EXPLORING THE LIFE NARRATIVES OF INDIVIDUALS WITH SCHIZOPHRENIA UTILISING OUT-PATIENT SERVICES AT A DISTRICT LEVEL HOSPITAL IN THE EASTERN CAPE, SOUTH AFRICA

A dissertation submitted in fulfilment of the requirements for the degree of
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Declaration

I, *Alicia O. A. Toumilovitch* hereby declare that this research report is my own work except as indicated in the references and acknowledgements. I am responsible for the content of this study and the conclusions presented. No part of this research report has been previously submitted for a degree at any other University/ Institution.

Signature: Date: 17/04/2020

Miss Alicia O.A. Toumilovitch

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ABSTRACT

Background: The study aimed to explore the lived experiences of 13 individuals with schizophrenia utilizing out-patient services at a district level hospital in the Eastern Cape, South Africa. Influences of context and culture on life experiences, and living with an ‘invisible’ disability, including the associated emotional, social, and cultural implications, were explored.

Methods: This study employed a qualitative design supported by the principles of face-to-face semi-structured interviews and participant observation, using purposive sampling. An interpretive paradigm was followed, aiming to explore the subjective reasons and meanings of the participant’s experiences. Data collection took place in English, Afrikaans, and isiXhosa. All data were audio-recorded, transcribed, and translated into English, and analyzed utilizing an inductive approach according to the principles of thematic analysis. Member checking took place, to ensure rigour.

Results: Themes identified included the perception of the participants on the cause of their condition (such as jealousy and bewitchment, family history, and substance abuse) and how they experience the symptoms of schizophrenia, the experiences of managing the condition on a day-to-day basis (including treatment), and how they are affected by the environment (such as poverty). Participants’ coping strategies mostly included turning to religion.

Implications: The integration of mental health into primary healthcare may help narrow the treatment gap. The role of the speech-language therapist (SLT) in mental health is one that requires development in South Africa. The implementation of community-based programs, and changes within policies, such as the National Mental Health Framework Policy, are needed to improve mental healthcare services, including overcoming barriers of accessibility and promoting awareness within the community.

Conclusion: Schizophrenia is a complex spectrum disorder, and the attached stigma leaves individuals feeling isolated and silenced. Hearing the life experiences may help provide perspectives on how to manage and understand this condition, which may contribute to improving accessible healthcare.

Keywords: coping; labelling; mental health; schizophrenia; stigma.

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LIST OF ABBREVIATIONS

CBR	Community-based rehabilitation
DSM	Diagnostic and Statistical Manual of Mental Disorders
ICD	International Statistical Classification of Diseases
ICF	International Classification of Functioning, Disability, and Health
SA	South Africa
SLPE	Schizophrenia-like psychosis in epilepsy
SLT	Speech-Language therapist
WHO	World Health Organization

LIST OF ISIXHOSA WORDS & ENGLISH TRANSLATIONS

Imanfriend	Boyfriend
Imphepho	Indigenous African sage plant used in traditional medicine
Intakato	Witch illness
Iqgirakhazi	Female witch-doctor
Isimnyama	Being bewitched, usually by black magic
Muthi	Medicine
Silon	Big winds, implying ‘crazy’
Ukuqhumisa	To burn (the plant)
Xhuzula	Fits (epileptic)

CHAPTER 1: INTRODUCTION

I.1 Research into Mental Health in the South African context

"The voice of the sufferer is silenced by virtue of being translated into the language of mental pathology, and the context of the suffering, is written out of the story" (Speed et al., 2014, p. 15).

The subjective perspectives of individuals living with a mental health condition, such as schizophrenia, in developing countries have not been sufficiently researched upon (Baumann, 2010; Read et al., 2015). Research has shown that in the South African context there is a poor understanding of severe mental health conditions, such as schizophrenia (Byrne & Baron, 2004; De Wet, 2013; Motlana et al., 2004). Therefore, it is important to consider not only biomedical aspects of mental health conditions, but also the subjective experiences of individuals diagnosed with severe mental health conditions, such as schizophrenia (Cohen & Minor, 2008; Davidson, 2003; Geekie & Read, 2009; Karp & Birk, 2013). This is significant in order to have better understanding of the perceived origins of mental health conditions, and to expand the database for building "an essential bridge between sufferer and helper - a platform for mutual understanding and for organising meaningful interventions" (Kirmayer et al., 2015, p. 648).

The World Health Organization (WHO) defines health as the "state of complete physical, mental, and social wellbeing, and not merely the absence of disease or "infirmity" (WHO, 2018). The definition of health therefore involves three major areas when focusing on the wellbeing of an individual: physical, mental and social health. Mental health is greatly affected by the environmental factors (McNally, 2011), as they influence the experience of disability by a person (Schneider et al., 2003). The environmental factors include all aspects of a person's external world, such as physical, attitudinal and social factors (WHO, 2001), which can either facilitate an individual's functioning or cause isolation of individuals with impairments and create disabling barriers (Schneider et al., 2003). Therefore, the role of the environment should not be underestimated and needs to be considered when the mental health condition is identified.

The identification of mental dysfunction is guided by the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). The DSM-5 is an effective tool in distinguishing between mental health disorders, however recently there has been much debate as to whether the use of the DSM-5 is feasible in the South African context (Kriegler & Bester, 2014), as it ignores the social area of health and does not consider psychosocial and environmental factors (Kriegler & Bester, 2014). Such factors include poverty and deprivation of needs, as causes of mental distress (Kriegler & Bester, 2014). Furthermore, the use of diagnostic labels may predispose the individual to negative experiences, as misconceptions around the diagnosis of schizophrenia may cause social rejection and stigmatization. Stereotyping by mental health professionals, as well as the likelihood for people to view themselves negatively, as the individuals around them may (Cardwell, 2014), contribute to the negativity that labels may bring. Intensified by stigma, negative experiences could carry feelings of depression and worthlessness; further impairing quality of life (Lepage et al., 2014). Due to fear of being judged or labelled as an outcast, people living with mental health conditions choose not to seek help, and so they become silenced (Henderson et al., 2013). This highlights the need to better understand the experiences of those living with schizophrenia and ways to improve on diagnosis and service delivery.

All individuals in South Africa, including those living with disabilities, have the right to healthcare, as is supported by the South African Constitution, and the country's ratification of the UN Convention on the Rights of Persons with disabilities (Sherry, 2014). However, evidence suggests that individuals with disabilities, including mental health conditions, as well as their families, systematically experience poorer access to care due to serious system limitations, such as the widespread absence of planning and resourcing (Sherry, 2014). An example of persons with schizophrenia not being able to access healthcare can be seen in the Eastern Cape where the poverty rate is 71-100% (DOH, 2013). As many people are living in poverty, they experience limited medical facilities and trained staff for mental healthcare, this makes it difficult for individuals to receive the help needed, which in turn affects their wellbeing. Individuals who are deprived of resources, and limited in their access to the mental health system require community-based support (Kirmayer et al., 2015). Such support might cover the gap left by the government health system, and is focused on raising awareness, stigma reduction and the improvement of support to individuals living with mental health conditions (Lund et al., 2012).

The information acquired from this project, where participants provided personal perspectives of their experiences living with a mental health condition, and described their needs and distress, may guide further research and planning, and improvement to existing outreach projects and community-based services. This dissertation explored how individuals living in a rural area in the Eastern Cape, utilizing out-patient services at a district level hospital, subjectively experience schizophrenia. I hope that my work can open the door for further enquiry, and may assist in organizing new (and improving current) interventions.

I.2 Research Aim and Rationale

According to research, individuals with mental health conditions who are vulnerable and at-risk for isolation, are often marginalized and silenced (Van Den Tillaart et al., 2009). They have expressed feeling invisible, and have their voice silenced by professionals, the health system, and even by their families (Van den Tillaart et al., 2009). In order to understand the participants' lives in a more holistic way, not only from a medical perspective, this study aims to give a few individuals from the silenced population an opportunity to express themselves, to voice their experiences in a safe environment, to share their thoughts and feelings, in order to be understood better.

The research is based on the first-hand experiences of individuals living with schizophrenia in the Eastern Cape. The lack of information available opened the door for inductive, open-ended exploration. The current research belongs to the interpretive paradigm, as it is based on interactions with people, and discovers their subjective and internal realities (Terre Blanche et al., 2006). Participants were interviewed in person; this method of gathering data is a more natural form of interaction with the individuals, as opposed to filling out a questionnaire.

Semi-structured interviews were used and were conducted in the home-language preferred by the participants (English, Afrikaans, isiXhosa), and then translated into English. Semi-structured interviews (as opposed to open-ended questions) guided the participants to talk about their feelings and experiences living with schizophrenia in-depth. To keep the participants focused on the topic, guiding questions were produced in advance. The key questions allowed me to explore the participants' own experiences, rather than reflecting their attitudes toward the experiences.

Individuals with disabilities often become vulnerable to discrimination and stigma (Neille & Penn, 2015; Niehaus et al., 2004), which may lead to social isolation and barriers in accessing support services. Vulnerable populations, such as those with a mental health condition who may face disability, are limited in their ability to communicate with service providers (Hill, 2015). It is important to accept the individuals living with a mental health condition, to increase awareness and understanding of their limitations and difficulties, to separate the truth from the stigma in order to allow for better communication (Mehta & Edwards, 2018).

Language and communication are the foundation of good mental healthcare (Swartz et al., 2014). Symptoms and experiences are expressed through language, which forms the medium through which the condition and treatment may be explained (Lund et al., 2014). When working with individuals with mental health conditions, a transdisciplinary team approach that includes the speech language therapist (SLT) may be effective. Thus, the current research was conducted from the SLT's perspective; this could assist the participants to convey their thoughts, ideas, and beliefs more effectively. The SLT has an important role to play in mental health, and working with individuals who have mental health conditions such as schizophrenia – where communication impairments are present (Novak & Kapolnek, 2001) – could help them. The SLT plays a role in identifying communication characteristics, developing speech, language and communication skills, and assessing and managing swallowing difficulties (Law & Garrett, 2004).

Communication difficulties have been identified as primary symptoms in individuals with mental health conditions (Novak & Kapolnek, 2001). Fallouts in any of the areas of communication, i.e. in speech, or language (including expressive language and receptive language), including that where syntax, semantics and morphology may be affected (Rees et al., 2018), may be present in individuals with mental health conditions (Cohen et al., 2014) such as schizophrenia. Communication may be difficult for individuals with a mental health condition, which may increase the individual's risk of experiencing abuse (Rees et al., 2018), and may act as a barrier to employment, as well as social opportunities, for example. Effective communication is vital for preserving mental health and resilience (Rees et al., 2018). The primary language impairment in schizophrenia is in the area of pragmatics (Novak & Kapolnek, 2001), where the SLT can intervene and help the individual convey their thoughts and ideas across as needed, by teaching strategies to the patient and their family. There is an estimation of one percent of the South African population having schizophrenia (STATS SA, 2019), however there is a lack of literature on the prevalence of schizophrenia in country, and more research is needed on this population.

Strengthening the voice of mental healthcare users, such as those with schizophrenia, may have many benefits, including improving the patient's insight and providing psycho-education indirectly, for example. As the mental healthcare system is under pressure, increasing awareness of treatment regimens and the importance of not defaulting, and taking responsibility, may assist in making more space in the system to assist mental healthcare users who require acute care. Those patients who may have the potential to have a good prognosis, but because they are silenced and have no voice, are not heard and therefore don’t seek the appropriate care needed, which results in not getting the help needed to improve.

There have been few articles published in the Journal of Speech, Language and Hearing Research regarding the provision of speech therapy to individuals with mental health conditions (Law et al., 2009; Meilijson et al., 2004; Novak & Kopalnek, 2001). In addition, it was noted that more research was being done in developed countries, for example Israel (Meilijson et al., 2004), than in developing countries. This study may help investigate what gaps there are in healthcare provisions to individuals with mental health conditions, such as schizophrenia. In developing countries, the availability of resources may be scarce – there may be higher burdens, and different factors that can affect which intervention is effective. There is a need for the SLT to be more involved in interventions within the multidisciplinary team in hospitals and clinics, with patients who have a mental health condition, in South Africa. The data acquired in my research may be helpful for future enquiry or could be used in interventions in mental health that include the SLT.

1.3 About the Researcher

I am a speech-language therapist and audiologist, and have been working in the Eastern Cape since the beginning of 2017. After completion of my community service year at a tertiary hospital in the Eastern Cape, I was employed at a district level hospital in the same province, but different region, where I have been running the Speech Therapy Department since January 2018. I have built good rapport with staff at the hospital, and have been involved in treating patients in a multidisciplinary team.

I provided SLT services to an individual with neuropsychiatric disorder (potentially undiagnosed schizophrenia) during my undergraduate research (Toumilovitch, Neille, & Penn, 2016). The strategies applied by those communicating with the individual, based on the results of the research – shared after the research by myself, improved the communication between the patient, medical staff and members of the family. As a result, people had some insight into the mental state of the patient that brought about a better understanding of her condition. This, in turn, allowed others to accept the person, to decrease the attached stigma, and therefore improve quality of life.

This has caused my interest in mental health conditions to grow. I have had experiences with individuals with various mental health conditions at the hospital, and have provided intervention to patients at the Mental Health Unit at the site. I noted that most of the patients seen came from backgrounds of poverty, abuse and neglect, and most felt discriminated and misunderstood. I decided to explore the lives of individuals with mental health conditions, (specifically schizophrenia), to hear their life stories first-hand, in the hope that I could place myself in their shoes and try to understand how their experiences affect them. I was hoping that by getting a glimpse of their lives, I could try make a small difference by having their stories heard.

1.4 Outline of Research

This research thesis consists of five chapters:

Chapter 1: Introduction & Rationale

This chapter focuses on introducing the researcher and topic of interest explored. Research in the South African context, and the research aim and rationale are introduced.

Chapter 2: Literature Review

An overview of literature and research on mental health, more specifically the mental health condition schizophrenia, disability, and poverty and its link with mental health are explored. Research into mental health conditions (both locally and internationally), the theoretical framework of The International Classification of Functioning, Disability, and Health (ICF) and the National Mental Health Policy Framework & Strategic Plan, are additionally introduced into the research.

Chapter 3: Methodology

The research aim and objectives are stated, followed by a detailed description of the research design, context, and data collection and analysis. Selection of the participants, the inclusion of a research mediator (including training), and description of the pilot study are also discussed. This chapter concludes with a section on ethical considerations, as the selected participants are considered to come from a vulnerable population due to the nature of their condition.

Chapter 4: Results & Discussion

Findings from the study are discussed in this chapter. An exploration of themes identified from the interviews, including quotes from participants are used to support and validate findings. Coping strategies, as defined by the participants, are also explored.

Chapter 5: Conclusion

This chapter summarizes the findings and discusses strengths and weaknesses of the study, as well as potential implications and recommendations for future research.

CHAPTER 2: LITERATURE REVIEW

2.1 Mental Health/ Illness Experience

Mental health can be defined as the effective performance of mental functioning, in which the individual is resilient to life stresses (Herman et al., 2005), has the ability to adapt to change and cope with adversity, is able to form meaningful relationships (WHO, 2001), and is able make a positive contribution to their community (Herman et al., 2005). It is a state of mental wellbeing (WHO, 2001). Medical practice focuses on the physiological functioning of the body and often pays little attention to the social and cultural, contexts of distress, and as a result, the lived emotional suffering of individuals in the world, especially in developing countries may be not considered (Meyer et al., 2005). The concepts of illness and health are complex (White, 2002) – where illness is a subjective experience, disease is a more objective perspective (White, 2002), and the biomedical description of a condition is not complete – it is also crucial to respect and consider the experiences and narratives of individuals diagnosed with severe mental health conditions (Cohen & Minor, 2008; Kirmayer et al., 2015).

Mental illness, on the contrary, is associated with distress and impairment of human functioning, and is identified through a cluster of symptoms and experiences (WHO, 2001). According to the South African Stress and health (SASH) survey, ratified in 2014 by Herman et al., one third of South Africans suffer from a mental health condition over the course of their lifetime. Current economic difficulties and a lack of access to mental health services contribute to a large number of individuals affected (DOH, 2013). Currently approximately 75% of individuals with mental conditions do not receive the required interventions *(*DOH, 2013). The South African government stated that it is committed to improving the wellbeing of South Africans through “the provision of evidence-based, affordable and effective promotion, prevention, treatment and rehabilitation interventions” (DOH, 2013, p. 19). Research into the field of mental health is important and may assist in increasing awareness and the understanding of individuals living with mental health conditions (Makgoba, 2016).

There has been an increase in the number of published accounts of the subjective experience of individuals diagnosed with a mental health condition such as schizophrenia (De Wet, 2013; Read et al., 2015), however, first-hand accounts are still infrequent, specifically those in developing countries (Geekie & Read, 2009). A collaborative European project (European Study of Gene-Environment Interactions [EU GEI], 2014) was created to investigate the contribution of genetic and environmental risk factors causing mental health disorders (including schizophrenia), which ran over five years, however a limitation was that it explored the incidence of schizophrenia in various (rural and urban) European countries only; little is known about African countries. Data from the current research, that explored the life narratives of people with a mental health disorder who live in informal settlements of the Eastern Cape in South Africa, may help to fill the gap in the existing research.

2.2 Disability as an Aspect of Health/ Illness Experience

In 2001, the World Health Organization moved away from an impairment-focused approach and described disability by developing the International Classification of Functioning, Disability and Health Framework (ICF). This framework brought together social and structural factors and recognized disability as a result of interactions between the health condition, environmental and personal factors. It allowed me to describe disability as an aspect of the health or illness experience, which may affect the majority of individuals during their lifetime – temporarily, permanently, or episodically (WHO, 2001). The ICF is used to describe the functioning and disability of an individual, by measuring health and disability, on individual and population levels. It is based on the integrative biopsychosocial model of functioning, disability and health (WHO, 2001). It can be used to address problems in the activity and participation of individuals with mental illness (Tenorio-Martínez et al., 2009), and to explore the impact of the illness on the individual's quality of life.

The ICF is important to consider for this study, as it can be used to discuss mental health conditions, such as schizophrenia, and allows for an exploration of functioning and disability of the individual. Furthermore, the individual's difficulties in activity and participation, for example, may be explored in a more holistic manner. Figure 6 in the *Results & Discussion* section depicts the ICF specifically when exploring schizophrenia. The ICF provides a universal language for describing health states (Figueira & Brissos, 2011) and interaction between the health condition and contextual factors (i.e. personal factors and environmental factors). Figure 1 (on the following page) depicts the ICF Framework.

Figure 1

The ICF Framework

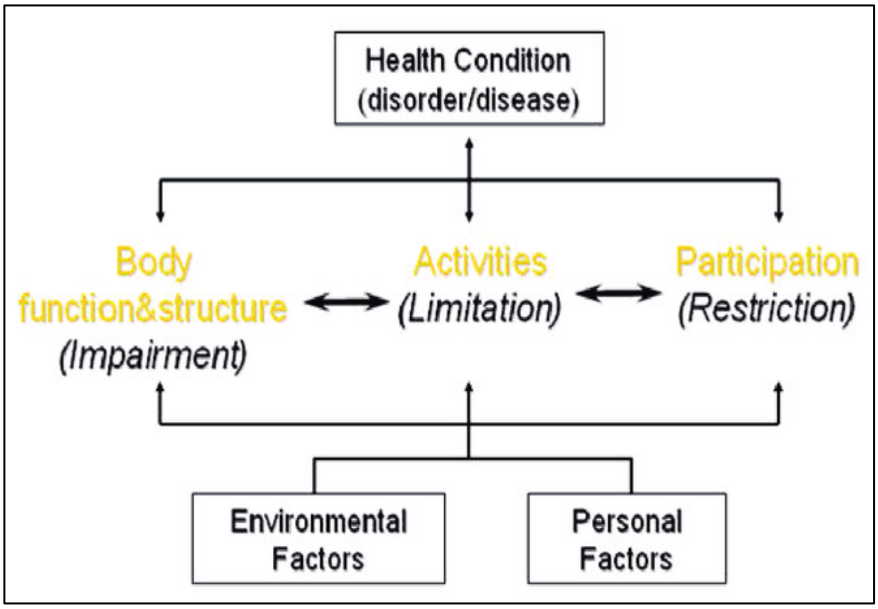

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Figure 1 depicts how impairments in body structure/ functions limit the individual's activity and restricts their participation in social life; environmental and personal factors have a great impact on limiting human activity. Functional impairments may include psychological distress, cognitive difficulties, and an irregular use of language, for example (Figueira & Brissos, 2011). Individuals with schizophrenia experience a variety of psychosocial difficulties (Switaj et al., 2012). Environmental factors, such as stigma, and family support, may have an impact on these psychosocial difficulties (Cohen & Minor, 2008). Literature in the past has analysed aspects of psychosocial disability in schizophrenia, which includes emotional experience, social functioning, and quality of life (Switaj et al., 2012). However little research has been done on the overall experience (Figueira & Brissos, 2011) and burden of living with schizophrenia (Cabello et al., 2012). Cabello et al. (2012) describes a need for schizophrenia research to focus more on the creation of profiles of psychosocial difficulties, regarding the disabling experiences of actual functioning of individuals with schizophrenia, which can be then used to help aid intervention over time. By identifying different psychosocial difficulties in different contexts, these profiles can be developed (Keshavan et al., 2010).

Various tools may be used to evaluate functioning of an individual with schizophrenia. This includes the World Health Organization Disability Assessment Scale 2.0.

(WHODAS 2.0; WHO 2010), which is an assessment tool used to evaluate functioning, and is based on the ICF framework (Nuno et al., 2018). It is used to assess functionality in individuals with mental health conditions, and is presently utilised in conjunction with the DMS-V (Nuno et al., 2018). The core sets from the ICF involve a selection of categories used for the assessment of functioning and disability in a specific health condition (Barrios et al., 2017). Regarding schizophrenia, a specific group of core sets for schizophrenia was developed in 2015, based on four different studies (Gomez-Benito et al., 2018), including – systematic literature review, qualitative study, expert survey, and empirical study. They may further be used to improve communication between members of a multidisciplinary rehabilitation team, and improve patient-focused interventions.

2.3 Poverty and the Link with Mental Health Conditions

There is an increased awareness about the role environment plays in the development of mental health conditions (McNally, 2011). Poverty could be described as the severe deprivation of basic human needs (Gough & McGregor, 2007). The discriminative policies of the past, adopted by the apartheid government, and lack of service delivery from the present government, has resulted in levels of extreme poverty. For example, in the province of the Eastern Cape, the second largest region in the country, the level of poverty ranges from 71-100 % (DOH, 2013). Social exclusion, high stressors and reduced access to social capital, as the result of poverty, influences mental health, causing higher prevalence, lack of care and a more severe course of mental illness (Kawachi & Berkman, 2001). Living in poverty, a person has no or very limited access to resources and is constantly worried about means for living; poverty creates a dangerous environment of overcrowding, exposes to violence, trauma and crime (Hjelm et al., 2017).

When environmental demands exceed an individual's ability to cope with a situation, it can be associated with a range of physical and mental health states (Hjelm et al., 2017). Previous research has recognized a relationship between poverty and development of a mental health disorder as a "vicious circle” (DOH, 2013). As a result of increased stress when living in deprived conditions, the risk of developing a mental health disorder also increases (Kuruvilla & Jacob, 2007). Murali and Oyebode (2004) describe poverty as both a ‘determinant’ and ‘consequence’ of poor mental health.

It has been researched that approximately 50% of mental health conditions begin before the age of fourteen, during the vulnerable years of childhood and adolescence, and are associated with post-traumatic stress disorder, depression, and substance-related disorders

(DOH, 2013). In South Africa, neuropsychiatric disorders rank third in their contribution to the overall number of all diseases, with over 16% of adults experiencing a mood, anxiety or substance-use disorder during the previous 12 months (DOH, 2013). South Africa has the second highest incidence of alcohol abuse in the world (DOH, 2013); furthermore, there are major challenges regaining substance abuse, with the common drug in the country being cannabis (DOH, 2013).

2.4 Primary Healthcare Principle

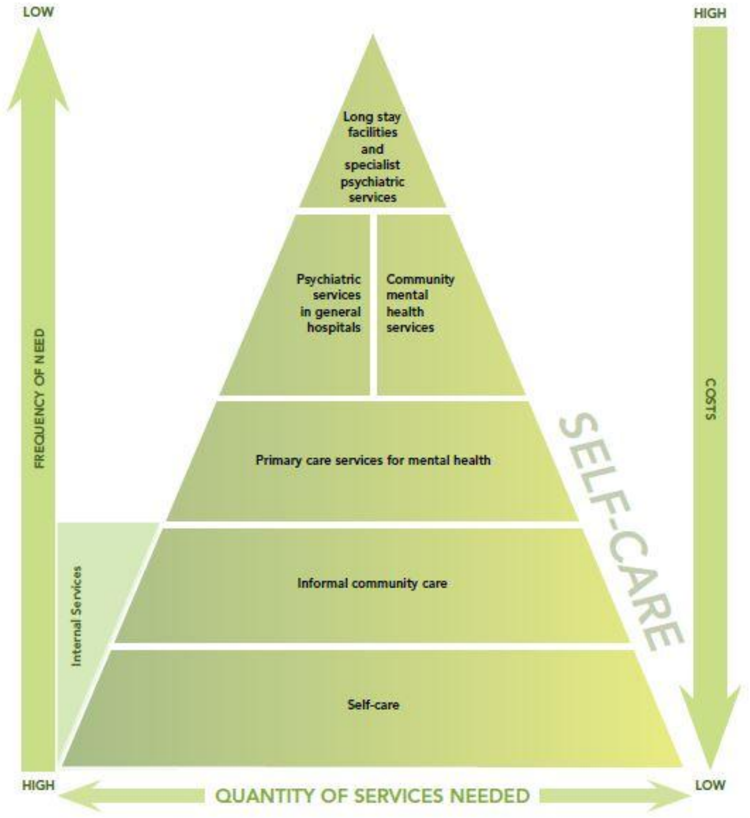
Approximately one third out of the 58.8 million of South African population lives in rural areas (Statistics SA, 2019), where access to running water and sanitation, as well as electricity, are not always available (Sukeri et al., 2014). People also lack access to essential medicines and healthcare (WHO, 2018). Rural areas are found to have lower rates of mental illness (Herman et al., 2014), as individuals might not be formally diagnosed, as a result of difficulties to accessing mental healthcare services, and fear to be labelled by the community (DOH, 2013). All individuals have the right to decent healthcare at all levels of the healthcare system (DOH, 2013). Therefore, it is crucial, that mental health services are accessible, affordable and acceptable.

It is important to position mental healthcare facilities in easily accessible areas, close to places of residence or work, and local community-based resources should be available to those that need them (DOH, 2013). The possibility for out-patient and community-based residential care should be explored before in-patient care is undertaken, and should focus on the patient, and be based on the collaboration of all stakeholders (DOH, 2013).

Primary healthcare is essential healthcare, affordable and accessible to communities in South Africa; it is the approach to follow to manage healthcare services in a way that reduces exclusion and social differences in the health system, and is a collaborative, patient-centred approach, promoting participation participation of all providers (DOH, 2013). In order to achieve efficient and quality health services, the mental health system should be integrated into primary healthcare at all levels, including Self-care, Informal community care, and Primary care services, as noted in Figure 2.

Figure 2

Structure of Mental Health Services



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Research worldwide (Byrne & Baron, 2004; De Wet, 2013; Thornicraft et al., 2009) has revealed that there is a lack of knowledge about mental health conditions, and the attached stigma, discrimination and prejudice. There are individuals with mental health conditions in every community, who are likely to be isolated, neglected, and deprived of their fundamental human rights (WHO, 2010). The Convention on the Rights of Persons with Disabilities (2006) emphasises that individuals with disabilities include those with “mental impairments”, and emphasises the need “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities” (United Nations Assembly, 2006), and to promote their participation with equal opportunities.

Studies have identified that there is a need to narrow the treatment gap in low and middle-income countries (Esponda et al., 2020; Lancet Global Mental Health Group, 2007; Semrau et al., 2015), that entails the integration of mental health into primary healthcare. This may offer various advantages, including a holistic approach to healthcare, increased accessibility of mental healthcare services, the reduction of stigma, and reduced costs (Lund et al., 2012). This may be achieved through the introduction of community-based rehabilitation programs.

Community-based rehabilitation (CBR), refers to a community development strategy aimed at enhancing the quality of life of individuals with disabilities (O'Dowd et al., 2015). CBR can assist with giving individuals with disabilities the opportunity to participate and contribute meaningfully to the community (Rule et al., 2006). The implementation of CBR programmes may contribute to service delivery in South Africa, including primary healthcare, social development, and the alleviation of poverty (Rule et al., 2006).

Using CBR in the management of those diagnosed with schizophrenia may be beneficial to the patient in a number of ways. Those with a mental health condition may have limited access to support and healthcare services, and the introduction of CBR may support recovery and facilitate participation and inclusion in their families and communities (Khasnabis et al., 2010). Research has shown that CBR may also contribute to the prevention of mental health problems, and promotion of good mental health within the community (Khasnabis et al., 2010). By increasing the awareness of schizophrenia in the community, it may also reduce stigma and discrimination towards individuals with the condition. Furthermore, family members may receive emotional and practical support (Khasnabis et al., 2010), and an overall attitude of unity may be endorsed.

There is an increasing interest in shifting tasks of professionals (e.g. psychiatrists) to less qualified workers (e.g. nurses, social workers, community healthcare workers) in the delivery of care (Lund et al., 2014). The implementation of a task shifting approach to the integration of mental healthcare into primary healthcare in South Africa can reduce the number of healthcare providers needed to narrow the mental health service gaps (Petersen et al., 2012).

2.5 Schizophrenia

Schizophrenia is a rare, chronic mental health condition that affects 1% of all adults globally (Baune, 2019). The word 'schizophrenia', of Latin origin (Bleuler, 1911), is used worldwide to describe the mental health condition being explored in this research.

2.5.1 Definition

Mental health literacy includes the understanding and beliefs regarding a mental health condition by an individual (Ganasen et al., 2008). An individual can make sense of their diagnosis through different definitions, such as a medical definition (provided by the physician, for example), a traditional definition (making sense through cultural and religious beliefs), and other definitions or understanding that the individual may have regarding what they understand schizophrenia to be.

Medical definition: Schizophrenia is described as '*a splitting of the mind'* in Latin (Bleuler, 1911), causing the individual to interpret reality abnormally. Schizophrenia is a chronic mental health condition that is complex and heterogeneous. It is diagnosed based on the presence of certain characteristic disturbances of thinking and perception (Bellack, 2013). More recently, schizophrenia has been described as a spectrum disorder (Schulz et al., 2016; Yanos et al., 2008). In the past, schizophrenia used to be described by five subtypes, which included (Kleinman et al., 2011; Miller & Mason, 2011; Rector et al., 2011): Disorganized, Catatonic, Paranoid, Undifferentiated, and Residual schizophrenia.

The word 'schizophrenia' is used worldwide to describe this mental health condition. Although different cultures have different explanations for it, and some have even created names for it, doctors and therapists (in the medical fields, in hospitals and clinics) who follow a Western medicine approach make use of this Latin word.

Traditional definition: Cultural and religious backgrounds contribute to the interpretation of the causation of mental health disorders (Mfoafo-M'Carthy & Huls, 2014). In their qualitative study Motlana et al. (2004) indicated that the out-patients perceived schizophrenia as an illness caused by medical and social factors.

Different cultural or traditional groups may offer various explanations regarding schizophrenia. The concept of being 'mad' has been termed as an illness – often individuals who have the mental health condition schizophrenia are described as being 'crazy' or 'mad', because of the characteristics, such as delusions and hallucinations (Angane, 2017). Literature globally discusses how individuals with schizophrenia are labelled as 'being mad' (Angane, 2017; Lambrecht & Taitimu, 2013; Motlana et al., 2004). Research in South Africa, for example, indicates that individuals often define schizophrenia, with Sotho names such as "bohafi" (madness), "boloi" (bewitchment), (Motlana et al., 2004), and "amafufunyana" (directly translated as "nerves"), (Lund & Swartz, 1998; Niehaus, 2004).

In many traditional African belief systems, mental health conditions are perceived to be caused by bewitchment and actions by their ancestors (Sorsdahl et al., 2009). Mental health conditions are often blamed on spirit possession, for example (Asmal et al., 2011). The concept of "ukuthwasa" is commonly used to describe the emotional disturbances of a person on the path to becoming a traditional healer (Swartz, 1998); the themes of jealousy, bewitchment, guilt and ancestral calling are commonly used for explaining the understanding of schizophrenia in Africa (Mbanga et al., 2005; Motlana et al., 2004); patients and families often support medical treatment as well as further intervention from a traditional healer (Mbanga et al., 2002).

2.5.2 Incidence and Course

Recent studies indicate more cases of schizophrenia have been detected in men (Ochoa et al., 2012; Toulopoulou et al., 2017). The age of onset of schizophrenia is usually between 18-35 years of age (Lieberman & Murray, 2012), therefore it appears that more recently young males appear to be diagnosed with mental health conditions such as schizophrenia. The course of schizophrenia generally begins with the 'Prodromal Phase', which usually precedes the onset of schizophrenia, and is characterised by functional decline and symptoms such as cognitive deterioration, psychosis, and a decline in socio-occupational functioning (Ritsner, 2011). The 'Active Phase' (acute phase) occurs when prominent psychotic symptoms begin to appear (such as auditory hallucinations), and then the 'Residual Phase', in which there is gradual recovery (Weinberger & Harrison, 2011).

2.5.3 Diagnosis

According to the *DSM-5*, in order to meet the criteria for a diagnosis of schizophrenia, the patient must have experienced at least two of the following symptoms, of which one must be a Positive symptom, (such as delusions, or hallucinations, or disorganized speech):

Table 1

Symptoms in Schizophrenia

DOMAIN	**Positive Symptoms**	**Negative Symptoms**	**Cognitive Symptoms**	**Mood Symptoms**
DESCRIPTION	*Distinct to mental health conditions, but not usually present in the normal population (Walsh et al., 2016)*	*When a normal behaviour, thought pattern or emotion is absent (Walsh et al., 2016)*	*Deterioration of a cognitive ability (including attention, working memory, speed of processing information) (Harvey, 2013)*	*Extreme or inappropriate moods (Bellack, 2013)*
EXAMPLES	Delusions	Poverty of speech	Poor understanding of abstract concepts	Feeling extremely depressed
	Hallucinations	Loss of interest and drive	Deficits in working memory	Displaying inappropriate moods in situations
	Disorganized speech	Inertia	Deficits in attention	
	Disorganised/ catatonic behaviour	Decrease in emotions	Deficits in executive functions	

Continuous signs of the disturbance must persist for at least six months, during which the patient must experience at least one month of active symptoms, with social or occupational deterioration (Harvey, 2013). The deficits in attention, executive functions, and extreme moods, influence the individual’s ability to participate in activities of daily living, and affect how they are perceived in society (Harvey, 2013). Communication difficulties are found in schizophrenia too. Research is being conducted on this area to explore these difficulties. For example, Meilijson et al. (2004) conducted a study on "Language Performance in Chronic Schizophrenia", where the pragmatic abilities of individuals with schizophrenia were analyzed, as disorders in cohesion, reduced syntactic complexity, and decreased verbal output are common in this population (Meilijson et al., 2004).

Following a Western approach in treatment, diagnosing schizophrenia involves a physical examination, tests and screenings, and a psychiatric evaluation. The final diagnosis is based on the results of the assessments and the diagnostic criteria for schizophrenia as defined by the DSM-5. There has been much debate as to whether the use of the DSM-5 is feasible in the South African context (Kriegler & Bester, 2014). The norms used in the manual that define mental health disorders are attributable to psychiatry and utilize medical and scientific explanations (Kriegler & Bester, 2014), which may not always correlate in the South African context.

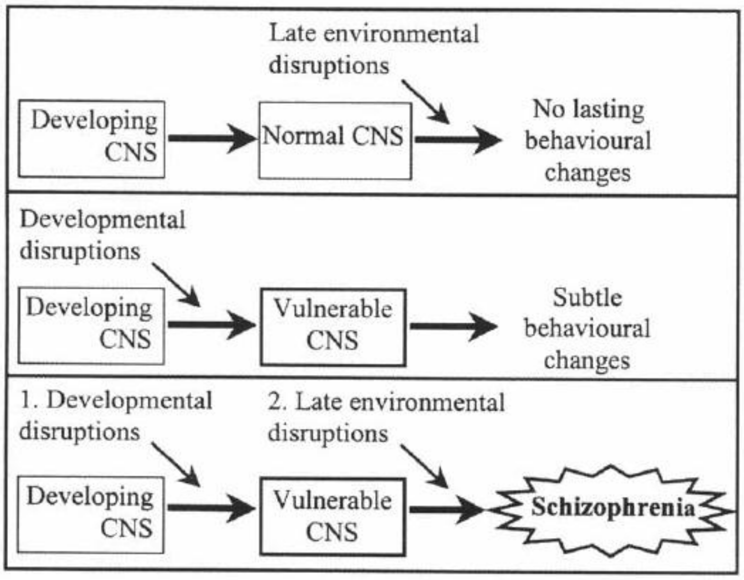
2.5.4 Impact of Environmental Factors on the Development of Schizophrenia

The exact cause of schizophrenia is unknown; but is believed to be caused by a combination of physical, genetic or biological, psychological, social, and environmental factors which may trigger a psychotic episode (Mueser & Jeste, 2011). Schizophrenia may affect the individual at any point in their life, (i.e. the onset may be as early as the fetal period, ranging to early adulthood), (Vilain et al., 2013). These factors may act on an individual or population level, according to Vilain et al. (2013), however more research is needed.

The Two-Hit Hypothesis, as first described by Bayer et al. (1999), has been used in various literatures as a possible explanation for the cause of schizophrenia (Davis et al., 2016; Maynard et al., 2001), as well as to understand the condition better. This hypothesis suggests that a prenatal genetic and/ or environment occurrence disrupts initial stages of brain development, causing increased vulnerability to a second 'hit' that may happen later in life, and therefore cause the onset of schizophrenia (Maynard et al., 2001). This supports the idea that the cause of schizophrenia is multifactorial, having both genetic and environmental causation factors. Figure 3 depicts this explanation:

Figure 3

The Two-Hit Hypothesis



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Two hypotheses are used and integrated into a pathophysiological concept (Bayer et al., 1999, p. 458):

- Multiple susceptibility genes contribute to schizophrenia, and
- Non-genetic factors contribute to the aetiology of schizophrenia.

An example of the first, is a genetic defect, which occurs during embryonic development, leading to a deficient neuronal network (Bayer et al., 1999). This results in the first hit, which causes the central nervous system to become vulnerable (Mayer et al., 2001). This then results in increased vulnerability to a 'second hit' which may occur later in life, such as an environmental disruption, or hazard occurs and affects the individual, which modulates the person's gene activity (Bayer et al., 1999). A single 'hit' is considered insufficient to induce schizophrenia, therefore the combined two hits are suggested to result in the psychotic disorder of schizophrenia. It has also been found that this may change in different contexts (Buuse et al., 2003), as the individual may face different challenges in different contexts.

Therefore, the impact of environmental risk factors cannot be ignored, and has been an area of interest in research regarding psychotic illnesses (Vilain et al., 2013). Examples of such environmental factors may include urbanicity, migration, substance abuse (such as cannabis), and psychosocial factors may also increase the risk of developing schizophrenia (Vilain et al., 2013). Although childhood traumas, infectious agents, and socio-demographic factors were also considered environmental disruptions, there is insufficient evidence to confirm this (Vilain et al., 2013).

2.5.5 Treatment

Medical approach: Although there is no cure for schizophrenia, the most common treatment for schizophrenia used is the combination of antipsychotic medications and psychosocial interventions. In the past, electroconvulsive therapy was used as well, (Rector et al., 2011). Antipsychotic medications (e.g. Clozapine, Haloperidol), as well as antidepressant or anti-anxiety medications, are used to manage signs and symptoms, and may be accompanied with psychological interventions such as counselling (Rector et al., 2011). It has been researched that individuals with schizophrenia are two to three times more likely to die from a cardiovascular disease (Krishnadev et al., 2008), and that the use of antipsychotic medications can increase the risk for coronary heart disease (Stoner, 2017).

Traditional Approach: In South Africa, traditional healers play an important role in mental healthcare (Sorsdahl et al., 2009). It appears that because of ease of access to treatments, this approach is favourable in the South African context, as seventy to eighty percent of the country uses, or has used, traditional medicine as a form of primary healthcare (WHO, 2018). For example, the smoke of the ‘”imphepho” plant (also known as “Helichrysum miconiaefolium”, or African sage), is considered to have healing qualities and is used for mental health conditions (Sobiecki, 2014). It is an indigenous African plant, which has been used for medicinal purposes for decades (Sobiecki, 2014), and is the most widely used medicinal plant in South Africa. It is considered a sacred herb, as it is used to communicate with people’s ancestors (Sobiecki, 2014), and for protection as well. The smoke is considered sedative (van Wyk, 2011), and can be inhaled to relieve headaches, or to cleanse evil energy (Sobiecki, 2014).

Holistic Approach to Treatment: People may follow more than one form of treatment. For example, individuals with a mental health condition, such as schizophrenia, may make use of a holistic approach to treatment, which involves not only taking the medication prescribed to them by their practitioner, but also talking to a therapist, or using prayer or meditation. It is important to treat schizophrenia in a holistic manner, as medication alone is not enough. Face to face support, for example, is important, and can help the individual achieve independence and avoid relapse.

2.6 Managing Life with Schizophrenia and Coping

Social support and coping are positively related with well-being (Ben-Zur, 2009). Individuals with mental health conditions may experience poor support from others, including healthcare workers, as well as their families, who may abandon them, or neglect them (Blashill et al., 2011). High levels of chronic stress contribute to the development of depressive symptoms and anxiety (Gloria & Steinhardt, 2016), further escalating the mental health condition.

The role of positive emotions in successful management of life with mental condition cannot be underestimated, as revealed by the research (Gloria & Steinhardt, 2016). Positive emotions can influence coping strategies and enhance an individual's resilience against stress (Gloria & Steinhardt, 2016). Often, individuals may be more inclined to turn to religion to help themselves cope, when they experience a large amount of stress (Rothmann & Malan, 2011).

Stigma can cause individuals with schizophrenia to experience high levels of stress on a daily basis. There is much stigma attached to schizophrenia, which prevents the individual from talking about their condition (Gaebel et al., 2017). Speaking about one's experiences first-hand allows others to gain a new perspective of what it is like living with schizophrenia in communities that are so deprived and neglected. One of the main reasons individuals with mental health conditions silence themselves is to avoid social stigma. However, when given an opportunity, studies have shown these individuals describe strong and complex emotional reactions to their symptoms, life situation and relationships (Flanagan et al., 2012). It is important to hear their voices.

Stigma is common in individuals with mental health conditions, including schizophrenia (Thornicraft et al., 2009). It is caused by people's attitudes, and behaviour towards the mental health condition, and may result in social marginalization and isolation (Byrne & Baron, 2004; Thornicraft et al., 2009). Stigma refers to the negative attitudes and beliefs towards someone or something based on a distinguishing characteristic that is considered undesirable (Gaebel et al., 2017). Stigma can cause prejudice - negative attitude towards a person, and that results in discrimination – negative behaviour directed towards an object of prejudice. Stigma and discrimination are the reality in the lives of people who have mental health disorders.

Negative stereotypes by the public and media contribute to stigmatization. This, in turn, could increase suicide attempts and violence (Thornicraft et al., 2019). Also, stigma may cause other negative consequences, such as disrupted relationships and a limited ability to socialize, causing depressed feelings of loneliness (Byrne & Baron, 2004). Self-stigma refers to negative feelings towards oneself (Gaebel et al., 2017). Self-stigma affects many areas of life, and has a destructive impact on the person's view of themselves, decreased self-esteem, poor self-care, and may cause social withdrawal. These may lead to social isolation, further affecting the functioning of the individual, leading to decreased quality of life (Holubova et al., 2016). Results from previous research indicated a significant relationship between self-stigma and the severity of the schizophrenia-spectrum disorder (Holubova et al., 2016). Many individuals choose not to engage or maintain contact with mental health services, due to stigma, and as a result, may cause a delay in seeking and continuing treatment (Gaebel et al., 2017), affecting quality of life (Rector et al., 2011).

2.7 Theoretical Framework for the Current Study

The process of my research is a form of social interaction aimed at exploring the subjective life experiences of individuals (Willig, 2001), therefore, I adopted an interpretive framework that relies on first-hand accounts and uses the power of ordinary language to describe the world in detail (Terre Blanche et al., 2006). An interpretive approach aims to explain the subjective meanings of people and grasp human phenomena in the context of their lives. Two key principles need to be applied for the successful interpretive research: understanding in context, and the position of the researcher as the primary agent by means of which information is collected and analyzed (Terre Blanche et al., 2006). Therefore, an interpretive framework accepts the person's subjective experience as their reality; it allows them to make sense of their experiences through interactions and listening to what they say (Terre Blanche et al., 2006).

The importance of understanding the participant's personal experiences within their social contexts was emphasized by Willig (2001). Understanding in context implies that the words, actions and experiences can only be understood in relation to the contexts in which they occur, including both personal and societal contexts (Geekie & Read, 2009). When the expressed life experiences of individuals are placed in their context, for example living with a mental health condition, or the context of poverty, they could be understood deeper and with more empathy.

The responses from the semi-structured interviews allowed me to focus on exploring the life experiences of individuals diagnosed and living with schizophrenia in the Eastern Cape, South Africa – how individuals understand the cause of the condition, how they experience the symptoms associated with their diagnosis, and how they are trying to manage it.

2.8 Conclusion

Many choose not to seek help due to fear of stigma and judgement from others (Gaebel et al., 2017). This behaviour emphasizes the need to delve deeper and explore the effects of psychosocial disability and first-hand experiences of the individuals. Conducting research in this area provided the affected with a chance to voice what they are going through on a day-to-day basis, particularly when published descriptions of first-hand accounts are still infrequent (Geekie & Read, 2009). Therefore, the collected data describing the detailed experiences of people living with a mental health condition could assist in the development of community-based rehabilitation outreach projects, and perhaps contribute to further research.

As noted in the literature, schizophrenia is defined and understood differently following a medical approach versus a cultural approach (Bellack, 2013; Mfoafo-M’Carthy & Huls, 2014; Motlana et al., 2004). In South Africa, where the country is largely rural, and culture impacts the population’s lives, this should not be disregarded, but rather explored. Although the aim of this study is not to compare or explore the cultural views of the condition, these will be considered when analyzing the findings, as it may influence the insight. Telling a story allows one to express oneself, to share one’s thoughts and feelings. Therefore, although there is the risk of negative feelings to be awoken concerning talking about one’s experiences with a mental health condition, this study will aim to give a few individuals from the silenced population an opportunity to express themselves, to contribute in providing a deeper outlook on schizophrenia, and communication in mental health.

CHAPTER 3: METHODOLOGY

3.1 Research Aim

To explore the lived experiences of individuals with schizophrenia utilizing out-patient services at a district level hospital in the Eastern Cape, South Africa.

3.2 Objectives

1. To elicit personal narratives from individuals with schizophrenia in the Eastern Cape.
2. To identify, and discuss the main themes that emerge across different narratives, and discuss these in relation to the influence of context and culture on life experiences.
3. To describe the experiences of living with an 'invisible' disability, and the associated emotional, social, and cultural implications within the community, including:
    a. The participant's view of their self
    b. The nature of stigma and discrimination
    c. Coping strategies utilised by the participant (if any)

3.3 Research Design

This study employed a qualitative design supported by the principles of semi-structured interviews and participant observation. Qualitative research emphasises the importance of the social context for understanding the social world (Terre Blanche et al., 2006). Qualitative research is concerned with how phenomena of interest are interpreted and understood (Mason, 2002). Understanding in context is one of the main principles of interpretive research (Elliot & Timulak, 2005).

This research followed an interpretive paradigm, aiming to explore the subjective reasons and meanings of the participant's experiences (Elliot & Timulak, 2005). Participant observation, a unique and powerful tool for investigating the life experiences of individuals (Elliot & Timulak, 2005), as well as the researcher's own reflections on the findings, contributed to the interpretation of the findings once analysed. Once data were obtained by interviewing several individuals with the same criteria, similarities were found, which contributed to strengthening the trustworthiness of the study, therefore resolving threats to validity. Member checking took place to ensure accuracy of information obtained. Both researcher and mediator wrote reflections after the interviews, which were sometimes discussed. It was important for the researcher to reflect, as it relates to the degree of influence that the researcher has (intentionally or unintentionally) on the findings (Jootun et al., 2009).

3.4 Research Context

This research took place in the Eastern Cape, the second largest province in South Africa. The size of the province and its vastness impacts access to healthcare facilities, especially individuals living in the rural areas, who face conditions of poverty, illiteracy, and lack medical facilities (Sukeri et al., 2014).

There is a population size of approximately 6 712 276 people in the Eastern Cape Province (STATS SA, 2019). As per the Eastern Cape Department of Health 2016/17 Annual Report, there is one central hospital, two tertiary hospitals, five regional hospitals, and 65 district hospitals. There are 772 Primary Healthcare facilities across the province, of which 731 are Primary Healthcare Clinics, and 41 Community Health Centres. There are only four psychiatric hospitals, and three regional hospitals that have psychiatric units. Figure 4 depicts the distribution of the four psychiatric hospitals and three regional hospitals with psychiatric units. This emphasizes how inaccessible the services are to many of the population living in the rural parts of the province. The four psychiatric hospitals are found primarily in the middle of the province, and the regional hospitals with two mental health units are found in the southern-most part of the province, and one in the eastern area. This highlights the difficulty that most patients with mental health conditions may face with regards to access to services, especially those who live in the deep rural areas.

Figure 4

Map of the Eastern Cape to show the distribution of government specialized psychiatric hospitals and regional hospitals with mental health units across the province

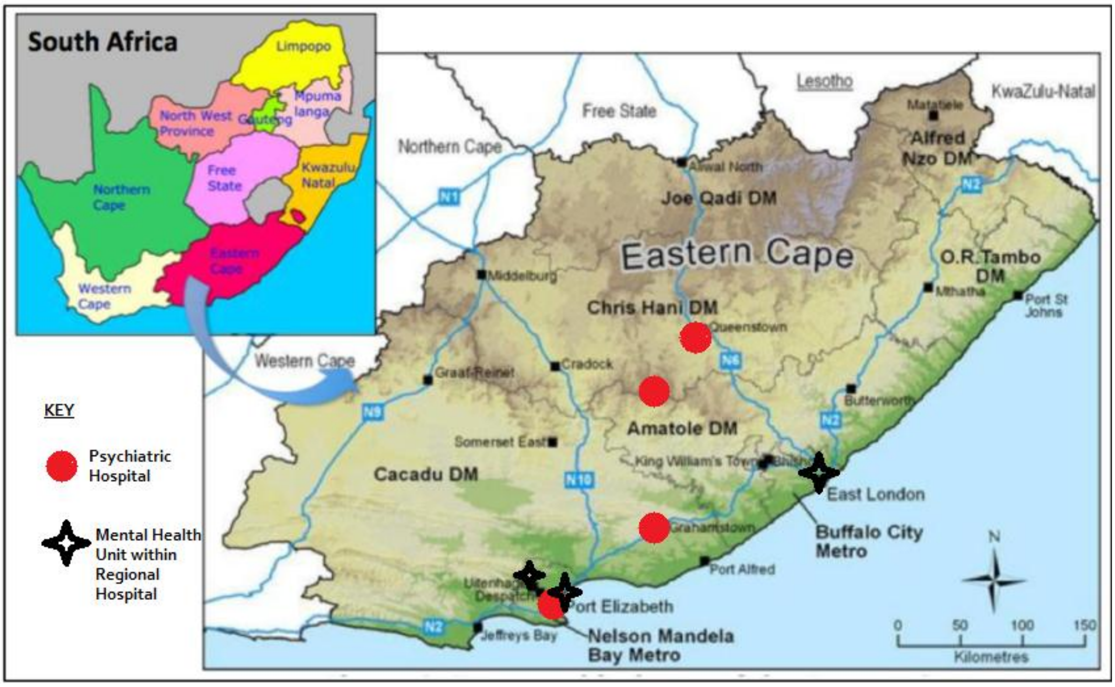


Figure 1 - Copyright 2016 by Sibanda et al.

This research took place at a district level hospital, based in the Nelson Mandela Bay Metropolitan Municipality – which consists of the city of Port Elizabeth (PE), towns of Uitenhage and Despatch, and surrounding rural areas. The informal settlements include Kwanobuhle, Ibhayi/ Bethelsdorp, Motherwell, and surrounding PE areas. The Eastern Cape is mostly rural and underdeveloped (Eastern Cape Department of Health 2016/17 Annual Report, 2017), with limited access to social and economic services.

There are approximately 365 973 households in the Nelson Mandela Bay Metropolitan Municipality, of which 5,9% (21 668) are estimated to be informal households (STATS SA, 2019). There is a 49% unemployment rate. The current population is 1 271 776 (STATS SA, 2019), with a dominating youthful population, with a mean age group of 5-14 years. The life expectancy is 67,1 years in females, and 59,6 years in males. Based on the above, participants were sourced from these areas, and the context was considered when discussing findings.

3.4.1 Access to Site & Participants

The researcher has been working the Eastern Cape Province since January 2018 and has a strong working relationship with individuals with mental health conditions. The chosen site was a district level hospital which provides out-patient services for individuals, mental health conditions included. Signed permission was granted by the head of the site (Appendix 3.iii). The researcher discussed the research with the doctors and nursing staff at the Mental Health Unit, who assisted in identifying potential candidates known to them with the diagnosis of schizophrenia.

3.5 Interview Data

Thirteen participants took part in the study. Initially, approximately ten participants were required, and another two for the pilot study. The sample size is generally dependent on various factors, including variability in the group, the focus point of the interview, and sampling method (Saunders et al., 2018). Two participants were involved in the pilot study, as it was decided that an English interview and an interview in another language (i.e. Afrikaans or isiXhosa), should be included, to ensure that both researcher and research mediator were prepared, and any necessary changes could be made. The piloted narratives were included in the actual study as there were no changes that were made to the interview questions, and ten participants took part in the main study. However, due to one of the participants not appearing to present with schizophrenia, which was noted during the interview and afterwards when she was referred to the doctor, who re-assessed and clarified she had been misdiagnosed, the researcher had to identify an eleventh participant. Therefore, in total, thirteen participants were interviewed in the study.

Size was determined by saturation – the point at which no new meaningful data are being found (Saunders et al., 2018). Research has shown that saturation may be reached from six to 12 interviews (Bernard et al., 2016). Guest et al. (2006) proposed that 11 interviews are generally required for saturation to take place. The researcher had to take into account that schizophrenia is a complex spectrum disorder, therefore it was difficult to determine full saturation (Schulz et al., 2016). The researcher stopped at thirteen participants, as some saturation had been reached, among other reasons.

All participants had reported a medical diagnosis of schizophrenia; therefore, it was trusted that the participants had some knowledge with regards to what their diagnosis was and what it meant.

3.5.1 Sampling Strategy

Participants were identified based on the inclusion and exclusion criteria using purposive sampling. Participants were out-patients, who were diagnosed with schizophrenia at least one year ago and were not admitted for acute episodes in at least six months. Participants were purposefully selected based on a particular interest in a characteristic (Terre Blanche et al., 2006), i.e. inclusion criteria. Each participant was interviewed individually, following a discussion and consent from their next of kin or relevant caregiver, given their vulnerability. Each participant was interviewed alone, however should the next of kin have requested to sit in the interview, they were allowed to do so, provided the participant agreed.

3.5.2 Inclusion Criteria

The inclusion criteria included:

- **Diagnosis of schizophrenia:** The participant should have been seen by a physician, assessed and formally diagnosed with schizophrenia. No record reviews were complete. Some of the participants had been invited to take part in the research by nurses at the Mental Health Unit, who were familiar with the patients, and could confirm their diagnosis of schizophrenia.

- **Residual Phase:** The participant would have been treated at the hospital as an in-patient while they were in the Prodromal or Active phase, therefore once discharged, they would be returning as an out-patient in the Residual phase.
- **Age:** Symptoms of schizophrenia usually start from 16 years of age, and peak between 21-30 years (Mueser & Jeste, 2011). Participants had to be at least 18 years of age, i.e. not a minor.
- **Language ability:** The individual must have been able to communicate verbally at a phrase/ sentence level – i.e. able to engage in a conversation on a topic of mutual interest, which was observed upon meeting the individual and having the research mediator describe the research process and ask them to recall verbally what they have understood. English, Afrikaans, or isiXhosa-speaking participants were invited.
- **Receiving out-patient treatment:** The individual would have been receiving out-patient treatment, i.e. obtaining medication from the pharmacy, and/ or coming for follow-up appoinments at the hospital. Limitations of conducting the interviews in a medical setting were acknowledged, however for interviewer and participants' safety, among other reasons, the hospital was the chosen site for data collection.

3.5.3 Exclusion Criteria

The exclusion criteria included:

- **Language ability:** Any individual who was not able to hold a conversation during the meeting time (e.g. introducing the research to the individual and their next of kin) adequately, or did not answer any of the questions appropriately as deemed by the researcher, was excluded.
- **Other home-languages:** Individuals whose home-language was anything other than English, Afrikaans, or isiXhosa, were excluded.
- **Diagnosis understanding:** Individuals who may have been identified by the nurse (for example) as having a confirmed medical diagnosis of schizophrenia, but who were personally unable to explain or confirm that they understood they had schizophrenia (when asked to describe it) were excluded.

3.5.4 Demographics of Participants

As no records were accessed prior to interviewing participants, the type of schizophrenia was not classified, and the exact age of diagnosis could not be confirmed with medical records. Some of the participants and families were unable to recall the first diagnosis date, therefore this information was not included.

There was an average of 3 people living at home with each of the participants. The exact relation of people living at home was also not analysed; in most cases it was immediate family (i.e. mother/ father), with some extended family members living with the participants (e.g. great-aunt). The table below is based on the interviews that were used for analysis to summarize the demographics. These are tabulated in no particular order.

Table 2

Demographics of Each Participant

			SEX		**LANGUAGE INTERVIEWED IN**		
Participant	**No. of people at home**	**Age (at time of interview)**	**Male**	**Female**	**English**	**Afrikaans**	**isiXhosa**
1	2	35	X		X		
2	4	65	X		X		
3	2	31		X	X		
4	3	30		X	X		
5	6	19	X			X	
6	4	29	X				X
7	3	57	X		X		
8	2	33	X		X		
9	5	21	X		X		
10	5	34	X			X	
11	4	39		X	X		
12	3	47	X		X		
13	5	41	X			X	
TOTALS/ AVERAGES	3	37	10 (77%)	3 (23%)	9 (69%)	3 (23%)	1 (8%)

The average age of the participants was 37 years. Seventy-seven percent were male, and 23% were female. As per the demographics information from the research, there were almost four times as many males as females, who were identified for the study. This may be multifactorial – the prevalence may indeed be higher in males as supported by literature

(Ochoa et al., 2012; Toulopoulou et al., 2017), who may be diagnosed earlier because of hospital admissions due to aggressive behaviours, for example, (therefore leading to earlier diagnosis).

Although initially the researcher was expecting to interview mostly isiXhosa-speaking participants, through the assistance of a research mediator, there were participants who chose to speak in English as they were able to speak fluently in all three languages. All thirteen participants were able to speak English, however four chose to have their interview done in their home language. 69% were interviewed in English, 23% in Afrikaans, and 8% in isiXhosa.

Regarding race, nine of the participants were of African (isiXhosa) background, two were coloured, one was Caucasian, and one Sesotho participant (who spoke English fluently). Therefore, there was a variety of demographics, which further highlights the diversity of cultures and backgrounds in the country.

3.6 Research Mediators

The research was conducted in collaboration with a research mediator, who was needed in interviews that were conducted in isiXhosa, and at times in Afrikaans. The research mediator also helped with translating data into English. A large portion of the population in the chosen area speak isiXhosa, and Afrikaans, which are not the researcher’s first languages, therefore the research mediator was required to translate data into English from isiXhosa or Afrikaans, should there have been a language barrier that existed between the researcher and participant.

Each participant was given the option of being interviewed in their home language. Most of the participants chose to tell their story in English, perhaps as they felt it would be better understood in the researcher’s home language. Participants were fluent in English and made use of code-switching in their narratives. This did not affect the quality of data, as much valuable information was obtained. Furthermore, the originally-trained research mediator was not available for the entire research process due to personal issues. This was a difficulty that the researcher faced but was able to overcome without affecting the nature of the data obtained. The researcher was able to conduct interviews by herself in Afrikaans, and had help to translate where necessary by another trained research mediator. An Afrikaans home-language speaker also read the translations to ensure accurate interpretation of data and ensure rigour.

3.6.1 Identification of the Mediators

The following criteria were used to identify the mediator (see Appendix 6):

- Fluent in isiXhosa, and English
- Residing in the Nelson Mandela Bay area of the Eastern Cape Province
- Over the age of 18 years
- Minimal matric completion
- Available between (April-December 2019)

The initially selected research mediator was a colleague of the researcher, completing their community service at the site. They were available at the discussed times, and were able to assist the researcher with data collection conveniently. The research mediator came from an isiXhosa background, therefore had a good understanding of the language and cultural beliefs. The research mediator was identified upon observation of how they worked with other patients at the site, and were deemed an appropriate candidate. It was considered that the chosen mediator's level of education (i.e. completed a bachelor's university degree) may create a potential power dynamic, however the mediator had been observed in her interaction with patients over the last few months at the site. The patients had appeared comfortable and had communicated freely with the mediator, and the mediator had been noted to build good rapport with patients easily.

The other mediators included an isiXhosa-speaking nurse at the site, and an Afrikaans home-language colleague. The researcher discussed the research process with the chosen mediators, and signed the contract of agreement (Appendix 6.ii), on which the terms were clearly stated. It was discussed that this was only a once-off contract between the individual and the researcher, where the mediator was remunerated for their time. Compensation for the time was discussed with the mediator beforehand, and was calculated based on the University of the Witwatersrand Student Vacation Rates as a guide.

3.6.2 Training of the Mediators

Training of the research mediator included a meeting with the researcher, who explained what was required of them. Hands-on training commenced once ethical clearance was obtained, where the research questions were discussed, and the structure of the interview was demonstrated. The research mediator was provided with guidelines, and had the opportunity to guide this process and was advised on any questions. A pilot study was completed with the researcher mediator present prior to conduction of the actual research.

3.7 Pilot Study

Following obtaining informed consent, a pilot study was conducted with two participants: one in English, and one in another language (Afrikaans). A pilot study is useful in assessing the cogency of the questionnaire (Kim, 2011), and modifying interview questions, as well as determining the feasibility of the proposed methodology of the research (Janghorban et al., 2014).

The aims of the pilot study were to assess rigour of the guiding questions, and to determine if they would be sufficient in guiding the participant to address all areas of interest of the research. The pilot study additionally validated the research methodology.

The participants for the pilot study were selected using purposive sampling, whereby a colleague assisted in the help of identifying an Afrikaans-speaking individual with schizophrenia previously seen by them, and a nurse assisted in helping identify an English-speaking participant who came regularly for their treatment.

Tools used, questions asked, the site, and research mediator, were assessed in the pilot study, after which pros and cons were noted, and the relevant changes were made to improve the data collection process. Furthermore, the researcher worked on ways to improve researcher-participant rapport, which was achieved as patients were able to trust the researcher and share their experiences.

Both participants were interviewed at the district level hospital, with the research mediator present. Participant A (PA) was English-speaking, and Participant B (PB) was Afrikaans-speaking. Interview data obtained from the pilot study was analysed using thematic analysis, as described by Braun and Clarke (2006). Although both participants were not very talkative and had to be prompted regularly, information was obtained, from which themes were identified.

The findings from the pilot study indicated potential themes that could come up in the actual study, as both participants had similar results for certain questions, and contrasting views on others. The researcher was able to work on the way in which she was to ask questions in the study, and thus make the alterations necessary. It was decided to include data from the pilot study narratives as there had been no changes made to the questions asked, as the guiding questions worked well.

It was decided that the physical set-up of the interview initially did not work and had to be changed. The chosen room was noisy, and the participant was easily distracted. Therefore, a different room was chosen, and the seating arrangements were altered. The researcher also made sure to have all the forms printed and available in the different languages and present at the time of the interview. The room was cleared of any distractions, and the door was locked during the interview to ensure nobody could walk in and disrupt the interview.

Furthermore, the researcher ensured there were extra batteries for the audio recorder available, as the batteries were low during the initial pilot study interview, which contributed to unnecessary stress to the researcher.

3.8 Methods of Data Collection

3.8.1 Materials

- Participant information form (English/ isiXhosa)
    - Appendix 2.i (participant) and 2.ii (next of kin)
- Signed consent or verbal assent (in cases where the participant was illiterate or unable to write, due to physical difficulties, or cognitive fallout); (English/ isiXhosa)
    - From the participant (Appendix 3.i); from the participant’s next of kin (Appendix 3.ii)
    - Audio Recording Consent Form (Appendix 4)
- Informed consent form for site
    - Appendix 3.iii
- Research mediator forms (including Sign-in and sign-out sheet; Guidelines)
    - Appendix 6
- Semi-Structured Interview Questions
    - Appendix 5
- Audio recorder
    - With informed consent only, the participant’s voice was recorded for analysing purposes during data collection, and will not be shared with anyone but the researcher, research mediator, and the supervisor
- External Hard Drive

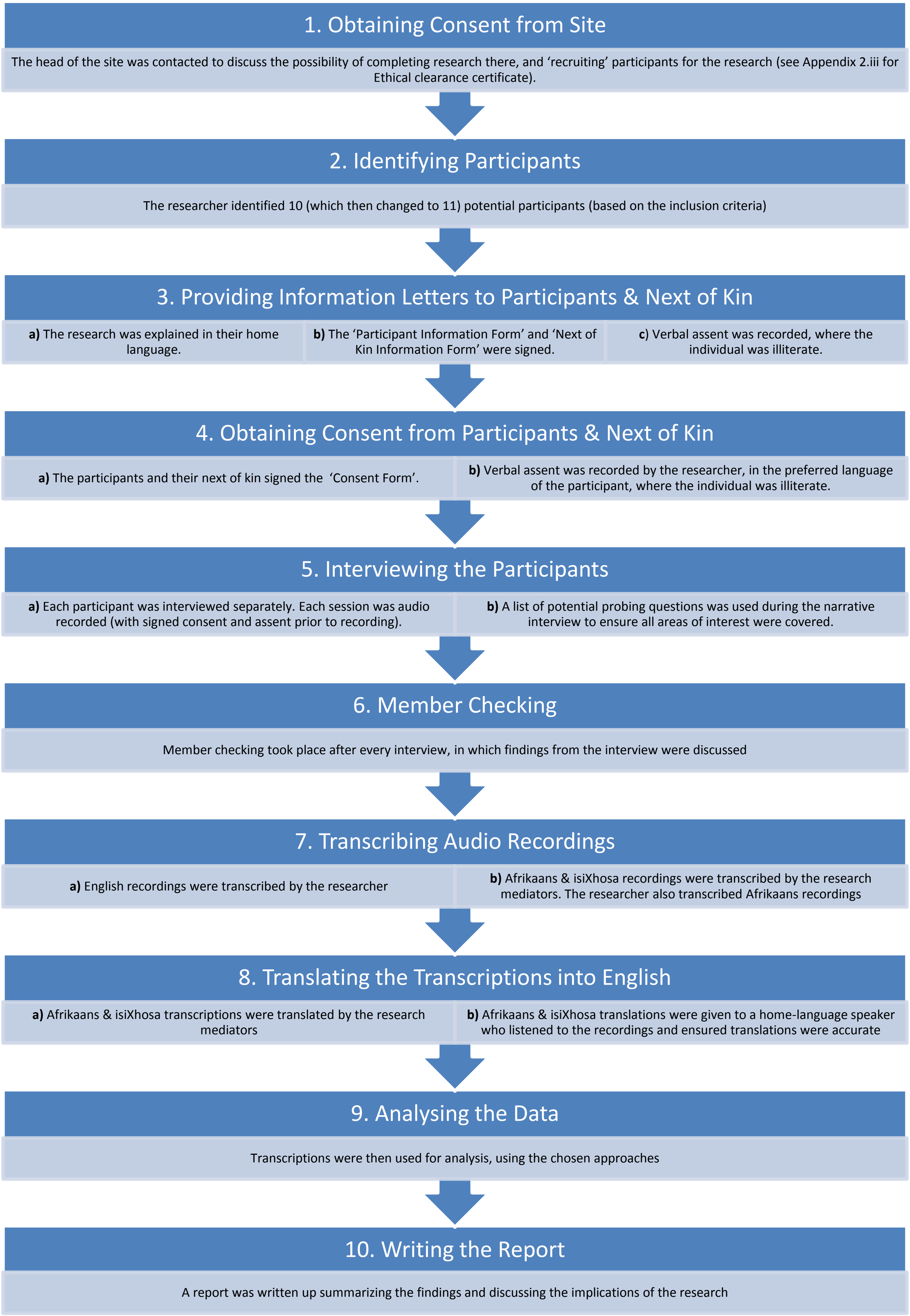
- One password protected device was used to store the data
- All audio recordings were kept on the device
- All transcriptions were stored on the device
- The device is password protected to ensure that only the researcher can access the data
- All data were additionally backed-up on a similar device for safety purposes should the given device crash, so data may be restored if necessary

3.8.2 Process of Data Collection

Data were collected between May and November 2019. The data collection process took longer than planned for initially, as there were unexpected situations, which involved participants not arriving for their scheduled appointments. New dates then had to be given to participants, which were a week or two later as there were other hospital patients who had dates already and could not be rescheduled. Following collection and translation of the data, the researcher was the primary instrument in analyzing data. Complexity, detail and context is considered, when analyzing data from qualitative research (Mason, 2002). The following steps were followed in the data collection process; they have been diagrammed for easier viewing on the following page:

Figure 5

The Steps Taken During Data Collection



1. Obtaining Consent from Site

The head of the site was contacted to discuss the possibility of completing research there, and 'recruiting' participants for the research (see Appendix 2.iii for Ethical clearance certificate).

2. Identifying Participants

The researcher identified 10 (which then changed to 11) potential participants (based on the inclusion criteria)

3. Providing Information Letters to Participants & Next of Kin

a) The research was explained in their home language.

b) The 'Participant Information Form' and 'Next of Kin Information Form' were signed.

c) Verbal assent was recorded, where the individual was illiterate.

4. Obtaining Consent from Participants & Next of Kin

a) The participants and their next of kin signed the 'Consent Form'.

b) Verbal assent was recorded by the researcher, in the preferred language of the participant, where the individual was illiterate.

5. Interviewing the Participants

a) Each participant was interviewed separately. Each session was audio recorded (with signed consent and assent prior to recording).

b) A list of potential probing questions was used during the narrative interview to ensure all areas of interest were covered.

6. Member Checking

Member checking took place after every interview, in which findings from the interview were discussed

7. Transcribing Audio Recordings

a) English recordings were transcribed by the researcher

b) Afrikaans & isiXhosa recordings were transcribed by the research mediators. The researcher also transcribed Afrikaans recordings

8. Translating the Transcriptions into English

a) Afrikaans & isiXhosa transcriptions were translated by the research mediators

b) Afrikaans & isiXhosa translations were given to a home-language speaker who listened to the recordings and ensured translations were accurate

9. Analysing the Data

Transcriptions were then used for analysis, using the chosen approaches

10. Writing the Report

A report was written up summarizing the findings and discussing the implications of the research

3.8.3 Semi-Structured Interviews

Semi-structured narrative interviews allowed for individuals with a hidden disability (i.e. mental condition), who would be seen as having no voice, an opportunity for their personal experiences to be heard (Clandinin, 2006), and participant observation which may provide behavioural cues (Spradley, 2016), which may help healthcare professionals to improve services to suit the needs of the population – not only medically but also holistically.

Although initially, interviews were open-ended, the researcher had to make use of certain prompting questions to elicit discussions on specific points. Therefore, semi-structured questionnaires were used. The questions guided the participant into speaking about specific areas of interest to the researcher. A few participants additionally went into much detail regarding their life story, and required guidance to focus on the areas of interest as they spoke more about topics that interested them (e.g. sports).

Using the same probing questions (Appendix 5) with each participant, when interviewed ensured reliability. Responses to questions were recorded for every participant: verbal responses were audio-recorded, and behavioural responses were observed by the researcher, using the 'Signs of Distress' table (Appendix 7). Any signs of distress or unusual behaviour, such as changes in voice, facial expressions, behaviour, or language, were noted in detail by the researcher on a separate document, during the interview. The interview was terminated should the researcher have noted that the participant was becoming distressed by the interview, (any behavioural signs as stated above, refusing to answer questions, avoidance, aggression) and suggested the rescheduling of the meeting date when appropriate. The Distress Protocol (Haigh & Witham, 2015) was used when necessary (Appendix 8).

All of the participants were interviewed once. The length of each narrative differed from participant to participant, depending on how much each person had to say, ranging between half an hour to more than an hour. Each interview was discussed with each participant afterwards, and the main points they provided were repeated, to ensure that stories are not hallucinogenic, and that the information conveyed and understood was accurate. The researcher asked for clarification on certain points where needed. Therefore, member checking still took place. Individuals with psychosocial disabilities are often silenced, as they are considered 'incompetent', due to the stigma of having a mental illness (Mestdagh & Hansen, 2014). Some of the participants admitted to feeling nervous or scared to tell their story, because they had never shared their experiences of living with schizophrenia with anybody.

Interviewing the participants gave them the opportunity to provide personal detailed perspectives of their experiences living with a mental health condition – to have their voices heard and share their stories of what it is like to live with an ‘invisible’ disability. By discussing the findings directly after the interview, member checking was complete, strengthening rigour. Remuneration to both participant for travel expenses, and research mediator for time, was discussed and agreed upon beforehand.

3.8.4 Reflections

Reflexivity refers to a social theory, in which the researcher actively reflects throughout the stages of the research process (Alvesson & Skoldberg, 2017). It involves becoming self-aware of certain factors, considering one’s own thoughts during the research, and examining the relationship between cause and effect (Jootun et al., 2009). Understanding how the researcher’s own values and views may influence findings adds credibility (Jootun et al., 2009). It also promotes rigour in qualitative research (Jootun et al., 2009).

During the interview, the researcher made notes on her interactions with the participant. After the interview, a self-reflective essay was written on each participant, discussing the presentation of the individual, their family or caregiver that arrived with them, and the content of their story. The researcher did not use literature for these essays, but based them purely on an objective self-reflection, expressing thoughts and ideas that may have occurred during the interview, exploring the researcher’s emotional responses to the participant’s story. These furthermore served as a method of debriefing for the researcher.

The researcher also encouraged the mediator to write reflections after each interview. The researcher’s and the mediator’s reflections were read by each other, and discussed afterwards. This helped to ensure that the mediator was also able to debrief. The possibility of referral to a psychologist was also made known to the mediator beforehand.

3.9 Data Analysis

Once transcribed, data were analysed, and a conclusion was created based on the findings (Kothari, 2004). Transcriptions of audio recordings of personal narratives from each participant were used for further analysis. All data were translated into English for analysing purposes. Audio recordings done in other languages (i.e. Xhosa/Afrikaans) were transcribed, and then translated into English, following an interpretive process (Bailey, 2008). The translated transcriptions were then given to someone to read to ensure rigour.

Data were analysed utilizing an inductive approach – which is considered a bottom-up approach, as the research moves from specific to general, i.e. from data to theory (Blackstone, 2018). Data was gathered (specific level of focus), patterns were searched for (analysis), and then a theory was developed (general level of focus). A set of observations were used, whereby a general set of propositions were created about the particular experiences (Blackstone, 2018). Induction involves beginning with empirical observations and identifying patterns within, upon which theories may be based (Babbie, 2010).

Data were analysed according to the principles of thematic analysis (Braun & Clarke, 2006). Prominent themes were identified, which appeared in the majority of narratives. All data transcribed were made anonymous for ethical reasons. The method of thematic analysis captures the patterns or themes within the data. Thematic analysis can be used to reflect reality, report experiences and meanings of the participants (Braun & Clarke, 2006).

All data were transcribed from audio data to written data for easier analysis. To identify themes and sub-themes, the researcher read through each narrative a multiple number of times, and coded sections where appropriate. A main theme was allocated to statements that were considered valuable to the researcher. Prominent themes were identified with supporting quotes from participants. The most prominently spoken-about themes were then selected for discussion and further analysis.

Themes were identified in the data following the six phases of thematic analysis:

- ***Phase 1*** – Familiarizing with data transcribed into the written form.

The initial list of ideas and meanings are generated (Braun & Clarke, 2006).

- ***Phase 2*** – Generating initial codes.

The entire text was coded, and data assembled together within each code, to organize the data into meaningful clusters (Braun & Clarke, 2006).

- ***Phase 3*** – Searching for themes.

Different codes were sorted into potential themes, using visual representations, for example, as it illustrates the relationships between different themes and subthemes (Braun & Clarke, 2006).

- ***Phase 4*** – Reviewing the themes.

The coded and organized themes were evaluated for consistency and logic, and the main themes and subthemes were captured in a thematic map (Braun & Clarke, 2006).

- ***Phase 5*** – Defining and naming themes.

The identified account of each theme and subtheme should be appropriate to the research and should be relevant to the research questions. The scope and content of each identified and named theme and subtheme was summarized in a couple of sentences (Braun & Clarke, 2006).

- ***Phase 6*** – Producing the report.

Based on the analysed data, a report is written, providing sufficient evidence for the themes, and demonstrating vivid examples. An argument in relation to the research question is made (Braun & Clarke, 2006).

3.9.1 Rigour

Qualitative research seeks to provide an understanding of issues involving the beliefs and values of the individuals. Therefore, the qualitative analysis uncovers subjective viewpoints. Rigour, is also described as trustworthiness in qualitative research. The same probing questions were asked with every participant to ensure trustworthiness of the research. To evaluate the rigour of the research, concepts of confirmability (the adequacy of information reported), credibility/ dependability (truth of the results), and transferability (the study's basis in the participant's reality) were considered. Trustworthiness of the observations is referred to as dependability, while trustworthiness of the interpretations and conclusions describes validity in qualitative research (Maxwell, 2012).

Reliability refers to replicability of research, namely "over time, different sites and populations, and with different researchers" (Schensul et al., 1999, p. 46). Replicability in qualitative research is often rare, events and people are not stable in changing contexts (Harvey, 2015). Data is more accurate and richer when it is provided in the participant's home language, as they would be able to express themselves more freely and descriptively (Nerenz et al., 2009). Four of the narratives were conducted in another language (i.e. three in Afrikaans, one in isiXhosa). Therefore, for analysing purposes, the transcribed interviews had to be translated into English. This was done by help of another individual, who was remunerated for their time and work. The individual signed a document to ensure confidentiality.

Credibility (or 'validity' in quantitative research), refers to the degree to which an instrument measures what it was designed to measure (Connaway & Powell, 2010), and indicates how applicable the results obtained are to other populations (Schensul, Schensul & Le Compte, 1999). As reality is reflected subjectively in qualitative research, it is problematic to identify and rule out specific validity. To ensure credibility, another translator read the isiXhosa, Afrikaans, and English transcriptions, to ensure that they were accurately translated, and no data was lost in the process. The pilot study additionally ensured rigour of the research methodology.

In the case where the participant made use of code switching, i.e. where a bi- or multilingual individual alternates between two or more languages during a conversation (Gardner-Chloros, 2009), the words in another language were identified, and then translated by the translator. This was then confirmed with another individual to ensure no meaning was lost in the context. Therefore, all transcribed data was translated into English for final analyses, and checked by another individual to ensure accuracy of translation, which therefore also evaluated rigour (Harvey, 2015).

Credibility means that the results of the research are believable and trustworthy from the perspectives of the participants and the researcher. Member checking, the process where participants may review their interviews for accuracy (Harper & Cole, 2012), allowed the researcher to confirm the accuracy of information provided and understood, therefore also increasing trustworthiness. Each participant's transcript was discussed with the participant to ensure that the information captured was what they intended to say.

The participants play an important role in evaluating trustworthiness of their accounts, and this technique allows for the participant's voice to be accurately heard or understood by the researcher, therefore eliminating the possibility of misinterpretation of the information provided (Carlson, 2010). During member checking, participants may obtain a therapeutic benefit (Harper & Cole, 2012), as they may feel relief that their experiences are validated. Member checking was done after every interview, where the researcher and mediator went through various points and commented on statements they may have written down. The participant was then asked to clarify a few points, if needed, or to confirm what the researcher had understood was indeed accurate.

3.10 Ethical Considerations

This study adhered to the Declaration of Helsinki's Principles for Medical Research Involving Human Participants (World Medical Association [WMA], 2001). The researcher obtained Ethical Clearance to complete the research, Clearance Certificate Number M190427 – Human Research Ethics Committee (HREC) Medical Form for Clearance of Research involving Human Subjects, through the University of the Witwatersrand (Appendix 1). The Belmont Report (1978), which summarizes ethical principles and guidelines for research involving human subjects, identifies three core principles, namely respect for persons, justice, and beneficence, (Department of Health, Education and Welfare, 1979).

According to the Health Professions Council of South Africa (HPCSA), which governs speech therapists and audiologists, among other professionals in South Africa (HPCSA, 2015), certain ethical considerations should apply in the study. The South African Speech-Language and Hearing Association (SASLHA) emphasises core principles of ethics, which include beneficence, non-maleficence, autonomy, justice, truth-telling and promise-keeping (SASLHA, 2011). Given the participants' vulnerability due to their mental health condition and associated contributors, increasing the likeliness for discrimination from the community and stigma, for example, the following measures were put in place in order to protect their autonomy: informed consent, confidentiality and anonymity, autonomy and the right to withdraw, and concern for others wellbeing.

3.10.1 Safety (of the researcher & mediator)

Individuals with mental health conditions may be unpredictable and violent, therefore extra precautions are necessary. Certain safety measures were put in place prior to each interview, to ensure safety of both the researcher and mediator. Although conducting interviews at the hospital may have affected the nature of the content, the priority was to ensure researcher and participant safety. Emotional and physical safety are important to consider (Williamson & Burns, 2014), where relevant referrals should be made where necessary should there be an incident. There are minimal guidelines available to researchers on safety parameters during research, however some research has emphasised on certain points of safety to consider, including prevention strategies for the researcher, such as maintaining state of awareness, preparing for the research, and identifying and responding to a threat (Williamson & Burns, 2014). These was implemented during data collection.

The interview was terminated if a participant stated they wanted to go sleep, or if they didn't have any more to say. None of the participants displayed aggression, and cooperated well with the researcher. Two of the participants agreed to a psychology referral, and were referred to the psychologist at the hospital as arranged prior to data collection. None of the participants were harmed (emotionally) during the data collection process; this was managed carefully through participant observation and during the interview process.

3.10.2 Informed Consent

A vulnerable population includes individuals who are at risk for harm or being taken advantage of during the research process, according to the Medical Research Council of South Africa (2013). Such individuals include those with mental health conditions, who cannot “truly consent freely to participation” in a research project (Le Compte & Schensul, 2015, p. 58), because of reasons such as feeling forced to participate, or may incur unnecessary risks because of their health, legal, or social status (Le Compte & Schensul, 2015).

The level of education and literacy of the participant was considered (Penn & de Andrade, 2017), to ensure that information was conveyed to the participant in the best possible manner (i.e. it was discussed verbally if the individual was illiterate), and the risks and benefits were understood clearly. The participant did not feel obliged or threatened to take part in the study; they were requested to notify the researcher or mediator immediately should they have felt the need to terminate the interview. All concerns were addressed prior to and during data collection, and member checking took place after the interview to ensure that the data provided was confirmed accurate by the participant.

The benefits and possible risks of the study were discussed clearly to the participant, as well as the next of kin – to avoid misunderstanding, ensure accuracy of information relayed, and assist with decision-making. The next of kin plays an important role as informal caregivers contributing to improvement of the patient’s health (Forde et al., 2016); the purpose of relaying information to the caregiver was not to take away autonomy from the participant, but rather to protect them. Informed consent was voluntary, and the individual making this decision had an established decision-making capacity (i.e. the ability to understand the information provided, as well as any possible consequences of their decision), (Dunn & Jeste, 2001).

A standard informed-consent approach was inadequate due to the vulnerability of the participants; therefore, adjustments were made accordingly to suit the participant’s abilities. When a participant did not wish to provide an immediate answer, they were given one day to think about whether they would like to participate in the research study, and were required to contact the researcher via the cellphone number provided. The researcher contacted the participant, should they have had financial difficulty (e.g. no airtime), in which case they were told to send a “Please Call Me” to the number, free of charge. The participant was not forced to participate and was able to refuse participation if they wished to. All participants and their family members were given transport money by the researcher, if they had to come in on a day that was not for collecting medication from the hospital, i.e. if they had to come specifically for the interview.

The participants' vulnerability was considered, and was overcome through the following ways:

- There was a *Participant Information Sheet* (refer to Appendix 2) regarding information about the research, in English and/ or isiXhosa. This was required to be read by an individual from the site (Appendix 3.iii), next of kin (Appendix 3.ii), and by the participant themselves (Appendix 3.i).
    - In the case where the individual was illiterate, the researcher discussed the information sheet verbally. Any responses, including verbal assent, were then recorded as necessary.
- The next of kin was only involved in providing consent, and was not interviewed further, so as not to take away autonomy from the participant.
- The *Participant Informed Consent Form* described the research and the requirements for the participant, as well as a description of any risks (if any) that the participant may face, and benefits (if any). The participants were asked to confirm that they understood what was required of them and were required to confirm that they agreed to take part in the research by signing the form.
    - In the case where the individual was illiterate, the researcher discussed the information sheet verbally. Any responses, including verbal assent, were then recorded as necessary. To ensure that the participant and/or their next of kin understand the information relayed, they were asked to reiterate the main points discussed back to the researcher. This way any information lost was repeated to ensure understanding.

3.10.3 Confidentiality & Anonymity

Vulnerable populations may face negative consequences if their identities are revealed (Baez, 2002). Therefore, confidentiality and anonymity were addressed during data collection, data cleaning, and dissemination (Kaiser, 2009). All names of participants and places were removed, to ensure the participants remain anonymous, and no identifying information about the individual or the site was revealed. Pseudonyms (i.e. a false name) were used during data analysis and dissemination, to protect the participant (Corden & Sainsbury, 2006), to ensure anonymity.

Personal and confidential information acquired in the interviews was not shared; any identifiable information was removed if points needed to be discussed outside of the interview (Wiles, Crow, Heath, & Charles, 2008). Verbal assent was recorded from the research mediator, who declared to keep all information confidential. Only the researcher has direct access to the audio clips, stored on the researcher's password-protected computer. Audio clips were backed up and stored on a password-protected hard drive, and other raw data (transcriptions) are kept safe on the researcher's computer in a separate file, accessible only to the researcher. The computer and hard-drive are kept in the researcher's home, in a locked room, to which only the researcher has access to. The narratives (if in isiXhosa or Afrikaans) were accessible to the research mediator, for translation purposes.

3.10.4 Autonomy & the Right to Withdraw

The participant may have diminished autonomy, i.e. voluntariness, and mental capacity (Roberts, 2002), which needs to be considered, and their next of kin was involved in the decision-making process (Oruche, 2009). The participant had the right to make their own informed choice, and should in no way be pressurized by the researcher or other person to take part in the study (Shenton, 2004). The researcher was aware of signs of distress from the participant, including any changes in behaviour, using the 'Signs of Distress Form' for guidance (Appendix 7), (Nolan, 2008).

The participant had the right to withdraw from the interview at any point, without negative consequences (Shenton, 2004). Participation in the study was completely voluntary, and there was no penalty should the participant change their mind. It was discussed with the participant beforehand, that they must not feel obliged to take part, and should at no point feel threatened. The participant was encouraged to be honest regarding their thoughts and feelings, so that any issues may be addressed beforehand.

In the case where the participant wished to terminate the interview, (noticing signs of distress, see Appendix 7), the researcher respected the participant's wish, and did not probe further. The participant was given the option of meeting on a different day to continue the interview. The participant was also referred for counselling (free of charge) at the site, as arranged with the psychologist, who made an appointment for the participant following a written referral letter from the researcher. Although none of the participants were in distress, they indicated a desire to speak to someone as they felt depressed.

3.10.5 Concern for Others Wellbeing

All participants were respected and treated fairly. The principles of non-maleficence and beneficence were adhered to (SASLHA, 2011). The principle of non-maleficence states that participants will not be purposefully harmed by the researcher, or acted against (Macklin, 2003). Furthermore, the researcher should prevent harm and remove existing sources of harm (Childress & Beauchamp, 2001). The researcher was aware when it was inappropriate to probe further, as the risk to an individual's emotional wellbeing may be considered more important than obtaining rich data (Townsend et al., 2010).

Regarding beneficence, the researcher acted in the best interests of the participants (Morrison, 2009), even when there was conflict with the researcher's personal self-interest (Macklin, 2003). The researcher had the responsibility of referring the participant to appropriate services should the need have arisen (Jelsma & Clow, 2005). All the participants were debriefed individually once the entire research process was complete and report submitted. Feedback was given, and any questions were taken care of. Further referral to a psychologist was discussed where needed.

CHAPTER 4: RESULTS & DISCUSSION

"My story is worth hearing," (P8)

4.1 Introduction

In line with the interpretive approach, this research focused on the subjective experiences of individuals with schizophrenia (Willig, 2001), therefore, reporting involves not only making convincing statements about the results, but at the same time, the collected and analysed data should be interpreted, the truth discovered, and the results placed in the context of the particular position or standpoint (Willig, 2001). Therefore, in my study the Results and Discussion sections are presented together.

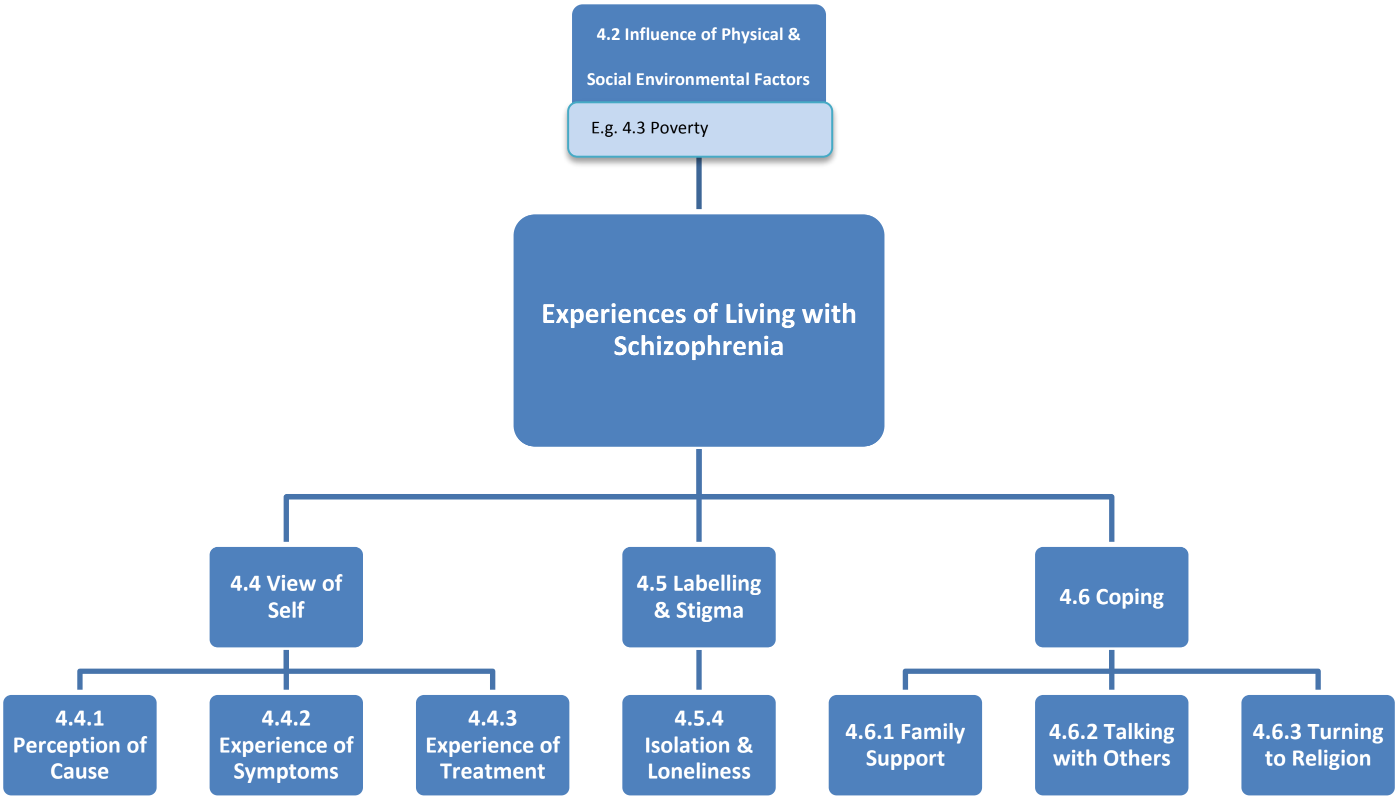
In this chapter the interview results of thirteen participants living with schizophrenia, are explored. I used face-to-face interviews, where questions were open ended and allowed the participant to express their own opinions. I listened without judgement and tried to make our encounter stress-free. Findings were presented in relation to the objectives. I used thematic analysis to identify the main themes, which I grouped into the leading themes.

The main themes allowed insight into the experiences of people living with schizophrenia as they view themselves, how they managed the condition and the effect of labelling and stigma on their lives. The main themes identified include: the perception of the participants on the cause of their condition and how they experience the symptoms of schizophrenia, the experiences of managing the condition on a day-to-day basis (including the treatment), and how their experiences are affected by the environment.

The main themes reflected in this chapter as reflected in Figure 5:

Figure 5

Overview of the Main Themes



4.2 The Effects of the Environmental and Personal Factors on the Participant's Experience of Life with Schizophrenia

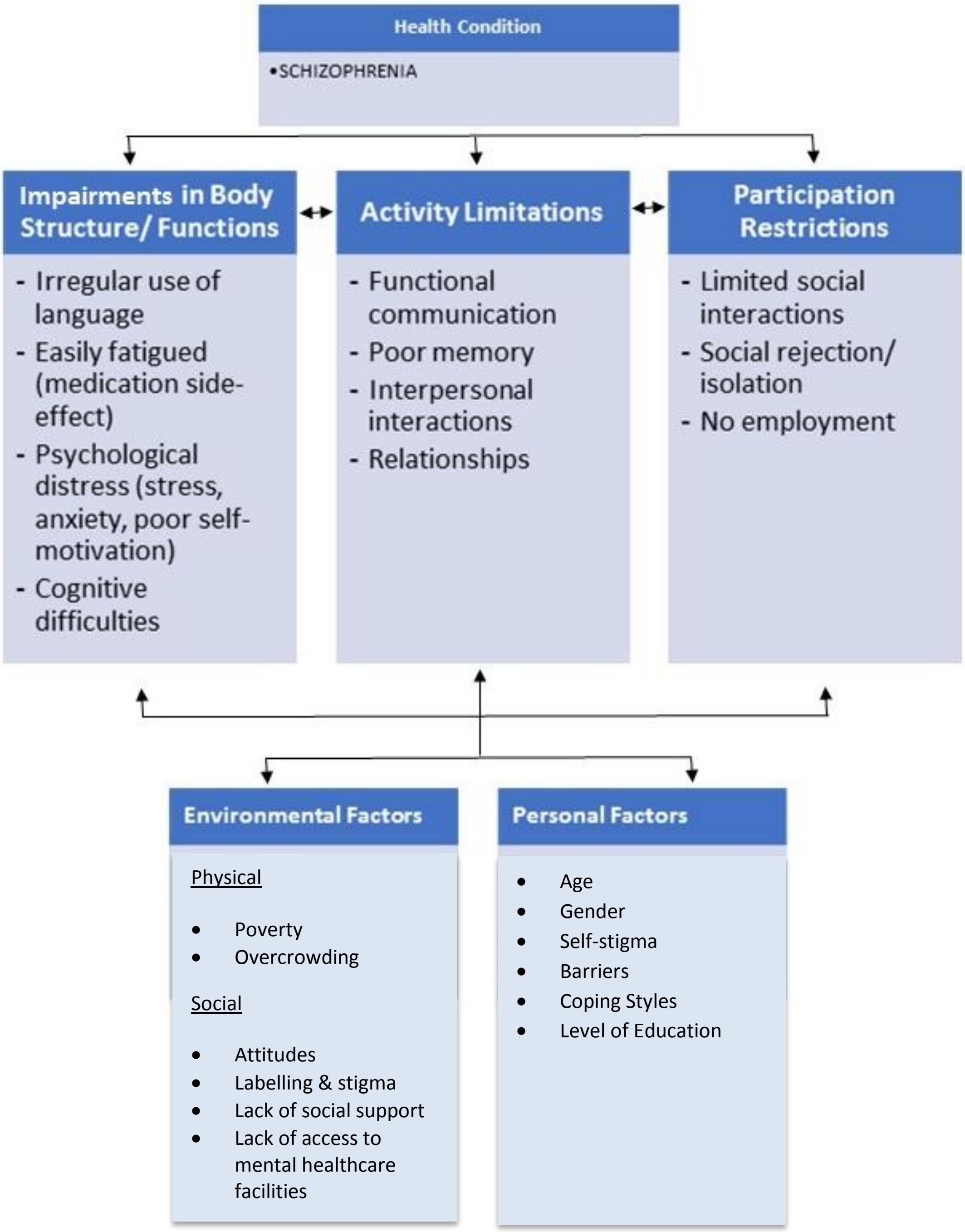
By applying the ICF framework to my research it was possible to recognise not only the health condition itself, but the influence of other factors on the participation in life activities. The impact of environmental factors cannot be ignored in research of mental illnesses (Vilain et al., 2013). It appears that all the participants have been affected by their environment, as was also found by Vilain et al. (2013).

The environmental factors influencing participants experiences of life included: physical - poverty and its effects, for example living in a settlement with overcrowding, lack of access to running water and sanitation, and social - attitudes, labelling and stigma, the presence or absence of social support, as well as the lack of accessibility to mental care facilities. Personal factors, such as age, gender, race, level of education, self-stigma, coping styles, also had an influence on the participation in life activities and the experiences of life.

I used the ICF to demonstrate how Environmental and Personal factors restricted their participation in social life:

Figure 6

The ICF and Schizophrenia



As depicted in Figure 6, schizophrenia can be explained within the ICF. Impairments in body structure or functions includes symptoms of the condition, for example irregular use of language (Meilijson et al., 2004); activity limitations may include weak relationships with others, and participation restrictions may be decreased social interactions with others. These areas are affected by environmental factors – for example poverty (Gough & McGregor, 2007), and personal factors – such as coping styles (Gloria & Steinhardt, 2016).

Environmental and personal factors can enhance or impair human activity. For people living with schizophrenia, environmental factors may have a great impact because of the severity of their mental condition (Switaj et al., 2012). The severe deprivations are caused by poverty (Gough & McGregor, 2007), dangerous environment of overcrowding, exposure to violence, trauma and crime (Hjelm et al., 2017). Lack of access to care due to serious system limitations (Sherry, 2014) make it difficult for individuals to receive the help needed, which affects their well-being (Kawachi & Berkman, 2001), and contributes to a large number of individuals affected (DOH, 2013).

Environmental factors, such as stigma, and social support, may have an impact on activity and participation, and overall quality of life (Cohen & Minor, 2008). The narratives from my research confirmed that stigma as a result of labelling, and social rejection, isolated and silenced people living with schizophrenia, and that affected the quality of their lives negatively. For example, P1 told me that "life is very hard… I don't want to do anything else with anyone…I'll never do that again, be amongst people". He added that "I do everything for myself…it's very dangerous outside". P11 complained that "Most don't know [that he has schizophrenia]. People gossip. I keep it a secret… The community doesn't know what it is. No one talks about it.", P12 confirmed: "I rather stay in my room".

As there is little research has been done on the overall experience (Figueira & Brissos, 2011) and burden of living with schizophrenia, Cabello et al. (2012) and Keshavan et al. (2010) emphasized the importance of creation and development of profiles of the psychosocial difficulties, and identify how they influence on the actual impaired functioning of individuals with schizophrenia; these psychosocial difficulties should be found in different contexts. As revealed through the semi-structured interviews, the lives of the participants were affected by support, or its absence, from their family members. It could be an interesting topic for further research to identify how the participant's life experiences living with a mental health condition, including experiencing of the symptoms, in informal settlements, depend upon the support from their family and the community.

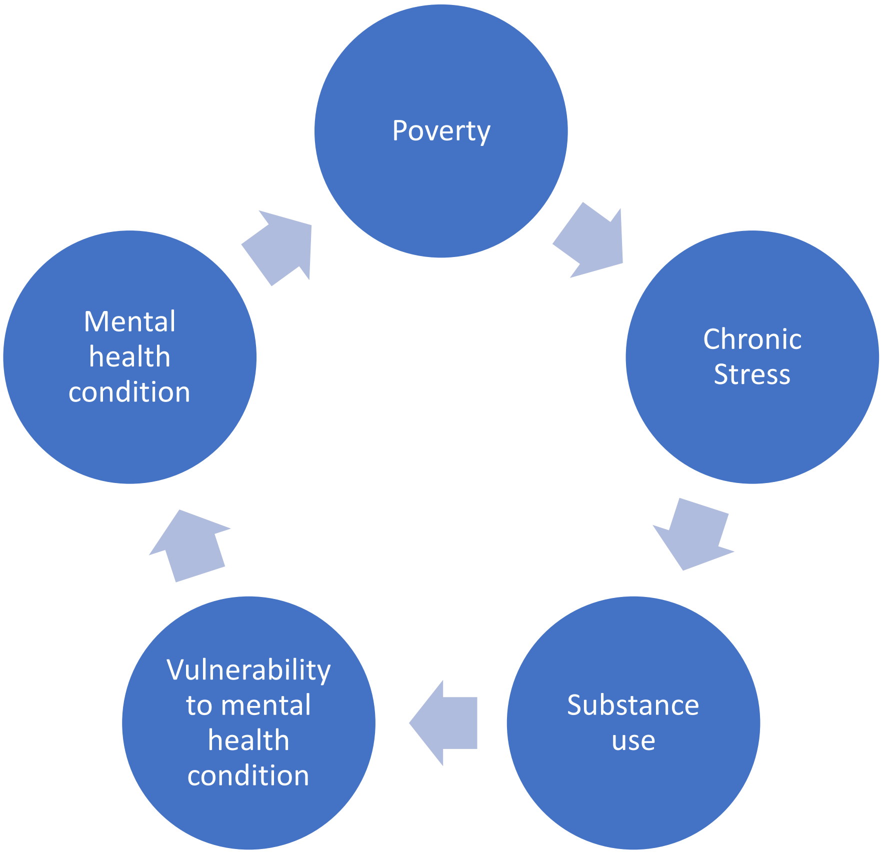
4.3 Context of Poverty

People who live in poverty, who experience social and economic disadvantages, are less able to exercise internal locus of control over their life circumstances, leading to negative emotions and stress (Hjelm et al., 2017). When environmental demands exceed an individual's ability to cope with a situation, it can be associated with a range of physical and mental health states, such as stress and depressive symptoms (Hjelm et al., 2017). People often use or abuse substances to ease an anxiety and the experience of stress, to cope with difficult emotions (Saxon et al., 2017). Five out of thirteen participant used or overused the substances such as alcohol, Mandrax, Tik, cannabis, ethanol and benzinum prior to symptoms of schizophrenia appearing.

Created by poverty, social and environmental situations indorse substance abuse and psychological distress, making a person more vulnerable to mental health conditions (Hjelm et al., 2017). The abuse of these substances increases problems in mental health, and mental health conditions can cause disability and unemployment, which in turn can lead to poverty Kuruvilla & Jacob, 2007). Therefore, the vicious cycle repeats. I depicted these dynamics into a diagram:

Figure 7

The Cycle of Poverty and Mental Health Conditions



Participants described living in an environment of poverty and deprivation. As P1 explained:

> I must save every cent I have. I cannot give a cent away from myself… I always count my money out and things. It's all stuff that I do today. I sit in the house, with the little money that I have. Ah, my life must go on… A cent is too much, I don't give it away.

Research has recognized a relationship between poverty and development of a mental health disorder (DOH, 2013). P9 described, "Where I'm coming from was bad bad bad… cos I was-, I remember I was seven years old, that time, I was in the street, I was a street kid. My mother wasn't looking after me that time.". As a result of increased stress when living in deprived conditions, the risk of developing a mental health disorder also increases (Kuruvilla & Jacob, 2007). Murali and Oyebode (2004) describe poverty as both a 'determinant' and 'consequence' of poor mental health.

4.4 Participant's Perceptions and View of Self

I was interested in the life stories of individuals, how they viewed themselves and experienced life; their perceptions about the cause of their condition, how they experience the symptoms associated with schizophrenia, as well as how they attempted to treat the condition.

4.4.1 Participants Perceptions of the Cause

When asked about their perceptions of the cause of their condition they expressed different beliefs. Most of the participants blamed the environment, including people in the community, and external factors, including supernatural forces. The overall findings have been summarized in a table:

Table 3

Participants Perceptions of the Cause of Schizophrenia

	Perceptions of Causes						
PARTIC-IPANT	**Jealousy**	**Family History**	**Substance Abuse**	**Preceding Illness**	**Environ-ment**	**Calling**	**Not sure**
1					X		
2	X		X				
3							X
4	X	X		X	X		
5	X		X				
6			X				
7	X			X			
8						X	
9		X	X	X			
10		X	X				
11		X					
12		X					
13	X						
Total	**5**	**5**	**5**	**3**	**2**	**1**	**1**

It appears that the most prominently named causes were: jealousy (where they believed to have been bewitched or poisoned by someone), a positive family history of mental disorder and substances use / abuse earlier in life. One participant believed that jealousy was the only cause, two believed family history was the only cause, and one participant believed that it was because of his substance abuse that he got schizophrenia. There were, however two participants that believed it was because of both substance abuse and jealousy, two believed it was because of substance abuse and family history, and one participant believed it was because of jealousy and family history. This therefore showed some relationship between the three perceived causes.

Each of the believed causes, as perceived by participants, have been discussed in detail below, with supporting quotes.

- **Jealousy**

Based on the narratives obtained from face-to-face interviews, I noted that five out of thirteen participants explained their illness was caused by bewitchment or being poisoned by someone, with jealousy being the primary motive. Two of the participants described the cause of their mental illness was due to "isimnyama", an isiXhosa term which refers to being "bewitched", by black magic (Watanabe, 2018). Jealousy can be described as the expression of insecurity and lack of trust (Beaumont, 2018).

Three participants described being poisoned by someone, two participants believed they had been bewitched, and one believed in both: P2 told me that he got schizophrenia from "It's muthi. Of people. They bewitched me.". When asked to elaborate, he explained the person who poisoned him "…had jealousy. I don't know if he likes/loves me, or he loves this wife and caused arguments.". He also said an isiXhosa saying, "ukubamba umntu ngentliziyo" (directly translated means to 'hold a person by the heart', which means to hold a grudge against somebody.), because of "jealousy. You take it… but you will always hate that person.".

P2 also added that "The thing that brings me here. Here at this place. The hospital… It's that money of mine. My money hey. Brought me here to this place.". He explained that he felt others were jealous of him because he had more money than them.

P4 told me about different beliefs as to how she got schizophrenia, and sought multiple treatment methods. She believed that the primary cause was bewitchment, where she had been poisoned by someone at school. She explained how someone had placed "grated poison on [her] paper", and had blown it into her face, therefore bewitching her. She explained this by acting it out and was adamant that she had gotten it from somebody who was jealous of her. When asked to explain why someone would bewitch her, she said:

> …the others don't want me to see, to be a-a- social worker or a teacher or a nurse, they said it is iblackout because of they don't want me to see… to see me in expensive um expensive side, you see… jealous things of that you are going to be a nurse, you are going to be a teacher, they don't want to see you in that place. (P4).

P5 provided another example: he was still at school when he was diagnosed with the condition, explains how he was smoking in the bush, "in a graveyard". He blames the people who gave him the substance to smoke as deliberately poisoning him, “maybe they jealous …they do not want me to go to school”, as the other children could not afford to. His onset of schizophrenia did cost him his schooling journey, as he was not able to go back to school to finish his grades.

P7, who believes he was poisoned, explained “he [a ‘friend’] put something in my beer.”. He claimed this was because he was considered popular amongst classmates in the past, “I loved school. I was beautiful.” … and as an afterthought he added, “you can see these people are jealous”.

And lastly, P13 stated “They be- bewitched me... The neighbour”. I asked the participant why he thought this had happened, and he explained “they’re jealous man. They did- gave me something to eat”.

In the narratives, the use of the exact word ‘jealous’ was prominent. Different participants used it to describe how they understood they got their disorder. The participants fully believe that they were bewitched because others wanted what they had, and therefore poisoned them or caused them harm by giving them their mental health condition so as to prevent them from living their life as they had done. They placed the blame on external factors, fuelled by jealousy, to be the cause of their schizophrenia. Jealousy was therefore a major theme identified in the research.

Many studies (both in South Africa and globally), identified that individuals across the country believe that their mental illness is caused by bewitchment by someone who was jealous of them (Ashford, 2005; Bellgrave & Allison, 2018; Steinberg, 2008; Swartz, 2009). I believe that healthcare professionals, to avoid bias and prejudice, should be aware of the traditional and cultural beliefs in the communities, show sensitivity towards them, and have attitudes of tolerance and respect.

- **Family History**

Five out of thirteen participants interviewed stated in their narratives that their mother, father, or nephew, had the same diagnosis as them. They had been exposed to the condition before their own diagnosis was made, and therefore had some idea of the symptoms and how it affects a person.

Three of the participants’ fathers had reportedly had schizophrenia:

P4 expressed how “even my father was like me. My father was got i… that illness. We are eating the same treatment…”; P10 stated “my dad also got schizophrenia so he’s also schizophrenia patient.”; P12 explained “my father started hearing voices and then he left me”. During member checking, this was confirmed. All three participants said they had experienced what it was like living with someone with schizophrenia.

Two of the participants’ mothers were diagnosed with schizophrenia:

P9 stated that “…not somebody gave it to me, I was feeling I am sick, cos my mother also was sick. Also, my mother, she was hearing voices.”. Similarly, P11 reported she had a family history of schizophrenia too, as she describes her experiences growing up (from 13 years), with her mother who had schizophrenia:

> My mother also heard voices. My mother. She was also a psychiatric patient. As I got older I found out she was a psychiatric patient, and she also had schizophrenia, because I had to monitor her the whole time, sometimes someone was calling for her, but there was nobody there…

Previous research implies the existence of a hereditary component for schizophrenia (Abi-Dargham & Guillin, 2007). Gejman et al., (2010) explains that schizophrenia belongs to a group of pathologies which are complex genetic disorders, implying that there is a strong hereditary component for schizophrenia. To support this, recent genetic studies from Nordic countries have revealed that a positive family history of schizophrenia is indeed a risk factor for having the condition, which can be used for early prediction and diagnostic improvements (Lu et al., 2018). A relatively strong family history was revealed through the narratives in my research. Some participants perceived their cause of schizophrenia to be as a result that their family member also had it.

As schizophrenia is such a complex condition, more research is required to explore the causes, and the extent to which there is a genetic component, and how this can be assessed in resource-constraint settings, such as South Africa. Although none of the participants had undergone genetic testing to identify a positive family history, the indication of a family history was revealed through the narratives in my research, when some participants perceived their cause of schizophrenia to be as a result that their family member also had it.

- **Substance Abuse**

The use (and abuse) of drugs, can result in substance-induced psychosis, and substance-induced schizophrenia (Nielsen et al., 2017). The participants named drugs that they used, such as Mandrax and Tik, smoked cannabis and benzinum, and spoke of ethanol overuse. Five out of thirteen participants described how they used or abused substances prior to their symptoms appearing.

Research has indicated that certain types of genes can increase the likelihood of having schizophrenia (Sullivan, 2005), and with the added use of substances, such as marijuana, can cause an earlier onset of schizophrenia (Veen et al., 2004). Delta-9-tetrahydrocannabinol (also known as THC), is found in marijuana, and causes psychotic symptoms, that mirror the psychosis noted in schizophrenia (Nielsen et al., 2017).

The following five participants described their understanding that schizophrenia may be caused by substance abuse, although only one participant (P6) thought that substance abuse was the only cause.

P5 explicitly stated that “I used drugs”, and when asked to elaborate which drugs he used, he said he had smoked benzimum. He described his experiences:

> I was at the XXX Street, in the town, with eh- with street kids. Yes, they are smoking the benzimum- you that benzimum is that one you (*gestures mixing*), yeah they are smoking benzimum, no they see things in front… I did smoke it in the- in the bush that time, you see…

P5 also described how “the time I got the fever I-I began seeing things that I didn’t see the time I didn’t have, and hearing voices in my ears, the time I-I used drugs”. He confirmed that prior to his using of drugs (Mandrax) he had never had any auditory hallucinations, therefore blaming the effects of the drugs for the cause of the schizophrenia.

The use of Mandrax also appeared to precede the symptoms of schizophrenia in P9, who understands that him taking drugs – such as “Mandrax and Tik”, and presenting with schizophrenia some years later “it’s not unrelated”. P9 described that “living with schizophrenia is, as you smoke eh some drugs, alcohol, you use alcohol, you be useless.”

Two participants reported using cannabis and linking the onset of schizophrenia to their use of weed: P6 stated he thinks he got schizophrenia because, “I was drinking over, and smoking [ghanja/ weed] over, I think it’s because of that.”.

P10 explained, “I was on cannabis, and normally after, the schizophrenia, I was hearing loud voices that I mustn’t hear. So that time is very dangerous, when it’s-it’s in a high level it’s very dangerous…”. He supported his statement by adding that “the cannabis does affect your brain with schizophrenia”.

P2 blamed others with whom he grew up for influencing him, explaining “I was drinking by then, from when I was growing up.”. He elaborated that:

X taught us the bad habit of making us drink Bell. I also ended up enjoying to sell it, although I drank beer. Black Label. And my full bottles of spirits. With my state grant. I started mine when I was little. By 13, 14.

Therefore, five out thirteen participants recognised substance use and overuse as the reason of their present mental state. As discussed in literature, the Two-Hit Hypothesis (Bayer et al., 1999), suggests that there are environmental risk factors that can influence the onset of schizophrenia, which include substance abuse (Vilain et al., 2013). Provided that the initial ‘hit’ occurred, for example a genetic defect (Bayer et al., 1999) – which would require formal genetic testing to identify, the individual would be more vulnerable to a second ‘hit’, which could be caused by substance abuse, which could be identified through case history, or narratives, for example. As discussed, the participants spoke about abusing substances such as alcohol, cannabis, and drugs, and believed this to be one of the causes of schizophrenia.

- **Other**

Although the majority of participants explained their perceived causes to be jealousy, family history, and substance abuse, there were participants that described other causes.

One participant (P3), when asked about her opinion on the cause of her illness, replied that:

> maybe I think too much… I think it was the stress of money … Eh I the psych doc ask me question and I- I- I- answer some question but I knew all the things happen. There’s no voices I hear, there’s no people are here.

During our conversation P3 described her main concern and the reason she had been admitted into the hospital in the past as “sometimes I wake and then I didn’t sleep and then, from that night I could sleep, didn’t sleep till morning”. She believed that her overthinking and stress caused her to feel anxious, but she did not report any auditory or visual hallucinations.

Two out of thirteen participants blame the environment and people around for the cause of their condition. For example, P4 explains “They said I’ve- I’ve got it… I’ve got it outside… Similarly, P1 described: “the people in the community … It’s a bunch of people. It’s not where you want to be and it’s things that affect you… It’s what made me like this.”. Both participants believe that they have been affected by their environment and people around them.

Three out of thirteen participants described some form of preceding illness. Two participants described how they had been physically ill before they started displaying symptoms of schizophrenia. Participants spoke of other symptoms they had experienced prior to the onset of schizophrenia:

For example, P7 described “it was the fever”. P9 describes how “I was having the low blood, and then I was slow, and I have a headache…I was sick”. The description of being “slow” may imply functional decline, which may occur in individuals with schizophrenia (Ritsner, 2011).

P4 spoke about how they had “xhuzula” (‘fits’ in isiXhosa), and “iblackouts”. P4 explained that one of their medical diagnoses was epilepsy, and understood that it was one of the reasons they had gotten schizophrenia. Research has shown that there is in fact a link, i.e. an increased prevalence, between epilepsy and mental health conditions such as schizophrenia (Wang et al., 2017); an example is schizophrenia-like psychosis in epilepsy.

Schizophrenia-like psychosis in epilepsy (SLPE) is one of the most severe comorbidities in epilepsy and may present similarly to schizophrenia. Differential diagnosis between SLPE and schizophrenia is difficult due to a lack of standardized methods (Wang et al., 2017) Also because of the difficulty accessing resources and their scarce, in settings such as the district level hospital, differential diagnosis may not always occur.

Therefore, although it appears P4 had SLPE, it was never formally diagnosed by a physician. It should, however, be taken into account.

In contrast to all the participants, P8, who viewed his condition positively, expressed his belief that the schizophrenia is “a calling from God”. He described how he and the people in his community call it “ancestors”. Therefore, he believed –

> My experiences is that …the ancestors are with me.”, when asked to elaborate he explained, “my life experiences living with schizophrenia is so amazing cos I’m having things that I’ve never had before. I’m with people I’ve never been before. There’s too much spirit in me, that I never experienced before. … they are living with me every day. That’s what I can explain.

He further explained that he was “the chosen one”, with whom the ancestors communicate, “I un- I understand that ancestors communicate… with me first, then to release me to communicate with God. And then, maybe I must listen to one voice only, the voice of God,”.

Traditional healers base their explanations of disorders on the understanding of ‘culture-bound syndromes’, i.e. the cultural interpretation of a medical diagnosis. This needs to be taken into consideration, as environmental factors play a role in mental health. A culture-bound syndrome, as defined in medicine and medical anthropology, refers to a combination of psychiatric and somatic symptoms considered to be a distinguishable health condition within a specific culture (Balhara, 2011), i.e. they are often restricted to specific cultural groups (Paniagua & Yamada, 2013).

As the result of culture-bound syndromes, beliefs and behaviours of the patient are not congruent with those of biomedicine (Simons & Hughes, 2012). This is noted in a greater cultural sensitivity throughout the latest revision of the DSM-5 (APA, 2015), in which criteria reflects cross-cultural variations and provides information on cultural concepts of distress (APA, 2015).

Some individuals with mental health conditions, as P8, may follow a cultural belief on the causation of their condition, which is important to consider in the South African context.

4.4.2 Participants’ Experience of Symptoms

As described in literature, the symptoms of schizophrenia are distinct to mental health conditions, and not usually present in the normal population, for example: hallucination, delusions, disorganised speech; absence of the normal pattern or emotions (Walsh et al., 2016); deterioration of cognitive ability including attention, working memory, speed of processing information, poverty of speech, loss of interest (Harvey, 2013); extreme or inappropriate moods, feeling depressed (Bellack, 2013).

When exploring the responses from the semi-structured interviews, I discovered that most of the participants had experienced hallucinations and had produced disorganised speech. For example, P10 described:

…schizophrenia is a danger point for your brain also…I was hearing loud voices that I mustn’t hear…you will hear voices, you’ll kill yourself, and, it’s something like that…so, schizophrenia is a very dangerous- my experience it was a very dangerous uh-uh-uh illness. P8 added:

> voice always say that …I’m walking, I see that they will look, cos each and every time, they look up to me, … maybe I must listen to one voice only, the voice of God… I even switch bodies with God.

P12 commented on his auditory hallucinations in the past, and how they affected him: "… so I hear voices, uh I get angry, um, and anxious, so I'm a bit scary…I'm scared the voices coming back, um, so I rather stay at home".

Experiences of depressed mood, deterioration of cognitive ability and working memory, loss of interest and drive could be also identified. For example, P1 said: "I became confused, I don't know what was going on around me…". Similarly, P6 disclosed some short-term memory loss, as he said that: "I was forgetting memories of my-my… most things that happened, earlier".

P3 described her experiences of being unable to sleep:

> I was trying- trying to go to my mother's… room, so that I can sleep. And then in my mother's room, there was no sleeping, and then I go back to my room, again….my eyes like I want to sleep and then, I wake…I didn't sleep but I sleep a little while, sleep… sometimes I wake and then I didn't sleep and then, from that night I could sleep, didn't sleep till morning.

P5, who provided descriptive accounts of how he experienced life with schizophrenia throughout the interview, sadly told me:

> Now I can feel myself like I'm a zombie…yes that way, you know what is a zombie? Yes, I feel that way…maybe if you look me in eyes you look like you can see a ghost, you see, you know a ghost like in a movie? I can say that the walk of ghost is my walk…

The participants described their experiences with various symptoms and how they made them feel, and they dealt with them. The coping strategies that were mentioned by some of the participants are explored more in-depth in the *Coping* section.

4.4.3 Participants Experience of Treatment

All the participants claimed to be taking the antipsychotic medication, as prescribed to them by the doctor. Some participants even described how they perceived the pills were helping them:

P1 commented that "the pills make me feel good… I sleep well…it's the right treatment… I take the right treatment." P6 thinks that "they're [the pills] helping me", P8 described pills as …" I just knew that they were just healing me", P12 "I speak to the ladies at the clinic every month when I get my pills, I drink my pills every day". P9 noted, regarding medication: "Medication is better than if you drink alcohol".

P12 expressed a desire to have more access to information, for himself as well as others, "people must, uh, tell you more about schizophrenia and they must be more educated and-and tell you more about what the pills do and how good it is"

The abovementioned participants brought about the relevance of counselling and providing patients with accurate information regarding their medication.

Although all participants said they were reportedly taking their medication received from the hospital to treat the schizophrenia, there were two out of thirteen participants who indicated that apart from the medication prescribed by the doctor they were also making use of traditional ways. For example, P5 explained how he chases the evil spirits away by burning, "ukuqhumisa", a plant to protect himself, as "he [the evil spirit] cannot get in with that smoke".

This emphasizes the need for awareness and promotion, as well as education regarding treatment methods, in the South African context, where the majority of the country makes use, or has made use, of traditional medicine to treat a health condition. Although there is a greater cultural sensitivity in the latest revision of the DSM-5 (APA, 2015), healthcare practitioners should be made aware of this during the case history process of examining the patient.

4.5 Participant's experience of labelling and stigma

4.5.1 Access to Information: The Word 'Schizophrenia'

The word 'schizophrenia' is linguistically long and complicated to articulate. In the isiXhosa language, the 'r' is pronounced as a glottal fricative – an 'h' (Strom, 2018), therefore making it even more difficult to pronounce. This difficulty was noted during the interviews, as all participants who mispronounced the word omitted the 'r'. Some of the participants, although they claimed there was no other name for the condition that they used, struggled to articulate the word 'schizophrenia', and produced their own versions. Below is a variation of pronunciations:

P3: "s**ax**oph**a**nia"
P6: "schizoph**o**nia"

P7: “schizo**is**”, “schizo**phe**nia"
P11: “**kisf**enia”

The way in which individuals say the word may also occur as a result of English not being their home language. Some difficulty was noted with a few of the participants when they said the name of the condition, which may also imply that it may not be spoken about. As one participant told me during the interview, that was her first time talking about the condition.

The inability of the patient to say the name of their condition may highlight the lack of knowledge and education about the condition (Simmons et al., 2017). Some participants had expressed how they were taking medication but were not sure what it was for. For example, P6 told me: “I don’t know what are they for, but I think the pills are for this schizophrenia”, and P3 stated: “They don’t tell me the- the name of the pills…”. This may show that it may not be well-understood in the community, as supported by what P11 said, “the people [in the community] don’t know really what schizophrenia is.”.

South African research has indicated that low levels of mental health literacy (Ganasen et al., 2008), poorly developed mental health services, and a lack resources including healthcare professionals, contribute to barriers to efficient treatment (Bruwer et al.., 2011). Mental health literacy is important as it aids in the identification, management, and prevention of mental health conditions (Ganasen et al., 2008). As observed, some of the participants appeared to have poor mental health literacy, as they struggled to name their condition accurately, or were not certain why they were using their medication. It may perhaps be beneficial to teach individuals with the condition how to say the word, how to write it or read it (if they are literate), so that should the individual wish to find out more on their condition they know the name for it, and may be more familiar with it. It may furthermore contribute to improving mental health literacy in the country.

4.5.2 Labelling

The diagnostic label of schizophrenia is associated with more stigma than other mental health conditions (Dinos et al., 2004). Living with a mental health condition differs than that of living with a ‘visible’ disability, such a missing limb, or a syndrome with obvious physical features, for example. A mental health condition is often referred to as an ‘invisible’ disability, because the external appearance of the individual may show no extraordinary features, as it is the mind (internally) which is affected (Mellor et al., 2017).

The data from this study revealed that stigma was common in individuals with schizophrenia. It is caused by people’s attitudes, and behaviour towards schizophrenia, and resulted in social marginalization (Byrne & Baron, 2004; Thornicraft et al., 2009). The participants spoke about how others called them names and described how having the diagnosis of schizophrenia affected them negatively – how others treated them differently because of the label of the diagnosis. Labels are related to judgements and can create stereotypes and attach stigma (Byrne & Baron, 2004).

Stigma and discrimination deteriorated the participant's mental health problems, as it affected recovery and support from society. The implications of labelling have detrimental effects on the individual, as it creates barriers to coping, as a study by Gulliver et al. (2010) indicates. Individuals with a mental health condition are often treated differently within their social environment, and by healthcare professionals (Staiger et al., 2017). This affects the individual negatively and may result in a lack of self-esteem and avoidance of help-seeking, as they are seen helpless or weak (Staiger et al., 2017).

Labelling, seeing as being different, stigmatises the person, and may cause discrimination. Ten out of thirteen participants described having negative experiences with members of the community. One participant did not speak about this. Six out of thirteen participants told me that they were labelled by other people in their communities. Labelling acts as a barrier to coping, because the individual feels victimised and may prefer to isolate themselves, as a result of fearing to be discriminated against and stigmatised.

Various words were mentioned by participants to describe how they felt they were seen by others. Participants felt that people in the community gossiped about them. P1 said that “they talk about other people”; P7 was upset and described how indivudals in the community gave him a nickname, a negative label: “They call me Silon” – meaning one who is crazy…”. P9 complained: “I live with my family but other guys there at home they laugh at me…they don’t feel like I feel…they speak about my name around” (gossip). Similarly P10 explained that “sometimes people in the community just uh-uh make f- make jokes out of you…yeah, you’re mad…you have schizophrenia”. P11 told me that “People think I’m unstable. They make it difficult for me.” P13 was distraught: “it’s not nice. People say I’m mad.”

When a person is being labelled, for example as being ‘mentally ill’, the power of label strips him from his identity. Participants described themselves as being ‘normal’ before they had schizophrenia:

P7 stated “I was normal, you see… then it started… it’s hard to say this…”, after which they became emotional and started crying.

P12 described:

> When I was small I was quite normal, um, I used to play with my friends, I used to go out and then suddenly my friends don’t want to speak to or play with me anymore, they say I’m talking to somebody that’s not there.. So I’ve got no friends actually anymore, um, so it is quite hard.

Labels of “crazy” and “mad” (by others and themselves) were identified too:

P11 explained that individuals in the community have called her crazy: “they gossip that I am crazy. And there are people that spread rumours, and I don’t like it…”. Similarly, P7 said, “Ever since I got ill, people think I’m mad.”

P4 said others described her: “you’ve got schizophrenia… you are out of your mind”, and throughout the interview she described herself “I’m out of my mind…. When I come back with my mind I’m going to talk,”.

P9 described that people in his community had labelled him, and because of the negative connotation of the label, he was not accepted by the community where he lived: “And then they say I’m a stupid guy and then I tell them something and then they take something to chase me away, you see.”

Participants described their experiences being labelled, and the impact that a single label can have on their life. Although participants spoke mostly about how others label them, the sub-theme of self-labelling was identified too:

The way in which people are perceived by others in the community may affect the way in which they see themselves. The results of my research made me aware about the theme of self-labelling. Being labelled by others may cause a negative impact on the person’s view of oneself, causing more distress, and severity of the condition (Holubova et al., 2016).

P7 told me that he felt “mad…[as he had a] sickness in the head’, P2 described himself as “I was crazy”. P5 labelled himself: “I am a robot, terminator, yes maybe you can see a terminator when you see me… yes I’m not a human… Alien, you can say alien, because I’m not… a human being.”. P8 “I call myself Lucifer” “when I was crazy, that woman was crazy too”.

It was an interesting and sad discovery to see how labels, when applied to oneself, could be so destructive, for example, another participant defined himself as being: a “ghost”, “zombie”, “robot”, “alien”, “terminator” (P5). This participant had a very poor self-image of himself, and had reported being labelled by others too.

Based on the data from my research I would agree with the author when they stated that there is relationship between self-stigma and the severity of the experiencing of schizophrenia (Holubova et al., 2016). The use of labels contributes to a more devastating experience by the individual. The use of diagnostic labels may predispose the individual to negative experiences, including stereotyping by mental health professionals, social rejection, as well as the likelihood for people to view themselves as negatively, as the ‘others’ around them do (Cardwell, 2014). This was indeed true, as almost all participants saw themselves in a negative light, describing themselves as being “…useless, see other people they can’t take you as person who-who you want to be…” (P9).

P4 understands that she has a mental health condition, as she is “taking the treatment of those who are mental disabled”. Similarly, P11, who described herself as being “a little mentally ill”, admitted that having the label “makes me very depressed too, and then I feel like giving up my life…”.

Labels can cause fear, for example P10 expresses, “when I got diagnosed, I was very scared. I was intoxicated with- with schizophrenia in my head.”. P11 explains how she feels discriminated against: “People think I’m unstable. They make it difficult for me.”. She discussed that she feels her quality of life has been affected by the labelling from others, as she can not take part in activities in the community, is isolated and judged, and felt depressed because of this. She admitted feeling that “Sometimes I felt that the people were going to hurt me, so I didn’t want to go outside.”

P11 explained that she does not talk to others in the community as she believes they will not relate to her, “Most of them don’t know [that she has schizophrenia], because I keep it as a secret”. She asked the researcher about support groups and wanted to know more about the condition as she does not have the resources accessible to her: “So I don’t know much about it [schizophrenia]. I did say I wanted to Google about it, but I don’t have a phone.”.

Although mental health diagnosis is used as an explanation of the symptoms, and act as a means of access to necessary intervention and support (Howe et al., 2014), literature has argued that that the diagnosis of schizophrenia may cause labelling and social exclusion, as it seems to carry negative meaning. The diagnostic label of schizophrenia is powerful, and can therefore have a devastating impact on the individual's self-identity (Howe et al., 2014).

Self-stigma affects many areas of life, and has a destructive impact on the person's view of themselves, decreased self-esteem, poor self-care, and may cause social withdrawal. These may lead to social isolation, further affecting the functioning of the individual, leading to decreased quality of life (Holubova et al., 2016). Lack of knowledge about mental health conditions, such as schizophrenia, may lead to a lack of understanding by others, and therefore negative beliefs about others and themselves.

Stigma related to mental health conditions, produces barriers to access and quality care (Knaak et al., 2017). This may create delays in help-seeking, as was noted in some participant's narratives, and the discontinuation of treatment (Knaak et al., 2017). Anticipated stigma from healthcare workers was also identified as a factor in individual's reluctance to seek help (Corrigan et al., 2014). This was noted in the interviews too, as P13 explained how he had tried to talk to a professional, but "it didn't help", and he refused referral to talk to another professional.

The incorrect use of labels, such as a case of misdiagnosis, may have many negative implications on the individual. One participant, P3, had been given the label of schizophrenia a few years ago. Her sister had treated her differently, thinking she had a "mental problem". During the interview, it was noted that the participant was not able to describe anything about schizophrenia, although her sister had assured me that the doctor had told her she was diagnosed with the condition on her last hospital admission into a psychiatric ward.

I referred P3 for a psychiatric re-evaluation on the same day as the interview, as she did not appear to present with schizophrenia. It was confirmed that day that there had indeed been a misdiagnosis. P3 never did have schizophrenia. She presented with generalized anxiety. She reported having one isolated incident of auditory hallucinations (the sound of a small stone being thrown onto the tin roof of her shack).

All these years her sister had believed she had schizophrenia and would "never be normal". She had been treated differently because of an error. She had been mis-labelled. The participant and her sister were referred to a psychologist for counselling.

This incidence of incorrect diagnosis and the added trauma that this had on P3 and her family emphasise the need for better services for those with a mental health condition.

Healthcare professionals who work with individuals with a mental health condition need to be trained to identify such cases and how to deal with them (Knaak et al., 2017). Often, lack of communication between the healthcare professional and patient (and their family) may influence the patient's understanding of their condition, which may affect treatment and help-seeking (Corrigan et al., 2014), which affects quality of life. As P3 expressed:

> they didn't give me paper to… to go back and he- hospital to see the doctor. I see that man, that man doctor I couldn't remember his name, and then we are talking with that doctor. And then that doctor said I must find- they didn't tell me that there's- that there's that problem in your life…

Humans are complex, and human error is inevitable. This participant's story just emphasises how thorough and careful we need to be, as healthcare professionals working with other humans. Policies and frameworks should be explained and taught from a university level, to emphasise the effects that misdiagnosis can have on a patient and their family.

4.5.4 Theme of Loneliness and Isolation

"Lonely, I'm so lonely… I have nobody for my own…", P2 became emotional during the interview, and burst into singing, after which he shed a few tears.

People's lives are affected by the relationships with others. Therefore, family and community members may influence the individual's experience of quality of life. Labelling and self-labelling may result in low self-esteem, may cause social withdrawal and poor self-care, leading to social isolation (Holubova et al., 2016). This affects the functioning of the individual, leading to decreased quality of life (Holubova et al., 2016).

For P1, he expresses his life experiences as:

> Life is very hard, I don't want to do anything else with anyone… they know I am sick, but, the people … don't worry about you or another person, they can't, not one person worries about another…. your sickness is your sickness. They are not worried about your sickness, you might as well die.

P1 adds that he is aware that it is not only him who feels so lonely and isolated: “it’s not only me that lives lonely”, however he fears the environment and the people in it: “I’ll never do that again, be amongst people…I do everything for myself …it’s very dangerous outside”.

P5 expressed feelings of isolation and depression, saying:

> See I cannot say friends is the friends… they there’s no friends now, friends are few and days are dark… no friends now…I am not living, you can see, you can see, maybe you can see something …I am dead... because of life.

Similarly, P11 told me about his feelings: “The community doesn’t know what it is. No one talks about it…I keep it a secret.”. Participants said they felt “tired of it,” (P13), and prefer to stay at home: “I don’t do anything a lot, I just stay at home, and do whatever I have to do there.” (P6).

Previous studies have found that perceptions of loss have a great impact on individuals’ lives (Deland et al., 2011; Kilkku et al., 2003). Loss of relationships, loss of social status, and loss of opportunities in life may result in demised locus of internal control over their life, and causing feelings of depression and isolation (Lysaker & Lysaker, 2010).

P9 described that he can’t be himself around people, become they do not see him for who he is: “See other people they can’t take you as person who you want to be…”.

The use of diagnostic labels may predispose the individual to negative experiences, including stereotyping by mental health professionals, social rejection, as well as the likelihood for people to view themselves as negatively, as the ‘others’ around them do (Cardwell, 2014). This was indeed true, as almost all participants saw themselves in a negative light, describing themselves as being “…useless, see other people they can’t take you as person who-who you want to be…” (P9).

P4 understands that she has a mental health condition, as she is “taking the treatment of those who are mental disabled”. Similarly, P11, who described herself as being “a little mentally ill”, admitted that having the label “makes me very depressed too, and then I feel like giving up my life…”.

P11 explained that others see her as her diagnosis, not who she is as a person. She felt alienated and does not talk to others in the community as she believes they will not relate to her, “Most of them don’t know [that she has schizophrenia], because I keep it as a secret”.

She asked the researcher about support groups and wanted to know more about the condition as she does not have the resources accessible to her.

The participants expressed a sense of loneliness as a result of labelling, and expressed seeing themselves as being separated from others. For example, P12 does not interact with others anymore, because of discrimination. He spoke about having friends in the past and now he is alone. P9 expressed self-pity, at being unable to complete his matric due the onset of schizophrenia.

Similarly, P13 expressed how isolated he feels, as he now refuses to seek help from others because he has given up hope after he attempted a session with a psychologist and it did not benefit him, leaving him despondent.

Another common theme identified by the participants was that the community saw them as ‘dangerous’. The participants further admitted to believing this, making them feel ‘abnormal’, as P7 describes “I was a normal person”, before they were diagnosed with schizophrenia.

P10 explains how believes he is a threat to others as well as himself, and should be kept in a contained environment, because if “you come outside…you will hear the voices, you will kill yourself”.

The only exception was P8, the participant who viewed himself in a positive light. He told me that others “look up to [him]”, because those in the community where he lives believe that he has supernatural power and is considered important – both by others and himself. This causes self-acceptance and possible acceptance by others. By exploring the life experiences of the participants, it appears that personal perception, the view of oneself, is influenced by other people. Although, the thinking, behaviour, and emotions of individuals with schizophrenia are affected by the condition (Sperry, 2015), it does not mean that individual will not experience what other people think of them, or be unable to interpret others’ views of themselves.

4.5.5 Participant Reflections

As described in the *Methodology* section, reflexivity took place, as I reflected on my experiences after each interview, taking into consideration how my own views may influence findings. This was considered when interpreting data from the interviews, summarizing, and finding themes. Furthermore, participants indicated a need to reflect on their experiences being asked to describe their life experiences living with schizophrenia. Although this was not a question that was included in the interview, it was interesting to analyse participant's responses and reflections.

At the end of each interview, the participant was asked if there was anything else they would like to add to their story. A few participants expressed their gratitude for the opportunity to share their life stories and to be heard. Participants articulated their dreams and ambitions, most of which were not known by their families, indicating a lack of communication and expression within the family.

P5 expressed that he was glad that he had come for the interview, and wanted to come again, as he had felt this interview was therapeutic. When asked if there was anything else he had wanted to say about his experiences living with schizophrenia, P5 said, "Yes I can tell you about it again…maybe we can see again each other, I want to see you again,". This shows that rapport can be built with patients with mental health conditions in a short period of time, when given the chance, and just by listening and giving them an opportunity to voice their story or their opinions, they can be made to feel more "alive" again.

P11 admitted she almost turned back and didn't come for the appointment, as she had never spoken about her mental health condition with anyone, "I don't talk about it with people. This is my first time today that I talk about it [schizophrenia]", as she felt scared. But she thanked her caregiver for persuading her into coming, as she felt so "relieved" after talking about it, and said it felt as though a weight had been lifted off from her shoulders.

P4 concluded her semi-structured interview by stating to me that "…you have make me feel ok, what you've done…about talking". She felt appreciative that I had taken the time to listen to her story, like nobody else had, which in turn had awakened a sense of identity: "Cos you did hear and you did hear what I am saying…"; "It-it is just make me feel that I am P4 (name of participant removed for anonymity), I'm ok, and I'm the one.". She explained that she felt ready to face the world again, despite her heart-breaking story, and that despite the never-ending negativity she had experienced, including a sense of abandonment from those closest to her, because of her mental health condition. She stated that she was ready to face what lay before her: "…but I'm not ill, I'm ok. That is why I'm ok.".

P9, who described himself as "I was a street kid", expressed his dream to "…be a preacher for children", as he wanted to help them live a healthy life where they "…go to the creche and they must go to church… eat healthy food… and sleep well."; "They must be happy.". He is young and ambitious, and is determined to do something with his life, because he wants to "be happy like other people".

A few of the caregivers that accompanied the participants (and had sat in the interviews, with permission from the participant) were emotional. After listening to her family member express himself in the interview, one family member admitted to feeling selfish because she had not taken the time to speak to her grandson and hear how he really feels. Another family member stated that they did not know their own son, and that this interview had changed their life because they had always seen the person as "ill" or "crazy", with "no chance of a normal life".

My life was changed too. P8, who had said "My Story is Worth Hearing", said to me at the end of the interview, "You got the keys, Alicia Keys,", "Do what you do now… keep on changing people life, keep on giving people life, that's the only thing,". This was confirmation that this research had made some difference to select few, and the power of listening, and giving others a chance to speak. This was validation.

4.6 Ways of Coping with a Mental Health Condition

The life experiences described during the interviews indicated that the participants despite their condition, attempted to manage and cope with life. Some of them turned to religion and prayed to a higher power, attended counselling sessions, or spoke to others about their condition. Support from their families was an important factor too. In this study I wanted to explore the ways participants were managing their condition, other than by taking medication; I wanted to hear the stories about their motivation and coping.

Coping, a term developed in social psychology, refers to a response to an encountered stressor (Omeni, 2019), originally defined as the "constantly changing cognitive and behavioural efforts to manage specific external and/ or internal demands that are exceeding the resources of the person", by psychologists Lazarus and Folkman (1984). Coping mechanisms help individuals maintain their emotional well-being.

It appeared that the participants were able to apply their coping strategies in day-to-day life, despite the challenges faced. Their way of coping gave the examples of 'appraisal-focused', and 'emotion-focused strategies', as described by Weiten et al. (2014). The narratives received during the interviews indicated that praying and turning to religion, seemed to be the most popular coping strategy, while making changes in the immediate environment was often used as well. The participants understood that taking treatment helped them and spoke about how it was helping them to cope with the symptoms.

Research has revealed that positive emotions can influence coping strategies and enhance an individual's resilience against stress (Gloria & Steinhardt, 2016), while high levels of chronic stress can contribute to the development of depressive symptoms and anxiety (Gloria & Steinhardt, 2016). Therefore, the consideration of various factors that may affect coping and help-seeking is important. Facilitating factors encourage the person to seek help, whereas barriers prevent the individual from seeking the help they may need (Staiger et al., 2017). It appears that support from the participant's families was the most important factor that facilitated help-seeking. Also, Staiger et al. (2017) found that social support together with encouragement and acceptance from others, as well as the desire for change increased motivation to seek for help and find coping strategies.

Prevention and promotion programmes in the community, following a support group, could be a potential solution to the barriers, temporarily, while policies are being developed and improved. This is therefore another area for potential further research, as well as further research on exploring and sharing coping strategies amongst individuals with mental health conditions other than schizophrenia.

4.6.1 Family Support

Often, individuals with mental health conditions may experience poor support from others, including healthcare workers, as well as their families, who may abandon or neglect them (Blashill et al., 2011). However, helping behaviours expressed in supporting someone physically and emotionally, by providing understanding and patience, may influence person's coping, and result in benefit to physical and mental health (Maisel & Gable, 2009).

Coping refers to the individual's ability to manage life events and to survive (Omeni, 2019). Therefore, coping and wellbeing are interrelated. One of the objectives in my research was to explore how people living with a mental health condition cope with life. Due to their impairments, the participants were unable to stay on their own and had to be supported by their families or caregivers during the time they were interviewed. Ten out of thirteen participants felt supported by their families, and three did not talk about their families at all, (and I did not probe further).

The participants who described having a good family support system felt accepted and expressed feeling safe and comfortable to be with their loved ones, with no desire to interact with others in the 'outside' environment. They also expressed that they could talk with their family members, who appeared to be patient with them, and more understanding. This facilitated them to cope better. P1, felt grateful for his family, and spoke primarily about how much they have helped him. He described:

> I still live with my family and well, I live well with my family, I can stay with my family and be together with them. I don't want to be amongst other people… I like my family. Here's my mother, my sister, there's my other sister, ahh but I love my family!

P10 exclaimed: "and with-with-with my family support it's alright", and P12 told me: "I've got a very good support system" at home, and that "[my] family like my aunt, um, and-and they are they are very supportive."

Participants were able to realise and acknowledge that their families looked after them and helped them to cope with their mental health condition. This was an important way of coping, as individuals with a severe mental health condition may need close support daily. Being cared for helps to lessen feelings of depression and isolation (Holubova et al., 2016), by improving the state of wellbeing and easing the everyday experience of mental condition.

4.6.2 Talking to Other People

The individual can learn to adjust one's emotions in order to tolerate or eliminate stress to be able to cope, which can help alleviate vulnerability and depression (Richards & O'Hara, 2014).

P4 and P12 explained how they talk to others, which helps them: "I speak to the-the-the ladies at the clinic every month when I get my pills" (P12). P10 added that "So it's very good to-to-to talk to a therapist or something like that, they help you with schizophrenia as well, so, and tips to guide you and how to live with it.". He spoke of seeing a "schizophrenia therapist" – i.e. "the therapist, is just helping you with-with how to cope with schizophrenia.". He later confirmed during member checking that he has had sessions with a psychologist in the past, which have helped him "keep the mind free". He concluded in saying that although "it's a dangerous illness… but you can live with it".

P11, who copes by attending church named other methods, where she manages by changing her behaviour and emotions, distracting herself: "sometimes to keep quiet. And other times, I keep busy.". She admitted she would love to attend a support group where people with schizophrenia could share their coping strategies and learn from each other. P11 was referred to a psychologist as she admitted to experiencing depression, and the idea of a support group was discussed further with the psychologist and social worker at the site.

P10 describes how he is able to communicate with others in the house on how to help him: “for the household they-they must always be quiet, in the house.” He added that he wanted to offer his advice to others with schizophrenia, to help them: “I just can give advice: stay quiet, drink lots of water, eat healthy, just eat your food.”

Talking to others can be therapeutic, provided they listen and act appropriately. If the other person talks and listens non-judgementally, as I did in the interview, the person was found to be able to open up and build trust. In cases where participants had tried to talk to others but were discriminated against and judged, it did not help them. Therefore, although talking to others did not benefit all participants, it was identified as a key strategy used for coping by participants.

4.6.3 Coping by Turning to Religion

Several participants tried to cope better with their mental condition by praying to a higher power. Religious beliefs and practices, which comfort the individual and give them a sense of hope, may improve the individual’s social support, and assist them in avoiding self-destructive behaviours (Rothmann & Malan, 2011). It has been found that individuals may be more inclined to turn to religion when they experience a large amount of stress (Rothmann & Malan, 2011). The reported experiences of seven out of thirteen participants revealed that they cope with their condition by going to church, praying to a higher power, and asking for help from God. Therefore, there could be a potential way in which prayer is used to promote health (Breslin & Lewis, 2008), as a way of coping (Paloutzian & Park, 2014).

Participants described how they attend church regularly. For instance, P2 attended many churches, trying to cope with his condition: “I’ve been attending all these churches; Zion, Baptist, Episcopal. Baptising. Again… Baptising at the sea. I’m present at the beach, as a Zion church member at that time, being preached too.”

P7 explained that he goes to church every Sunday to pray for his condition to improve: “I take treatment and pray, I go to church… coloured people church”.

P9 expressed “I’m going to church, and I’m coming back home. I do the same stuff every day. I pray and pray. Other people they tell me I must go to church”. He believed that by “asking the Lord to help”, attending church and praying he may receive help and cope better with his condition. He explained how during the day he is at home, and every night before he sleeps, he prays:

> I was doing everything inside at home, and around the location, I was going only to the shop and then I come back to the home again and I must stay there. And then after I- at night, before I sleep, then I pray.

P4 believed that "God is going to help me while you [the social workers] are not helping me". P4 still believes in the power of God, and continues to pray, even though she felt that her condition had not changed after using the holy water that was used on them to cleanse her, to help bless her and chase the evil spirits away: "Cos even with I've got some water, someone who's preaching, that thing [schizophrenia] it is not stopping".

P4 explained further how she prays to remember to drink her treatment, "even me I'm going to pray, I'm going to pray for me that God help me not to forgot that medical- medical treatment that I eat,", as she believes that the medicine will help her. Therefore, P4 copes by praying and taking her medication as prescribed.

According to Breslin and Lewis (2008), prayer may affect health in different ways, including: improving health because of the placebo effect, engaging in health-related behaviours, diverting attention away from health problems, promoting health through supernatural intervention by God, and providing a sense of unity which promotes healing between individuals. Apart from the expression of using prayer as a coping strategy, there were biblical connotations throughout the interviews: P8 described himself as the "fallen angel, Lucifer", P7 mentions Satan, P11 refers to "the Devil is there and then he comes and does his thing", and P2 mentions a "demon" as well.

It would be interesting to explore in greater detail the beliefs of supernatural causes, culture-bound syndromes, and biblical connotations, such as possession by an evil spirit, bewitchment, but that was not an objective in this particular study.

4.7 Chapter Summary

In this chapter the elicited life experiences of individuals with schizophrenia were explored inductively, through which themes and sub-themes were identified and discussed. These themes allowed me to describe the participant's experiences of living with the condition. Most of the participants believed that their condition was caused by bewitchment or poisoning, as people were jealous towards them, because their family member had a schizophrenia too, or because of the abuse of substances prior to their symptoms appearing. The vicious cycle of poverty and mental health conditions was discussed, and as per literature, how poverty can be a determinant and consequence of poor mental health (Murali & Oyebode, 2004).

Schizophrenia is a complicated, multifactorial condition (Schulz et al., 2016). All of the participants were taking the prescribed medication, and the majority of their experiences could be summarized by P6, when he said that the pills: "…make me feel good… I sleep well…it's the right treatment…". Two out of thirteen participants indicated that apart from the medication prescribed by the doctor they were using traditional ways which is an important factor that cannot be ignored in the South African context.

Due to their mental health limitations the participants were unable to stay on their own, however, only half of the participants described their experiences of being supported and cared for by their family. People's lives were affected by relationships with others. The data from my research indicated that labelling and self-labelling affected the participant's quality of lives, depressed their mood and caused social withdrawal. This appeared to lead to isolation, as explained by Holubova et al. (2016). Ten out of thirteen participants described having negative experiences with members of the community because of being labelled.

Participant's coping strategies included turning to religion and praying to a higher power for help, adjusting the immediate physical environment (e.g. asking people to keep quiet, changing the temperature in the room), controlling one's own bodily responses to stress (e.g. breathing deeply, drinking water). The discussion of a possible support group, as suggested by one participant, was explored, as a further strategy for coping as a clinical implication from this research.

CHAPTER 5: CONCLUSION

"You are not your illness. You have an individual story to tell. You have a name, a history, a personality. Staying yourself is part of the battle," (Julian Seifter)

5.1 Summary of findings

Major themes, including the participants' views of themselves - such as their perception regarding the cause of their condition and how they experience the symptoms of schizophrenia, (including treatment), and how their experiences are affected by the environment, labelling and stigma, and coping strategies were identified. Contextual factors, such as poverty and stigma affect the individual's quality of life in great ways; prejudice and discrimination surrounding an invisible disability may outweigh that of a physical disability.

Poverty is a source of deprivation, high stressors and social exclusion (Kawachi & Berkman, 2001). It affects lives of people living with mental condition causing more severe course and higher prevalence of mental illness (Kawachi & Berkman, 2001). When environmental demands exceed an individual's ability to cope with a situation, it can be associated with a range of physical and mental health states (Hjelm et al., 2017).

The implications of labelling have detrimental effects on the individual as it creates barriers to coping (Gulliver et al., 2010). Individuals with a mental health condition may be treated differently within their social environment, as well as by healthcare professionals (Staiger et al., 2017). The participants expressed feelings of loneliness and isolation; they saw themselves as being separated from others. Labelling affected the functioning of the individual, leading to decreased quality of life (Holubova et al., 2016).

Many of the diagnostic labels that are given by the physician are linguistically complex and often not adequately explained to the patient. Misdiagnosis, misunderstanding, and lack of communication between doctor and patients adds to the burdens that these individuals carry, therefore causing more suffering. Labelling and stigma lead to isolation and loneliness.

Thirteen individuals that were interviewed believe their mental health condition was caused by different factors, with the primary perceived causes being jealousy exacerbated by substance abuse and increased risk due to a positive family history of schizophrenia. As schizophrenia belongs to a group of pathologies which are complex genetic disorders, there is a strong hereditary component for schizophrenia (Abi-Dargham & Guillin, 2007; Gejman et al., 2010). Although none of the participants had undergone genetic testing to identify a positive family history, some participants perceived their cause of schizophrenia to be as a result that their family member also had it. Almost half of the participants described how they used or abused substances prior to their symptoms appearing. Environmental risk factors, which include substance abuse, may influence the onset of schizophrenia (Vilain et al., 2013).

Studies in South Africa and globally identified that individuals believe that their mental illness is caused by bewitchment by someone who was jealous of them (Ashford, 2005; Bellgrave & Allison, 2018; Steinberg, 2008; Swartz, 2009).

When conducting research, to avoid bias and prejudice, cultural beliefs cannot be ignored, the researcher should be aware and gain a more holistic understanding of the way in which participants view their own mental health conditions, and what they base their coping strategies on.

Moving away from an impairment-focused approach, disability can be described using the ICF (WHO, 2001). This framework is used to describe psychosocial difficulties, specific to schizophrenia, such as impairments of mental functions (e.g. emotional functioning), activity limitations, and participation restrictions (in the environment). By defining limitations and restrictions, as well as identifying what contextual factors can be changed, the quality of life of the individual may be improved (Figueira & Brissos, 2011). This framework has brought together social and structural factors and recognized disability as a result of interactions between the health condition, and environmental and personal factors.

Environmental factors, such as social support, may impact greatly on the psychosocial difficulties (Cohen & Minor, 2008). An adequate support system is vital in coping with a mental health condition. Social support, together with encouragement and acceptance from others, increases motivation to seek for help and find coping strategies (Staiger et al., 2017). It appeared that support from the participants' families was the most important factor that facilitated their help-seeking.

Community-based rehabilitation and support may be beneficial to the participants and other members in the community. Prevention and promotion programmes in the community, following a support group, could be a potential solution to the barriers (Lund et al., 2012), and therefore another area for potential further research.

Data from first-hand encounters with individuals who have specifically schizophrenia could potentially aid in providing information for the establishment of support systems for individuals with mental health conditions. It could be used in primary and community-based care, promoting a more holistic approach to healthcare, and may help to fill the gap and add to the existing knowledge (Lund et al., 2012).

The discussion of a potential support group with a multidisciplinary approach, enquired by a participant, has inspired me initiate it and to make a difference in these people's lives; I will dedicate my time to doing so. Understanding schizophrenia, and other mental health conditions, invisible disabilities, are so vital in our fast-paced, stressful, technological world today. Mental illness is more common than is realized. It can be treated. Stigma and discrimination can be addressed. Quality of life can be improved. It's giving those affected a chance to be heard that will help in giving more light when "days are dark".

5.2 Critical Evaluation of the Study

This study was not an easy one to conduct. My background – ethnicity, education, language, belief system, differed greatly from the participants, and I had to learn to be open-minded and put myself in the participant's shoes. In a setting where the majority of the population speak a different language, and have various cultural views which may often not be well-known to people from other backgrounds, I had to immerse myself in such a setting, and to see every individual as someone who was bringing valuable information, a life story, that would hopefully allow for a better understanding of the condition and experiences living with it. The subjective perspectives on the experiences of schizophrenia, which have not been researched in-depth in developing countries (Baumann, 2010), were explored, which allowed for different perspectives to be heard.

I faced many difficulties along the way. Having to replace the initial research mediator posed as a challenge, but was luckily overcome. Learning to gain the trust from participants so that they would open up and share their stories took practice to build good rapport in a short period of time. Additionally, data collection took place at the hospital; perhaps some of the participants did not feel comfortable or in their natural environment, which may have influenced the participants into focusing on a Western approach of their condition initially.

It was difficult to not get emotionally involved in participant's stories. Although there were times when I felt anger and shock, disbelief and heartbreak, at some of the things I was hearing, I had to learn to control her emotions, and not allow the participants experiences to influence my work. I learnt to remain professional, although there were times when it was impossible to show emotion. Stigma may cause disrupted relationships and poor socialization, leading to depressed feelings of loneliness (Byrne & Baron, 2004). This was expressed by participants who explained how they would isolate themselves in order to protect themselves.

By allowing a small group of individuals with a mental health condition, such as schizophrenia, to voice their experiences, much information has been gathered, that may be useful both locally and internationally, for further research understanding schizophrenia.

5.2.1 Strengths of the study

Firstly, this study allowed thirteen individuals with schizophrenia to voice to their life experiences living with this condition. Many had never dared to speak about their condition, as they had admitted to me that they had initially felt scared to talk about schizophrenia as no one else had ever asked them about it, and that members of the community did not discuss it. Some participants had even appeared surprised when I had explained the aim of the study. I was able to gain trust from participants and their families rather quickly, which allowed for their life stories to be shared openly.

Living with an invisible disability is most difficult, especially in a setting where resources are scarce or difficult to access. I was able to educate the participants more on their conditions, when they had questions, and they felt that they were being heard, instead of told what to do, as they were used to. It allowed them to express emotions and ideas, dreams and thoughts.

Themes of the view of oneself (including sub-themes of perceptions on the cause, symptoms, and treatment) living with schizophrenia, labelling and stigma (including isolation and loneliness), and coping (such as family support, talking with others, and turning to religion), were discussed, in relation to the findings from the described life experiences that were analyzed in-depth, and answers compared amongst transcriptions.

Methodological strengths of using semi-structured interviews included having questions to guide the participants on what areas in their lives I was interested to learn about, and the use of interviews allowed for individuals with a hidden disability a chance to voice their personal experiences (Clandinin, 2006).

Further areas of potential research were identified and have been discussed.

5.2.2 Limitations of the study

Only thirteen participants were interviewed, therefore it was difficult to reach saturation. Unfortunately, there were various factors which contributed to no more participants being interviewed. This included primarily time constraints, having participants commit to taking part in, and arriving for the interview. The complexity of the nature of schizophrenia (Gejman et al., 2010) – i.e. being a spectrum disorder (Schulz et al., 2016; Yanos et al., 2008), it potentially presenting differently in individuals, was further taken into account. My position as the researcher may have acted as a limitation in my research too, as I do not come from an isiXhosa background and may not share the same cultural beliefs as my participants, and my background differs – for example my working at the hospital.

Changing the research mediator also contributed to the delays in obtaining data. Should this research ever be duplicated in future, it is recommended that more participants are interviewed, to allow for greater saturation.

In a setting where resources are few, there was some difficulty in getting participants and their family members to commit to coming. A few potential participants had identified themselves, and had promised to arrive, but did not pitch, even when they were told they would be reimbursed for their travelling expenses. This may be due to a number of reasons, such as fear of stigmatization, financial difficulties, paranoia, context, and other reasons not mentioned.

Furthermore, this research only focuses on one mental health condition, schizophrenia. It does not take into account any other condition, therefore when researching mental health in particular, it would be interesting to conduct this research with a different population, e.g. those with bipolar disorder.

Additionally, the same population group could be explored, but from a different geographical area. Cultures and beliefs can change with context; therefore views of health conditions can change across the country. This research focused on a small area in one province in the country. The limitations should be considered and overcome where possible, should this research be conducted again in other regions of the country or with different population groups.

5.3 Potential Implications and Recommendations for Future Research

Findings of qualitative research are suggestive of further enquiries, as they identify potentially important variables and generate hypotheses about their possible relationships

(Hesse-Biber & Leavy, 2010). Gaining a clearer perspective of the cultural understanding of mental health conditions may help in improving medical services, increasing awareness, or having deeper insight into such conditions in the country.

There is a need for further research on the lived experiences of individuals living with mental health conditions, versus a fully medical approach. This will help healthcare professionals to understand patients better, and to improve intervention. Although there are more published accounts of the subjective experience of individuals diagnosed with a mental health condition such as schizophrenia (De Wet, 2013; Read et al., 2015), first-hand accounts are still infrequent (Geekie & Read, 2009). Therefore, the data from my research may contribute to such work in the future, and may contribute to further research regarding the caregivers' experiences looking after someone with a mental health condition such as schizophrenia.

More recommendations on how future researchers could recruit more participants may include the researcher going to clinics and offering information to potential participants, accessing the database of patients with the explored condition, searching for advocacy organizations or support groups online and getting in touch with relevant stakeholders, going into the community and completing awareness programmes to identify potential participants to be recruited.

Every person is important, every person must be heard and counted. In my research I was trying to explore the life narratives of people living with mental condition in the informal settlements in rural areas of Eastern Cape, during semi-structured interviews I heard the voices of thirteen people, who often were stigmatized, silenced, were not considered by the society and failed by the health system. The data from the narratives could be used for more in-depth research and used for practical application in outreach or outpatient services.

More research is still required to explore the links to mental health conditions, such as schizophrenia, with personal and environmental factors in South Africa. The data from my research may contribute to such work in the future.

5.3.1 Implications for Practice

In healthcare facilities, a transdisciplinary team approach, involving a psychiatrist, occupational therapist, social worker, as well as a speech-language therapist (SLT), are suggested for management of individuals with mental health conditions, as per research conducted by Novak & Kapolnek (2001). The SLT, who is the prime facilitator and specialist in communication, does indeed have a role to play in multidisciplinary team at hospitals and clinics. Research on the role of the SLT in mental health conditions has indicated that speech therapists are in fact needed in the management of such patients (Law & Garrett, 2004). Communication difficulties have been identified as primary symptoms in individuals with mental health conditions (Novak & Kapolnek, 2001), and speech deficits are present in individuals with mental health conditions (Cohen et al., 2014), such as schizophrenia.

Most of the research regarding the provision of speech therapy to individuals with mental health conditions (Law et al., 2009; Meilijson et al., 2004; Novak & Kopalnek, 2001) was conducted in the developed countries (Meijilson et al., 2004), and there is little research available on developing countries, such as South Africa. This study may help investigate what gaps there are in healthcare provisions to individuals with mental health conditions, such as schizophrenia. There is a need for the SLT to be more involved in interventions within the multidisciplinary team in hospitals and clinics, with patients who have a mental health condition, in South Africa. The data acquired in my research may be helpful for future enquiry or could be used in interventions in mental health that include the SLT.

Individuals with mental health conditions such as schizophrenia may experience difficulty expressing themselves adequately, which places a barrier between them and other people. The SLT can help the patient to overcome these limitations by teaching them and their families alternative ways of communicating. By making it possible for the individuals to express themselves, healthcare workers may identify individuals who may be, for example, depressed and need counselling.

The role of the SLT in mental health conditions should be re-evaluated and emphasized upon, as we can make a difference. For example, a couple of the participants, when debriefed, expressed their desire to meet others like them, to form a support group, where information could be shared on their condition, and a platform to talk to other individuals with schizophrenia, share their stories and teach others about their coping strategies and learn new ones; therefore this emerged as a need in the data. More in-depth research investigating coping mechanisms implemented by individuals with mental health conditions, such as schizophrenia, as well as other conditions, may be another area for further research. We learn by watching others (Sutton, 2014), therefore by exploring and identifying various strategies, and sharing them with the public through research reports and presentations at conferences, these may be implemented (if beneficial) by various populations worldwide.

Support groups are created to help individuals who share a common problem, to learn to cope with it (Videbeck, 2010). It is usually facilitated by a leader, who explored member's thoughts and feelings, creating an environment where the individual feels comfortable and accepted. Support groups may be open – i.e. members can join and leave according to their needs (Videbeck, 2010). Most of the participants expressed a need to make a difference in the community, or to contribute, as one participant stated, "I'm willing to help anybody".

It was furthermore noted that there is a lack of understanding of the condition from the participant's perspective, who knew they had the condition but could not define it. Starting a support group for the participants, as well as other individuals with schizophrenia in the community, could promote a better understanding of the mental health condition. Following this request, the researcher held a meeting with the psychologist at her workplace, in which the starting of a potential group was discussed. This will be investigated further, but the idea was to hold a meeting, in which the participants (with their caregivers) could attend an information afternoon, where the doctor heading the Mental Health Unit would give a brief description of schizophrenia, followed by a discussion from the psychologist. The researcher, i.e. the speech therapist, would also be present at the meeting to facilitate communication.

The members in the group would be able to decide after the initial meeting whether they would like to continue coming (monthly) to the hospital for this support group, facilitated by the speech therapist, psychologist, and social worker, with the idea of promoting the understanding of the mental health condition, coping mechanisms, ways of acceptance within the community, etc. This will be done towards the middle of 2020, after the results of the research have been discussed with the participants, who wish to receive them. The notion of the support group is to help individuals express themselves and improve communication, to promote coping and a feeling of belonging (Videbeck, 2010). Furthermore, the introduction and facilitation of support groups for mental healthcare users has not been well-integrated into the speech-language therapy syllabus, therefore there is a need for more in-depth training, as a recommendation to improve the program.

5.3.2 Policy Implications

The National Mental Health Policy Framework (DOH, 2013) declares the importance of collaboration between all levels in mental health services and allocates culture a key role in this system. The government committed to foster person-centred recovery paradigm, respecting the autonomy and dignity of all persons, and is responsible for building links with traditional and complimentary health practitioners (DOH, 2013). Based on my encounters with the people living with mental disorder in the settlements of Eastern Cape, I think a lot has to be done for the planned to become a reality.

It is important to promote mental health literacy in order to recognise, manage and prevent mental health conditions. Understanding the risk factors, causes and how to seek help can increase the patient's and members of the community's knowledge about mental health conditions and the treatments available. The aspects of the conceptual framework of mental health literacy, such as recognition of the mental health condition, and knowledge about it, are important areas for establishing interventions. These aspects involve the ability to identify the presentation and manifestations of a mental health condition, awareness and management. People have to know where to seek professional help, and be perceptive towards the risk factors, such as lack of education, stereotyping, discrimination, and violence.

It is crucial to improve mental health literacy, as it affects the management and prevention of mental health conditions. The National Mental Health Policy Framework and Strategic Plan emphasises the importance of research and the need to translate its findings into practices and policies (DOH, 2013). Research in mental health should not only be promoted but its evidence should be utilised to inform the strategic planning of mental health services (DOH, 2013). This could be achieved through intersectoral collaboration and undertaking mental health education and training programmes for the general health staff and in communities.

Mental health literacy could be achieved through collaboration between the health professionals and the community. The National Mental Health Policy Strategic Plan emphasises the establishing and maintaining of the community-based rehabilitation programmes (DOH, 2013). To achieve that, district health services should play an important role in the routine screening for mental illness, management and medication of mental disorders, provision of counselling and referral. District services have to conduct mental health training programmes for the general health staff and community health workers (DOH, 2013). All levels of the self-care, consisting of primary care for mental health, informal community-based care and self-care cannot be underestimated, and should play a bigger role in recognising, managing and preventing mental health conditions.

The National Mental Health Policy Framework (DOH, 2013) emphasizes the establishing of comprehensive mental health surveillance mechanism, and also allocates a special place to supporting the development of research and innovation in mental health.

Mental health services should be affordable and accessible to the places where people live and work, with emphasize on local community-based resources; all options for out-patient and community-based care should be explored before in-patient care is assumed (DOH, 2013).

Primary healthcare is the approach to manage healthcare by focusing on a person, by reducing the exclusions, and by collaboration between all stakeholders (DOH, 2013). The National Mental Health Policy Framework stated that the mental health system should be integrated into the primary healthcare for efficient and quality healthcare services, so as to narrow the treatment gap in low and middle-income countries (Esponda et al., 2020; Lancet Global Mental Health Group, 2007; Semrau et al., 2015). For individuals whose needs are deprived and who have very limited access to the mental health system, there is a need for community-based support (Kirmayer et al., 2015).

In a country so culturally and linguistically diverse as South Africa, the inclusion of other healthcare professionals – such as community healthcare workers in clinics, as well as the inclusion of community members themselves, may promote better care for individuals with mental health conditions, help decrease stigma, and improve communication to the patient regarding their condition and intervention (Lund et al., 2014).

The health services in South Africa are recommended to be structured in line with the World Health Organisation, and include the range of different service stakeholders (DOH, 2013). The current research was conducted in the Eastern Cape, where participants came from informal settlements in rural areas, and were out-patients in the district hospital, as well as prim1ary health-care clinics. Data from first-hand encounters with individuals who have mental health disorder (specifically schizophrenia) could potentially aid in providing information for the establishment of support systems for individuals with mental health conditions and used in primary and community-based care, therefore, it may help to fill the gap and add to the existing knowledge.

5.4 To Conclude…

There is an overall message of isolation and loneliness as a result of stigma, which has been voiced by the participants. Hopefully my research allowed for a select few to be heard, to feel worthy, and ease their pain. This research focused on participant's residing in rural areas of the Eastern Cape.

Individuals with mental health conditions, such as schizophrenia are seen as having an invisible disability, as it is not obvious to the naked eye. By exploring life experiences of my participants first-hand, I discovered the complexity of human existence, and the importance of sharing our experiences to understand each other. The National Mental Health Framework Policy (DOH, 2013) is crucial for achieving adequate and accessible healthcare for individuals living in settlements in the Eastern Cape. Without its implementation individuals will continue to suffer in silence, waiting to be heard.

The collected data exploring the subjective experiences of people living with a mental health condition could assist in the development of community-based outreach projects, which are needed as most of the people living in settlements go to their clinics, rather than the hospital. The implementation of community-based programmes can promote mental health within the community (WHO, 2010), by: creating an inclusive environment that respects and protects the basic rights if individuals; strengthening the community networks and creating awareness on the prevention of substance abuse, and community violence, for example; developing partnerships with stakeholders involved in promoting mental health and wellbeing; and creating community support groups.

Little research has been complete on such projects in South Africa specifically, therefore there is a need in the country. I believe that this research may suggest further, more in-depth investigation into the lives of people living with a mental condition, and become the “key to the path” (P8) of allowing the silenced to be heard.

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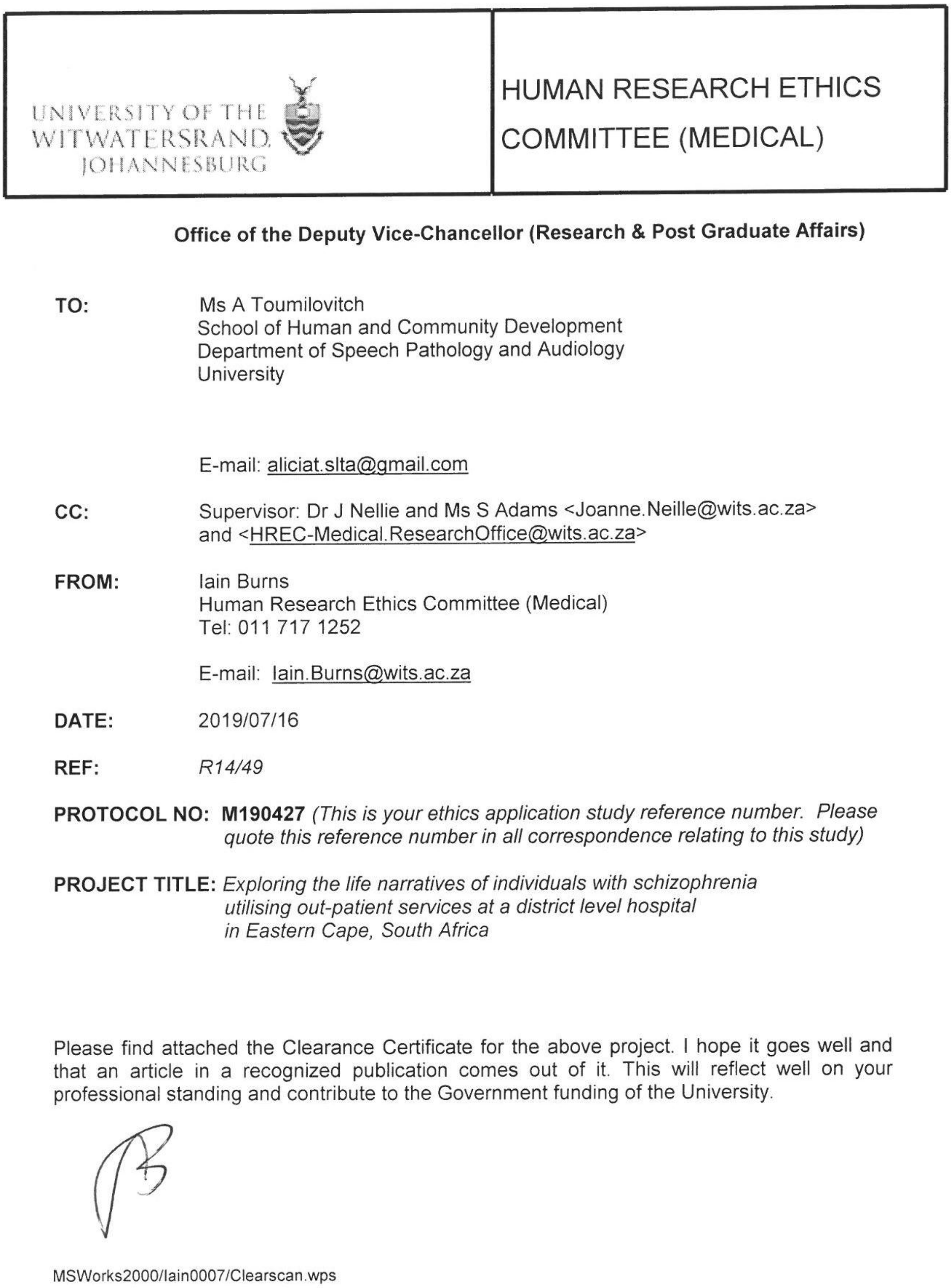
APPENDICES

1. Ethical Clearance Certificate



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

HUMAN RESEARCH ETHICS
COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Post Graduate Affairs)

TO: Ms A Toumilovitch
School of Human and Community Development
Department of Speech Pathology and Audiology
University

E-mail: aliciat.slta@gmail.com

CC: Supervisor: Dr J Nellie and Ms S Adams <Joanne.Neille@wits.ac.za>
and <HREC-Medical.ResearchOffice@wits.ac.za>

FROM: Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 2019/07/16

REF: *R14/49*

PROTOCOL NO: **M190427** *(This is your ethics application study reference number. Please quote this reference number in all correspondence relating to this study)*

PROJECT TITLE: *Exploring the life narratives of individuals with schizophrenia utilising out-patient services at a district level hospital in Eastern Cape, South Africa*

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 the Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

R14/49 Ms A Toumilovitch

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M190427

NAME: **(Principal Investigator)**	Ms A Toumilovitch
DEPARTMENT:	School of Human and Community Development Department of Speech Pathology and Audiology University
PROJECT TITLE:	Exploring the life narratives of individuals with schizophrenia utilising out-patient services at a district level hospital in Eastern Cape, South Africa
DATE CONSIDERED:	2019/04/26
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr J Neille and Ms S Adams
APPROVED BY:	CB Penny Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2019/07/16

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary 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 will therefore reports and re-certification will be due early in the month of **April** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature ______________ Date ______________

PLEASE QUOTE THE CLEARANCE CERTIFICATE NUMBER IN ALL ENQUIRIES

2. Participant Information Sheet

i. For the Participant

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

Dear Sir/Madam,

My name is Alicia Toumilovitch and I am a Masters student in Speech Pathology at the University of the Witwatersrand in Johannesburg. As part of my studies I must undertake a research project. The title of my project is "Exploring the life narratives of individuals with schizophrenia utilizing out-patient services at a district level hospital in the Eastern Cape, South Africa". The aim of this research project is to find out how the diagnosis of schizophrenia affects the life experiences of individuals living within the community in the Eastern Cape.

As part of this project I would like to invite you to take part in an interview at Uitenhage Provincial Hospital, where I will ask you about your experiences of living with schizophrenia. This activity will involve my asking you questions, and hearing your story, and will take around one hour. I may need to meet with you on a different day again, for one hour, to confirm that my information is correct. My research mediator will be with us, and will conduct the interview in isiXhosa if you would prefer. With your permission, I would also like to record the interview using a digital device. The audio recordings will be stored safely on my computer, and only I, the researcher, will have direct access to them.

You will not receive any direct benefits from participating in this study, and there are no disadvantages or penalties for not participating. If you are coming to the hospital only for the interview, you will be remunerated for your taxi fare. You may leave at any time or not answer any question if you do not want to.

The interview will be completely anonymous as I will not reveal your name or any identifying information, and the information you give to me will be held securely on my computer and not disclosed to anyone else. I will be using a false name to represent your participation, in my final research report. There is the risk that you may feel uncomfortable retelling your story; if you feel distressed at any point of the interview, we will stop or continue another time. If you need some support or counselling services after the interview, these are available free of charge at the clinic. I will write you a referral letter for the psychologist, and arrange an appointment, should you wish to be counselled.

If you have any questions afterwards about this research, feel free to contact me on the details listed below. This study will be written up as a research report which will be available online through the university library website. If you have any queries, concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (medical), telephone + 27(0)11 717 2700, email hrec-medical.researchoffice@wits.ac.za/ Rhulani.Mkansi@wits.ac.za

Sincerely yours,

Alicia Toumilovitch

Researcher:

Alicia Toumilovitch, aliciat.slta@gmail.com, *(041) 995 1255*

Supervised by:

Dr. Joanne Neille, joanne.neille@wits.ac.za, *(011) 717 4574*

Ms. Skye Adams, skye.adams@wits.ac.za, *(011) 717 4484*

(In isiXhosa)

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

Mhlekazi/Nkosazana,

Ndingu Alicia Toumilovitch ongumfundi we Masters in Speech Pathology kwi University yase Witwatersrand eRhawutini. Inxalenye yezifundo zam kukwenza uphando-nzulu. Isihloko sophando endilwenzayo sithi, "Ukuphicotha imbali yobomi babantu abaphila nesifo sokuchaphazeleka engqondweni (schizophrenia), ngokusebenzisa abantu abaphila nesisifo abafumana uncedo kwisibhedlele esiseMpuma Koloni". Injongo yoluphando kukufuna ukuqonda ukuba esisifo (schizophrenia) sibuchaphazela njani ubomi boluntu lwaseMpuma Koloni.

Ngokoluphando ndilwenzayo ndiyakumema ukuba ube ngomnye wabantu endizokubenza uvavanyo eUitenhage Provincial Hospital, ngokubabuza imibuzo mayela nokuphila nesisifo. Oluvavanyo luqulethe ukuba ndikubuze imibuzo, ndive imbali yobomi bakho, izakuthatha iyure enye. Ndingaphinda ndicele ukudibana nawe ngolunye usuku , iyure enye, ukuqinisekisa ukuba ibali lakho ndilibhale kakuhle na. Umququzeleli wam koluphando uyakube enathi, kwaye oluvavanyo sakulenza ngesiXhosa ukuba unqwenela njalo. Ngemvume yakho, ndikwacela ukulushicilela oluvavanyo ngomtshini wokushicilela, ndilugcine ngokukhuselekileyo kwi computer yam, lwaziwe ndim kuphela.

Akukho nzuzo ozakuyifumana ngokuthatha inxaxheba koluphando, kwaye akukho nasohlwayo uyakusifumana ngokungathathi nxaxheba. Ukuba uzakuza esibhedlele ukuzothatha inxaxheba koluvavanyo, uzakuyibuyiselwa imali okhwele ngayo. Unako ukuphuma nagaliphi ixesha eluvavanyweni okanye ungawuphenduli umbuzo ongafuniyo ukuwuphendula. Oluvavanyo aluzukuveza gama lakho nangcombolo yakho, nayo yonke ingcombolo oyinikezileyo izakugcinakala kwi computer yam, ingafumaneki nakomnye umntu ngaphandle kwam. Ndizakusebenzisa igama elingelilo ukumela wena nokukhusela isazisi sakho ekuphetheni kwam uphando nzulu olu.

Kungabakhona ingxaki yokungaziva mnandi ukuphindaphinda ukbalisa imbali yakho, xa uziva ngolohlobo phakathi novavanyo, sizakuyeka siphinde siqale ngelinye ixesha. Ukuba udinga uncedo lwenkxaso okanye uncedo emva kovavayo, ezinkonzo ziyafumaneka eklinik azihlawulelwa. Ndizakukubhalela incwadi eya kwi psychologist, ndikucwangcisele nexesha lokudibana naye xa udinga inkxaso noncedo.

Ukuba unemibuzo mayela noluphando nzulu, wamkelekile ukuqhakamshelana nam kwezi nkcukacha zingezantsi. Oluphando nzulu luyakubhalwa njengengxelo eyakufumaneka kugcino lwethala lweencwadi zaleUniversity. Ukuba ufuna iingcombolo, ukuqonda into okanye ukukhalazela into mayela nokubasemthethweni koluphando, qhakamshelana nalenombolo ilandela + 27(0)11 717 1408, email hrec-medical.researchoffice@wits.ac.za/ Rhulani.Mkansi@wits.ac.za

Alicia Toumilovitch

Researcher:

Alicia Toumilovitch, aliciat.slta@gmail.com, *(041) 995 1255*

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Dr. Joanne Neille, joanne.neille@wits.ac.za, *(011) 717 4574*

Ms. Skye Adams, skye.adams@wits.ac.za, *(011) 717 4484*

ii. For the Next of Kin

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

Dear Sir/Madam,

My name is Alicia Toumilovitch and I am a Masters student in Speech Pathology at the University of the Witwatersrand in Johannesburg. As part of my studies I must undertake a research project. The title of my project is "Exploring the life narratives of individuals with schizophrenia utilizing out-patient services at a district level hospital in the Eastern Cape, South Africa". The aim of this research project is to find out how the diagnosis of schizophrenia affects the life experiences of individuals living within the community in the Eastern Cape.

As part of this project I would like to invite your family member to take part in an interview at Uitenhage Provincial Hospital, where I will ask them about their experiences of living with schizophrenia. This activity will involve my asking questions, and hearing their story, and will take around one hour. I may need to meet with them on a different day again, for one hour, to confirm that my information is correct. My research mediator will be with us, and will conduct the interview in isiXhosa if they would prefer. With your permission, I would also like to record the interview using a digital device. The audio recordings will be stored safely on my computer, and only I, the researcher, will have direct access to them. While you will not be interviewed, you are welcome to see the types of questions I will be asking. In addition, your family member may request you to be present in the interview

Your family member will not receive any direct benefits from participating in this study, and there are no disadvantages or penalties for not participating. If you are coming to the hospital only for the interview, you will be remunerated for your taxi fare. You may leave at any time or not answer any question if you do not want to. The interview will be completely anonymous as I will not reveal your family member’s name or any identifying information, and the information you give to me will be held securely on my computer and not disclosed to anyone else. I will be using a false name to represent their participation, in my final research report. There is the risk that they may feel uncomfortable retelling your story; if they feel distressed at any point of the interview, we will stop or continue another time. If you or your family member need some support or counselling services after the interview, these are available free of charge at the clinic. I will write you a referral letter for the psychologist, and arrange an appointment, should you wish to be counselled.

If you have any questions afterwards about this research, feel free to contact me on the details listed below. This study will be written up as a research report which will be available online through the university library website. If you have any queries, concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (medical), telephone + 27(0)11 717 2700, email hrec-medical.researchoffice@wits.ac.za/ Rhulani.Mkansi@wits.ac.za

Yours sincerely,

Alicia Toumilovitch
Researcher:

Alicia Toumilovitch, aliciat.slta@gmail.com, *(041) 995 1255*

Supervised by:

Dr. Joanne Neille, joanne.neille@wits.ac.za, *(011) 717 4574*

Ms. Skye Adams, skye.adams@wits.ac.za, *(011) 717 4484*

(In isiXhosa)

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

Mhlekazi/Nkosazana,

Ndingu Alicia Toumilovitch ongumfundi we Masters in Speech Pathology kwi University yase Witwatersrand eRhawutini. Inxalenye yezifundo zam kukwenza uphando-nzulu. Isihloko sophando endilwenzayo sithi, "Ukuphicotha imbali yobomi babantu abaphila nesifo sokuchaphazeleka engqondweni (schizophrenia), ngokusebenzisa abantu abaphila nesisifo abafumana uncedo kwisibhedlele esiseMpuma Koloni". Injongo yoluphando kukufuna ukuqonda ukuba esisifo (schizophrenia) sibuchaphazela njani ubomi boluntu lwaseMpuma Koloni.

Ngokoluphando ndilwenzayo ndiyakumema ukuba ube ngomnye wabantu endizokubenza uvavanyo eUitenhage Provincial Hospital, ngokubabuza imibuzo mayela nokuphila nesisifo. Oluvavanyo luqulethe ukuba ndikubuze imibuzo, ndive imbali yobomi bakho, izakuthatha iyure enye. Ndingaphinda ndicele ukudibana nawe ngolunye usuku , iyure enye, ukuqinisekisa ukuba ibali lakho ndilibhale kakuhle na. Umququzeleli wam koluphando uyakube enathi, kwaye oluvavanyo sakulenza ngesiXhosa ukuba unqwenela njalo. Ngemvume yakho, ndikwacela ukulushicilela oluvavanyo ngomtshini wokushicilela, ndilugcine ngokukhuselekileyo kwi computer yam, lwaziwe ndim kuphela.

Akukho nzuzo ozakuyifumana ngokuthatha inxaxheba koluphando, kwaye akukho nasohlwayo uyakusifumana ngokungathathi nxaxheba. Ukuba uzakuza esibhedlele ukuzothatha inxaxheba koluvavanyo, uzakuyibuyiselwa imali okhwele ngayo. Unako ukuphuma nagaliphi ixesha eluvavanyweni okanye ungawuphenduli umbuzo ongafuniyo ukuwuphendula. Oluvavanyo aluzukuveza gama lakho nangcombolo yakho, nayo yonke ingcombolo oyinikezileyo izakugcinakala kwi computer yam, ingafumaneki nakomnye umntu ngaphandle kwam. Ndizakusebenzisa igama elingelilo ukumela wena nokukhusela isazisi sakho ekuphetheni kwam uphando nzulu olu. Ilungu losapho lingkwazi ukungena nawe eluvavanyweni olu.

Kungabakhona ingxaki yokungaziva mnandi ukuphindaphinda ukbalisa imbali yakho, xa uziva ngolohlobo phakathi novavanyo, sizakuyeka siphinde siqale ngelinye ixesha.

Ukuba udinga uncedo lwenkxaso okanye uncedo emva kovavayo, ezinkonzo ziyafumaneka eklinik azihlawulelwa. Ndizakukubhalela incwadi eya kwi psychologist, ndikucwangcisele nexesha lokudibana naye xa udinga inkxaso noncedo.

Ukuba unemibuzo mayela noluphando nzulu, wamkelekile ukuqhakamshelana nam kwezi nkcukacha zingezantsi. Oluphando nzulu luyakubhalwa njengengxelo eyakufumaneka kugcino lwethala lweencwadi zaleUniversity. Ukuba ufuna iingcombolo, ukuqonda into okanye ukukhalazela into mayela nokubasemthethweni koluphando, qhakamshelana nalenombolo ilandela + 27(0)11 717 2700, email hrec-medical.researchoffice@wits.ac.za/ Rhulani.Mkansi@wits.ac.za

Alicia Toumilovitch

Researcher:

Alicia Toumilovitch, aliciat.slta@gmail.com, *(041) 995 1255*

Supervised by:

Dr. Joanne Neille, joanne.neille@wits.ac.za, *(011) 717 4574*

Ms. Skye Adams, skye.adams@wits.ac.za, *(011) 717 4484*

3. Informed Consent Form

i. For the Participant

UMTHOMBO WOPHUHLISO LOLUNTU
SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

I, ………………………………………..(name), agree to participate in this research project, “Exploring the life narratives of individuals with schizophrenia utilizing out-patient services at a district level hospital in the Eastern Cape, South Africa”. The research has been explained to me and I understand what my participation will involve.

I agree that I am willing to participate from my own will

YES **NO**

I agree that my name, or identifying information will not be mentioned

YES **NO**

I agree that the researcher may use anonymous quotes in the research report

YES **NO**

I agree that the interview may be audio recorded

YES **NO**

………………………………………………..…… **(Signature)**

…………………………………………………….. **(Name)**

…………………………………………………….. **(Date)**

(In isiXhosa)

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

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Mna, …………………………………………… (igama, igama lesizalwane) ndiyavuma ukuthatha inxaxheba koluphando nzulu. Uphando olu lucacisiwe kum kwaye ndiyaluqonda ukuba luqulethe ntoni.

"Ukuphicotha imbali yobomi babantu abaphila nesifo sokuchaphazeleka engqondweni (schizophrenia), ngokusebenzisa abantu abaphila nesisifo abafumana uncedo kwisibhedlele esiseMpuma Koloni"

Ndiyavuma ukuba ndithatha inxaxheba ngokwentando yam **EWE HAYI**

Ndiyavuma ukuba umphandi angasebenzisa amanqaku

ngokukhuselekileyo kulenkcaza **EWE HAYI**

Ndiyavuma ukuba uvavanyo lungashicilelwa **EWE HAYI**

……………………………………………...…… **(Insayino-gama)**

……………………………………………...……**(Igama)**

……………………………………………...……**(Umhla)**

ii. **For the Next of Kin**

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

I, ………………………………………..(next of kin’s name), agree for ………………………………………..(name), to participate in this research project. The research has been explained to me and I understand what their participation will involve.

I agree that I am willing to allow my family member to participate from my own will

YES NO

I agree that my name, and family member’s name, or identifying information,
YES NO
will not be mentioned

I agree that the researcher may use anonymous quotes
YES NO
in the research report

I agree that the interview may be audio recorded
YES NO

…………………………………………………..…… **(Signature)**

………………………………………………………. **(Name)**

………………………………………………………. **(Date)**

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

(In isiXhosa)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

Mna, ………………………………………… (igama, igama lesizalwane) ndiyavuma ukuthatha inxaxheba koluphando nzulu. Uphando olu lucacisiwe kum kwaye ndiyaluqonda ukuba luqulethe ntoni.

"Ukuphicotha imbali yobomi babantu abaphila nesifo sokuchaphazeleka engqondweni (schizophrenia), ngokusebenzisa abantu abaphila nesisifo abafumana uncedo kwisibhedlele esiseMpuma Koloni"

Ndiyavuma ukuba ndithatha inxaxheba ngokwentando yam **EWE HAYI**

Ndiyavuma ukuba umphandi angasebenzisa amanqaku **EWE HAYI**

ngokukhuselekileyo kulenkcaza **EWE HAYI**

Ndiyavuma ukuba uvavanyo lungashicilelwa **EWE HAYI**

…………………………………………………..…… **(Insayino-gama)**

…………………………………………………..……**(Igama)**

…………………………………………………..……**(Umhla)**

iii. For the Site

UMTHOMBO WOPHUHLISO LOLUNTU
SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

To whom it may concern,

<u>Request for Permission to Conduct Research at Uitenhage Provincial Hospital</u>

My name is Alicia Toumilovitch and I am a Masters student in Speech Pathology at the University of the Witwatersrand in Johannesburg. I am currently employed by the Eastern Cape Department of Health, at Uitenhage Provincial Hospital, as a Speech Therapist & Audiologist.

As part of my studies I have to undertake a research project. The title of my research project is “Exploring the life narratives of individuals with schizophrenia in the rural Eastern Cape, South Africa”. The aim of this research project is to find out how the diagnosis of schizophrenia affects the life experiences of individuals living within the community in the rural Eastern Cape.

I would like to please request permission to conduct research at Uitenhage Provincial Hospital. As part of this project I would like to invite participants to take part in an interview, where I will ask them about their experiences of living with schizophrenia. This activity will involve my asking them questions, and hearing their story, and will take around one hour with each participant. I may need to meet with them on a different day again, for one hour, to confirm that my information is correct. My research mediator will be with us, and will help translate if necessary. With their permission, I will also record the interview using a digital device. The audio recordings will be stored safely on my computer, and only I, the researcher, will have direct access to them.

I would like to conduct the research in the Speech Therapy office in the hospital, where I see patients on a daily basis. I will only need a little space in which I can have an hour of privacy with the patient, as the interview will be audio recorded for analyzing purposes. I intend to interview the participant at the site, and therefore require the use of site when agreed on.

The interview will be completely confidential and anonymous as I will not reveal any identifying information, and I will be using a pseudonym (false name) to represent their participation, in my final research report. If they experience any distress or discomfort, we will stop the interview or resume another time. If they need some support or counselling services following the interview, these are available free of charge at the clinic, which they will be referred to with a letter.

If you have any questions afterwards about this research, feel free to contact me on the details listed below. If you have any queries, concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (medical), telephone + 27(0)11 717 2700, email hrec-medical.researchoffice@wits.ac.za/ Rhulani.Mkansi@wits.ac.za

Yours sincerely,

Alicia Toumilovitch

STA0035068

Researcher:

Alicia Toumilovitch, aliciat.slta@gmail.com, *(041) 995 1255*

Supervised by:

Dr. Joanne Neille, joanne.neille@wits.ac.za, *(011) 717 4574*

Ms. Skye Adams, skye.adams@wits.ac.za, *(011) 717 4484*

UMTHOMBO WOPHUHLISO LOLUNTU
School of Human & Community Development

SPEECH PATHOLOGY AND AUDIOLOGY
School of Human and Community Development
Faculty of Humanities
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4571 Fax: (011) 717 4559

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

Agreement Form

I, Dr Bongani Alson Mabaso (*name*), **do /** ~~**do not**~~ give permission (*please circle*), for Miss Alicia Toumilovitch (Principal Investigator), to complete her research study, titled "Exploring the life narratives of individuals with schizophrenia in the rural Eastern Cape, South Africa", at Uitenhage Provincial Hospital. The researcher may use the site – i.e. the Speech Therapy office (or an alternative room may be suggested), to interview participants. The procedures have been explained and I understand that all participant information will be anonymized. All questions have been addressed. No data will be collected until Ethical Clearance has been granted by the University of the Witwatersrand Human Research Ethics Committee (Medical). A copy of the certificate may be provided once issued.

Signed:		**Signed:**	
Name:	Bongani Mabaso *(CEO of site)*	**Name:**	Alicia Toumilovitch *(Principal Investigator)*
Contact:	0833884747 *(Email/ Phone number)*	**Contact:**	072 283 9989 *(Email/ Phone number)*
Date:	26/2/2019	**Date:**	26/02/2019

iv. Referral to Psychology

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

To whom it may concern,

Agreement for referring participants post-interview for counselling at Uitenhage Provincial Hospital

My name is Alicia Toumilovitch and I am a Masters student in Speech Pathology at the University of the Witwatersrand in Johannesburg. I am currently employed by the Eastern Cape Department of Health, at Uitenhage Provincial Hospital, as a Speech Therapist & Audiologist.

As part of my studies I have to undertake a research project. The title of my research project is “Exploring the life narratives of individuals with schizophrenia in the rural Eastern Cape, South Africa”. The aim of this research project is to find out how the diagnosis of schizophrenia affects the life experiences of individuals living within the community in the rural Eastern Cape.

This activity will involve my asking them questions, and hearing their story, and will take around one hour with each participant. I may need to meet with them on a different day again, for one hour, to confirm that my information is correct. My research mediator will be with us, and will help translate if necessary. The interview will be completely confidential and anonymous as I will not reveal any identifying information, and I will be using a pseudonym (false name) to represent their participation, in my final research report. If they experience any distress or discomfort, we will stop the interview or resume another time.

Because the participant may be at-risk of experiencing psychological stress and stigmatization, when retelling their life experiences about living with schizophrenia, they may need to be referred for counselling following the interview.

I would like to please request permission to refer potential participants to the psychology department at Uitenhage Provincial Hospital, where they can be counselled free of charge. I will

provide the participant with a referral letter, and ask for your assistance in helping the participant, by counselling them or referring them to the nearest psychologist at the clinic.

If you have any questions afterwards about this research, feel free to contact me on the details listed below. If you have any queries, concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (medical), telephone + 27(0)11 717 2700, email hrec-medical.researchoffice@wits.ac.za/ Rhulani.Mkansi@wits.ac.za

Yours sincerely,

Alicia Toumilovitch

STA0035068

Researcher:

Alicia Toumilovitch, aliciat.slta@gmail.com, *(041) 995 1255*

Supervised by:

Dr. Joanne Neille, joanne.neille@wits.ac.za, *(011) 717 4574*

Ms. Skye Adams, skye.adams@wits.ac.za, *(011) 717 4484*

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Agreement Form

I, MARISKA SINGLETON *(name)*, agree that Miss Alicia Toumilovitch (primary researcher) may refer participants (who are out-patients at Uitenhage Provincial Hospital) to the psychology department at Uitenhage Provincial Hospital to be counselled after their interview, if needed. The services will be free of charge, or as per the policy classification system at the hospital. The participant may be referred to the nearest clinic for counselling if necessary; this will be arranged for the participant. The research has been explained and I am aware of the data collection process.

Psychology Department:	***Primary Researcher:***
Signed	*Signed*
MARISKA (GMMIG) SINGLETON	A. Toumilovitch
Name	*Name*
041 995 1034.	041 995 1255
Contact Number	*Contact Number*

4. Audio Recording Consent Form

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

I, ………………………………………..(name), agree to participate in this research project. The research has been explained to me and I understand what my participation will involve.

Mna, …………………………………………… (igama, igama lesizalwane) ndiyavuma ukuthatha inxaxheba koluphando nzulu. Uphando olu lucacisiwe kum kwaye ndiyaluqonda ukuba luqulethe ntoni.

I agree that the interview may be audio recorded

YES **NO**

Ndiyavuma ukuba uvavanyo lungashicilelwa

EWE **HAYI**

…………………………………………………..…… **(Signature)**

……………………………………………………….. **(Name)**

……………………………………………………….. **(Date)**

5. Semi-Structured Interview Questions

Main Question:

“Please tell me about your life story about what it is like living with schizophrenia…”

Guiding Questions:

- What do understand by schizophrenia?
- How do you think you got it?
- Are you treating it? How?
- Do the people around you in the community know you have schizophrenia?
- Are you able to do things like everybody else in the community?
- Do you think it will go away?
- What are your biggest challenges living with schizophrenia?

6. Research Mediator Forms

i. Checklist Form

Used by the researcher:

The researcher made a list of potential research mediator candidates, based on the following criteria: The individual must be…

- Verbally fluent in isiXhosa and English (and Afrikaans)
- Understand isiXhosa and English (and Afrikaans)
- Of isiXhosa background
- Over the age of 18 years
- Minimal matric completion
- Have a basic understanding of schizophrenia
- Available between February-December 2019

ii. Agreement Form/ Contract

I, Zusiphe Ruxwana (name and surname), agree to take the role of the research mediator for the duration of this research project. I have been given *Guidelines*, and understand what is required of me. I understand that this is a once-off project, and I will not be employed by the researcher, but will be remunerated at the end for my assistance, based on the *Wits Student Vacation Rates Form 2019*, which has also been provided to me.

My details are:

Date of birth: 6/04/1996

Contact number: 041 995 1349

Home language: isiXhosa/ English

Other language(s): English

Highest level of education: Bachelor of Communication Pathology (Audiology)

I confirm that I am: *(please tick)*

- ☐ Fluent in isiXhosa and English
- ☐ Of isiXhosa background
- ☐ Over the age of 18 years
- ☐ Have a minimal matric completion
- ☐ Available between (March-August 2019)

Signed: *Z. Ruxwana*

Date: *30/01/2019*

7. Signs of Distress

To be used during the interview to note any signs of distress

I = Increased

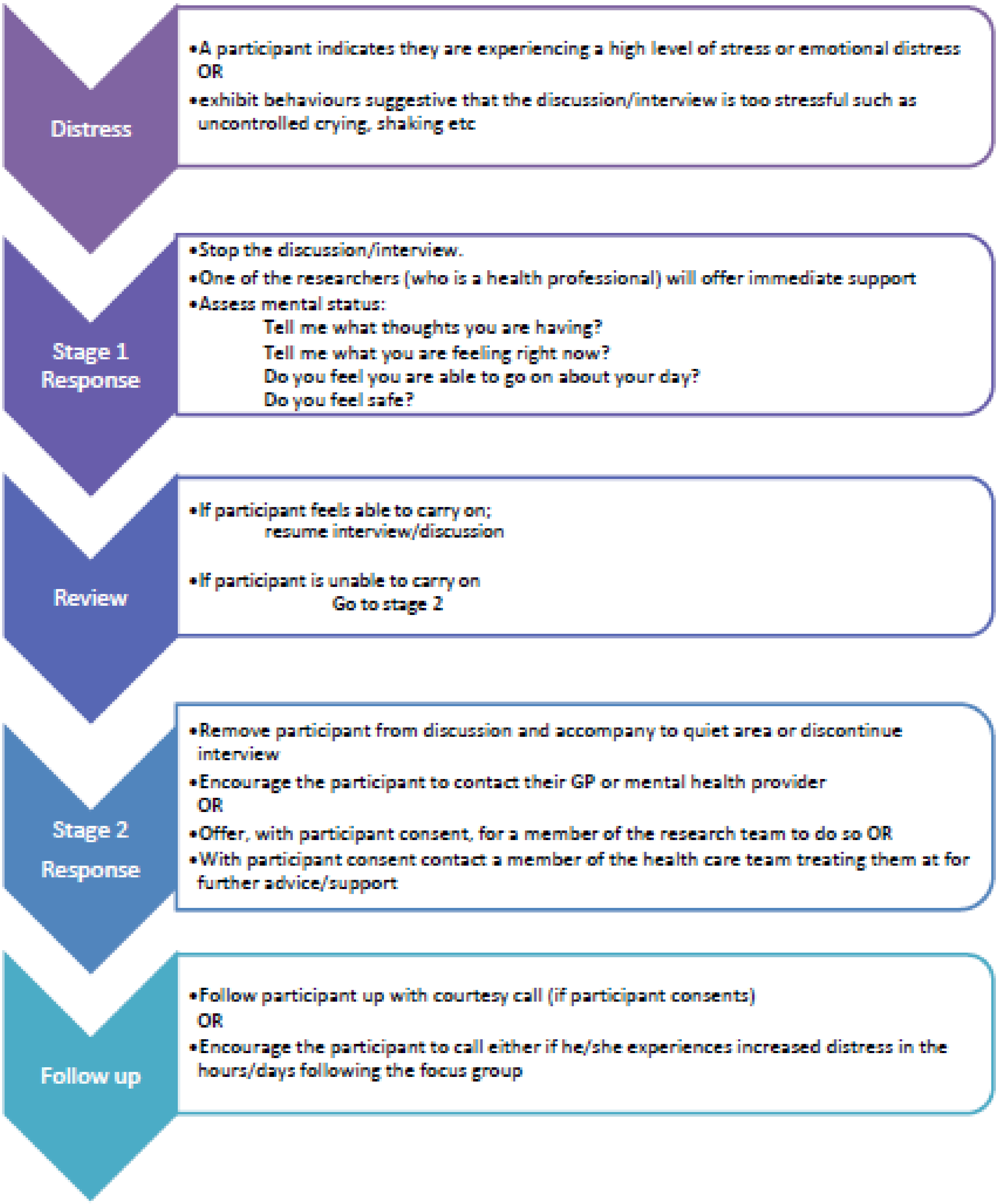
D = Decreased

CHANGES IN:	**HOW IT CHANGED:**	**INTERVIEW TERMINATED:**
Voice	Intensity I/D Tone I/D	
Facial expression	Complete mood change Emotionally labile	
Behaviour	Aggressive Withdrawn	
Language	Change of topic/ avoidance Sudden refusal to talk/ silent	
Other		

8. Distress Protocol (Haigh & Williams, 2015)

Distress Protocol 1:The protocol for managing distress in the context of a research focus group /interview

(Modified from : Draucker CB, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350)



Distress

- A participant indicates they are experiencing a high level of stress or emotional distress
OR
- exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking etc

Stage 1 Response

- Stop the discussion/interview.
- One of the researchers (who is a health professional) will offer immediate support
- Assess mental status:
  Tell me what thoughts you are having?
  Tell me what you are feeling right now?
  Do you feel you are able to go on about your day?
  Do you feel safe?

Review

- If participant feels able to carry on;
  resume interview/discussion
- If participant is unable to carry on
  Go to stage 2

Stage 2 Response

- Remove participant from discussion and accompany to quiet area or discontinue interview
- Encourage the participant to contact their GP or mental health provider
OR
- Offer, with participant consent, for a member of the research team to do so OR
- With participant consent contact a member of the health care team treating them at for further advice/support

Follow up

- Follow participant up with courtesy call (if participant consents)
OR
- Encourage the participant to call either if he/she experiences increased distress in the hours/days following the focus group

Distress Protocol 2: The protocol for managing distress in the context of a research focus group /interview management

McCosker,H Barnard, A Gerber, R (2001). Undertaking Sensitive Research: Issues and Strategies for Meeting the Safety Needs of All. Forum: Qualitative Social Research, 2(1)

Pre-data collection

- The researcher should consider the potential physical and psychological impact on the researcher of the participants description of life experiences
- The researcher should consider how many interviews could be undertaken in a week
- The researcher should be aware of the potential for emotional exhaustion

Data collection stage

- If the topic is potentially sensitive/distressing data collection to be undertaken by two members of the research team
- regular scheduled debriefing sessions with a named member of the research team
- may be encouraged to journal their thoughts and feelings which may then become part of fieldwork notes in some research approaches

Analysis

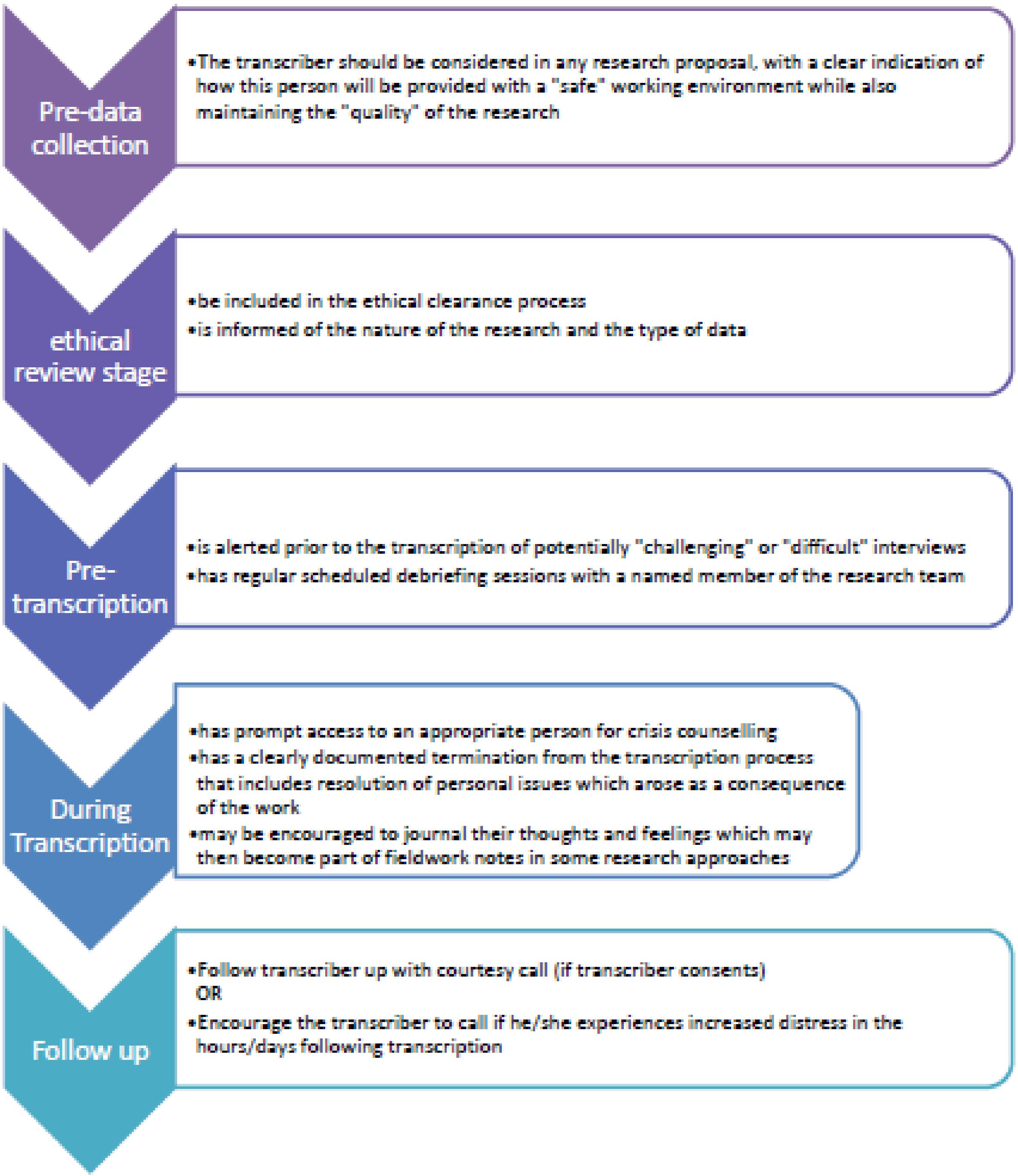
- is alerted prior to transcription review of potentially "challenging" or "difficult" interviews
- has regular scheduled debriefing sessions with a named member of the research team

Follow up

- Encourage the researcher to access a research mentor if he/she experiences increased distress in the hours/days following transcription

Distress Protocol 3: The protocol for managing distress in the context of a research focus group /interview transcription

(Gregory, D Russell, C Phillips, L (1997). Beyond textual perfection: transcribers as vulnerable persons. Qualitative Health Research, 7(2), 294-300.)



Pre-data collection

- The transcriber should be considered in any research proposal, with a clear indication of how this person will be provided with a "safe" working environment while also maintaining the "quality" of the research

ethical review stage

- be included in the ethical clearance process
- is informed of the nature of the research and the type of data

Pre-transcription

- is alerted prior to the transcription of potentially "challenging" or "difficult" interviews
- has regular scheduled debriefing sessions with a named member of the research team

During Transcription

- has prompt access to an appropriate person for crisis counselling
- has a clearly documented termination from the transcription process that includes resolution of personal issues which arose as a consequence of the work
- may be encouraged to journal their thoughts and feelings which may then become part of fieldwork notes in some research approaches

Follow up

- Follow transcriber up with courtesy call (if transcriber consents)
  OR
- Encourage the transcriber to call if he/she experiences increased distress in the hours/days following transcription