nel

Chairperson Tara Research Committee

Date: 5 April 2022

Comments:

Recommendation contained in paragraph 5: supported/ not supported/ As amended

Dr. R. Price-Hughes

Clinical Manager

Date: 5 April 2022

Comments:

Recommendation contained in paragraph 5: approved/not approved/ As amended

Dr. F. Otieno

Chief Executive Officer

Date: 5/4/22

Appendix E: Information Sheet

Study Information Document

Study title: Factors that promote and impede treatment adherence of out-patient mental health care users at Tara Hospital in Johannesburg.

Good day,

My name is Savannah Rowse. I am doing research on treatment adherence in mental health care users. In this study, adherence means the extent to which one sticks to or complies to the treatment recommended by a healthcare provider. Research is a process used in seeking new knowledge and information.

In this study, I want to learn about the factors that help adhere to treatment and the factors that make it difficult to adhere to treatment for mental health care users that are using services in the outpatient department at Tara hospital.

I am inviting you to participate in this research study.

Your participation in this study would involve an interview with the researcher as well as a short questionnaire about yourself. This interview will take place in a private room in the out-patient department at Tara Hospital and will last between 60 and 90 minutes. The interview questions will be related to your experience with treatment adherence. The interview will explore factors that promote or help treatment adherence as well as factors that make it difficult to adhere to treatment.

Discussing treatment adherence for mental illness might be a sensitive topic. If you become triggered, distressed, or feel at all uneasy at any point during the research process, the examiner will stop the process at that point and follow a prepared guideline to assist you. This includes a psychiatric nurse, if necessary, that will be available should you need any counselling or containment.

This study will have no direct or immediate benefits to the participants involved but may provide valuable information in developing treatment programmes or interventions in future for mental health care users.

As a Participant, you will be given all relevant information on the study while involved in the project and after the results are available.

Your participation is entirely voluntary. If you decline or refuse to participate, there will be no penalty or loss of benefits to which a Participant is otherwise allowed to, for example, continued follow up services at Tara Hospital. You may stop your participation at any time during the interview process and there will be no penalty or loss of benefits to which a Participant is otherwise allowed to. There is no requirement to provide a reason for withdrawing and information collected on such a person will in default be destroyed, unless a Participant specifically consents to the researcher keeping the data.

There is no payment or cost associated with participating in this study.

Confidentiality is important to this study and will always be maintained. This means that no identifying information will be recorded on any questionnaires or field notes. The researcher will adopt a specific numbering system to ensure this. Any personal information will only be available to the researcher and her supervisor.

If the results are published, there is a slight chance that it may lead to follow up, or and more rarely, individual identification. All data collected during the study will be securely kept for two (2) years if a scientific publication arises from the study and six (6) years if there is no publication. Thereafter it will be destroyed accordingly.

Contact details of researcher/s:

Savannah Rowse,
Principal Investigator,
Telephone: 078 7140749
E-mail: savannahrowse@gmail.com

Dr Tinstwalo Mercy Hlungwani,
Supervisor.
Telephone: 011 717 2734
E-mail: Tintswalo.Hlungwani@wits.ac.za

Contact details of HREC administrator and chair

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Counselling services
If you would like to receive counselling, you may contact the below organization:

Tara Out-Patient Department
011 535 3000

Thank you for reading this Study Information Sheet.

Appendix F: Interview Consent Sheet

Participant Consent Sheet

Study title: Factors that promote and impede treatment adherence of out-patient mental health care users at Tara Hospital in Johannesburg.

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Contact details:

Savannah Rowse,
Principal Investigator,
Telephone: 078 7140749
E-mail: savannahrowse@gmail.com

Dr Tinstwalo Mercy Hlungwani,
Supervisor.
Telephone: 011 717 2734
E-mail: Tintswalo.Hlungwani@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za. Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Appendix G: Audio-recording Consent Sheet

Consent Form For Audio Recording Of Study Participation

Study title: Factors that promote and impede treatment adherence of out-patient mental health care users at Tara Hospital in Johannesburg.

I hereby consent to audio recording of the interview

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research.
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Appendix H: Distress Protocol