

Caregivers' perception regarding mental health disorders, living conditions and access to psychiatric programs: A case study of KwaXimba, eThekweni Municipality, KwaZulu-Natal, South Africa.

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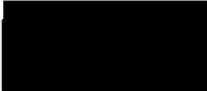
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Declaration

I, Zenelise Nosipho Mbambo (216003895) acknowledge that all work presented in the thesis entitled: *Caregiver perception regarding mental health disorders, living conditions and access to psychiatric programs: a case study of KwaXimba, eThekweni Municipality, KwaZulu-Natal, South Africa* is my own work. All sources that were used have been duly recognised and the research that has been conducted has not been submitted in any form to any other institution for the fulfilment of a degree. It is being submitted to fulfil the requirements for the degree of Master of Science in Geography and Environmental Management in the College of Agriculture, Engineering and Science at the University of KwaZulu-Natal, South Africa.



Signature

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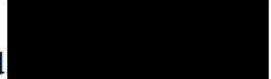
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The research was carried out under the supervision of Dr Sphumelele Lucky Nkomo (University of KwaZulu-Natal) and co-supervisor Dr Sumaiya Amod Desai (University of KwaZulu-Natal).

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Abstract

In rural clinics within developing countries MHC is limited to medication. Taking medication without psychiatric evaluation and the necessary rehabilitation leads to continuing impairments in patients, implying a continued need for assistance from caregivers. The lack or absence of any of these critical components increases the burden of caregiving for caregivers and their households, without the possibility of patients being rehabilitated and reintegrated into their communities.

Educating communities about MHDs has been identified as a key part of destigmatising MHD, improving adherence to medication, leading to a decreased burden on caregivers and their households. This research aims to explore the awareness, knowledge and perceptions about MHDs, the challenges, and opportunities available for rural caregivers and to analyse accessibility and availability of MHC services for patients with MHDs and their caregivers in rural communities of KwaXimba. This research adopted a case study approach utilising a descriptive research design. Also, this study utilised triangulation. Quantitative questionnaires were administered to 35 purposively and snowball sampled caregivers in KwaXimba. Data collected from questionnaires was processed through Statistical Package for Social Science version 28, presented, and analysed descriptively. The key informant was purposively sampled for the qualitative interview and data from the interview was analysed thematically.

The results of this study indicated that witchcraft was perceived to be the most common cause of MHDs (89%). Majority of patients (80%) sought traditional methods as the first choice for treating the MHD. Strong common beliefs about MHDs exist and influence treatment routes preferred by caregivers. Stigma and discrimination were common affecting patients (60%) and caregivers (60%) respectively. Lack of awareness about MHDs was predominantly influenced by instilled traditional beliefs about MHDs (71%). The nearest clinic was 6-10 km away and the nearest hospital 55-60 km away from KwaXimba. There were no rehabilitation or facilities for the disabled. Only 3% of patients had accessed and engaged with a rehabilitation program in the nearest town, Pietermaritzburg. Social grants were the most available social service for patients and caregivers. Psychiatric medication was the only available MHC service available in the local clinic. There are no other MHC services that were available. Mental health literacy needs to be improved to enable timely seeking of medical assistance, adherence to medication, empowerment of patients and caregivers as well as decrease stigma. Collaboration between traditional and medical care needs to be introduced, where traditional leaders, caregivers, patients, health care personnel, non-governmental organisations and communities are informed about the rehabilitation of patients.

Key words: mental health disorders, rehabilitation, caregivers, psychiatry and stigma

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List of acronyms

AIDS	: Acquired immunodeficiency syndrome
CBR	: Community Based Rehabilitation
CREATE	: Community Recovery Achieved Through Entrepreneurship
GLAAS	: Global Analysis and Assessment of Sanitation and Drinking-Water
HIC	: High Income Countries
HIV	: Human immunodeficiency virus
IEA	: International Energy Agency
KZN	: KwaZulu-Natal
LMICs	: Low- and Middle-Income Countries
MHC	: Mental Health Care
MHDs	: Mental Health Disorders
NDoH	: National Department of Health
NGOs	: Non-Governmental Organisations
NIDS	: National Income Dynamics Study
PMB	: Pietermaritzburg
PHC	: Primary Health Care
PWSMI	: Persons With Serious Mental Illness
RDP	: Reconstruction and Development Programme
SA	: South Africa
SAHRC	: South African Human Rights Commission
SASH	: South African Stress and Health
SASSA	: South African Social Security Agency
SDGs	: Sustainable Development Goals
SMHDs	: Severe Mental Health Disorders
SONA	: State of the Nation Address
SPSS	: Statistical Package for Social Science
SSA	: Sub-Saharan Africa
TB	: Tuberculosis
UNAIDS	: Joint United Nations Programme on HIV/AIDS

YLD : Years Lived with Disability

WHO : World Health Organisation

Chapter 1 Introduction

1.1. Contextualisation of the study

Mental health disorders (MHDs) have become a significant health challenge worldwide. In 2008 MHDs accounted for 14% of the disease burden (Ganasen et al., 2008:23; WHO, 2013; 4355, WHO, 2020). MHDs are responsible for 19% of years lived with disability in Sub-Saharan Africa (SSA) (Vancampfort et al., 2017:2) and are expected to reach 500 million people by 2050 (Addo et al., 2018). MHDs are, therefore a significant contributor towards disability, which render people incapable of living and developing to their full potential. Approximately 45 million people in SSA are expected to have a MHD by 2050 (Charlson et al., 2014:4). MHDs are ranked the third highest disease burden in South Africa (SA) (Bradshaw et al., 2007; Ramlall et al., 2010; WHO, 2015). Therefore, a significant part of the SSA population (45 million) will require mental health care (MHC) services. Despite such staggering statistics of MHDs and their ability to render people disabled, they continue to receive insufficient resources.

The mental health sector is prevalently not prioritised compared to other diseases that take precedence, leading to decreased funding, resources, and opportunities (Davids et al., 2019). This makes caregiving for patients with MHDs challenging for households and caregivers, as MHC services are limited. Due to existing challenges, developing nations are bound to experience the effects of MHDs profoundly. These challenges include poor service provision, poverty, unavailability and inaccessibility of MHC, low expenditure for the mental health sector, poor implementation of policies, mental health illiteracy, and shared religious and cultural beliefs, which lead to stigma.

1.1.1 Lack of service provision

SSA rural areas predominantly lack development and essential services, such as roads, schools, sanitation, and other services. Approximately half of the African population cannot access safe drinking water (Atangana and Oberholster, 2022). Seventy-six percent do not have access to electricity (Nilsson and Lindqvist, 2019:1). SSA has the poorest road access, with over half of roads remaining unpaved (Wenz et al., 2020). Development and service provision remains a challenge. Most Africans live in rural areas facing poverty and lacking primary resources (Mubila and Yepes, 2017). More than half of the population thus lives in areas with minimal access to essential services. According to Burns and Tomita (2015), rural areas continually have inadequate access to Primary Health Care (PHC). MHC could be very little or non-

existent in rural areas lacking essential health care services. This is partly due to only 2.1% of the health expenditure being spent by the mental health sector in SSA (WHO, 2021:54).

1.1.2. Poor policy implementation

Another challenge for African countries is the poor implementation of MHC policies. This is partly due to the lack of resources to adequately implement policies and the racial past, which excluded the majority from MHC. In the case of SA post-democratic elections, all South African were provided with the right to access all health care services. However, bridging the gap between those with access and those without has proven difficult for the South African government. Rural areas lack development and face poor service provision (Parry and van Eeden, 2015; Gradín, 2021). Nonetheless, we cannot overlook the great strides the government has made in providing equality and more equitable distribution of resources by prioritising populations and areas previously disadvantaged (Giraut and Maharaj, 2002).

1.1.3. Poverty

Poverty in Africa is another challenge, as SSA is home to the majority of the extremely poor population with a very small chance of escaping poverty (Beegle et al., 2016; Winsemius et al., 2018). Living in poverty could lead to MHDs, as people experiencing poverty survive under stressful, food insecure, unemployable, and vulnerable circumstances (Patel, 2007; Myer et al., 2008; Sorsdahl et al., 2011). Additionally, there is a stigma attached to poverty, which might make people living in poverty hesitant to request assistance. This could make the role of caregiving even more difficult for people with low incomes. Family members predominantly assume this role for patients with MHDs. Households could be further pushed into poverty by the MHD as they may lose income upon the patient's illness. Available financial capital will now be directed towards acquiring assistance for the patient, leading to financial strain on the household.

1.1.4. Caregiving

The role of caregiving has become prominent due to the shift from institutionalisation towards deinstitutionalisation. This shift advocates for community rehabilitation instead of being kept in mental institutions, which were known for unfavourable conditions (Andersson et al., 2013; World Health Organisation (WHO) 2013; Schierenbeck et al., 2013). This shift was in line with MHC into PHC advocated for by the WHO. However, this is only achievable in community settings where there are available MHC services for patients to engage with after being discharged. Therefore, in rural communities where development and access to essential

services are poor, caregiving becomes difficult as caregivers must provide care with minimal to no medical assistance to the patients, intensely increasing the socio-economic burden on caregivers (Savage and Bailey, 2004; Addo et al., 2013; Bhimani, 2014; Allers et al., 2015; Vaingankar et al., 2016). This lack of MHC services is detrimental not only for the caregivers but also to the patient, as the patient's state may debilitate, adding more responsibilities for the caregiver.

1.1.5. Rural MHC

The WHO has recommended that MHC be included or introduced into PHC (WHO, 2008), the local clinics in SA where patients seek medical assistance at entry (Cullican, 2006). The primary objective of PHC is to provide health care to communities within the areas in which they live and work to allow improved living (Ssebunnya et al., 2010). Including MHC in PHC implies that local clinics make MHC services available to the rural community. The strong relationship between mental and physical health has further indicated the need for integrating mental health into PHC (Saxena and Skeen, 2012). MHD research conducted in High Income Countries (HIC) countries suggests that integrated health care services are more effective (Archer et al., 2012; Hay et al., 2012). Rural clinics, however, work in under-resourced conditions leading to poor health care service provision. For instance, nurses do not have the right to diagnose and initiate patients with MHDs on treatment; patients are referred to the nearest hospital (Cullican, 2006). Post-diagnosis patients can collect medication from the local clinic, but that is the only psychiatric service the clinic can offer (Brooke-Sumner et al., 2016). This presents another challenge, as psychiatric medication cannot rehabilitate the patient and enable reintegration into society without psychological evaluation and rehabilitation (WHO, 2001; Government Gazette, 2002; Angermeyer and Dietrich, 2006; Pereira et al., 2011; Balaji et al., 2012; Wozniak et al., 2015). Furthermore, impairments tend to continue for patients who only take medication (Phahladira et al., 2019).

1.1.6. Rehabilitation

Rehabilitation is an essential component of MHD treatment for patients. Psychiatric rehabilitation enables patients to perform physical, social, emotional, and intellectual activities optimally with minimal assistance (Anthony and Liberman, 1986; Angermeyer and Dietrich, 2006) thus enabling their reintegration into society. The continuance of impairments in patients who only take medication indicates the dire need for rehabilitation in patients. Absentia of such critical components of MHC services results in numerous challenges for patients with MHDs and caregivers in rural areas of SSA and SA. This could subsequently lead to the imprisonment,

homelessness and hospitalisation of patients suffering from mental health disorders (Angermeyer and Dietrich, 2006; Slade et al., 2008; Moran et al., 2016).

Where MHC services are available and accessible, facilities have insufficient professional staff and lacking in health resources to enable health care service provision. Therefore, patients with MHDs in rural areas face numerous challenges in accessing MHC services and predominantly lack the much-needed psychiatric help (Murray and Keller, 1991; Gale and Lambert, 2006; Yellowlees et al., 2008; Saraceno et al., 2007; Smalley et al., 2010; Willcox et al., 2015; Hoeft et al., 2018; Hughes et al., 2019), more specifically in SSA (ABABA, 2012; Selamu et al., 2015).

1.1.7. Mental health illiteracy and stigma

Mental health illiteracy is a challenge because when people cannot recognise MHDs and misdiagnose MHDs, it could lead to inappropriate treatment options with no possibility of rehabilitation. Jorm (2000) asserts that mental health literacy includes recognising mental illness, knowing about risk factors, causes and knowing how to acquire available professional help. Mental health illiteracy impedes recognition of MHDs, seeking appropriate aid and medication adherence. Misconceptions about MHDs from shared religious and cultural beliefs about MHDs lead to stigma and discrimination against patients.

According to Stefanovics et al. (2016), stigma remains a widely acknowledged challenge in providing mental health services, which shapes perceptions about MHDs and their treatment negatively. Stigma raises hesitation and distrust of psychiatric treatment, hindering treatment instigation and continuance (Stefanovics et al., 2016; Szabo et al., 2017). Stigma simultaneously impacts the way both society and mental health professionals treat patients of MHDs. A strong relationship exists between shared beliefs and attitudes towards patients with MHDs (Angermeyer et al., 2015). Beliefs about the causes of MHDs, such as bad omen, witchcraft, angry ancestor or even punishment from God (Shankar et al., 2006; Vijayalakshmi et al., 2013; Razali et al., 1996; Patel et al., 1997; Sheikh and Furnham, 2000; Suhail, 2005; Okello and Ekblad, 2006; Waqas et al., 2014) have a negative influence. Such beliefs trigger stigma towards patients with MHDs, leading to patients and caregivers choosing not to seek out MHC to avoid having connections to negative connotations (Shankar et al., 2006; Vijayalakshmi et al., 2013; Razali et al., 1996; Patel et al., 1997; Sheikh and Furnham, 2000; Suhail, 2005; Okello and Ekblad, 2006; Waqas et al., 2014).

Educating communities about mental illness was identified as a critical opportunity for destigmatising MHDs in rural communities (Gurung et al., 2017; Davids et al., 2019). Early detection and initiation of medication for MHDs can be improved by (improving mental health literacy) and educating people and general health care workers (Fekadu et al., 2016). Informed community members could support patients with MHDs leading to treatment instigation, adherence, and improved state of patients. The burden of caregiving can be reduced significantly.

Shared beliefs about MHD causes tend to influence the route taken by caregivers in dealing with MHDs. The preference for traditional methods frequently leads to patients delaying seeking medical assistance (Saravanan et al., 2005; Sorsdahl et al., 2013). MHC services are often sought-after traditional methods have not led to improvement in patient's state (Ikwuka, 2021). Delays in seeking appropriate treatment may lead to the patient developing more than one MHD, making it difficult to treat. The responsibility of providing care for patients suffering from MHDs thus is quite challenging, specifically in rural areas, due to the many factors interwoven into the burden of disease and lack of access to MHC services. Improving MHC services in rural areas is, therefore, complex. It requires many parts of the community, government, caregivers, health workers and patients to work together. This could enable the reintegration of patients into society, decreasing the burden of caregiving while enabling patients to be productive members.

1.2. Problem statement

The lack of MHC services and mental health illiteracy, linked to shared beliefs about MHDs, hinder the possibility of patients to be reintegrated into their communities. MHDs receive inadequate funding, resources and opportunities contributing to mental health illiteracy. Communicable diseases in SSA, which have received more attention, have improved rates of treatment instigation, continuance and adherence leading to improved states of patients. Early detection and treatment are possible for such diseases, including prevention. Information on MHDs, however, remains lacking (Weller, 2006; Saxena et al., 2007; UNAIDS, 2010; Saxena and Setoya, 2014; WHO, 2019); this lack of knowledge about MHDs hinders its early detection, its effective treatment, and the possibility of rehabilitating patients of mental health disorders. Patients suffering from other illnesses can seek medical attention timeously, acquire appropriate treatment, recover, and continue to lead a normal life, reach their full potential and contribute significantly to their households and communities.

1.2.1. Significance of study

The lack of knowledge and understanding of MHDs and their treatment (mental health illiteracy) hinders the possibility of patients receiving appropriate medical treatment timeously and their chance to rehabilitate and reintegrate into society. The absence of the opportunity for patients with MHDs to be treated and rehabilitated imposes the role of caregiving as a lifetime commitment for caregivers and households. Poor mental health literacy contributes to the disease burden in poor rural communities where health services are scarce, reinforcing economic inequalities and disempowering patients suffering from mental disorders. The caregivers and patients cannot engage in any developmental activities, which may drive households into poverty by creating economic hardship, food insecurity and debilitating mental states of patients. The patient is deprived of the opportunity to reach their full potential and contribute significantly to their households and communities. The discrimination and stigma attached to MHDs, and poverty make it even more difficult for caregivers and their households to seek assistance rendering them powerless. This leads to patients with MHDs being perceived as inferior, with no societal role and people who cannot amount to anything leading to stagnant, if not deteriorating, states of patients and households without any chance of improvement. In the worst case, patients are imprisoned, kept in mental institutions, and never found by families until mortality. It is, therefore, essential to conduct research on mental health disorders in particularly vulnerable communities where the burden is carried by caregivers and their households solely with minimal to no chance of rehabilitation. In an environment where development is lacking and services are unavailable, it is of dire importance that rehabilitation and other initiatives which assist caregivers are available. Mental health research thus needs to be conducted to enable increased accessibility, availability, and psychoeducation, leading to improved lives of MHD patients and caregivers. There is a significant number of research in HIC pertaining to children's MHC (Klasen and Crombag, 2013) hence the common strategies for preventing and treating MHDs within educational institutions (Fazel et al., 2014). This indicates that research enables countries to effectively implement policies and strategies rendering MHC accessible at all levels.

Existing studies on MHD have focused on the following:

1. Traditional beliefs about MHD and stigma (Razali et al., 1996; Jorm, 2000; Adelek, 2001; Harries et al., 2002; Agara et al., 2008; Kpobi et al., 2019; Forthal et al., 2019; Kitafuna, 2022);

2. Strengthening mental health systems and the integration of mental health into PHC (Angermer and Dietrich, 2006; Lund et al., 2008; Kiima, and Jenkins, 2010; Betancourt and Chambers, 2016; Mugisha et al., 2016; Lund et al., 2016; Hoeft et al., 2018; Abdulmalik et al., 2019);
3. State of mental health (Constitution of the Republic of South Africa. (No. 108 of 1996); Demyttenaere et al., 2004; Lund et al., 2010; Harris et al., 2011; Saxena et al., 2014; Paruk et al., 2016; Adu-Gyemfi, 2017; Davids et al., 2019);
4. Experiences of caregiving (Mavundla et al., 2009; Banyini, 2012; Coomer, 2013.; Bhimani 2014; Anokye et al., 2018);
5. Preferred route of treatment (Abiodun, 1995; Patel et al., 1997; Chuma et al., 2007; Lasebikan et al., 2012; Odinka et al., 2014; Benedicto et al., 2016; Roberts et al., 2018; Nartey et al., 2019);
6. Access to health care (Addow et al., 2013; Hodgkinson et al., 2017; Mangundu et al., 2020 Spivak et al., 2018); and
7. Rehabilitation (Uys et al., 1997; Botha et al., 2008; Simpson and Zambuko, 2011; Lund et al., 2013; Peck et al., 2014; Rosenbaum et al., 2014; Lemmi et al., 2017; Brooke-Summer et al., 2016; MacDougall et al., 2022).

This research, however, seeks to explore the living conditions of caregivers and MHD patients in rural KwaZulu-Natal (KZN), customised by poverty and lack of services. It seeks to unpack the everyday challenges of caregivers living with MHD patients and accessing psychiatric services. Furthermore, the research explores the impact of low mental health literacy on preferred methods of treating MHDs, and delays leading to the deteriorating states of patients. The manner in which poor mental health literacy disempowers caregivers, patients, and their households. Lastly, this research explores coping mechanisms and strategies utilised by caregivers living with MHD patients in under-resourced and lacking conditions. This research aims to contribute towards that gap in mental health research in SSA by drawing on case studies, research conducted in SSA and conducting fieldwork in KwaXimba, eThekweni Municipality, KZN one of the poorest provinces (KwaZulu-Natal) (StatsSA, 2017).

1.3. Aim

To explore and describe caregivers' perceptions on mental health disorders and the challenges faced by rural caregivers looking after patients with mental health disorders in rural communities of KwaXimba, eThekweni Municipality, KZN.

1.4. Objectives

1. To explore caregivers' perception on the causes of mental health disorders in patients within KwaXimba eThekweni Municipality, KZN.
2. To identify the socio-economic conditions of caregivers looking after patients with mental health disorders within KwaXimba eThekweni Municipality, KZN.
3. To critically analyse caregivers' perceptions about traditional beliefs, stigma, and the experiences of caregivers of patients suffering from mental health disabilities.
4. To identify the accessibility of mental health care services for patients with mental health disorders in KwaXimba eThekweni Municipality, KZN.
5. To provide recommendations for the improvement of mental health care policies.

1.5. Research questions

1. What do caregivers perceive to be the cause of mental health disorders in patients?
2. What are the socio-economic conditions of households with patients suffering from mental health disorders?
 - 2.1 Is poverty and social issues exacerbating the condition of patients suffering from mental health disorders?
 - 2.2. Is the lack of mental health literacy hampering the patient from obtaining a proper diagnosis from a health professional?
3. According to caregivers is the lack of mental health literacy, common beliefs and traditional pathways hampering the patient from obtaining a proper diagnosis from a health professional?
 - 3.1. How does the lack of a proper diagnosis impact the household, especially the caregiver?
 - 3.2. What traditional beliefs about MHDS exist within the community and in what manner do these influence the treatment methods sought by patients and caregivers?
4. Do the health care services offer adequate and accessible services to the mental health patient and caregivers?

5. What strategies and improvements can be implemented to lessen the burden on caregivers?

1.6. Chapter outline

This chapter provides the background, motivation, aim, objectives and research questions for the entire research. Chapter two is the conceptual framework and literature review. This chapter reviews the literature pertaining to research topic, starting from global, Africa, SSA and then South African rural areas. Chapter three focuses on the methodology. All methodological tools are explained. Data collection and analysis steps are explained. Chapter four is the data analysis. The quantitative data that was collected is analysed through Statistical Package for Social Science (SPSS) version 28 and the qualitative data was interpreted thematically. Lastly, chapter 5 will assess the findings of the research in relation to the objectives, provide suggestions and deliver a conclusion to the research. The conceptual framework will also be re-evaluated in relation to this study.

1.7. Chapter summary

This chapter has provided the background, motivation, aim, objectives and research questions for the entire research. A brief overview of the literature pertaining to the challenges faced by poverty-stricken caregivers and the complexities interwoven into the burden of caregiving for caregivers of patients with MHDs has been provided. In order to improve access to MHC services in rural areas, collaboration and participation of all stakeholders is recommended alongside MHD education to decrease mental health illiteracy.

Chapter 2 Literature overview

2.1. Introduction

In the previous chapter the overall research aim, objectives and research questions were discussed whilst elaborating on the background and motivation for the study. This chapter focused on the literature overview. In order to identify gaps in research, studies need to initially investigate the state of mental health in terms of what is existing (Opondo et al., 2020). Therefore, this review seeks to review relevant literature in relation to the challenges faced by patients and caregivers in SSA. This review seeks to provide a comprehensive evaluation of literature on the subject matter by evaluating the state of mental health in SSA, challenges faced by the MHC sector in SSA, as well as challenges for patients and caregivers. This literature overview focused on the following key areas, (i) the condition of and availability and accessibility of MHC services for rural communities, (ii) mental health literacy as a contributory factor to the challenge of mental health, (iii) beliefs and stigma, (iv) living conditions and (v) rehabilitation programmes.

2.2 Literature overview

2.2.1. Overview of Mental Health in Sub-Saharan Africa

Human and resource shortages remain some of the biggest challenges to mental health in Africa, specifically in rural areas (Burns, 2011; Kverno, 2016; WHO, 2017; Davids et al., 2019). According to the World Bank (2015) in 2011 approximately 900 million people lived in SSA with majority of them living in rural areas, which are faced with poverty as well as a lack of resources (Mubila and Yepes, 2017). In SSA rural areas continually face the challenge of having inadequate health care services as clinics and hospitals are under resourced and unable to provide appropriate health care to surrounding communities (Saraceno et al., 2007; Peck et al., 2014; Burns and Tomita, 2015). Underdevelopment of rural areas in SSA is largely attributed to the colonial era, in which rural areas, occupied by Africans were left undeveloped (Jacobs and Hart, 2014). Such colonial legacies of segregation and underdevelopment of rural areas are still evident despite governments' efforts (Giraut and Maharaj, 2002; Gilson and McIntyre, 2007; Coovadia et al., 2009; Richards., 2018). A plethora of studies have shown that rural health care in SSA remains to have the highest shortage of human resources and the largest treatment gap (Kohn et al., 2004; Alem et al., 2009; Kakuma et al., 2011; Federal Democratic Republic of Ethiopia Ministry of Health, 2012; Patel et al., 2013; Paula et al., 2014; Selamu et al., 2015). The lack of research on MHDs in SSA also contributes towards the treatment gap, as policy implementation will continue to be poor due to the lack of research.

Rural health research in SSA has gained considerable attention considering major outbreak of diseases such as malaria and Human Immunodeficiency virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) amongst others, however limited studies have focused on MHDs (Weller, 2006; Saxena et al., 2007; (Joint United Nations Programme on HIV/AIDS) UNAIDS, 2010; Saxena and Setoya, 2014; WHO, 2019). Health care access for researched diseases has improved significantly, as communities are more informed about symptoms, where to seek medical assistance and collect medication leading to improved adherence, continuation, and results (Gray et al., 2015; Geffen, 2017). However, access to MHC remains inadequate. Patients with MHDs in rural areas face numerous challenges in accessing MHC services and predominantly lack the much-needed psychiatric help (Murray and Keller, 1991; Gale and Lambert, 2006; Yellowlees et al., 2008; Saraceno et al., 2007; Shah et al., 2009; Smalley et al., 2010; Willcox et al., 2015; Hoeft et al., 2018; Hughes et al., 2019), more specifically in SSA (Federal Democratic Republic of Ethiopia Ministry of Health, 2012; Selamu et al., 2015).

This lack of access to MHC in SSA is further contributed to by the low expenditure dedicated to the mental health sector. Shockingly until 2005 many of SSA had not been able to integrate mental health into PHC (WHO, 2005; Skeen et al., 2010). This implies that MHC services were unavailable in rural settings where only PHC was available. In 2007 majority of African states dedicated less than 1% of their health expenditure towards the mental health sector (Saxena et al., 2007:881). In SSA only 2.1% mental health expenditure is dedicated to this sector (WHO, 2021: 52) which remain inadequate reinforcing the neglect faced by the mental health sector. The mental health expenditure is different in SSA countries. For instance, in Botswana only 1% was utilised for mental health, in comparison to South Africa where approximately 7.7% (Docrat et al., 2019:716) to 8% (Aloshore et al., 2019:2; WHO, 2013) was utilised in certain districts; Vancampfort et al., 2017). MHDs are prevalently given inadequate, and less attention compared to other physical illnesses leading to decreased funding, resources, and opportunities for MHC services (Davis et al., 2019). Subsequently leading to the imprisonment, homelessness and hospitalisation of patients suffering from MHDs (Angermeyer and Dietrich, 2006; Slade et al., 2008; Moran et al. 2015).

The treatment gap between MHDs and other illnesses is approximately 92% in SA, implying that the treatment rates for MHDs remains extremely low (Docrat et al., 2019:717; Lund et al., 2015). As such approximately only 10% of the patients with MHD receive treatment. However approximately half of patients in high income countries received treatment (Jorm et al.,

2017:90). These are staggeringly low numbers indicating deficient treatment rates and the severity of the lack of access hence the challenges associated with it. Patients in rural areas carry an even heavier burden of disease as medication remains the solely available MHC service for them (Brooke-Sumner et al., 2016). The reintegration of patients into their communities however requires psychological evaluation, treatment and rehabilitation (WHO, 2001; Government Gazette, 2002; Angermeyer and Dietrich, 2006; Pereira et al., 2011; Balaji et al., 2012; Wozniak et al., 2015). The deficiency of such critical components renders it impossible for the reintegration of patients, whilst creating numerous challenges for patients and caregivers. The lack or absence of services needed by patients increases the burden and responsibilities of caregiving.

The lack of knowledge about MHDs or the lack of mental health literacy hinders caregivers and patients from acquiring appropriate MHC timeously (Jorm, 2000; Ganasen et al., 2008). Poor mental health literacy leads to patients and caregivers failing to recognise MHDs leading to mistreatment or even not knowing where to acquire appropriate assistance. Delays in seeking MHC have been known to be caused by stigma leading to hesitation and reluctance in patients due to cultural beliefs associated with MHDs (Omenyo, 2006; Twumasi, 1975; Nsereko et al., 2011). In many non-western cultures, there exists common cultural beliefs about the causes of MHDs such as bad omen, witchcraft, bad relations with ancestors, the evil eye, sickening of the soul and punishment from God (Shankar et al., 2006; Vijayalakshmi et al., 2013; Razali et al., 1996; Patel et al., 1997; Sheikh and Furnham, 2000; Suhail, 2005; Okello and Ekblad, 2006; Waqas et al., 2014). Such beliefs trigger stigma towards patients, which influences caregivers and patients towards not seeking MHC to avoid being associated with such sensitivities (Shankar et al., 2006; Vijayalakshmi et al., 2013; Razali et al., 1996; Patel et al., 1997; Sheikh and Furnham, 2000; Suhail, 2005; Okello and Ekblad, 2006; Waqas et al., 2014). The lack of knowledge and mental health literacy together with cultural beliefs about MHDs associated with evil and bad connotations become another barrier for rural patients and caregivers.

High levels of poverty and the geographical isolation for many rural communities further contributes to delays in seeking medical attention, as costs of travelling to health facilities and acquiring medical attention are often unaffordable (Linard et al., 2012; Lund et al., 2013; Burns, 2015). Poor socio-economic conditions, unavailability, and inaccessibility of MHC in rural areas implies limited to no possibility of rehabilitation of patients thereby contributing immensely to the burden of diseases caused by MHDs (Yellowlees et al., 2008; Uys, 2009;

Gurung et al., 2017; Stefanovics et al., 2016; Hoeft et al., 2018). The lack of access to MHC in rural areas indicates that MHC has not been successfully integrated into PHC (clinics) which is available in rural areas. The integration of mental health into PHC (advocated for by the (WHO, 2013)) holds the potential of improving access to MHC thereby decreasing the burden of caregiving for caregivers and households.

Considerable improvements have been acknowledged in countries where the integration of mental health into PHC have been successful. This improvement has led to improved lives for patients and caregivers through increased involvement in mental health initiatives. For instance, increased involvement of caregivers and families of patients in Senegal, the collaboration of the mental health sector with traditional healers in Ghana, group therapy in Uganda and agricultural villages used as rehabilitation in Tanzania (Wiley-Exley, 2007; Patel et al., 2007; Montia, 2008; Monteiro and Balogun, 2014). Initiatives such as the combination of mental health and sustainable livelihoods programmes by the BasicNeeds in Ghana, Kenya, Tanzania and Uganda and community-based rehabilitation (CBR) in rural Ethiopia also indicate progress towards alleviating poverty amongst households with patients suffering from MHDs (Raja et al. 2012; Lund et al. 2013; Asher et al., 2016; Tirfessa et al., 2019). In Ethiopia the integration of mental health into PHC has improved access for patients through the Programme for Improving Mental health care (PRIME) project which is active in two other SSA countries namely South Africa and Uganda (Shidhaye, 2015; Fekadu et al., 2016). PRIME has the potential of a 50% success rate in replicable sites (Shidhaye, 2015:36). All these initiatives have yielded results through improvements in patients' lives (require less assistance), caregivers and their households as the burden of caregiving has decreased.

Despite these achievements, mental health research remains limited throughout rural areas on the African continent (Wei, 2008; Davids et al., 2019) regardless of it being crucial to strengthening mental health systems in Low-Middle Income Countries (LMICs) (Saxena et al., 2011; Betancourt and Chambers, 2016). Without research on MHDs, its challenges and the potential of rehabilitation programs within SSA, the mental health sector will continue to be neglected and receive very little resources. Evidence of improvement in the lives of patients as a result of CBR in middle-income countries is much more visible than in less developed countries (Asher et al., 2016). The lack of evidence of the outcomes of CBR hinders the effective implementation of such programmes (Sharma, 2007; Finkenflügel et al., 2008; Alavi and Kuper, 2010). There is evident paucity of research on the burden carried by caregivers of patients with MHDs (Addo et al., 2018).

The Africa regions (consisting of 35 African countries) contributed the lowest percentage (2%) to mental illness research (WHO, 2019:24). According to the WHO (2019:24) a total of 64 646 research papers were published in 2019 globally, which accounted for only 4.6% of published research. This means that the Africa region published approximately 1293 papers of mental health research in 2019 compared to approximately 5300 papers published by the European regions (WHO, 2019:24). The lack of research and evidence of successful implementation of rehabilitation programmes which assist patients and caregivers hinders proper implementation and adequate allocation of resources towards such initiatives. The latter implies that caregivers and patients with MHDs in SSA will continue to bear the burden without adequate MHC services. In an environment where development is lacking, and services are unavailable it is of dire importance that rehabilitation and other initiatives which assist caregivers are readily available. It is thus undisputable that mental health in SSA warrants for more research to be conducted to enable increased accessibility, availability and psychoeducation leading to improved lives of patients and caregivers.

In order to identify gaps in research, studies need to initially investigate the state of mental health in terms of what is existing (Opondo et al., 2020). Therefore, this review seeks to review relevant literature in relation to the challenges faced by patients and caregivers in SSA. This review seeks to provide a comprehensive evaluation of literature on the subject matter by evaluating the state of mental health in SSA, challenges faced by the MHC sector in SSA, as well as challenges for patients and caregivers. In addition, this literature review will focus on the following key areas, (i) the condition of and availability and accessibility of MHC services for rural communities, (ii) mental health literacy as a contributory factor to the challenge of mental health, (iii) beliefs and stigma, (iv) living conditions and (v) rehabilitation programmes.

2.2.2. Review methodology

A few key words were utilised throughout this review: rural, mental disorders, caregiver, stigma, and rehabilitation. These terms are explained below:

Rural: is a term which is very difficult to explain as it has different connotations for developing and developed countries. However, this paper focuses on a developing context thus this term will be used when referring to a sparsely populated area, lacking development, with villages or small towns as centres and located away from the city centre (Cousins, 2016; IFAD, 2010; Wiggins and Proctor, 2001).

Mental disorder: is a term that is used by the WHO to “denote a variety of mental and behavioural disorders that can be categorised with the International Statistical Classification of Diseases and Related Health Problems, Tenth revision (ICD-10)” (WHO, 2013:6).

Caregiver: is generally defined as a friend or relative who provides aid without receiving monetary compensation from a person with chronic or disabling condition (Pearlin et al., 1990; Family Caregiver Alliance, 2006).

Rehabilitation: comprises of health care services that help patients to maintain, improve or restore impaired functioning due to illnesses, injury or disability (WHO, 2017). Psychiatric rehabilitation focuses on “helping individuals develop skills and access resources needed to increase their capacity to be successful and satisfied in the living, working and learning and social environment of their choice” (United States Psychiatric Rehabilitation Association 2007) cited in (Barrett et al., 2013:16).

Based on the nature of this research, these are the key engines utilised Google Scholar, databases such as AJOL, Science Direct, Scopus and Jstor to obtain literature amongst others. Key words such as “mental illness” or “mental disorders” and “stigma”, “caregiver”, “COVID-19 and mental health”, “integration of mental health”, mental disability”, “Africa and colonialism” “poverty and mental illness”, “cultural beliefs about mental health” “mental rehabilitation”, “mental health literacy”, “mental health care” or “psychiatric rehabilitation”, “rural health services”, “rural living conditions”, “mental health in SSA” “mental burden of disease in SSA”, “mental disability grants” and “beliefs about mental illness” were used interchangeably to collect literature from secondary data sources. For institutional references associated with mental health the relevant organisational websites such as WHO. All searches were done in the English medium language. Majority of the literature is focused on SSA, LMICs as the research will be conducted in a LMIC located in SSA. The diagram below depicts internet search results after the use of key terms in relation to the research topic.

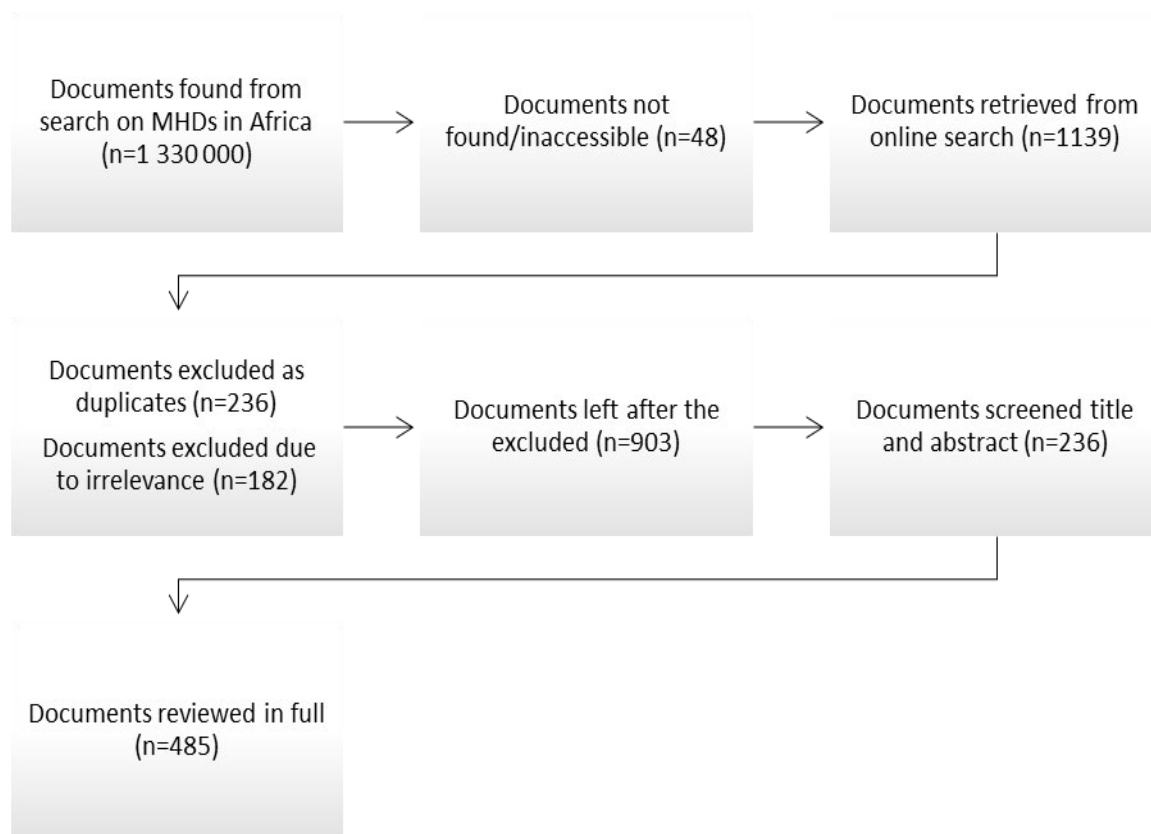


Figure 2.1. Scholarly papers retrieved from databases search engines

2.2.3. Results and discussion

MHDs remain a global challenge (WHO, 2008; WHO, 2012) with the most prevalent being anxiety, substance use and depressive or mood disorders (South African Stress and Health (SASH), 2009; Andersson et al., 2013; Umubyeyi et al., 2014; WHO, 2017). Approximately 300 million (4,4% of the total population) suffer from depression globally while about 264 million suffered from anxiety by 2015 (WHO, 2017). MHDs are conditions which occurs as a disturbance in the patient's brain functioning or reasoning leading to a change in perception, failure to have control over emotions resulting in abnormal behaviour (Addo et al., 2018). Almost 45 million people are expected to have a MHD by 2050, this shall increase the 19% burden of disease which is the principal cause of Years Lived with Disability (YLD) (Vancampfort et al., 2017; Addo et al., 2018). SSA similarly has notable numbers of patients with MHDs and increasing future projections as depicted in Figure 2.2 below.

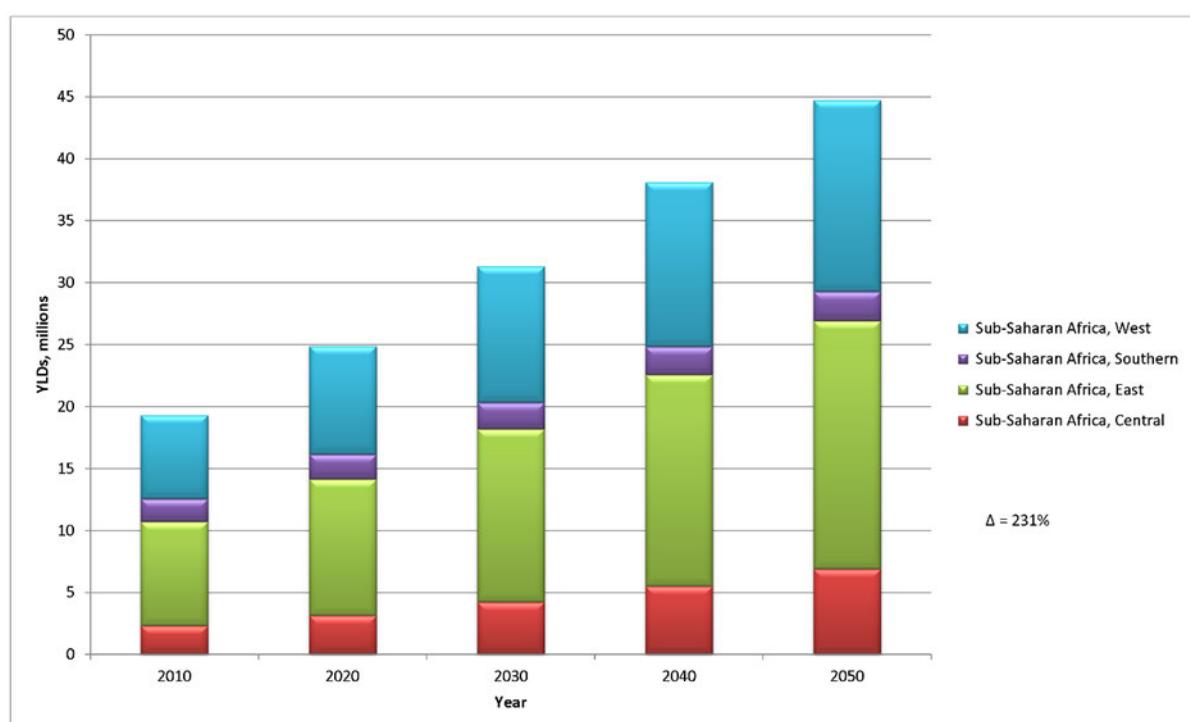


Figure 2.2. Disability burden of mental and substance use disorders in Sub-Saharan Africa over time, all ages (Chrlason et al., 2014)

In relation to Figure 2.2. prevalence of MHDs will increase by 231% before 2050 in SSA (Chrlason et al., 2014:5). However, many SSA countries have a challenge of insufficient health care services which falls short in addressing the increasing burden of commutable and non-commutable diseases inclusive of MHDs (Stein et al., 2008; Murray et al., 2015) due to inadequate infrastructure and being under resourced (Saraceno et al., 2007; Peck et al., 2014; Ofori-Atta et al., 2010). This increase of 231% in MHDs by 2050 implies immense pressure on fragile health care systems, operating in under resourced facilities, more so in rural areas leading to many people having limited to no access to MHC services. Such an increase MHDs will require increased MHC services and resources and better implementation of mental health policies and legislation.

The challenges faced by the mental health sector in SSA are not limited to the lack of services, resources and poor implementation. Strong traditional beliefs exist and influence the treatment methods sought by patients and caregivers. Table 2.1 below provides an overview of the preferred method of treating MHD in SSA.

Table 2.1. Overview of traditional beliefs and preferred methods of treating MHDs in SSA

Country	Reference	Overview	Methods used	Believed causes of MHDs	Preferred method of dealing with MHDs
Ethiopia	Bekele et al. (2009)	To elaborate on the path preferred by patients prior to psychiatric care in Ethiopia.	Participants screened and interviewed. Data collected from patient medical noted where necessary (<i>n</i> = 1044).	(Not provided in article)	5% - traditional healer 31% - religious healer 23% - PHC 41% - MHC
	Girma and Tesfaye (2011)	To explore patterns of treatment seeking behaviour for MHDs in Southwest Ethiopia (hospital-based study).	Quantitative study. Questionnaires provided for participants (<i>n</i> =384)	Spiritual possession (51.6%), the evil eye (15.9%) and 19.0% did not have knowledge of the causes. However, 97.9% believed MHDs are a severe mental health problem.	20% - traditional healer 30% - religious healer 15% - PHC 35% - MHC.
Nigeria	Nonye and Oseloka (2009)	To determine the health-seeking behaviour of mentally ill patients in Enugu, Nigeria.	Questionnaire to determine socio-demographics, common knowledge of MHDs and preferred methods in Enugu hospital Nigeria (<i>n</i> =397).	Demonic and spiritual forces (31.1%), psychological stress (20%), hard drug use (12.4%), enemy poison (8.3%) and familial caused (2.8%).	14 %– traditional healer 34 %– religious healer 20% - PHC 32% - MHC

	Lasebikan et al. (2012)	To determine the relationship between social networks and preferred pathways for MHDs.	Descriptive study utilising structured questionnaires (n=652). Study assessed pathways utilised by patients to assess current MHC.	(Not provided in article)	33% - traditional healer 46% - religious healer 9 %– PHC 12% - MHC
	Odinka et al. (2014)	Study investigated socio-demographic characteristics and their relationship with delays in seeking MHC.	Cross sectional study at Federal Neuropsychiatric Hospital in Enugu, South-eastern Nigeria. Questionnaire adapted from WHO	Cultural and religious beliefs	14.7% - traditional healer 61.1% - religious healer 17.8% - PHC 6.4% - MHC
South Africa	Mkize and Uys (2004)	To unpack the understanding of health care workers of pathways preferred by patients prior to MHC.	Research survey in PMB mental health institution with first time admitted patients (n=15)	MHDs caused by witchcraft (ukuthakatha).	20% - traditional healer 20% - religious healer 60% - PHC 0% - MHC
	Temmingh and Oosthuizen (2008)	To explore pathways to care and treatment delays	Semi-structured questionnaire. Interviews with patients and family members to determine pathways to care	(Not provided in article)	6.6% - traditional healer or religious healer 41.2%-primary health 23.8% - MHC 24.9% - police 3.4% - other

Zimbabwe	Patel et al. (1997)	To determine preferred pathways to care for patients with MHDs and influencing factors.	The Pathways to Care Schedule (PACS) was developed from questionnaires used in previous studies ($n=109$)	Aetiological beliefs believed to be the cause. Spiritual explanation often provided by n'angas.	15 % - traditional healer 9% - religious healer 76% - PHC 0% - MHC
	Booyesen et al. (2016)	To investigate, socio-demographics, common knowledge, preferred methods of treating MHDs with the Muslim community in Harare, Zimbabwe.	Descriptive cross-sectional research. Congregants above 18 years were invited across 3 mosques. Questionnaires were provided to participants ($n=71$).	Possession of evil spirits(jinn) (66%), brain chemical imbalances (65%), stress (62%), witchcraft, sorcery, black magic (43%), traumatic experiences (44%), Envy (24%), genetics (21%), excessive studying (4%), physical and emotional abuse (3%) and use of drugs (3%)	N/A - traditional healers 52% - religious healer 48% - PHC and MHC
Ghana	Ibrahim et al. (2016)	To assess process patients, go through in seeking care and to explore first point of contact pathways.	Cross-sectional study in Pantang psychiatric hospital in Accra, Ghana ($n=107$). Chi Square test utilised. Different regression used to analyse.	Issue of spiritual factors.	23.48% - Traditional and religious healers 26.09% - PHC 50.43% - MHC

			Semi-structured interviews		
	Nartey et al. (2019)	To determine factors which have an influence on pathways to care in Ghana.	Quantitative study utilising questionnaires on demographics, common beliefs (n=542)	Brain dysfunction (36.9%), substance abuse (33.9%), spirituality (25%)	31.6% - Traditional and religious healers 41.4% - PHC 27.3% - MHC
Malawi	Kauye et al. (2015)	To contribute towards knowledge about MHDs prior to preferred pathways of acquiring care.	Interviews through encounter form. Collects demographics of participants. Analysis done with SPSS. (n=128)	Cultural and spiritual beliefs.	22.7% - Traditional and religious healers 62.5% - (nurses and primary clinicians) PHC 11.7% - MHC 3.1% - police
Tanzania	Benedicto et al. (2016)	To assess common knowledge, understanding of MHDs in the Dodoma municipality.	Semi-structured questionnaires. Analysis through SPSS. (n=380)	Causes included heredity, drug abuse, unemployment, family issues, bewitched, poverty, cursed. Medical issues, accident, unaware and others.	26.6 % - traditional healer 23.7% - religious healer - PHC 86.2% - MHC 76.2% - primary health 11% - other (these percentages are derived from different questions)

About a decade ago (2014), 15 out of 48 (31.3%) African countries did not have any legislation for mental health whilst roughly 40% did not have any allocated budget for the sector (WHO, 2005:24; Vancampfort et al., 2017). By 2005 more than 40% of African states had mental health legislation (WHO, 2005; WHO, 2011:17), however evidence of their implementation was lacking (Skeen et al., 2010). Encouragingly by 2017 approximately 69% of countries in SSA had mental health legislation (Vancampfort et al., 2017:11). Despite these encouraging figures, the implementation of mental health policies remains inefficient, this is also attributed to the minimal expenditure dedicated to the sector underlining that the sector remains unprioritised. According to the WHO (2021:52) the Africa (AFR) region dedicates 0.46\$ per capita for MHC which is staggeringly low in comparisons to regions such as Europe (EUR) and Eastern Mediterranean (EMR) which have 46.49 US\$ and 12.8 US\$ (which is both developed regions). It is important to note that WHO Member States are grouped into six regions comprising of (AFR), the Americas (AMR), (EMR), (EUR), South-East Asia (SEAR) and Western Pacific (WPR) (WHO, 2021:52).

Dedicating minimal for the mental health sector brings about a deficit and poor mental health service provision, leading to the high treatment gap in Africa. SSA spends 2.1% for the mental health sector (WHO, 2021:54). The high prevalence of mental health disorders in SSA and future projection (from Figure 2.3.) advocates for more attention, resources, and funds towards this sector. This high prevalence also necessitates for mental health educational programmes which could contribute towards mental health literacy, increasing knowledge about MHDs dispelling myths and stigma associated with this disorder (Hofmann-Broussard et al., 2017).

2.2.4. Access to services in Sub Saharan Africa

Rural areas in Africa remain undeveloped despite great strides made by governments to address the socio-spatial inequalities through more unbiased resource distribution methods (Giraut and Maharaj, 2002; Gilson and McIntyre, 2007; Coovadia et al., 2009; Richards, 2018). Socio-spatial inequalities consisting mainly of undeveloped or underdeveloped rural areas are directly linked to apartheid and its bias colonial rule (Parry and van Eeden, 2015; Gradín, 2021). As such the rural areas in SSA lack development and have poor access to services (Parry and van Eeden, 2015; Gradín, 2021) compared to their urban counterparts (Onokerhoraye, 1978; Olayiwola and Adeleye, 2005; Akpan, 2012). SSA has the poorest access to electricity compared to other developing regions (International Energy Agency (IEA), 2011; World Bank, 2011a; Nilsson and Lindqvist, 2019). Almost 76% of the SSA population still lacked access in 2016 (Nilsson and Lindqvist, 2019:1). Yet access to energy or electricity remains an important

driver for enabling poverty alleviation, financial development, and minimising income inequality (Poloamina and Umoh, 2013).

Inequalities with access to water also remain high as approximately half of Africa's population has limited access to safe drinking water (WHO/UNICEF, 2015:6; WHO/UNICEF, 2019:25 Global Analysis and Assessment of Sanitation and Drinking-Water (GLAAS), 2019)). In SSA approximately 25% has gained access to safe drinking water since the year 2000 (WHO/UNICEF, 2019:24). Many SSA countries have increases access to safe drinking water by up to 25% in 2017 (WHO/UNICEF, 2019:25). Uganda and Ethiopia had a 22% increase, Nigeria had a 23% increase and Mozambique with a 36% increase (WHO/UNICEF, 2019:25). In Kenya it is estimated that only 41% of the population has access to water (Bukachi et al., 2021:677). The SSA region subsequently failed to reach the Sustainable Development Goals (SDGs) from 1990, as the total number of people without access to basic services has increased (WHO/UNICEF, 2019). The inequality to accessing water and sanitation however persists as urban areas have better access than rural areas (Adams and Smiley, 2018; Roche et al., 2017; Adams et al., 2016).

Access to roads is no different, only 34% reside and have access to 2km of rural roads (African Monitor, 2012:10). There is a dire need for the improvement of roads in rural areas in SSA to enable development (Ngezahayo, 2019). Inaccessibility and unavailability remain distinct barriers to health care services in SSA rural areas (Weinert and Long, 1987; Peters et al., 2008; Ganle et al., 2016, Sewell et al., 2019). In Zimbabwe access to health care is influenced by time and distance travelled, financial ability, as well as the availability of health resources (Loewenson et al., 2014). The geographical location of rural communities is a barrier to accessing health care services as these are often located far away and travelling to them can be time consuming and unaffordable. In rural Zimbabwe clinics are a minimum of 10 km away and frequently have a shortage of medication (Nyazema, 2010; Kevany et al., 2012; Mangundu et al., 2020). In Ghana the state of rural roads was identified as an important factor towards accessing health care services (Agbenyo et al., 2017). Good roads improve accessibility, distributing of health care resources and enables timeous referrals of patients but sadly most rural roads in Ghana are not in a good state (Galaa and Daare, 2008; Atuoye et al, 2015; Oppong et al., 2023). Rural areas also struggle to attract qualified professionals due to their remote location and under resourced facilities resulting in poor access and opportunities (Pothier, 1991; British Medical Association Board of Science, 2005; Humphreys, 2009). Combined, the

latter suggests rural health is in a state of paucity which renders caregiving for patients in rural communities extremely difficult and challenging.

2.2.5. Access to mental health services in rural SSA

Past socio-spatial inequalities fragmented health care resulting in MHD patients receiving even greater discrimination and challenges in accessing MHC (Mkhize and Kometsi, 2005; Ramlall, 2012). As such health care facilities remain in centralised urban areas which remain inaccessible to the rural poor in SSA countries such as Ethiopia (Federal Democratic Republic of Ethiopia Ministry of Health, 2012). Post-independence governments have made attempts to address the socio-spatial inequalities and decentralise services however inequities remain (Giraut and Maharaj, 2002; Gilson and McIntyre, 2007; Coovadia et al., 2009; Richards, 2018). The South African National Department of Health (NDoH) has acknowledged that majority of people with MHDs receive no treatment (Kahn, 2013). Most of all MHC services in rural areas are provided by local clinics (Gale and Lambert, 2006; Federal Democratic Republic of Ethiopia Ministry of Health, 2012) which is limited to screening, referrals, and medication (Wallen et al., 2021). In cases where there is a mental health specialist in a rural area, the mental health specialist struggles to deliver services due to limited access to resources (Hoeft et al., 2018). Table 2.2 below briefly depicts the status quo of MHC services and resources in SSA.

County	Reference	Mental health policy	Mental health expenditure	Mental hospital	Psychiatrists	Other Mental health professionals
Botswana	Sidandi et al. (2011)	Enacted in 1971. Developed in 2003, Botswana National Policy on Mental Health provides a framework	-	-	8	Medical officers, psychologists, occupational therapists, social workers, psychiatric and general nurses. There are also about 100 community health nurses.
	Opondo et al. (2020)	Mental health policy was developed in 2003	-	1	11	-
	Brooks et al. (2021)	-	-	1	0.29 per 100 000	17.1 per 100 000 mental health staff, 4.05 mental health nurses, 1.52 psychologists per 100 000, 212 social workers
Kenya	Kokonya et al. (2007)	-	-	-	53 (9 in rural, 44 in urban)	418 trained psychiatric nurses (250 still working in Kenya), 10 medical social workers and very few psychologists.

	Sidandi et al. (2011)	-	-	-	67	-
	Kwobah et al. (2017)	-	-	1	+100	-
	Kiima and Jenkins, (2010)	Draft policy and strategy in 2003/4. Mental Health Policy Guidelines 2009	-	-	16 in 2001, 46 in 2009. 24 in private sector	250 psychiatric nurses, 1 social worker per province
Zimbabwe	Mangezi and Chibanda (2010)	Mental Health Act of 1976 was repealed in 1996. Mental health policy was introduced in 1999.	-	6 public institutions with psychiatric beds	7 (1 working for government, 2 in medical school and the rest in private)	1 director, 1 mental health manager and 9 provincial mental health coordinators
	Kidia et al. (2017)	Mental Health Act was launched in 1996 remained outdated until 2016. Mental Health Policy (2004). Mental Health	-	-	17 (of the 17 registered psychiatrists, only 14 works in MHC in Zimbabwe)	25 clinical psychologists, 463 psychiatric nurses, and 150 occupational therapists

		Strategy (2014-2018).				
Ghana	Bird et al (2011)	Revised in 2000	6.2%	-	0.07 per 100 000	2.58 psychiatric nurses
	Kpobi et al. (2014)	-	-	-	1 per 1.4 million people	-
	Smalls-Mantey (2019)			3	+1 per 1.7 million people	
		Mental Health Act passed in 2012				
South Africa	Ramlall et al. (2010)	MHC Act No. 17 of 2002	0.03% in KZN	-	8 in KZN	
		-	-	-	32 in KZN (6 In rural areas) 0.28 per 100 000	0.32 psychologists, 0.4 social workers, 0.13 occupational therapists and 10 nurses.
	Lund et al. (2010)	First post- apartheid mental health	-	23	0.28 per 100,000 are psychiatrists	11.95 per 100,000 population. (0.45 other medical doctors, 10.08 nurses, 0.32 psychologists, 0.40 social

	policy guideline was approved in 1997. Adoption of the new MHC Act (2002), promulgated in late 2004.				workers, 0.13 occupational therapists, and 0.28 other health or mental health workers)
			-		
Bird et al. (2011)	Developed in 1997	1-8% for different districts		0.28 per 100 000	10.08 psychiatric nurses
			-		
Docrat et al. (2019)	Reformation and strengthening of the Mental Health Care Act 17 of 2002. development of the South African National Mental Health Policy Framework and Strategic	-		0.31 per 100 000 (public sector)	0.97 public sector psychologists, senior clinical psychologists, and principal psychologists per 100 000. 1.53 public sector occupational therapists; 1.07 public sector speech therapists and audiologists, and 1.83 social workers per 100 000 uninsured population.

		Plan 2013– 2020				
Nigeria	Jack-Ide and Uys (2013)	-	-	8	0.09 per 100 000	4 psychiatric nurses, 0.02 psychologists and social workers per 100 000
	Jack-Ide et al. (2012)	A draft Mental Health Bill at the National Assembly. Mental health was adopted into the nation's (PHC) in 1991,	-	8 funded federally and 6 state owned	0.15 per 100 000	2.41 psychiatric nurses, 0.07 psychologists, 0.12 social workers, 0.05 occupational therapists, 8.03 other mental health workers.
	Abdulmalik et al. (2019)	Existing mental health policy premised on the colonial laws, enacted in 1958 as the Lunacy Act. National Mental Health Bill has been drafted	+3.3%	-	1 per 1.6 million people in 2014	7 nurses per 1 million, 1 psychologist per 5 million, 2 social workers per 5 million, and 1 occupational therapist per 10 million people

Uganda	Bird et al. (2011)	Developed in 2000	4%	-	0.08 per 100 000	0.78 psychiatric nurses
	Kgosi et al. (2010)	Mental health program was initiated in 1996. Strengthened by the National Policy and Health Sector Strategic Plan in 1999/2000	4%	28 mental health facilities, 1 hospital	0.08 per 100 000	1.3 per 100 000 mental health workers 0.08 psychiatrists; 0.04 other medical doctors; 0.78 nurses; 0.01 psychologists; 0.01 social workers; 0.01 occupational therapists; and 0.2 psychiatric clinical officers.
		Uganda's first Mental Health Treatment Act (1964). Reviewed in 2010 by Mental Health and Poverty Project. new Mental Health Treatment Act, passed in 2019.	-	-	-	-
Zambia	Bird et al. (2011)	Finalised in 2005	0.38%	-	0.025 per 100 000	0.833 psychiatric nurses

Mwape et al. (2012)	The Mental Health Care Act 1951. Mental health policy in 2005. Still based on the Mental Health Ordinance of 1951.	0.38%	-	3 for 12 million people	132 mental health workers in 2001
Munakampe (2020)	1951 Mental Disorders Act, repealed. The Mental Health Act of 2018 has not been implemented.	>1%	-	-	-

Table 2.2. Table showing an overview of the development of mental health policies, mental health expenditure and available mental health resources in SSA

In many SSA states, MHC professionals are scarce (Murray and Keller, 1991; Selamu et al., 2015; Hoeft et al., 2018). This leads to available resources being overstretched and unable to provide adequate health care services.

The shortage of human resources contributes to the lack of or the late detection of MHDs thereby increasing the treatment gap (Patel et al., 2013; Paula et al., 2014; Liu et al., 2016). The treatment gap in SSA between MHDs and other illnesses is approximately 90%, implying that relatively only 10% of patients with MHDs receive treatment (Luitel et al., 2017:8; Demyttenaere et al., 2004; Kohn et al., 2004; Patel et al., 2013; Paula et al., 2014; Lund et al., 2015).

Fekude et al. (2017:5) argue that around 20% of people suffering from depression in SSA do not have access to MHC services. These statistics clearly indicate that patients predominantly do not have access to MHC services. Human resources are crucial towards MHDs, and the lack of human resources is a huge barrier towards achieving good mental health. In terms of the African region which has the lowest number of mental health workers which is 1.67% per 100 000 population (WHO, 2021). In 2010 Zambia dedicated only 0.4%, Uganda 4%, Ghana 6%, and SA (1-8%) (Omar et al., 2010:3). An increase in the number of mental health specialists is crucial to improve access to mental health and rehabilitation programmes and decreasing the treatment gap (Liu et al., 2016). The integration of mental health into PHC is greatly motivated by the shortage of mental health professionals.

There was a very insignificant increase in the mental health workforce per 100 000 of the population in Africa from 1.4 in 2014 to 1.6 in 2020 (WHO, 2021). These figures indicate that the mental health workforce remain extremely insufficient and therefore rendering it impossible to provide MHC services efficiently. These figures are shockingly low when compared to figures from developed regions such as Europe, where the number increased from 43.5 in 2014 to 44.8 per 100 000 population in 2020 (WHO, 2021). Africa remain with the lowest number of the mental health workforce globally. In SSA countries such as Botswana and SA MHC is made available at all levels (from PHC such as, clinics to psychiatric hospitals), this is inclusive of outpatient care, screening, follow-up, and referral (Jack-Ide et al., 2012; Opondo et al., 2020). General practitioners are responsible for primary MHC in SA (Jack-Ide et al., 2012). In most SSA countries emphasis has been placed on the biomedical with the dispensation of

medication for MHDs (Mugisha et al., 2016), this is indicated by the availability of psychological medication at local clinics.

2.2.6. Poverty

Increased rates of poverty in rural areas are a barrier to accessing MHC services, as health services are already fragile and limited (Yellowlees et al., 2008). A strong unquestionable multifaceted relationship exists between poverty and mental health (Lund et al., 2013; Burns, 2015). Poverty increases the risk of developing MHDs as people living in poverty face food insecurity, social exclusion, lack economic and social support leading to stress or feelings of failure, depression (Patel and Kleinman, 2003; Lund et al., 2010; Tsa et al., 2012; Chiavegatto Filho et al. 2013; Pabayoy et al. 2014). Poor people face food insecurity (Sabin et al., 2003) vulnerability and exposure to challenging life occurrences (Goodman et al., 2001; Hiday et al., 2001; Myer et al., 2008), financial duress due to low or no income (Ludermir and Lewis, 2003; Vorcaro et al., 2004) and bad physical health (DOH, 2013; Scott et al., 2009; Kverno, 2016; Hodgkinson et al., 2017). In Ethiopia, Tirfessa et al. (2019) found that food insecurity and disability was more evident amongst people with MHDs than in households without patients with MHDs.

Living under poor economic conditions leads to the seclusion of poor people from services, opportunities, increased vulnerability, and limited access to social capital (Patel, 2001; Woolard and Leibbrandt, 1999; World Bank, 2000; Philip and Rayhan, 2004). People experiencing poverty predominantly do not have resources and capital due to lack of income or income inequalities. MHDs such as substance use disorders (Galea et al, 2007), first-episode psychosis (Burns and Esterhuizen, 2008) and schizophrenia (Burns et al. 2014) have been identified as some of the MHDs which are associated with income inequality. Depression and anxiety were also found to have a strong correlation with food insecurity (Hadley and Patil, 2006; Sorsdahl et al., 2011; Cole and Tembo, 2011; Hadley et al., 2008; Maes et al., 2010; Jebena et al., 2015). Mortality of patients with Severe Mental Health Disorders (SMHDs) in Ethiopia was found to be associated with malnutrition (Fekadu et al., 2015). Further it was distinguished that households with MHD patients were at a greater risk of facing food insecurity (Tirfessa et al., 2019). The stigma of poverty makes it difficult for poor people to seek mental health related medical attention as this could increase stigma towards themselves and their households (Smith et al., 2013).

On the contrary increased health expenses, loss of employment or income and stigmatisation of people with mental illness leads to MHD patients being at a higher risk of falling into poverty and having lower economic status (Costello et al., 2003). Transportation costs over long distances, consultation fees and the cost of medication become barriers where health services may be available (Kalk et al., 2010; Harris et al. 2011; Nsereko et al., 2011; Jack-Ide and Uys, 2013; Coomer, 2013; Saraceno et al., 2005). Medical expenses inclusive of transportation and the purchasing of medication which are often out of pocket (Zahid and Ohaeri, 2010; Lasebikan and Ayinde, 2013; Jack-Ide et al., 2015; Allers et al., 2015; Hailemariam et al., 2017; Addo et al., 2018). Out of pocket fees are unplanned or budget for but rather the use of any available or borrowed money to cover health expenses. The economic burden has been so severe that infrequently (23%) households of patients with schizophrenia are forced to sell their assets or even taking out loans to accommodate medical expenses (Ohaeri, 2001; Ae-Ngibise et al., 2015). In Ghana 71% caregivers reported a decreased economic income of \$223 coinciding with the estimates of \$224 less for 94% of caregivers for persons collecting pension (Addo et al., 2013; Nortey et al., 2017). Addo et al. (2018) found that approximately 17% to 50% of caregivers of patients with SMHDs in SSA were unemployed, employed caregivers reported having limited time to work due to caregiving. Holistically, decreased time in economic activity and productivity places an additional economic burden on caregivers and the household as a whole and can accelerate the household into poverty (Addo et al., 2018).

Loss of productivity due to caregiving places strain and increases the economic burden on caregivers (Addo et al., 2013). Loss of productivity implies less income generated for households. More studies need to be conducted on research on the extent that caregiving for patients with SMHDs has and its contribution to the economic burden on caregivers as SMHDs are frequently with debilitating symptoms (Addo et al., 2018). A study conducted by Addo et al. (2018) on the economic burden carried by caregivers of patient with MHDs was one of the first in SSA. The paucity of studies in SSA on the economic burden carried by caregivers of patients with MHDs leads to an underestimation and misrepresented data for the planning and legislation for caregivers (Addo et al., 2018). Studies done on the challenges and the burden carried by caregivers have not placed emphasis or their sole focus on the economic burden nonetheless it is crucial to understand the economic burden precisely to enable formulation of appropriate legislation and interventions (Kobelt, 2002; Tarricone et al., 2006; Costa et al., 2012). MHC expenses compiled with decreased time to engage in income generating activities

leads to decreased incomes and reduced standards of living for the caregiver, patient and their households.

2.2.7. Caregiving

Providing care for patients with MHDs in rural areas is significantly difficult as access to MHC is limited. The geographical isolation of rural areas and poor economic conditions create additional barriers to accessing MHC. As such patients rely heavily on caregivers. The shift towards deinstitutionalisation of patients into communities implies shifting responsibilities to households and caregivers (Low et al., 2013). Caregivers provide emotional, financial, and physical support for patients (von Kanel et al., 2006; Swartz and Collins, 2019; Anokye, 2018 WHO, 2001; Inogbo et al., 2017; Addo et al., 2018). Assistance includes providing meals, collection and taking of medication, assistance with day-to-day activities and monitoring the mental state of the patients (Ntsayagae et al., 2019). Assumption of the caregiving role disrupts and may hinder the caregiver's ability to undertake mundane activities, as a significant amount of their time is dedicated towards the patient (Szmukler et al., 1996; WHO, 2001; Awad and Voruganti, 2008). Family roles and plans are disrupted in efforts to accommodate the patient, as the households needs to be mindful of the patient (Ntsayagae et al., 2019). Caregiving can prove challenging and frustrating to the family and specifically the caregiver (Butcher et al., 2001; Swartz and Collins, 2019).

The responsibilities of caregiving for patients with MHDs often lead to the neglect of the caregiver's health, physical and emotional exhaustion (Mavundla et al., 2009; Ntsayagae et al., 2019). An unwell caregiver cannot provide the necessary care and assistance to the patient adequately which could lead to undetected issues, illnesses, and deteriorating state of patients. Challenges associated with caregiving places the caregivers under duress exposing the caregiver to the possibility of developing psychological distress (Faridi et al., 2009; Block al., 2023). Related caregivers are at a greater risk due to genetic predisposition (Ola, 2013). Most caregivers have reported experiencing moderate to very high burdens from caregiving (Saunders, 2003; Caqueo-Úrizar and Gutiérrez-Maldonado, 2006; Vancampfort et al., 2017). This burden of caregiving is evidently difficult on caregivers however households are also affected.

Households are often unable to maintain good social relations as most of their time may be spent on caregiving for patients (Mall et al., 2017; Hailemariam et a., 2017) rather than socialising. Households may struggle to find time to socialise and keep relations good with

other community members, as caregiving takes precedent and minimising free time. This may lead to social exclusion of these families as they receive minimal to no support from their communities (Shankar and Muthuswamy, 2006; Anokye, 2018; Tawiah et al., 2015). The social exclusion is twofold, on the one hand households may not be able to find time to attend social gatherings while on the other hand households were uninvited (Wankiiri et al., 2013; Moahi, 2007). Caregiving thus strains family, social relations, household resources and members, this is aggravated in communities where rehabilitation services are lacking (Ntsayagae et al., 2019).

2.2.8. Beliefs and stigma

Stigma remains a widely acknowledged challenge in the provision of mental health services which shapes perceptions about MHDs and their treatment in a negative light (Stefanovics et al., 2016). Stigma, discrimination and the neglect of MHD patient rights is common in LMICs (Botha et al. 2006; Alonso et al. 2009; Drew et al. 2011; Sorsdahl et al. 2012; Lasalvia et al. 2015). Stigma associated with MHDs leads to the seclusion, rejection, shunning and distancing of communities from patients with MHDs (Shankar et al., 2006; Vijayalakshmi et al., 2013). Stigma towards patients, caregivers and households is predominantly influenced and shaped by certain religious and cultural beliefs about MHDs leading to negative behaviour and discrimination from community members (Thornicroft et al., 2016; Davis et al., 2019). In a study by Tawiah et al. (2015:33) patients experience stigma and discrimination in the form of blame, being ridiculed and mocked (13%), job loss (2%), dropping out of school (3%) and loss of friends (9%). In some non-Western cultures, supernatural or spiritual phenomena, such as witchcraft and possession by evil spirit, are recognised as important causes of MHDs (Razali et al., 1996; Patel et al., 1997; Sheikh and Furnham, 2000; Suhail, 2005; Ikwuka, 2021). A study in Pakistan found that most popular beliefs for causes of MHDs included the evil eye, black magic, punishment from God or demonic possession (Waqas et al., 2014). In different SSA countries MHDs are defined as a ‘mental disturbance’ or the “sickening of the soul” (Okello and Ekblad, 2006) or “burdened hearts” (Kidia et al., 2015) or “madness” (Okello and Ekblad, 2006; Ventevogel et al., 2013). In Zambia participants mentioned that people refer to patients as being mad, bewitched as the MHD is caused by evil spirits (Kapungwe et al., 2010). In Ghana MHDs were believed to be the work of witches and curses (Ofori-Atta et al., 2010). Medical doctors in Nigeria perceived MHDs to be of spiritual causes (Adewuya, 2007). SA perceived MHDs to be associated with context or witchcraft (Mavundla et al., 2009). One of the participants from the study in Ghana by Tawiah et al. (2015:34) mentioned that “If you accept you are mad, people will shun your company, no job, no marriage, no home, so one has

to deny it and when the sickness grows, they roam on the streets, beg for food and that is their end, they cannot get well again”.

Unpleasant relationships with ancestors were also recognised as the spiritual cause of MHDs (Mayston et al., 2020). Kpobi and Swartz (2018) found similar results to (Omenyo, 2006; Twumasi, 1975) where the most common belief for the cause of MHDs was placed on spiritual factors associated with evil. Therefore, people with MHDs are scared of the discrimination and stigma and would rather not seek medical attention to avoid being publicly known as having an MHD. Stefanovics et al. (2016) asserts negative attitudes and social rejection experienced by people with MHDs has an antagonistic impact on the prevention, primary treatment, rehabilitation and the overall quality of life of mentally disabled individuals. As such common religious and traditional beliefs about the causes of MHDs influence the treatment method adopted by caregivers and patients.

Caregivers from rural areas prefer to utilise traditional or religious methods in times of sickness such as dealing with MHDs (Sodi et al., 2011; Nortje et al., 2016). Traditional methods are further encouraged by that their utilisation is without discrimination. Traditional healers have also been known to be affordable as patients can pay on credit (Campbell et al., 2008). In Tanzania Hailemariam et al. (2017) found that participants preferred traditional or spiritual healing as their choice of treatment (Hailemariam et al, 2015) while in another study participants indicated utilising biomedical alongside traditional and spiritual. Nsereko et al. 2011 found that patients with MHDs in Uganda frequently utilised traditional healers and later sought medical mental health services (Ikwuka, 2021) argues that this was done after traditional methods showed no improvement in the patient's state. The use of traditional and religious methods is preferred however Kgobi et al. (2018) also found that in Nigeria patients that use medical services has also increased. Nonetheless people remained unwelcoming to prolonged taking of medication despite the positive outcomes (Hailemariam et al., 2017).

The high availability of traditional and religious healers in rural communities is another contributory factor towards traditional and religious methods being the preferred route of treating MHDs. The comparison between the availability of psychiatrists and traditional healers in Ghana was overwhelming as there was approximately one psychiatrist for 1.4 million people compared to one traditional healer per 200 people (Ae-Ngibise et al., 2010; Kpobi, et al., 2014). The abundance of traditional and religious healers within rural communities increases availability and accessibility drastically compared to mental health care which is often lacking.

Rurality and stigma create an environment where patients suffering with MHDs are stranded, unable to seek help or assistance (Maart et al., 2007) leading to disability, imprisonment, resentment and sometimes mortality. Cultural and environmental barriers have been well documented (Legg and Penn, 2013). Burns and Tomita (2015) argue that a significant part of traditional categorisation of MHDs overlapped with psychiatric classifications, this is an important point which commands the convergence of traditional and psychiatry practitioners to improve pathways to MHC. However, this might prove challenging in environments where biomedical knowledge about MHDs is scarce.

2.2.9. Lack of knowledge about MHDs

Many people continue to lack information about MHDs despite such high prevalence (Jorm et al., 2006; Altweck et al., 2015; WHO 2001). This lack of information implies that mental health literacy is lacking in many communities. Mental health literacy includes the ability to recognise MHDs, to be knowledgeable about risk factors, causes (Jorm, 2000) and its management and possibly its prevention (Ganasen et al., 2008). In many communities when a health problem with which little is known appears, people tend to fall back on commonly held belief systems (Jorm, 2000). Illnesses such as fever, flu or colds are perceived as a momentary occurrence of nature which can be resolved within a few days (Dlamini et al., 2019). However, MHDs are however often misunderstood, misdiagnosed and unrecognisable to majority of rural people as they do not get solved easily which leads to delays in proper diagnosis and treatment. Patients who seek initial assistance from traditional or spiritual healers have been observed to delay seeking assistance in medical attention (Saravanan et al., 2005; Sorsdahl et al., 2013). Delays in seeking medical attention impacts negatively on the patients, caregiver and entire household and could result in the disability and even mortality of patients. For instance, in some cases people suffering from psychiatric disorders have waited for approximately one to three years or more before seeking medical intervention (Ganasen et al. 2008; Wang et al., 2007; Spivak et al., 2018). In Northern Malawi delayed time in seeking help was found to be longer compared to more developed countries (Chilale et al., 2014). Reasons for delaying include lack of biomedical knowledge about MHDs, cultural and religious beliefs about MHDs, trying to handle the illness traditionally or religiously, fear of humiliation and medication (Omenyo, 2006; Twumasi, 1975; Nsereko et al., 2011).

Rural people do not recognise MHDs as medical illnesses leading to misdiagnosis mistreatment resulting to deteriorating and debilitating conditions or state of MHD in the patient. The lack of biomedical knowledge about MHDs thus contribute towards the burden of caregiving. A

study in Rwanda found that the most common barrier to seeking medical attention for MHDs was the belief that the problem would just disappear by itself amongst men whilst women believed they would not get the effective help or treatment (Umubyeyi et al., 2016). Resultantly educating communities about mental illness was identified as a key opportunity of destigmatising mental illness in rural communities (Gurung et al., 2017; Davids et al., 2019). Early detection and starting of medication for MHDs can be improved (improving mental health literacy) by educating people and general health care workers (Fekadu et al., 2016). Informed community members will be able to help people with MHDs efficiently and effectively. The lack of biomedical knowledge about MHDs impedes on the implementation of evidence-based mental health services (Jorm, 2000). High prevalence of MHDs advocates for greater need to improve mental health literacy (Paruk and Karim, 2016; Semrau et al., 2018).

Delays in seeking MHC due to the lack of information could prove fatal for patients. Patients who have suffered from MHDs and substance use disorders from an early age frequently face imprisonment (Slade et al., 2008), development of other mental disorders (Bakken et al., 2004; SAMHSA, 2013) and early death (Clark et al., 2008; Kverno, 2016). Therefore, it is unquestionable that patients with MHDs should seek and acquire medical attention as early as symptoms of MHDs are recognised. Patients suffering from multiple MHDs are more challenging to diagnose and medically assist, they discontinue treatment and have poor results compared to patients with one MHD (Herbeck et al., 2005; Kelly et al., 2012). Delayed detection or recognition of MHDs leads to severe symptoms leading to deteriorating conditions of patients and in some cases even mortality. Thus, it is important that communities are made aware of MHDs which will lead to appropriate and timeous diagnosis followed by treatments resulting in improved and positive outcomes for patients, caregivers, their households, and communities. It is also common for patients to develop other illnesses such as diabetes and hypercholesteremia, however these sicknesses often lie undetected and untreated (Monteiro and Noronha, 2017). The lack of biomedical knowledge about MHDs leads in caregivers being unable to recognise other illnesses which the patients might have developed, this further contributes to the burden carried by the caregiver.

Low levels of education were found to influence the burden of caregiving, low levels are associated with low economic status and social disadvantage which may hinder the ability to provide caregiving namely due to limited understanding of MHDs (Zahid and Ohaeri, 2010; Saunders, 2003; Caqueo-Urizar and Gutiérrez-Maldonado, 2006; Lasebikan and Ayinde, 2013;

Inogbo et al., 2017). Households or families living with patients are often unknowledgeable and illiterate about mental health therefore lacking informational support (Brodaty and Donkin, 2009; Jones, 2010). This leads to feelings of fear due to aggressive behaviour of patients and hopelessness due to unchanging if not deteriorating mental conditions as caregivers are unaware of other means which can be taken to assist the patient (Banyini, 2012; Ntsayagae et al., 2019). Zwane (2012) and Shifiona (2014) note that coping strategies adopted by caregivers often proved ineffective as caregivers were uncertain and uninformed about MHDs. The lack of knowledge is a challenge in SSA and leads to caregivers and patients not seeking or engaging with rehabilitation programs if available.

2.2.10. Rehabilitation

Patients suffering from MHDs find it difficult to interact with society (Freeman, 2017) complete tasks (whether for school or employment) or provide for themselves and their families (Substance Abuse and Mental Health Services Administration, 2013; Christopher et al., 2017). Adhering to treatment solely is inadequate in reintegrating patients back into society or enabling patients to live to their full potential. The overall objective of psychiatric rehabilitation is to enable the patients with MHDs with the ability to perform physical, social, emotional, and intellectual activities which are needed to live, learn and work in society through social skills training and encouraged social participation (Chaturvedi, 2020). Psychiatric rehabilitation enables patients to perform physical, social, emotional, and intellectual activities optimally with minimal assistance from caregivers (Anthony and Liberman 1986; Angermeyer and Dietrich, 2006). Psychiatric rehabilitation is inclusive of anti-psychosis medication, physical well-being improvement, psychological interventions namely occupational and behavioural therapy as well as family support with the creation of employment opportunities for patients (Morgan et al., 2014). Mental health is an integral part of health and well-being, as reflected in the definition of health in the Constitution of the World Health Organisation: *"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"* (Kühn and Rieger, 2017:887). Thus, mental health is an integral part of an individual's holistic well-being.

In the past treatment of patients with MHDs was confined to mental asylums (Intagliata, 1982). This approach to treating MHDs was premised prioritising the safety of communities at the expense of patient rights (Burns, 2008; Jack-Ide et al., 2012). This was due to patients being perceived as a danger to their communities. However psychiatric facilities were often overpopulated, under-resources leading to poor MHC services as the environment became

inhumane and infringed the rights of patients (Andersson et al., 2013; World Health Organisation 2013; Schierenbeck et al., 2013). The shift towards deinstitutionalisation towards a more people centred approach for patients with MHDs (Gerry, 2018) was therefore necessary. Patients with MHDs may still undergo admission into mental health facilities and thereafter get discharged to continue with treatment and rehabilitation in their own communities. This process however needs to be closely monitored as patients, caregivers, households need guidance in working with Non-governmental Organizations (NGOs). Data can be collected at every stage of this outpatient process (Robertson and Makgoba, 2018). This is a lesson learnt from the Life Esidimeni tragedy which involved the death of 144 patients after being discharged from mental institutions in Gauteng South Africa between October 2015 to June 2016 (IDurojaye and Agaba, 2018; Kabagambe, 2019). This tragedy was a result of under resourced NGO facilities accepting an influx of patients leading to the mortality of patients under “unlawful circumstances” (Durojaye and Agaba, 2018; Kabagambe, 2019). Providing support and care for patients needs to be monitored as patients still need assistance during and after being discharged (Robertson and Makgoba, 2018).

The process of outpatient from psychiatric institutions is lengthy and with challenges hence the need for close monitoring. Following this outpatient process, patients require rehabilitation to enable their integration back into society. This progression from institutionalisation to community-based care with the supplementing of hospitalisation, requires empowering of caregivers as well as reintegration of mentally disabled people into mainstream society (World Health Organisation, 2001). Research studies have indicated that despite de-hospitalisation having positive outcomes, however the socio-economic burden on caregivers has increased intensely (Savage and Bailey, 2004; Addo et al., 2013; Bhimani, 2014; Allers et al., 2015; Vaingankar et al., 2016). This change from institutionalisation towards community-based care has meant that caregivers take on accumulated responsibilities as they are now responsible for the day-to-day care of patients with MHDs (Addo et al., 2018). According to WHO (2021) more than 98% of patients are sent back to their communities within 5 years of admission. A challenge for SSA is the lack of rehabilitation services (community-based care) and support resources. This increases the burden of caregiving as caregivers take on full responsibilities of taking care of the patient (Addo et al., 2018). The lack of rehabilitation services is one key element which impedes reintegration of mentally disabled persons back into society (Uys, 2009).

Patients who only take medication for MHDs (such as schizophrenia) display improvements (Wiffen et al., 2010; Segarra et al., 2012; Pijnenborg et al., 2015) however without rehabilitation impairments continued (Phahladira et al., 2019). Persistent mental illnesses which have disabling, or impairing effects have been identified as “serious mental illness” such as schizophrenia have effects of hallucinations and delusions (SAMHSA, 2013). The continuance of effects or impairments places emphasis and a desperate need to have rehabilitation programmes in place to provide needed assistance to patients. Implementation of rehabilitation programs however faces many challenges in developing countries especially with deinstitutionalisation due to inadequate community support services and the socioeconomic characteristics of the community of mental health resources (Mzimela, 2001). The challenge of shortages in medical resources in LMICs impedes the possibility of these countries having community based psychiatric rehabilitation (PSR) (Hanlon et al., 2014; Brooke-Summer et al., 2016).

“Community-based rehabilitation is a model of community care based on the active participation of people with physical disabilities and their families in rehabilitation that takes specific cognisance of prevailing social, economic, and cultural issues” (Rathod et al., 2017:7). Nevertheless, the Table 2.3 below provides examples of community rehabilitation programs which have yielded significant improvement in MHD patients in SSA.

Country	Reference	Location of study	Community rehabilitation program	Obstacles	Achievements
South Africa	Uys et al., 1997	Rural KwaZulu Natal		Not provided.	Home industry approaches and hospital-based approaches were the most effective. Multi- and inter-sectoral collaboration that included traditional authorities.
	Simpson and Zambuko (2011)	KZN	PSR	Not provided.	Advocated for an integrated PSR program focusing on collaborative an individual aliated treatment plan.
	Botha et al., 2008	Western Cape	Community treatment teams were created for 3 psychiatric hospitals. Team had a principal medical officer, professional nurse, and a social worker. Programme aimed to support patients known for readmissions by facilitating available services.	Lack of resources (such as residential placement) at community level was a challenge.	Community treatment teams decreased the number of patient readmissions and reduced hospital stay for patients. Patient became employable.

	Brooke-Sumner et al., 2016	Northwest	Community based psychosocial rehabilitation programme facilitated by social workers.	Challenges in finding and communicating with caregivers and patients, lack of suitable locations and challenges with antipsychotic medication. Patient participation was another challenge, influenced by caregivers and family members not recognising the importance of patient participation in such programmes.	Improvement in mental health literacy, patients being able to take care of themselves, improvement in self-esteem, increased social interactions and patients being able to contribute towards their households.
Kenya	Lund et al., 2013	Rural Kenya, Meru South, and Nyeri	BasicNeeds' Mental Health and Development programme in rural Kenya.	Could lead to high dependence of households and	Improvement in mental health, quality of life (decreased care from caregivers), meaning social

	North districts.	Programme improves access to medication and encourage patients to engage with self-support groups.	caregivers on the programme. This may become a problem if funding for the programme is unavailable.	interactions and significant engagement with income generating activities. Decreased loss of employment for caregivers. Reduced burden of caregiving, enabling households with a chance to escape poverty through increased engagement in income generating activities (economic empowerment)
MacDougall et al., 2022	Machakos, southeast of Nairobi, Kenya	Community Recovery Achieved Through Entrepreneurship (CREATE). The overall goal of CREATE was to promote wellbeing, health and participation among Persons with Serious Mental Illness (PWSMI) in Kenya. Focused on forging pathways and opportunities for PWSMI to be rapidly engaged in work within their communities instead of waiting for and/or depending on the receipt of formal treatment, support, and rehabilitation services.	Not provided	Improved social relations for patients, sense of belonging and growth within communities. Involvement of family members (patients) in the CREATE strategy had positive impacts. Less disruption of family units and households' routines leading to improved family relationships. Patients able to act responsibly and contribute financially towards their households, decreasing if not alleviate financial distress.

Ethiopia	Lemmi et al., 2017	Sodo district, Gurage Zone, Southern Nations, Nationalities, and Peoples' Region in Ethiopia	Community-based rehabilitation intervention for people with schizophrenia	Not provided	Reduced disability among people with schizophrenia, particularly with social relations. Caregiver stress was reduced, and medication adherence was improved.
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Table 2.3. Table showing rehabilitation outcomes in SSA countries

Collaboration of the local community with families, caregivers, patients, and improved access to psychiatrists has proven to be most effective and appropriate (Patel, 2015). Community-based rehabilitation is recommended in LMICs where psychological support is offered or done by non-specialist workers utilising a task sharing model (Mari et al., 2009). Support groups in communities have proven to be very effective to patients, as patients experienced less social isolation, felt encouraged to adhere to treatment, were more mental literate and were able to engage more in household chores or community activities (Brooke-Sumner et al., 2017). This involvement of patients and caregivers in MHC services and plans is crucial as patients and caregivers are most knowledgeable about the challenges and realities of MHDs (Shaw and Baker, 2004). Such involvement has been occurring but remains highly limited to high income countries (HIC) (Crawford et al., 2003; Rutter et al., 2004). Nevertheless, involvement of patients and caregivers has increased over time in SSA, namely as Uganda, Zambia, Kenya, and Tanzania because of patient networks, organisation and groups (Katontoka, 2007).

The challenge remains as most patients with MHDs, and caregivers remain unaware of the possibility of being involved in MHC services in rural areas (Gurung et al., 2017). Involvement of patients and caregivers was also hindered by mental illiteracy, people having to engage in economic activities to sustain their livelihoods, being located away from urban areas where most system level processes occurred and not having free time with which to engage in mental health plans and programmes (Gurung et al., 2017). Collaboration of different sectors is vital, specifically in the provision of psychosocial rehabilitation (PSR) (Brooke-Summer et al., 2016).

2.2.11. Lessons learnt during COVID-19 from MHD patients

SSA remains with a paucity of research on COVID-19 impacts on mental health (Semo and Frissa, 2020), however, these effects have been well-documented in other countries. The psychological impacts of COVID-19 are unique to different groups, and these impacts are influenced by stress due to fear of losing income, employment and disruption of life among communities (Li et al., 2020; Tang et al., 2020; Xiao et al., 2020; Yuan et al., 2020; Fullana et al., 2020; González-Sanguino et al., 2020; Zhang and Ma, 2020; Wang et al., 2020; Hamel et al., 2020).

Furthermore, COVID-19 threatens to increase the treatment gap for MHDs (Kola et al., 2021). The stigma attached to COVID-19 combined with MHDs led to challenges for patients in accessing health care (Li et al., 2018; Yao et al., 2020; Kumar and Nayar, 2020). This increases

the burden of caregiving alongside decreased support from social and human capital for caregivers. During the pandemic, WHO advised that response initiatives be informative, coherent and easy to understand to reduce all negative connotations associated with COVID-19 and MHDs (Moreno et al., 2020). Educating communities and caregivers about COVID-19 and MHDs empowers them to participate actively in their health care. Wilkinson et al. (2017) mention that strategies that treated caregivers and patients passively were unsuccessful. Therefore, empowering patients and caregivers is crucial during these uncertain times when face-to-face mental health services are limited (Moreno et al., 2020; Kola et al., 2021). Semo and Frissa (2020) predicted that the pressure on SSA mental health would be strenuous due to the weak systems in place. Rural areas' lack of health resources and uncertainty surrounding COVID-19 contribute to deteriorating mental health (Pfefferbaum and North, 2020). The prioritising of mental health, appropriate coordination, support and involvement of patients and caregivers in their treatment, and training community health care workers are probable solutions for SSA (Semo and Frissa, 2020).

2.2.12. Policy implementation

The WHO advocates for the integration of MHC into PHC (WHO, 2013). This means MHC services should be available at PHC facilities such as local clinics. In some African countries (Ghana, South Africa, Uganda) have existing MHC policies however plans to implement these policies were occasionally non-existent for example in Zambia (Omar et al, 2010). Botswana like SA had a mental health policy which aimed to integrate mental health into PHC in order to improve access to services (Botswana National Policy on Mental Health, 2003; Sidandi et al., 2011; Government gazette 2002). The effective implementation of these however remains a challenge. In countries where plans were existing, lack of funding, training, skills, resources, and unclear roles of provincial planners led to the failure of implement of policies (Omar et al, 2010; Petersen et al., 2017). In Ghana implementation remains weak due to the lack of direct responsible institutions from the Ghana health service (Omar et al, 2010). The lack of skills and the limited capacity to implement mental health policies is the main cause of poor implementation. Other African countries such as Nigeria and Uganda had outdated policies which are disregarded while Ethiopia still has non-existent policies (Petersen et al., 2017). Poor planning, coordination and management from responsible people also meant poor implementation. Nepal, Nigeria, South Africa and Uganda stated that their PHC also had issues of deficient funding (Petersen et al., 201). The implication is effective implementation of mental health policies is unachievable and the lack of boards to oversee implementation of such

policies is also a challenge. There remains a great need for improvements and integration of the provision of mental and health services for chronic disease and MHDs in PHC as these recurrently co-exist (Sadik et al., 2011; Kolappa et al., 2013; Rule et al., 2014). This integration is likely to have positive outcomes such as continuation and adherence to medication and a feasible way of treating MHDs (WHO, 2008; Patel et al., 2009; Sadik et al., 2011; Patel et al., 2013). There is a notable gap in initiatives aimed at dealing with patients with MHDs need which should encompass comprehensive community base methods (Lund et al., 2013).

2.2.13. Discussion and future directions

Patients with MHDs in rural SSA continue to face challenges in accessing MHC due to the sector continually receiving inadequate attention, funds, and resources (WHO:2011: Mugisha, 2016; Mugisha et al., 2016). Rural clinics face challenges in providing MHC to patients as the only available resources is medication for MHDs (Brooke-Sumner et al., 2016). The geographical isolation of rural areas, its lack of resources coupled with poverty becomes barriers towards accessing MHC. This barrier is multifaced, firstly patients face challenges of inaccessibility as health facilities are located far away leading to unaffordable travel cost (Linard et al., 2012; Lund et al., 2013; Burns, 2015). Secondly the lack of human and health care resources in rural clinics diminishes any eagerness to travel to the clinic as patients may return home without receiving assistance. Developing regions such as SSA find it difficult to meet mental health standards of the WHO (2013), as they lack basic services and are underdeveloped. Efforts to deracialise services delivery in SSA made by government have been insufficient as rural areas remain undeveloped, lacking in resources and services provision (Giraut and Maharaj, 2002; Gilson and McIntyre, 2007; Coovadia et al., 2009; Richards., 2018).

The undeniable relationship between MHDs and poverty is another challenge (Lund et al., 2013; Burns, 2015). Increased time dedicated to caregiving, hinders caregivers from engaging in income generating activities. The unexpected medical expenses which come with sudden MHDs, loss of employment for the patient or caregiver may also push households into poverty. Caregiving also decreases time for socialising leading to broken social relations. This could make it difficult for households or caregivers to ask for assistance and the stigma attached to poverty renders it even more challenging. All these factors increase the burden of caregiving on households and particularly caregivers as households are left without support from their communities.

The lack of biomedical knowledge about MHDs adds to the burden for caregivers and households. On the contrary in communities who are mental health literate, there is early detection and diagnosis of MHDs. Improved treatment adherence, less stigma and possible reintegration of patients into their communities (Fekadu et al., 2016). Communities need to be knowledgeable about MHDs as they play a significant role towards decreasing the burden of caregiving, decreased stigma, and rehabilitation of patients (Gurung et al. 2017, Davids et al. 2019). While also reducing the burden carried by caregivers and rural households with patients with MHDs.

Stigma stemming from commonly held beliefs about MHDs which influences treatment methods adopted by patients and caregivers remain added barriers and prevent timely seeking of MHC (Omenyo, 2006; Twumasi, 1975; Nsereko et al., 2011). This is exacerbated by the lack of biomedical knowledge about MHDs in rural. The strong association between MHDs and evil spirits inspires rural people to utilise traditional and religious methods. However, delays in seeking MHC leads to deteriorating mental states of patients and an increased burden of caregiving. Research indicates that patients often seek psychiatric health care after traditional methods have failed (Saravanan et al., 2005; Sorsdahl et al., 2013). Therefore, there is a need to formulate all-inclusive approaches for SSA which converge traditional, religious, and biomedical services into the rehabilitation of patients.

To enable the rehabilitation and reintegration of patients into society, there needs to be communication and close monitoring of the out-patient process into their communities. Rehabilitation is crucial for MHD patients, as research has proven that patients who take medication solely have continuing impairments (Phahladira et al., 2019). Continuing impairments imply patients still rely on caregivers and are not reintegrated into their communities. Integration necessary for community rehabilitation will also remain a challenge in rural areas as relevant stakeholders such as NGOs are still scattered and often completely absent (OTA, 1990; Lishner, 1996; Strasser, 2003; Strasser 2016). Releasing patients into community care without proper structures in place to provide appropriate assistance will lead to deteriorating MHDs, increased burden on rural households and caregivers subsequently leading to the homelessness, relapse or even imprisonment of patients. The unavailability or inaccessibility of such pivotal MHC services results in the infringement of patients' rights and decreased standards of living for households with patients with MHDs. It is vital that MHC structures and systems are set up in rural areas to prevent the relapses, homelessness, imprisonment and even mortality of patients.

Access to rehabilitation services need to be improved dramatically. Improved access to rehabilitation services decreases the burden carried caregivers (Poon et al., 2017). Rehabilitation service equip patients with the necessary skills to live to their full potential independently (Craig et al., 2004; Rangaswamy and Sujit, 2012). As such patients require less assistance from caregivers. It is important to integrate MHD patients into society as caregivers will then be able to engage in income generating activities whilst taking care of their households and improving the overall circumstances within the household. Once patients are integrated into society caregivers can thus have more time to engage in income generating activities, take care of their households and hence improved standards of living. It is therefore crucial that rehabilitation structures and platforms are established in rural areas along with campaigns focusing on informational support and mental health literacy. The latter will combat stigma and discrimination whilst encouraging early medical diagnosis and treatment which will lead to appropriate rehabilitation and possibly patients with MHDs leading normal lives.

Mental health research remains limited throughout the African continent (Davids et al., 2019) regardless of mental health research being crucial to strengthening mental health systems in LMICs (Saxena et al., 2011; Betancourt and Chambers, 2016). Research focusing on mental health in African rural areas is still very much necessary. Therefore, there is a dire need for more research to be conducted on MHC and health issues in SSA. This research aims to contribute towards that gap in mental health research in SSA and hopefully towards the educating of communities. Other possible areas linked to the issue of access to MHC services in rural areas include exploration of the challenges faced by patients in rehabilitation programs, to endeavour more into strategies utilised by rural caregivers in trying to deal with MHDs. Moreover, it is also important that the perceptions, ideas, and beliefs of caregivers are investigated, and this will enable appropriate remediation strategies to be applied to rural communities in terms of patient's mental health.

2.4. Chapter summary

This chapter has provided an overview of existing literature on MHDs in SSA. This has been achieved through literature, tables and figures depicting the status quo of MHC in Africa, which remains inadequate. The associated challenges have also been highlighted bringing forth the need for this research to be conducted.

Chapter 3 Conceptual framework

3.1. Introduction

This previous chapter focused on providing an overview of the literature pertaining to MHDs focusing on SSA. This chapter will focus on the conceptual framework utilised in this study. Bridging two or more different concepts to understand empirical data is commonly known as a conceptual framework (Rudestam and Newton, 2014). Conceptual frameworks conjoin different concepts to form an overarching framework for research. It can be understood as finding an integrated method to research a problem (Liehr and Smith, 1999). The conceptual framework is derived from concepts to understand particular research (Imenda, 2014). This research converges Sustainable Livelihood Approach (SLA) and Ubuntu to investigate living conditions, challenges, and available mental health services for caregivers in KwaXimba, eThekweni Municipality, KwaZulu-Natal.

3.2. The sustainable livelihood approach

The SLA has been successfully utilised to research societal issues facing vulnerable groups, particularly those experiencing poverty (Fahad et al., 2023). The SLA unpack and seeks to understand issues from the perception of the researched population. It further seeks to understand how communities have adapted and found survival strategies within unfavourable conditions. Mazibuko (2013) mentions that the SLA is premised on community's strengths, their asset and understanding of their everyday conditions. This research will utilise the SLA to explore caregiver perceptions, challenges, opportunities, and strategies adopted by caregivers in providing care for patients with MHDs in a rural community lacking MHC services. This research will investigate living conditions, available resources and how caregivers utilise their assets and capabilities to sustain their livelihoods. A livelihood encompasses assets, capabilities, and activities necessary for living (Chambers and Conway, 1992; Krantz, 2001; McLean, 2015).

“A livelihood comprises the capabilities, assets (including both material and social resources) and activities required for a means of living. A livelihood is sustainable when it can cope with and recover from stresses and shocks, maintain or enhance its capabilities and assets, while not undermining the natural resource base” (Krantz, 2001:1).

Livelihood assets are categorised into five, encompassing social, natural, human, physical and financial capital.

3.2.1. Natural capital

Natural capital (considered vital in rural areas) includes natural resources such as water and land (De Haan, 2012; Fahad et al., 2023). Such environmental resources are important, as livelihoods are derived from them (Carney et al., 1998). All elements of nature which can be utilised or are beneficial to humans can therefore be considered natural capital. The use of natural capital is often to sustain a livelihood (Pereyra-Marinez et al., 2022). Land, for instance, can be utilised for agricultural purposes benefiting the household through increasing food security and financial income if produce is traded. In this way, the land has been utilised to contribute and sustain the household's livelihood.

3.2.2. Physical capital

Physical includes infrastructure such as shelter or roads and physical resources which can be utilised to produce goods (Fahad et al., 2023). Plantations and other forms of constructed assets with the potential for providing different capitals (Horsley et al., 2015). Physical capital includes all physical assets which can be utilised to generate other capitals, such as financial capital. Examples of physical capital include housing, transport, and water (Brocklesby and Fischer, 2003).

3.2.3. Financial capital

“Financial capital refers to wages, savings, remittances, income, royalties, rent and other financial flows including access to employment. This is the form of capital that is most dominant in market economies and hence relates to the most comprehensive existing literature on indicators of economic growth, financial stability, and poverty reduction” (Horsley et al., 2015:373).

Financial capital includes credit or debt, remittances, wages, pensions and any form of cash used to sustain the livelihood (Fahad et al., 2023). Financial capital thus includes all forms of financial streams an individual can generate. Financial capital is about monetary value. Access to credit can be utilised as an example of financial capital (Brocklesby and Fischer, 2003).

3.2.4. Social capital

Serrat (2017) states that social capital includes networks such as kinships, community trust and support, commonly held beliefs and values, leadership institutions and participatory decision-making. Social capital can also be inclusive of *“networks, membership of groups, relationships of trust and reciprocity, access to wider institutions of society”* from which communities base their livelihoods (Carney et al., 1998:7). Social capital can be understood in terms of social

relations an individual may have with the community in which they live. These relations are premised on common interests, social participation, and truthfulness reciprocation (Pereyra-Marinez et al., 2022). Increased social connections and relations between groups of people can lead to increased access to services and other benefits. People from a similar setting, often with the same characteristics, are more likely to assist one another. Social capital could be resources that have been gained through existing relations between people.

3.2.5. Human capital

Human capital would then be the knowledge and skills to sustain the livelihood (Fahad et al., 2023). Human capital thus includes all characteristics of an individual which can be utilised to define and bring about development in one's life. An example of human capital could be labour (Brocklesby and Fischer, 2003). In addition, human capital includes an individual's demographics, their state of health, acquired skills and level of education which can be channelled into obtaining an income (Horsley et al., 2015).

A livelihood is considered sustainable if it can cope, survive, and recover from shocks and stress while maintaining or improving its capabilities without infringing on the opportunity for future generations to live sustainably (Chambers and Conway, 1992; Krantz, 2001). "Livelihoods rarely refer to a single activity. It includes complex, contextual, diverse, and dynamic strategies developed by households to meet their needs" (Gaillard et al., 2009:121). The SLA is considered an approach rather than a theory as it does not explain any phenomenon but is a perspective or a way of seeing things and recognising patterns (Mazibuko, 2013). It acknowledges that people have assets and capabilities that they utilise to sustain their livelihoods, and sustaining their livelihoods also depends on their access to these assets (Mazibuko, 2013).

The SLA will therefore be utilised to assess households and caregivers' assets in KwaXimba, eThekweni Municipality, KZN. It will explore households' natural, social, physical, and financial assets. It will seek to assess these to explore their living conditions. Furthermore, it will seek to investigate available services for the community and how these services serve caregivers.

Misconceptions and shared beliefs about MHDs lead to stigma in rural areas and minimise social capital for caregivers and MHD patients. Limited access to services and opportunities due to rurality, poverty, stigma, and the lack of health care services decreases the ability of caregivers and patients to live a normal life as their livelihood assets are compromised. They

are exploring how households generate an income under unfavourable conditions (Guo et al. 2022). The SLA will be utilised to understand how households cope with family members suffering from MHDs, and live and organise their livelihood strategies with the associated challenges. SLA provides a greater understanding of the livelihoods of the poor (McLean, 2015). As the study is based in rural areas associated with poverty and a lack of access to services, namely psychiatric services, the SLA will be utilised to unpack and understand how caregivers cope and what alternate methods or resources are used in the absence of professional MHC services and how these alternatives improve their standard of living. It will also investigate how caregivers cope under stigmatised circumstances while providing care for patients with MHDs. McLean (2015) further argues that SLA has been advocated as the most suitable approach to the core development, based on the needs of those most exposed and vulnerable in society.

The SLA will be utilised to investigate if any caregiving challenges render households' livelihoods unsustainable. The stigmatisation and discrimination against patients with MHDs, caregivers and their households can infringe on the household's ability to maintain a livelihood. The SLA seeks to find strengths and empower people for what they may be lacking (Mazibuko, 2013).

Chambers (1995) speaks of the changing reality, new ideas derived from experiences and the tolerance of competing ideas. This new paradigm will be utilised in the research through the three determinants. The changing reality will be utilised to unpack all changes the caregiver underwent upon the development or the initial stages of the MHD in the patient as well as the way households and caregiver's daily activities changed to accommodate the patient. Secondly are new ideas derived from experiences; caregivers are most knowledgeable about MHDs and its challenges and opportunities. The reason being all the caregivers experienced all these first hand. Caregiving is a challenging experience for caregivers and patients, respectively. However, solutions can be identified by the caregiver themselves.

Lastly, caregivers are an important stakeholder, and they have their own beliefs, ideas, preferred methods, and strategies when dealing with MHDs. The SLA is based on five sustainable living assets: social capital, financial capital, natural capital, physical capital, and human capital. This research aims to understand the lives and experiences of caregivers through these five capitals. Natural capital would include land ownership of caregivers, financial capital would include unpacking the household income streams and physical capital would include

infrastructure such as electricity and running water. Human and social capital would unpack the relations between the caregiver and the community. The extent to which support is received by the caregiver from the local community of KwaXimba, eThekweni Municipality, KZN is evaluated. Does the caregiver of KwaXimba, eThekweni Municipality, KZN have the opportunity to voice their opinions on MHDs in terms of their challenges and concerns? Caregivers are most knowledgeable about the challenges faced by their households and the MHD patient. Moreover, they have a lot to contribute to the rehabilitation programmes or initiatives to improve MHC services in rural areas such as KwaXimba, eThekweni Municipality, KZN. The SLA enables the recognition of practical priorities premised on the perceptions of those concerned. The livelihood and experiences of caregivers alongside strategies adopted to cope with and provide assistance to patients. Additionally, this would include indigenous knowledge, which could be improved to initiate culturally appropriate initiatives. The SLA is appropriate as it is based not on the eradication of existing strategies but rather on the convergence of existing strategies in collaboration with the new strategies which aims to improve the lives of MHD patients and caregivers.

3.3. Ubuntu

Ubuntu has been defined in numerous ways: showing kindness, caring and being considerate of others without regard for their position in society (Ramose, 2002; Mabovula, 2011; Mayaka and Truell, 2021). It is also understood as the responsibility of one individual towards the next in terms of good deeds (Letseka, 2000). Ubuntu is still recognised as an important component of living in African communities (van Breda, 2019). Within African communities, when a problem arises, community members collaborate to discuss and develop plausible solutions (Mabovula, 2011). Rural communities believe that no one lives in complete independence, but everyone is part of a community, having relations and living interdependently (Turaki, 2006; Letseka, 2012). Community members know each other and each other's children, and, in this way, Ubuntu is still evident as communities still look out for one another. Ubuntu premised on the African culture, argues that an individual becomes human through connecting with other people and continuous relations (Tambulasi and Kayuni, 2005; Nyaumwe and Mkabela, 2007; Lutz, 2009; Mayaka and Truell, 2021). Communities always come together to assist those who may require aid after a death, disaster or for a celebratory function (Chisale, 2018).

Ubuntu is based on solidarity and seeing one's self only in relation to others, arguing that people are interdependent rather than independent (Sambala et al., 2020). In addition, Ubuntu refers to people who are only recognised as human because of their relationship with others, their

obligations, and their sense of responsibility for one another. As such, if an individual has contracted (Tuberculosis) TB, it is their responsibility to themselves and their community to seek treatment, adhere to treatment and even quarantine if needed (Sambala et al., 2020). In this way, an individual with TB has not only protected themselves but has also protected those around them. Another critical area of Ubuntu is compassion which means that individuals see the hardship or pain of others as their own (Sambala et al., 2020). This implies that if an individual is sick, other community members must treat that individual in the same manner they would like to be treated, if they were also in that situation, including patients with MHDs (Sambala et al., 2020).

However, Mwiripikeni (2018) argues that Ubuntu has been eroded over time due to changing times and lifestyles. This has been influenced by corruption, modernisation, poverty, and the neoliberal capitalist system (Dudzai, 2021). Modernisation, rural-urban migration, poverty, and urbanised lifestyles have decreased social relations while increasing independence (Cloke et al., 2014; Hamnett, 2014). These urban challenges erode Ubuntu as people strive for independence. There are notable challenges to Ubuntu, such as crime and the infusion of people from other communities leading to a lack of trust within communities (Mabovula, 2011). The erosion of traditional ways of living and the emergence of anti-traditional features contributes towards Ubuntu diminishing within African communities (Mabovula, 2011). This erosion contradicts Ubuntu's principal characteristics, which are humanity, tolerance, and respect (Mabovula, 2011). Neoliberalism has led to most life necessities being accessed through the market and with monetary value (Brown, 2006), leading to a considerable proportion of poor households' incomes going into accessing these services (Tsui et al., 2010). Neoliberalism, therefore, emphasises providing for one's self and household, increasing economic selfishness while benefiting the rich and placing the poor at a disadvantage (Mwiripikeni, 2018). Ubuntu aims to empower communities rather than individuals and, in that sense, may be a contradictory facet as there are community members who may have special needs compared to everyone, and those individuals may reject the notion of Ubuntu by trying to achieve those needs for themselves before anyone else (Sambala et al., 2020). Again, this is a weakness of Ubuntu, where the world we live in today is very competitive, each to his own and thus undermines and diminishes the notion of Ubuntu, where the individual is supposed to place others above themselves. Despite these challenges and weaknesses of Ubuntu (Louw, 2010; Ngubane-Mokiwa, 2016), it still guides moral life and living in good relations with God and ancestors (Chisale, 2018). Ubuntu is the core of most African beliefs invoking traditional cultures

(Ncube, 2010). Showing kindness, understanding towards others, forgiveness, and respecting others despite their contribution or significance to the community are critical components of Ubuntu (Ramose, 2002; Mabovula, 2011). These components hold the potential to alleviate the burden of caregiving for caregivers. Caregivers have been acknowledged as a normative party of Ubuntu (Metz, 2007). This is due to caregiving being associated with nurturing and being feminine (Chisale, 2018).

Patients require extra kindness, care and understanding; these qualities are already a part of Ubuntu which would make it easier for communities to understand and support caregivers in caring for patients with MHDs. Challenges that remain are stigma, cultural beliefs and negative connotations associated with MHDs which create a barrier and often lead to community members distancing themselves from patients with MHDs. This challenge could be overcome by making communities literate about mental health, thereby decreasing the stigma. As the concept of Ubuntu already exists in most African cultures and communities (Mugumbate and Chereni, 2019) it would be easier to reintroduce Ubuntu towards patients with MHDs. Mabovula (2011) mentions tolerance as a principle of Ubuntu which entails living in harmony with people who are different from us. This difference can include patients with MHDs and one such example is KwaXimba, eThekweni Municipality, KZN.

3.4. Chapter summary

This chapter has elaborated on the conceptual framework utilised in this study. The two concepts adopted were the SLA and Ubuntu which explained MHDs and their related challenges in SSA.

Chapter 4 Research Methodology

4.1. Introduction

The previous chapter focused on the conceptual framework. This chapter explores the methodologies adopted focusing on sampling, data collection techniques and data analysis. This chapter elaborated on the suitability of the methodologies chosen for this research. This study utilised a triangulation method. For the quantitative aspect, purposive and snowball sampling were utilised to sample the 35 caregivers from KwaXimba, eThekweni Municipality, KZN. Questionnaires were administered to the 35 caregivers. Data collected from the questionnaires was captured into Statistical Package for Social Science (SPSS statistics) version 28. Thereafter generated results were presented and analysed descriptively. Qualitatively purposive sampling was utilised to identify the key informant with whom an interview was conducted. Data collected from the interview was analysed thematically. Data collected aided in exploring and achieving the research aim by responding to the study's objectives on MHDs, living conditions and access to psychiatric intervention: lessons from KwaXimba, eThekweni municipality, KZN.

4.2. Research approach

The research approach underpins the chosen approach for research by elaborating on the adopted methodologies, data to be collected and ways of analysing data. The appropriate research method ensures that the procedures taken are adequate to obtain valid, objective, and accurate answers to the research question ensuring the validity and reliability of research findings.

4.3. Research design

4.3.1. Case study design

The case study is an example of qualitative research and is effective as it unpacks complex societal issues (Yazan,2015).

Hoaglin et al. (1992) in Beeton (2005:28) provided the following justification for the case study approach:

- Case studies can provide insights into the reasoning behind the success or failure of certain experiments;
- can prove to be relevant currently as well as for future reference;
- can underpin underlying complexities of a situation by identifying contributory factors;

- can depict the influence of outside issues such as politics and personalities; and
- can provide data applicable to different scenarios from a wide range of sources.

This research had adopted a case study approach due to its ability to underpin underlying complexities related to societal issues. MHDs are a societal issue interwoven into the burden of caregiving carried out by caregivers, their households and communities. The use of the case study approach in this study will further emphasise the challenges of the caregivers related to the KwaXimba community which maybe applicable to other rural areas in SSA.

4.3.2. Descriptive design

The descriptive design is premised on simple or comparative description of data (Grove et al., 2012). Descriptive design in research aims to describe people, occurrences or the circumstances without any interference (Houser, 2008). This type of research design seeks to provide an understanding of individuals, events and their surroundings without adding any form of interpretation. Siedlecki (2020) mentions that descriptive research enables data to be presented without any manipulation of variables. Thus, the descriptive research design allows research data to be presented as is without the imposition of the researcher's objectivity. The rationale behind this research design is to provide real experiences and perceptions of participants (Sandelowski, 2010). This research aims to identify the challenges experienced by caregivers in KwaXimba while unpacking their lived experiences and perceptions about MHDs.

This research design will allow the researcher to present findings in their primary state without interference or rather much interpretation. This shall allow the reader to understand and analyse the data further without any or minimal biases. Doyle et al. (2020) states that descriptive research design is best utilised for research topics where minimal data is available. *"A qualitative descriptive design may be deemed most appropriate as it recognises the subjective nature of the problem, the different experiences participants have and will present the findings in a way that directly reflects or closely resembles the terminology used in the initial research question"* (Bradshaw et al., 2017:444). This type of research allows data to be collected in a subjective manner (Kim et al., 2017). *"In qualitative descriptive research, this translates into researchers being concerned with understanding the individual human experience in its unique context"* (Doyle et al., 2020:445). Descriptive research allows researchers to collect data, explore different realities and have non-objective experiences on a particular topic (Long et al., 2018).

4.4. Description of Study Area

KwaXimba, this study area, is located in the province of KZN. KZN has the second-highest number of rural areas in SA. KwaXimba was one of the first rural communities incorporated into the eThekweni municipality in 1996 (Miya, 2010). KwaXimba, eThekweni Municipality, KZN has four communities, which are eBhobhonono, eMvini, eNkandla and kwaDenge. The KwaXimba area is located off the N3 between Durban and Pietermaritzburg (PMB), under the Cato Ridge magisterial district (Mathieson and Attwell, 2013; Gumede and Okech, 2009). This area is predominantly rural and under the tribal authority of King Z.M Mlaba (Gumede and Okech, 2009).

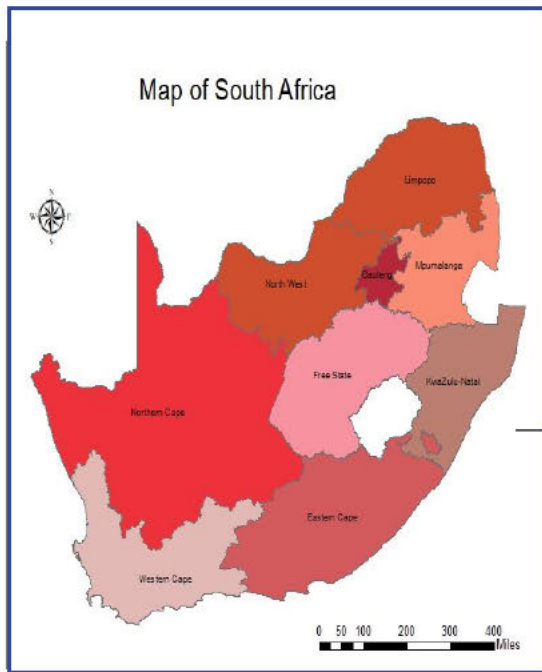


Figure 4.1. Map showing South Africa with the nine provinces

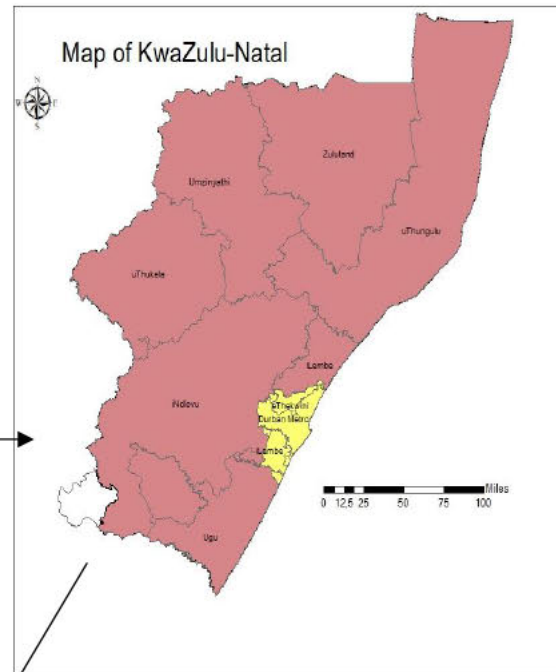


Figure 4.2. Map showing KwaZulu-Natal boundary and districts municipalities

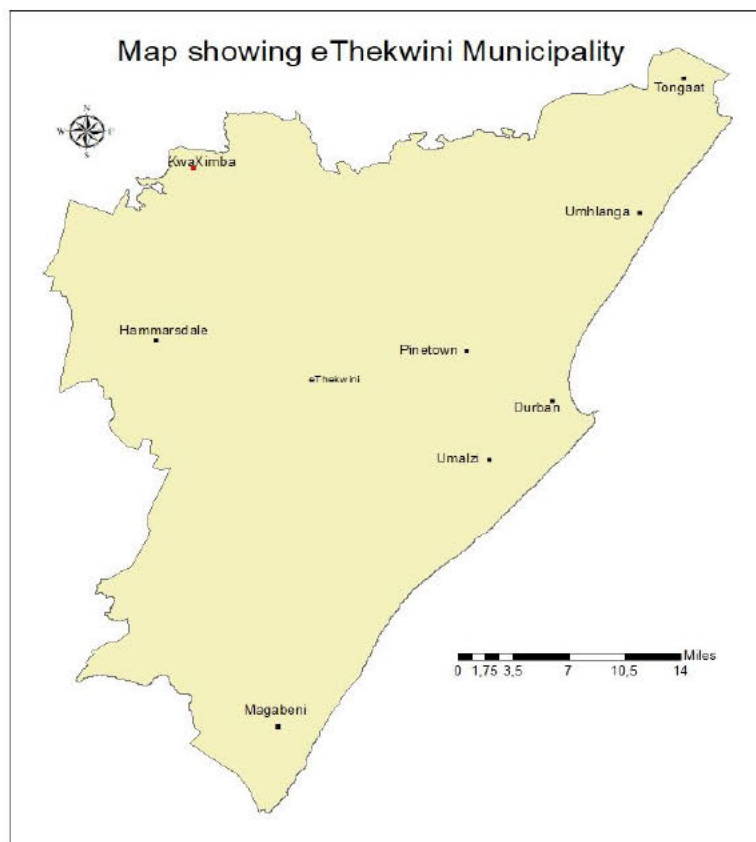


Figure 4.3. Map showing KwaXimba in relation to eThekweni Municipality

4.5. Population

The area's population was estimated to be over 1587 (Stats SA, 2011). For this research the sample was caregivers from the community. Research has shown that 12%-13% of the global population suffer MHDs (Ganasen et al., 2008:23; WHO, 2013; 4355), adopting and applying these figures to this study implies that approximately 190 people suffer from MHDs in the study area. A representative sample of that population would be 10% of the approximate 190 people which would place this research' sample at 19 participants. The research however was able to locate a total of 39 caregivers of which 4 did not participate in this study due to differing reasons. As such only 35 caregivers were sampled and participants of this research. This is the total number of willing caregivers which were located after canvassing the area study area at the time of data collection.

In 2011 KwaXimba, eThekweni Municipality, KZN had a population of 1587 (Stats SA, 2011). These are the latest available and reliable statistics of KwaXimba, eThekweni Municipality, KZN, as the 2022 census has yet to release new statistics. However, these numbers have likely changed or increased since the last count. This research utilised the 2011 statistics for its research purposes.

KwaXimba, eThekweni Municipality, KZN is a densely populated rural area. Predominantly rural populations are scattered and have low densities (Park et al., 2018). During the 1990s, there was a mass movement of people from KwaNyavu, a neighbouring chieftaincy, across the uMsunduzi river into KwaXimba, leading to the area having a dense population. This mass movement was motivated by the war between KwaXimba and KwaNyavu, associated with chieftaincy and political endeavours in which KwaXimba gained the upper hand (Krämer, 2016). As a result, KwaXimba is densely populated compared to most rural areas. KwaXimba, however, still possesses characteristics of being rural such as strong traditional structures and institutions. The area has a ruling king (headmen), *izinduna*, a respected traditional council, traditional ways of living (farming and rearing livestock), traditional household structures (rondavels and kraals), and high respect for cultural and traditional practices. Furthermore, the study area is located far away from the urban and developed areas.

The large population of KwaXimba is advantageous for this research. MHD remains an issue of sensitivity in communities which might hinder and limit community members willing to be participants in this research. Therefore, the larger the population there is an increasing probability of locating more willing participants. The sensitivity and stigma associated with

MHDs could be challenging when locating participants due to common rural beliefs about MHDs and the lack of awareness about MHDs. SA has good MHC legislation (Government Gazette, 2002); however, implementing this policy remains challenging. The eThekweni municipality has been pronounced with mismanagement of funds, corruption, and poor service provision, which leads to poor implementation of legislation and policies. KwaXimba is located within the eThekweni Municipality. This municipality has had poor governance and collaboration within the mental health sector presents another challenge (Peterson et al., 2017). Rural areas located away from development and services predominantly have challenges of access; therefore, caregivers and patients in KwaXimba, eThekweni Municipality, KZN, should have challenges when accessing MHC. As such, the research aimed to investigate challenges experienced by caregivers in KwaXimba in accessing MHC services.

4.6. Sampling method, technique and size

4.6.1. Sampling methods

Sampling methods are differentiated between probability sampling and non-probability sampling. The probability sampling process includes selecting participants randomly and every person has a known or knowable chance of being selected (Wiśniowski et al., 2020). Participants are therefore selected randomly in probability sampling, providing everyone with a fair chance of selection (WHO: 2018A). *“In non-probability sampling, subjective judgement, convenience or quota are used to determine which population members are included in the sample”* (WHO, 2018A). Non-probability sampling is bias in that only individual who sign up or choose to be participants may be recruited which can lead to limited responses or participation (Lamm and Lamm, 2019). This study will utilise non-probability sampling methods namely, snowball and purposive sampling.

The selection of a group of participants believed to be representative of the entire population is commonly known as sampling (Sharma, 2017). This study adopted two methods to sample the population, namely purposive and snowball sampling. According to Statistics SA KwaXimba, eThekweni Municipality, KZN had a population of 1587 (2011), These statistics are from 12 years ago; thus, KwaXimba currently has a higher population. The research purposively selected and located a total of 35 caregivers distributed within the community of KwaXimba, eThekweni Municipality, KZN. This selection was not based on the population size of KwaXimba due to the sensitivity of MHDs. These caregivers are not a representative of the entire population but the number of all located and willing caregivers in the community (snowballed during the period of the data collection). A total of 39 caregivers were located in

the community, 4 of which were not willing to be participants of this research due to varying reasons.

MHDs remain a sensitive topic hence caregivers do not engage with activities or services which might identify and link them to the stigma attached to MHDs (Shankar et al., 2006; Vijayalakshmi et al., 2013; Razali et al., 1996; Patel et al., 1997; Sheikh and Furnham, 2000; Suhail, 2005; Okello and Ekblad, 2006; Waqas et al., 2014) such as partaking in this research. The number of caregivers chosen is adequate due to the sensitivity pertaining to the research topic on MHDs. Sensitivity to issues also triggers painful and unwanted memories for participants. Therefore, conducting such research, whether in urban or rural remains challenging. It is important to note that every rural place is unique (Chibgu, 2013); however, rural experiences should be similar. This is due to shared characteristics and challenges of service delivery and development faced by rural communities. Challenges of poverty, accessibility and availability when it comes to mental health in rural settings are mirrored and common and lead to an increased burden on caregivers (Yellowlees et al., 2008; Uys, 2009; Gurung et al., 2017; Stefanovics et al., 2016; Hoeft et al., 2018). As such, data collected and obtained from this research should apply to other rural areas in South Africa.

Notably, the researcher may find more than one caregiver per household, increasing the number of participants.

4.6.2. Purposive sampling

Purposive sampling is not premised on finding a sample representative of the entire population nonetheless it can provide specifically what is required on a limited population (Bachman and Schutt, 2008:100). Purposive sampling entails selecting participants for the knowledge and lived experiences participants have which are required to achieve the research objectives (Etikal et al., 2016). Past experiences and knowledge of particular issues become the inclusion criterion for purposive sampling. Sharma (2017) asserts that participants are purposively selected based on the researcher's judgement. Selected participants should therefore have similar characteristics and qualities (Etikal et al., 2016). Caregivers for patients suffering from MHDs in KwaXimba were purposively selected. Thereafter, caregivers were recruited for the research. This was done with the aid of a field assistant who was born and has been living in the community for over 30 years. Purposive sampling is advantageous because it specifically focuses on a homogenous population (Andrade, 2021). The inclusion and exclusion criterion for purposive sampling is always clear and stringent. However, this could also be regarded as

its weakness, as the more a population is kept homogenous, the less likely it is to acquiring differing responses from participants (Andrade, 2021).

Caregivers of patients with MHDs have first-hand knowledge of the challenges, opportunities, and services available to patients. Additionally, caregivers have experience residing with a MHD patient. In addition, caregivers are responsible for patients daily, rendering them appropriate participants for this research. These caregivers possess the knowledge sought out for this research.

4.6.2.1. Inclusion and exclusion criterion

The inclusion criteria was inclusive of;

- All caregiver for patients suffering from MHDs residing in KwaXimba;
- all caregivers above the age of 18 years; and
- all caregivers available to partake in this study.

This inclusive criteria mentioned above does not limit the study to patients diagnosed medically but is also inclusive of all patients suffering from MHDs. Thus, differing methods of diagnosis and treatment for MHDs was obtained which enhanced the data. As such, comparisons can be made between the different routes' caregivers prefer and their perspectives as well as strategies adopted to accommodate the patient. This further enables the possibility of differing opinions among caregivers. Furthermore, this inclusion provided a variety of methods and perspectives utilised by caregivers as well as strategies adopted, to reside with the patient within communities lacking MHC services. All households without caregivers for patients suffering from MHDs were excluded. Caregivers for patients suffering from MHDs were selected due to their knowledge about issues, challenges, and opportunities available for patients. Furthermore, in this way, the researcher can establish how caregivers have utilised the minimal resources available to them, what other strategies may have been adopted and whether these strategies were effective in these circumstances.

4.6.3. Snowball sampling

Snowball sampling is one of the most common methods of non-probability sampling (Etikan et al., 2016). The locating of a few participants who are thereafter asked to recommend other potential participants is commonly known as snowball sampling (Micheal, 2008). The sample size is increased in this manner. All participants located are requested to recommend or invite other potential participants to be part of the research (Micheal, 2008; Parker et al., 2019). The

snowball sampling method depends on the connections between people created through shared experiences, characteristics, and social networks. Snowball sampling is advantageous in research scenarios where participants are difficult to locate as well as recruit to be part of the research process (Fossey et al., 2002). Participants who recommend others thus make it easier for the researcher to locate potential participants. A disadvantage of snowball sampling is linked to its advantage; if recommended participants want to avoid being a part of the research, it may become difficult for the researcher to locate other potential participants (Bhardwaj, 2019).

MHDs are associated with increasing discrimination and stigma in rural communities (Schroeder et al., 2021); therefore, people do not want to be associated with them. As such, it was challenging to recruit participants for the research as being part of the research may indicate that participants are associated with MHDs, thereby attracting unwanted stigma and discrimination towards the caregiver or their households. The snowball sampling procedure is most suitable for this research as willing participants (caregivers) can point the researcher towards more participants with whom they share the same challenges and the associated stigma in these communities. Furthermore, if participants enquire as to how they were located, snowballing sampling will be explained to them. Understanding that other caregivers have been participants in this research may motivated others to be willing participants, due to shared beliefs, challenges and experiences within the community of caregivers for MHD patients.

4.7. Data collection process

4.7.1. Triangulation

This study adopts a triangulation method. Triangulation denotes utilising multiple research approaches (Heale and Forbes, 2013). Triangulation is based on the convergence of different research methodologies where data is collected in two or more ways, usually including qualitative and quantitative research methods (Heesen et al., 2019). Data collection was conducted in two ways which are frequently used to acquire differing perspectives on a research issue. Triangulation increases the credibility and validity of research, enabling the researcher to comprehensively understand the research issue (Noble and Heale, 2019). As such, data collection and extraction were conducted through quantitative and qualitative research techniques (Johnson and Schoonenboom, 2017).

This study utilises the quantitative and qualitative research approaches. The quantitative research explores the perceptions of caregivers and the challenges caregivers, and patients

encounter in accessing appropriate MHC services. The qualitative research approach aims to explore the perspective of the key informant about MHDs and the available services for caregivers and patients.

4.7.1.1. Qualitative

“Qualitative research is the systematic inquiry into social phenomena in natural settings. These phenomena can include, but are not limited to, how people experience aspects of their lives, how individuals and/or groups behave, how organizations function, and how interactions shape relationships” (Teherani et al., 2015:669).

Qualitative research explores individuals' subjectivities, lived experiences and the in-depth knowledge of the researched population (Rajasekar et al., 2013). This research approach seeks to explore knowledge gained through the experiences of participants. Qualitative research potentially uncovers important issues, shedding light on underlying dynamics and marginalised groups (Tracy, 2019). Qualitative research may explore the researched population's beliefs, perceptions, and past experiences, why things happen the way they do, and why people act in specific ways. Qualitative research allows the researcher to understand people's everyday reality (Silverman, 2020). This approach sheds light on perspectives and knowledge of a population, bringing forth unknown or overlooked issues which may impact the researched community. Qualitative data is gathered through open conversations (Prosek and Gibson, 2021) as data collection methods are unstructured or unrestricted, allowing the participant to respond in a comfortable manner. This enables participants to include more information; the participant may deem necessary, as questions are predominantly open-ended. *“Qualitative research embraces subjectivity”* (Haven and Van Grootel, 2019:234). It unpacks each individual's knowledge, perception and experiences. Therefore, qualitative research enables minor, marginalised, or excluded populations to be heard and their issues to be understood from their perspective.

Qualitative data is collected through interviews, focus groups and the observation of participants (Fossey et al., 2002; Haven and Van Grootel, 2019). Creating open and unlimited engagement with participants. Qualitative methods are advantageous because a vast amount of data can be acquired from a single participant (Fossey et al., 2002). Qualitative research has been criticised for its analysis which is based on human interpretation, which could limit the generalisability of findings (Mwita, 2022). Analysis of qualitative data may therefore be influenced by the understanding and interpretation of the researcher, thereby limiting the

generalisability of research findings and conclusions. The generalisability of qualitative research has been further questioned due to its limited or small sample size (Vasileiou et al., 2018). Generalising from a small sample is questionable, as data collected from a few participants is utilised to provide a general overview of the entire population under research (Groenland and Dana, 2020). This research utilised one interview to collect data qualitatively, where the key informants' knowledge and perception were acquired.

4.7.1.2. Quantitative

Quantitative research focuses on collecting data which can be analysed numerically or statistically (Goertzen, 2017). Quantitative research methods focus on statistical or numeral analysis by asking questions. Participants are often provided with options and may choose an option most relatable to their circumstances. Withers (2016) defines 'quantitative research' as the systematic scientific investigation of quantitative properties, phenomena and their relationships using statistical methods. Quantitative research methods include surveys, questionnaires, field research and experiments. Quantitative data is advantageous because it is applicable and representative of the target population (Goertzen, 2017). Quantitative data generally has a larger sample size which is believed to be a better representation of the researched population.

Data collected quantitatively is interpreted or analysed using pie charts, tables and graphs from which conclusions can be drawn. Quantitative research is criticised for collecting data based on preconceived assumptions (Mwita, 2022). Tools utilised to collect quantitative data usually provide options for participants from which they can choose. The options provided are based on what the researcher believes participants would state hence the preconceived assumptions. This could limit participant responses, as participants may be unable to add information. Furthermore, the options provided may be not fitting, leading to participants choosing options closest to their experience, knowledge or understanding of the question. This could be a limitation with unexpected and unknown experiences (Mwita, 2022). As such, all data collected is controlled and limited to the researcher's preconceived knowledge and understanding, thereby limiting the whole research. This research administered questionnaires to caregivers as part of its quantitative research approach. The questionnaires provided caregivers with various options, as well as incorporating other where participants had to provide clarity. This was done to try and overcome the weakness of preconceived assumptions limiting responses and data collection. Furthermore, the questionnaire had questions that allowed participants to elaborate after the chosen option and a section for recommendations and all other information the

caregiver wished to add. Hammargerg et al. (2016) asserted that it is important for researchers to evaluate the strengths and weaknesses of their research approach. This could allow the researcher to find ways to combat weaknesses of their research approach.

4.7.2. Permission to conduct study

Permission to conduct this study was applied for through the ethical clearance process. An application with a summary of the research proposal was submitted to the ethical clearance committee. This application was returned to the student for corrections and adjustments. The application was then resubmitted to the ethical clearance committee for a second time. The application was then approved, and the student was able to commence data collection by visiting the study area and communicating to the caregivers.

4.7.3. Informed consent

The informed consent form prepared by the student was uploaded via the ethical clearance application process. This form provided information on this research topic as well as what was expected of the caregiver or participant. All information was written in English and IsiZulu to allow adequate understanding for all participants prior to becoming part of this research.

4.7.4. Recruitment method

Purposive and snowball sampling methods were utilised to locate and select potential participants. Utilising the inclusion and exclusion criterion, the researcher and community member located and approached a few potential participants in KwaXimba. A total of 35 caregivers were selected to be a part of this research process. KwaXimba community has been in the forefront of media politics as well as war (Isolezwe,2024; Isolezwe,2021; Isolezwe; 2013). The community of KwaXimba also has an eThekwini district municipality profile from 2017. This profile indicated that there was one primary health care centre, community health centres, hospitals and rehabilitation or hospice facilities were non-existent. It also stated that there was 70 traditional healers operating but only 20 registered (eThekwini Municipal profile, 2017). All KwaXimba residents have access to water and sanitation (eThekwini Municipal profile, 2017). Therefore, in terms of development in South African rural areas KwaXimba has a lot of progress in terms of development (eThekwini Municipal profile, 2017). The researcher decided to go into KwaXimba to speak to community members at ground level.

4.7.5. Data collection methods

Data is variables which could be statements or figures from which conclusions are drawn (Ajayi, 2017). Data can be obtained in two ways, namely through secondary (desktop) and primary (fieldwork) data sources.

4.7.5.1. Primary data

Primary data is collected for that specific research purpose through fieldwork, and the researcher collects the data first-hand (Johnston, 2014). Primary data is collected by the researcher specifically for that research. Primary data is advantageous because it contributes to new knowledge or adds to existing knowledge (Hox and Boeijs, 2005). However, collecting primary data is expensive and time-consuming. This is because primary data predominantly requires the researcher to conduct fieldwork. Primary data for this research consists of questionnaires administered to caregivers and an interview with the key informant in KwaXimba. *“A questionnaire is a survey instrument containing the questions for a self-administered survey”* (Bachman and Schutt, 2008;146).

The researcher prepared informed consent forms (appendix iv), a questionnaire (appendix i) and an interview schedule (appendix iii). The researcher received assistance from a community member of KwaXimba, in purposively identifying the initial participants for the research who are caregivers of MHD patients. The community member is a relative of the researcher who has been requested and agreed to assist in this regard. The community member was born and has lived more than 30 in KwaXimba community and was therefore familiar with households that have patients suffering from MHDs.

This research administered 35 questionnaires to caregivers which will take approximately 45 minutes to an hour at the caregiver's home or another location suitable for the caregiver. The researcher would read out the questionnaire to caregivers and tick their responses in the questionnaire. Additional information provided by caregivers was noted down. This was done to speed up the duration of the questionnaire administering and was the most preferred and convenient method for caregivers.

The researcher will recruit participants, obtain consent, and administer the questionnaires in open spaces in households, preferably outside with good ventilation and to adhere to COVID-19 restrictions. The questionnaires will be administered in IsiZulu or English, depending on participant's preference.

4.7.5.2. Secondary data

Secondary data is collected for other research purposes and utilised for another research goal (Johnston, 2014). Secondary data consists of all literature reviewed from books, journals, articles, newspapers, and other media outlets. Secondary data may not adequately achieve the research objective due to the data being previously collected for different purposes (Hox and Boeijs, 2005). Online searches were done to find articles related to the whole research with the use of key terms such as mental disorders, rehabilitation, MHC, rural services, stigma, to mention a few to help with the analysis.

(i) Questionnaires

Questionnaires were administered to caregivers of patients with MHDs in KwaXimba, eThekweni Municipality, KZN. Caregivers who are often family members reside with patients and dedicate most of their time to helping the patients with MHDs (Gutierrez-Herrera et al., 2021). Questions in the questionnaires sought to explore the experiences, challenges and opportunities available for caregivers and patients in KwaXimba, eThekweni Municipality, KZN. Qualitatively an interview was conducted with the king (King Mlaba) as the key informant.

The researcher met up with the community member in KwaXimba when going to collect data due to his knowledge of a few households with patients suffering from MHDs. The community member accompanied the researcher to these households. The researcher knocked from door to door, requesting for the head of the household or the oldest person. Upon determining who the caregivers were, the researcher then recruited participants by requesting the caregiver to spare some time and talk to the researcher. Participants were then given the informed consent form (which the researcher reviewed with the caregiver). This was done to ensure clarity before participants signed the informed consent form. The researcher and caregiver found a suitable location to administer the questionnaire.

(ii) Face to face semi structures interview

The key information identified and chosen is the king of KwaXimba, eThekweni Municipality, KZN (refer to appendix iii), who has been identified and purposively sampled by virtue of his position in the community. The king will be purposely selected by virtue of his position in the community to provide a perspective of those in leadership concerning mental health disorders in rural areas. The interview will be conducted in an open space adhering to all COVID-19 regulations.

4.8. Procedure for the analysis of data

Upon acquiring ethical clearance, data collection began in KwaXimba. Caregivers were requested to participate in the research and provided with informed consent forms to read and sign. Clarification and explanation of the informed consent form were provided where necessary. Thereafter, the questionnaires were administered to available and consenting caregivers. All data collected was transcribed. Caregivers became reluctant to respond to the questionnaire if it was handed to them; however, the process was easier and quicker when the researcher went through the questionnaire with the caregiver. In addition, the data was translated from isiZulu to English prior to analysis. Responses from the quantitative questionnaires were uploaded and analysed via SPSS version 28. SPSS provides tables which were utilised to create graphs and pie charts from which an analysis was derived.

Interview with the key informant was also conducted in isiZulu, transcribed, and translated into English. The key informant interview was analysed thematically. Qualitative thematic data analysis is done by sifting and finding recurrent themes within the data, which are then grouped for meaningful relations within the data collected (Fossey et al., 2002; Ritchie et al. 2013). Data from the key informant was then compared to the data from caregivers.

4.5. Ethical consideration

Ethical considerations are crucial in research, starting from the introduction to the conclusion (Fossey et al., 2002). Conducting research in an ethical manner denotes protecting the rights of participants, respecting their values and beliefs, protecting participant identities, and informing participants of their rights before initiating the data collection. Ethical considerations were utilised for this research initially for the questionnaire by ensuring all questions were ethical, easy to understand, unambiguous and insensitive. After which, the application for ethical clearance began. Once ethical clearance was granted, the researcher could engage with community members and the key informant of KwaXimba, eThekweni Municipality, KZN. Ethical considerations strictly forbid patients with MHDs from being participants in this research endeavour. The researcher engaged only with caregivers, and the patient was absent during the administration of the questionnaire.

Data collection for this research was during the COVID-19 pandemic when regulations had been eased (October 2022 to January 2023); however, the fieldwork took place when all restrictions and lockdown measures had been eased. All COVID-19 regulations were adhered to during data collection. The administration of questionnaires was mostly outside, with a safe

distance of two arm's lengths between the participant and researcher. The researcher carried her sanitiser, twenty pens and questionnaires which were sanitised and placed in plastic sleeves before administering the questionnaires. These were sanitised in the evening in preparation for the next day. All participants were required to wear a mask while administering the questionnaire. The researcher sanitised herself and the participant at the beginning and at the end of the questionnaire administration. The same procedure was followed for interviewing the key informant. The community member assisting the researcher also wore face masks during caregiver engagements.

All participants' identities were protected, as participant details will not be mentioned or published in any research chapters.

This research was granted ethical clearance by the Humanities and Social Sciences Research Ethics Council with the HSSREC/00004742/2022 (refer appendix VI).

4.9. Fieldwork experiences and limitations to the study

KwaXimba is such a large area that the researcher used public transport. Travelling between households was time-consuming as households with caregivers and patients were far apart. This also proved to be costly and time-consuming as public transport was utilised.

Caregivers were reluctant to sign the informed consent form and provide their details. Caregivers would understand the objective of the research and agree but become reluctant after being informed about their signatures being required. This is due to underlying assumptions that their information may be used in illegal activities. Other households were hesitant to participate in the research as they were unfamiliar with the researcher.

During data collection, the researcher came across many households who did not want to be part of the research if the researcher could not aid their circumstances. Questions like “*Are you a social worker, community health care worker*” were common. Caregivers often expect the researcher to assist them or their patients with social services or finances.

In one household, the patient was quite violent and used vulgar language; the researcher was told to leave, or the patient may hurt the researcher. The patient was in a bad mood.

In some cases, the questionnaire was administered at any place where the caregiver felt was deemed suitable. This could be at the shops, alongside the road or community gardens. This made it difficult to record information as both the researcher and caregiver were standing.

In most cases caregivers did not want to wear face masks during the administration of questionnaires; however, the researcher always wore her facemask and engaged with such participants in open spaces. In some cases, participants were recruited publicly and did not have masks.

Participants were willing to engage with the researcher but did not grant permission for pictures of themselves to be taken due to confidentiality reasons.

The researcher carried a notebook in which all important data from participants was written down during the administering of the questionnaire. This data was transcribed and translated into English and inserted into the research analysis. This was done to enhance and provide clarity for research themes and significant points.

This research recommends that future researchers acquire field assistants from studied communities when conducting research on sensitive topics. This encourages community members to be more receptive to the research. Caregivers were more receptive and open to speaking to the researcher after recognising, engaging and agreeing to speak about the MHD to the researcher and the field assistant. In some household's caregivers were hesitant however the existing relationship between the research assistant and the caregiver led to increased trust and openness hence participation in this research.

4.10. Previous studies data

Table 4.1. below depicts data collected from studies with caregivers in India, Tanzania, Zimbabwe and South Africa. It serves to highlight the most common challenges, findings and caregiver comments on issues remaining most relevant to their circumstances. The next chapter analyses data collected from this study also pertaining to caregivers for patients with MHDs in KwaXimba. These studies were conducted in a similar setting which implies that there should be similarities in the results obtained. The following studies are from India, Tanzania, Zimbabwe and South Africa. This Table 4.1. can thus be utilised as a drawing point and serve as a validation point to be applied to the results obtained from KwaXimba.

Country	Reference	Caregiver challenges	Study main findings	Caregiver commen
South Africa	Ndlovu and Mokeone, 2023	Older, less educated female caregivers in various socio-economic contexts need additional resources to support and provide care.	Self-reported depression of caregiver (89%). Receiving help with care-giving role (27%). Gender of the patient (70%). History of relapse after admission (17%). Unemployment of patients 100%. Age of caregiver. Monthly family income. Caregiver unemployment 83% - poverty (had to quit jobs, 77% depend on disability grant). Family members assume this role.	
India	Narasipuram and Kasimahanti, 2012	Caregivers perceived to have a greater burden of caregiving in comparison to their urban counterparts.	Mostly married unemployed mothers no formal education or less than high school education. More challenges for caregivers in rural areas . Main caregiving responsibilities are the preparing of meals, taking medicines, managing money, performing household chores, being supervised and the potential to wander were associated with higher burden. Caregivers need social support and family intervention programmes to cope with the burden of caregiving and enhance their quality of life.	

South Africa	Mavundla et al. 2009	MHD patients require assistance with food preparation, shelter, cleanliness, and taking medication which requires a lot of time and effort from caregivers	The most important finding of this study was that responses of the caregivers were mainly negative conceptualisations of their experience, despite the neutral nature in which the interviews were conducted and the neutrality of the questions.	<i>“Sometimes he just and takes out what despite what the fa intending to cook t asks (for) foods that he cannot affo</i> <i>“The support we g has taken his medication correct refuses to take (his) medication. I</i> <i>“I need help. Twelv play. To tell you the honest fact, soc anything for me.”</i>
Zimbabwe	Marimbe et al. 2016	The findings on financial burden, carers frequently forego economic opportunities in order to take on caregiving roles, a pattern that can further entrench the poverty of a given household. Receive less medical attention as more goes towards patients.	Caregiver challenges were mainly the following “physical harm/illness, psychological and emotional impact, financial burden, material burden, social factors and stigma”.	<i>“I was really affect we were staying wi threatening that he several times the w me and I started ha pressure.’ (FDG, m</i> <i>“I think the time th and nurses is very that you won’t und If you get into a ses becomes difficult to are not told how yo patient. I think that wish we could be g</i>

South Africa	Mazabane and Petersen, 2021	Mental health illiteracy. Reluctant to seek medical services due to stigma attached to common beliefs.	Financially, caregivers also highlighted that mental illness in the family posed a tremendous household strain, amplified in low-income and low-educational families. Mental health stigma reduction interventions in Africa should not only focus on caregivers, services users, and immediate families. Social media can be used to improve mental health education.	helped as carers and to cope.' (FDG, sis) "They think that one are most likely to undress in the street things that other people don't know about mental illness, which are misjudged." "When she started thought she is bewitched, or she is community isolate her, and they wanted to leave the community just because illness". ~ Caregiver
South Africa	Ntsayagae et al. 2019	The important theme was that the family caregivers	Mental health illiteracy. Fear and helplessness.	"A support group be advice from some of the things What I need most is advice on how is having an episode, and social counselling." ~ Caregiver 04 "There is no problem caring for the ment

		experienced challenges with caregiving; They did not know how to seek help. Helplessness seems to be a determinant of fear for most family caregivers. The demanding caregiving role does not only interfere with their day-to-day work, but reduce outside social opportunities as well.	The review also reported that family caregivers' inability to effectively cope with caregiving could lead to emotional distress.	<i>he is forever...I don't do completely". (Wan 2013:60)</i> <i>"The support that I have that he has taken has been because he often requires medication. I always (2006:30)</i> <i>"To me the transportation medication is almost the drug ...this has caused financial problems very far to come to do this every month (2013:60)</i> <i>"There is an increase compared to when the patient is well" (patient with bipolar disorders).</i> <i>"About clothing, she because she was not aware of herself and was necessary to ensure that she get washed and ironed (female caregiver for depression).</i> <i>"I think all community and caring</i>
Tanzania	Isiseko and Ambeliko, 2020	Caregivers and patients have mixed experiences of patients' involvement in various home activities. Caregivers mentioned how medication often had a drastic impact on patients and the way they behaved often not beneficial to the patient (lethargic).	The main findings from this study show that most patients with mental illness do not have their needs met appropriately to facilitate recovery. The involvement of the patients in various social activities, either at home or in the community, is not adequately practiced since some caregivers and community members are not aware of how people with mental disorders could be assisted to meet their needs. Reinforcing self-care activities is an important factor to be.	

attitudes to people
illness. Because of
the high percentage
illness lack lovely
care. For example,
having a problem
and comes to you for
help you need to
respond politely, if
can change sudden
So, love is very crucial
that they
can improve their
community member
age 40 years).

“Because the way I
wander in the
street, the female
mental illness can
impregnated. The
of getting an
unfriendly environment
peoples become
affected, the baby
can delay recovery
for this patient” (female
member, age 35 years)
Participants also
should be protected

Table 4.1. Studies conducted in rural settings in India, Tanzania, Zimbabwe and South Africa

4.11. Chapter summary

This chapter has highlighted and elaborated on all appropriate methodologies utilised to collect and analyse data for this study. In addition, this chapter further included a table of studies showing results obtained from caregivers providing care for patients with MHDs. This table will be utilised as an inferential component in comparing data from the current study and similar studies. Moreover, a triangulation method was used. Purposive and snowball sampling methods were utilised to select participants. Each methodological tool has strengths and weaknesses which have been elaborated upon. This chapter has further provided background information on this study area, KwaXimba. The background of this study area sheds light on existing challenges which may pose additional challenges for accessing MHC services in KwaXimba. This chapter also elaborated on ethical considerations and mentioned challenges encountered during data collection.

Chapter 5 Data presentation, analysis and discussion

5.1. Introduction

The previous chapter focused on methodologies adopted by this study when conducting data collection in KwaXimba, eThekweni municipality, KZN. This chapter presents, analyses, and discusses data collected from 35 caregivers in KwaXimba concerning challenges of accessibility and availability of MHC services and the burden of providing care for patients with MHDs. The data has been analysed quantitatively and qualitatively. Quantitative data collected through the administration of questionnaires has been analysed through IBM Statistical Package for the Social Sciences (SPSS) statistics version 28. Qualitative data collected through the conduction of an interview has been analysed thematically. A total of 35 questionnaires were administered to caregivers of patients with MHDs in KwaXimba. The administration of questionnaires was through the indigenous language in the area, which is Isizulu. In addition, one interview was conducted with the king of KwaXimba in IsiZulu. All data was transcribed and translated into English. This research was able to locate 35 willing caregivers in the community up until saturation at the time of data collection. Therefore, 35 caregivers were presentative of caregivers with MHD patients in the study area. The analysis is divided into sub sections for easy flow, understandable analysis utiling SPSS, thematic analysis and descriptive analysis method.

The chapter is sub-divided into the following sections

- Caregiver demographics and household background information;
- Patient with MHD demographics;
- Diagnosis;
- Caregiver perception;
- Community awareness;
- Access to social services;
- Providing care;
- Access to psychiatric help;
- Access to rehabilitation programmes;
- COVID-19 impacts;
- Suggestions; and
- Interview with key informant

5.2. Caregiver demographics

Caregiver demographics provide information on participants who were engaged as part of data collection for this research. Demographic information including age, sex, race and religion are common in research studies (Bachman and Schutt, 2008). Caregiver demographics explored include gender, education, employment, age, nationality, home language and whether participants were heads of households. This data was collected from a total of 35 caregivers of patients with MHDs in KwaXimba, eThekwin Municipality KZN.

All participants were South Africans and fluent in IsiZulu. Black South Africans usually populate rural areas in SA, and this can also be attributed to the colonial legacies of segregation. During the colonial era, all black South Africans were discriminatingly placed in the outskirts of rural areas dominated by poverty (Aliber and Mdoda, 2015; Jansen et al., 2015). According to the 2011 census data, people of African descent were the dominating population in KZN. KZN is largely dominated by the Zulu tribe, which uses the isiZulu dialect for communication. Approximately 81% of people in KZN utilise the isiZulu dialect (StatSA, 2014). Below is Plate 5.1 depicting the Bhobhonono community, one of the communities in KwaXimba.



Plate 5.1. The Bhobhonono community in KwaXimba, eThekwin Municipality, KZN

KwaXimba is a rural but congested area (as depicted in Plate 5.1) within the eThekwin Municipality. It is clearly visible that the houses are not far apart from one another, which is commonly associated with rural areas. This image is from one of the communities within KwaXimba, known as Bhobhonono. The table below shows the demographic information of participants in the study area.

Variables		<i>n</i> =35
Gender	Female	96%
	Male	4%
Age	26-35	9%
	36-45	14%
	46-55	48%
	56-65	23%
	>65	6%
Head of household	Yes	77%
	No	23%
Marital status	Single	45%
	Married	20%
	Widow	29%
	Separated	3%
	Living with partner	3%
Level of education	None	9%
	Level 1 (preschool)	9%
	Level 2 (std 6/grade 8)	6%
	Level 3 (std 8/grade 10)	14%
	Level 4 (std 10/grade 12)	45%
	Level 5 (diploma/ degree)	6%
	Short courses	11%
Occupation	Unemployed	53%
	Domestic worker	9%
	Pensioner	29%
	Professional	6%
	Shop assistant	3%

Disability	Yes	6%
	No	94%
Existing health issues	Yes	49%
	No	51%
Relationship to patient	Mother	37%
	Grandparent	9%
	Relative	17%
	Guardian	6%
	Sibling	31%

Table 5.1 Demographic information of caregivers

The majority (94%) of the participants were female. The role of caregiving represents providing care or taking care of, which is associated with nurturing; hence the role is assumed by females more than males (Pretorius et al., 2009). This can also be attributed to the migration whereby males seek employment opportunities from rural areas (StatSA, 2012), leaving behind the women. Almost half of the caregivers (48%) ranged between the ages of 46 to 55 years. Rural-urban migration could be another factor where the youth migrate to urban areas in search of better opportunities (Zhang, 2015), leaving the older generation behind. Caregivers have noted that providing care consumes a lot of time, whereby caregivers have very little time for socialising as more time is spent on patients (Mall et al., 2017; Hailemariam et al., 2017). Therefore, younger people within households would refrain from taking such responsibilities upon themselves. The role of caregiving in KwaXimba was generally assumed by an older person within the household or the oldest household member. All caregivers in this study, were 26 years and above.

Most of the caregivers (77%) were heads of households or had assumed the responsibility of being the head of the household, while 23% were members of households. Caregivers who were heads of households were responsible for the patients and their entire households. One of the caregivers elaborated:

“Our parents passed away, and then I had to assume the role of head of household” (December 2022, Participant 8)

Caregivers who were not heads of households either stayed home with their siblings, at their maternal side or at the *Inyanga* (herbalist) house. Additionally, as evident from Table 5.1, 6% were male caregivers, 3% of which was head of households implying that from the 77% of caregivers who were head of households, 74% were female. Therefore, the majority of caregivers (74%) were female and were heads of households. In some cases, the caregiver was the eldest member of the household. This placed them as the head of the household, but they did not recognise themselves as such and still regarded the household as led by their deceased parents. Below, the level of education and marital status data is presented.

It is evident from Table 5.1 that most of the caregivers (45%) had completed their high school education. Eleven percent of caregivers indicated that they obtained certificates for home base care, sewing and administrative courses (short courses). A total of 9% of caregivers have never received any level of education. Only a few went onto tertiary educational institutions (6%).

Neelyand and Ponshunmugam (2019) have pointed out that rural people have limited education. Caregiver's limited education influences their ability to provide care due to a limited understanding of MHDs (Zahid and Ohaeri, 2010; Saunders, 2003; Caqueo-Úrizar and Gutiérrez-Maldonado, 2006; Lasebikan and Ayinde, 2013; Inogbo et al., 2017). From this research, however, 91% of caregivers had attended an educational institution at some point. In 2017 74% of South Africans attended educational institutions in KZN (StatSA, 2017). This is a significant stride toward achieving Sustainable Development Goal (SDG) 4 on providing quality and inclusive education for all by 2030 (Akintolu and Uleanya, 2021).

Nearly half of the caregivers (45%) were single. This included caregivers who are siblings to patients, children of patients and caregivers who were not legally married but whose lobola had been paid. Twenty percent of caregivers were married, while 29% were widows. Combining the married (20%) and widows (29%) indicates that nearly half of the caregivers were married. Furthermore, another 3% were separated, meaning they had also been married, increasing the percentage to 52%. Additionally, 3% were living with partners. The occupation of caregivers is presented in Table 5.1.

From Table 5.1, it is visible that more than half of the participants (53%) were unemployed. In SA, as of 2021, the unemployment rate escalated to 30% as per the State of the Nation Address (SONA) by Mr president Cyril Ramaphosa (SONA, 2022). Nevertheless, more than 1.5 million jobs have been created (SONA, 2023). Accounting for the high unemployment rate of caregivers in KwaXimba (53%) could also be linked to the responsibilities of caregiving which require caregivers to dedicate much time to care for patients. The implication is that caregivers cannot dedicate extended periods to another activity (such as employment) (Ohaeri, 2001; Addo et al., 2018). It is common for caregivers (almost half) to be unemployed, while caregivers who work have limited time due to caregiving being time-consuming (Addo, 2018). MHDs are responsible for 17% of YLD in SSA (Vancampfort et al., 2017), rendering patients disabled and needing more support. Furthermore, employed caregivers might have had to leave their jobs, leading to a high number of caregivers being unemployed and needing more support. This could indicate that caregivers rarely have time for employment besides providing care. High unemployment rates imply the absence of income, leading to impoverishment and food insecurity. Rural areas are highly associated with poverty, (Aliber and Mdoda, 2015; Jansen, et al., 2015). Twenty-nine percent were pensioners, dependent on the South African Social Security Agency (SASSA) grant. People experiencing poverty relied heavily on SASSA grants (StatSA, 2018). An analysis by National Income Dynamics Study (NIDS) (2009),

approximately 63% of Africans live in poverty (Argent et al., 2009). The remaining 9% of caregivers were domestic workers working 2 to 5 days weekly. SASSA grants also supplement their income, creating a safety net in times of difficulty. Shop assistants accounted for 3% of the caregivers who also collected the SASSA grant. The only group that did not collect the SASSA grant was professionals comprising of 6% of caregivers in KwaXimba. Limited education is associated with low economic conditions and social status in communities (Zahid and Ohaeri, 2010; Saunders, 2003; Caqueo-Úrizar and Gutiérrez-Maldonado, 2006; Lasebikan and Ayinde, 2013; Inogbo et al., 2017).

It was common for caregivers not to have any disabilities (94%). Caregivers with disabilities mentioned being unable to walk due to sicknesses such as diabetes and arthritis. One of the caregivers who had a disability due to illness made use of a walker to be mobile or to improve mobility. This may also be associated with the need for caregivers to be healthy, mobile and able to assist the patient within the household. This may prove more challenging for someone who is disabled hence the responsibility of caregiving being assumed by household members who were not disabled. Some of the mentioned health issues included arthritis, asthma, high blood pressure and diabetes. As illustrated in Table 5.1, 49% of the participants indicated having a health issue; however, some of the patients were not willing to disclose their health status. Forty-nine percent of the caregivers indicated having no health issues. During the administration of the questionnaires, all caregivers were made aware of their choice not to respond to any questions they may be uncomfortable with. As such, some of the caregivers may have not divulged their actual health status. Due to caregiving being frustrating and challenging for caregivers (Butcher et al., 2001; Swartz and Collins, 2019), it may lead to the development of health issues in caregivers. Caregivers have reported moderate to high burdens of caregiving (Vancampfort et al., 2017). Caregivers face enormous stress, which negatively affects their health conditions.

From Table 5.1, it is evident that 37% of the caregivers were mothers of the patients, 31% were the patient's siblings, 17% were relatives, 9% were grandparents, and 6% were guardians. It is evident from Table 5.1 above that the role of caregiving is predominantly assumed by family members. The role of caregiving has been acknowledged to be commonly assumed by relatives or friends who provide care for patients without expecting or receiving any form of payment for their services (Pearlin et al., 1990; Family Caregiver Alliance, 2006).

Of the 6% who were guardians, 3% was a caregiver who had married into the family of the patient, and the other 3% was *Inyang*, who had been placed as a guardian while the patient was in his care.

5.3. Household background information

Variables	Total (n=35)
Type of dwelling	
Formal house	71%
Traditional house	6%
RDP	23%
Number of people living in a household	
0-3	3%
4-6	29%
7-10	57%
>10	11%
Number of dependents within participant households	
All	40%
1-3	14%
4-6	40%
7-10	6%

Table 5.2 Household background information

Formal houses accounted for 71% often built with block and cement or with mud and plastered with cement. An example of a formal house is provided below;



Plate 5.2. Formal house constructed and owned by participant

From Table 5.2 it was evident that Reconstruction and Development Programme (RDP) houses accounted for 23%. Traditional houses accounted for 6%. These were houses constructed strictly with mud and different types of sand. It is worth noting that some of the formal households also had Reconstruction and Development Programme (RDP) houses in the yard, but the RDP was not used as the main house. The remaining 23% had RDP houses in which they were residing. Each household must generate a monthly income of less than R3500 to qualify for the RDP house (Mashwama et al., 2018). All caregivers with traditional, formal or RDP houses had built on premises or pieces of land they owned. Therefore, the houses were also owned by them. Caregivers had either bought the land themselves or were bought by their parents or grandparents. This land belonged to the caregiver's family. Some of the formal houses were initially RDP houses which have been renovated and enlarged to accommodate larger families. Almost every household in KwaXimba had the RDP house, but for some households, the RDP was not the main house in their yard. Access to adequate housing has been recognised as a right for all South Africans (RSA, 1994). In attempts to address the social-spatial inequalities left by the colonial era, the South African government introduced the RDP (Narsai et al., 2013). Through this program, South Africans received low-cost housing commonly known as the RDP houses. A plate is provided below depicting an RDP house constructed for a participant.



Plate 5.3 RDP house constructed by the municipality in KwaXimba, eThekweni Municipality, KZN

In the study area many of the homesteads have RDP houses in their yards. The RDP houses are part of the low-cost housing programme initiated in 1994 as part of increasing service provision and redressing past imbalances, mainly in rural areas of SA (Mashwama et al., 2018; Thakur et al., 2019). Only, South African households earning less than R3500 or unemployed qualify to get the RDP houses (Gryling 2009; Mashwama et al., 2018). These figures indicate that RDP houses are for the poor. The escalating number of RDP houses in the study area indicates that KwaXimba, is a poverty-stricken community. The reason being a high portion of the community qualified for the houses, implying that heads of households were either unemployed or earning less than R3500 per month. Furthermore, KZN has been listed as one of the provinces with the highest number of RDP houses (StatsSA: 2016; Msindo, 2018).

In most caregiver households, there were 7 to 10 household members (57%). RDP houses can accommodate small families. The RDP house has two bedrooms, one small room for a bathroom, and one open room to be used as a dining or kitchen area. The RDP house, therefore, can support a family of 3 to 5 comfortably. The increasing number of household members indicates that the household needs to have more than just the RDP house to live comfortably with some form of privacy. This explains why households in KwaXimba, have more than one house in the yard and the RDP house as well. According to caregivers, household members have increased significantly in the last ten years due to grandchildren, nephews and nieces being born into the families. The most common number of dependents (40%) were in households where all members were dependents and there were also households where 4 to 6 members were dependents (40%). Dependents were either children or unemployed with no source of income.

Caregivers who often assumed the role of caregiving were also heads of households or the breadwinners. This meant that they provided emotional, physical, and financial support for their entire households. In such households, the caregiver brings the primary source of income for the household. For some caregivers, the income consisted of different grants, including the disability grant, pensions, and child support grants. Provided that 83% of participants are unemployed (Figured 5.1 on page 69). This indicates SASSA grants are the main source of income, and households largely depend on them. The analysis by NIDS and Sharaunga and Mudhara (2021) asserted that households living in poverty usually have a higher number of people living within their households. This is due to the high number of people burdening the employed individual. Sharaunga and Mudhara (2021) further argue that the type of family structure within a household impacts the household's potential to generate an income.

All participant households have access to water. Taps were installed by the municipality in their yard to collect water free of charge. Free access to water is due to the Free Basic Water Policy of 2001, which aimed to include people experiencing poverty in having access to water (Lebek et al., 2021). All households with RDP houses were also provided with water tanks which collect rainwater. Participants elaborated that rainwater is used for domestic activities other than drinking and cooking. However, municipality-installed taps are often dry and need water. Lebek et al. (2021) also mention how water infrastructure has improved drastically in SA. However, water being available from their infrastructure is another challenge as reliability has decreased to 42% in district municipalities (Department of Water and Sanitation, 2019). In many areas of KZN (89%), there is water infrastructure (Lebek et al., 2021), however, water availability is at a deficient 42%. An example of a municipality-installed tap is provided below;



Plate 5.4. Formal tap in KwaXimba, eThekweni Municipality, KZN installed by the municipality

In as much as the taps have been installed in people's homes water is often unavailable, which continues to indicate disparities in access to water between rural and urban counterparts with better access (Adams and Smiley, 2018; Roche et al., 2017; Adams et al., 2016). From Plate 5.4 above, it is evident that the tap has been installed for the KwaXimba, community; however, it can be observed that the area around the tap indicates the unavailability of water

(approximately two years ago). Water shedding took place for extended periods leaving residents with no access to water. During these times, water trucks come into the community. Thus, community members must go to the trucks to collect water. Water trucks are part of the National Norms and Standards for Domestic Water and Sanitation, which aims to make water available for communities during water infrastructure repairs or construction (Department of Water and Sanitation, 2017). Below is a plate of a water tank in the participant's household.



Plate 5.5. Water tank in KwaXimba, eThekweni Municipality, KZN, provided alongside the RDP

Accessibility of water continues to be unequal in SA regardless of governments primary focus being on service delivery (Oosthuizen, 2020). Dependence on water trucks is wary as trucks do not come regularly. This contradicts the National Norms and Standards for Domestic Water and Sanitation goal, which aims to provide people with water within 24 hours of water unavailability (Lebek et al., 2021). There are other challenges, such as water trucks coming during the day when some people are at work or school and limits placed on the amount of water each household obtain. This is to ensure all households receive water. Occasionally water comes back in the early hours of the morning when residents are sleeping. This is approximately between 2 am and 6 am. Thereafter, the water shedding resumes. The lack of access to water implied that poor households found themselves in a difficult dilemma during the COVID-19 pandemic. Households were caught in between saving water for households needs or having to frequently wash their hands (Oosthuizen, 2020).

The bulk of caregiver households (86%) utilised pit latrines. Pit latrine or pit toilets are located outside of the main house were either built by the municipality (which most houses had) or by household members. Only 14% of households used chemical toilets. In some households, both toilets were used. The most common form of pit latrines in KwaXimba is depicted in Plate 5.5. This is the slab pit latrine. The slab pit latrine is constructed by the municipality for the community, while the traditional pit latrine is constructed by household members. A slab pit latrine is illustrated below:



Plate 5.6 Slab pit latrine or pit toilets in KwaXimba constructed by the eThekweni Municipality, KZN

Plate 5.6 illustrates that a pit latrine or pit toilet constructed with a concrete slab is the most common in SSA (63%) (Nakagiri et al., 2015). The increasing use of pit latrine toilets in KwaXimba, indicates low economic conditions and poor access to water, which is linked to sanitation. Rural areas in KZN have been associated with having limited access to water and sanitation (Msweli and Ngobese, 2013). The South African Human Rights Commission (SAHRC) asserts:

“Those areas which lack water and sanitation mirror apartheid spatial geography. Former homelands, townships and informal settlements are the areas in which communities and schools, which are black and poor, predominantly do not enjoy these rights and many others” (SAHRC, 2014: 3).

As the community struggles with water availability, it makes sense for community members to utilise pit latrine or pit toilets as these do not require water. Caregivers elaborated that these

slab pit latrine toilets require household members to pour sand or ash into the pit latrine after use. The challenge of water accessibility influences rural communities to utilise pit latrine or pit toilets outside of their houses, which are contaminated and unhygienic (Mngadi et al., 2023). Bisung and Elliott (2017) mention that using pit latrine toilets may be embarrassing to household members when they have visitors due to the unsanitary conditions of pit latrine or pit toilets.

According to caregivers, the challenge with these toilets provided by the municipality is that they get full quicker than ordinary pit latrines due to the short hole. Once the pit latrine or pit toilet gets full, the seat is changed to the other side whilst waste on the initial side decomposes. Caregivers mentioned that if the toilet is utilised as per the instructions (sand or ash thrown in after use), the waste decomposes well and is quicker. Therefore, when the toilet needs to be emptied, the waste has decomposed and is easier to remove. Waste removed from the toilet may be left behind the toilet or discarded into a dug-up hole. There is clearly no plan for the disposal of waste emptied from the toilet. This could lead to contamination. Caregivers further mentioned the use of chemicals to ‘burn’ the waste. This chemical is poured directly into the waste overnight and burns the waste leaving the toilet almost empty and ready for use. A traditional pit latrine toilet structure is presented below:



Plate 5.7. Traditional pit latrine or pit toilet built by household members in KwaXimba, eThekweni Municipality, KZN

Plate 5.7 shows a pit latrine or pit toilet built by household members where household members made their holes and then constructed the toilet on top of it. The structure was built by the community to provide shelter and privacy for anyone utilising the toilet. Caregivers elaborated that they prefer the pit latrine or pit toilet constructed by the community rather than the one provided by the municipality. However, these toilets have longer holed, which may present a danger for household members, especially children. The issue of children falling into pit latrines continues to be a challenge in KZN, where in 2021 over 3000 schools still utilised pit latrines which learners fall into (Odeku, 2022). This deprives learners of their dignity.

All households indicated having access to electricity in KwaXimba. Electricity was the main source of energy; however, it is frequently supported by other sources due to power cuts known as load-shedding. The plate below depicts an electric cable installed by the municipality going into a community' members house.



Plate 5.8. Electric cable connected to a homestead in KwaXimba, eThekweni Municipality, KZN

Caregivers utilise two sources of energy so that the electric token can be utilised for an extended period. Access to electricity was at 84% in 2018 in SA (STATS, 2018). This is a high percentage in terms of access which accounts for all the caregivers in KwaXimba having access.

Eighty-nine percent used candles, 40% used wood, 20% used paraffin, and 14% used gas. The other participants (11%) included rechargeable and battery-sustained lights. For instance, a household could use gas for cooking and candles for studying and lighting up the room at night, while another uses rechargeable lights, which require batteries while cooking with wood. The

electricity connections by the municipality are connected to each household. An example of the connection is presented in Plate 5.9 below:



Plate 5.9. Collected firewood to be utilised as energy sources in KwaXimba, eThekweni, Municipality, KZN

SA has been facing episodes of continuous power cuts since 2014 due to the inability of Eskom to supply electricity to the country (Gehringer et al., 2018). Load-shedding occurs frequently in KwaXimba, possibly 4 to 8 hours per day. During load-shedding, participants stated that they utilise gas stoves, paraffin, and firewood for cooking and boiling water. Candles, chargeable light bulbs, and lights powered with batteries are utilised at night to light their homes.

Other issues linked to the power supply included cable theft and unwarranted connections, which led to electric transformer issues. Electric cable theft has become a common issue in SA, where criminals steal electric cables to sell copper wires to metal companies (Modipa, 2022).

Additionally, people interfere with household electric meters to bypass the token. After the bypass, the electric token does not run out and is continuously utilised. Eskom has acknowledged that electricity theft is one of the significant contributors to load-shedding (Mujuzi, 2020). According to caregivers' parts of KwaXimba (Bhobhonono community) have not had electricity for the past three months (December 2022 to February 2023) due to a faulty electric transformer which supplies electricity to the area. The community was informed by Eskom to pay for the electric transformer since many of the households connected to the transformer were not registered with the municipality, and others had bypassed their electric meters leading to the malfunction.

Collecting firewood has become a challenge for households where firewood is utilised. Most of the land in KwaXimba, has been allocated to households; therefore, forests with firewood automatically belong to those households. Moreso, households do not want people to be collecting firewood from their land, as the wood belongs to them. Theft of firewood was also mentioned by caregivers.

“There have been cases where I go to collect wood, take some home only to come back and find that someone has taken my wood.” (November 2022; Participant 15)

Caregivers did not indicate any significant challenges with other forms of energy, such as gas or paraffin. In general, caregivers did not experience challenges with other forms of energy.

Households generally have more than one source of income, which are combined to achieve households' needs and wants. As shown in Table 5.2, almost every household (86%) had a household member who collected a SASSA grant. This comprised of the child support grant, foster child grant, care dependency grant and disability grant. This was the highest source of income amongst households with patients suffering from MHDs in KwaXimba. Additionally, another 80% collected the mental disability grant and 29% collected pension SASSA grants. In 2018 in KZN, more than half of the people experiencing poverty relied heavily on SASSA grants as their primary source of income (STATS, 2018). In some households, it is important to note that there was more than one patient with the MHD. Therefore, the disability grant was collected for more than one patient. Following that were wages (23%), remittances (17%), relative assistance (9%), selling of beadwork in Durban (6%) and selling products (3%). These are some of the responses from caregivers:

“I collect a pension for myself and the disability grant for the patient, and my daughter sends some money home also to assist.” (November 2022; Participant 5)

“I work three days a week as a domestic worker, collects three children’s social grant and the disability grant for the patient.” (November 2022; Participant 12)

“I am unemployed and rely solely on the disability grant and social grants for the children” (November 2022; Participant 15)

The majority of the caregivers collect more than one grant from SASSA, which consists of different sources of income for the households. The pension and disability grant were approximately R1990, the children’s social grant was R480, and the foster child grant was

R1070. According to the presidential financial speech, all these amounts will increase as of the 1st of April 2023 (SONA, 2023).

It is important to note that KZN is recognised as the province with the highest number of impoverished people (StatSA, 2017; StatSA, 2018). This high reliance on SASSA grants can be linked to the high unemployment rate in SA (Ramaphosa, 2021). This also creates a dependency relationship. Assuming the role of caregiving may lead to caregivers losing a source of income.

Table 5.2 indicates that 66% of households lost a source of income when the patient started being unwell with the MHD. Some of the patients were working or employed when the MHD started and had to return or be returned home, and in that sense, the household lost a source of income. Additionally, patients who might have been engaging in trading activities also lost an income when they became sick. Furthermore, caregivers who were employed or engaging in income-generating activities had to stop or decrease time spent engaging in those activities to enable more time for caregiving. Loss of income due to MHD for caregivers could push households into abject poverty (Addo et al., 2018).

From Table 5.2, It is evident that only 34% of households did not lose an income. For households which did not lose an income, the caregiver was already unemployed, the patient got sick at a young age or was born with the MHD, or the patient was unemployed. In some cases, the caregiver continued working or engaging in income-generating activities as the patient did not require a lot of assistance, and the household did not lose a source of income.

Most of the households (91%) did not make any changes to their home to accommodate the patient. The household continued to live with the patient, or the patient already had a room or another building on the same property. Only 9% of households made changes to accommodate patients, including building a room for the patient or exchanging household members with rooms to allow patients to have more space or a space in which patients could be relaxed or comfortable. In addition, this can also be linked to issues of affordability, as some households could not afford to make changes to accommodate the patient.

Caregiver demographic and household background information provide the context of caregivers. This background information paints a clear picture of the living conditions and briefly overviews caregiver and household access to services. From this information, existing challenges for caregivers and households are derived. These are general or common challenges for the community of KwaXimba. It is important to have knowledge of caregiver living

conditions, access to basic services and existing challenges. This enables the researcher to fully comprehend the burden of caregiving experienced by caregivers of patients suffering from MHD.

5.4. Patient with MHD demographics

Variables	Total (n=35)
Gender	
Female	86%
Male	14%
Age	
<18	6%
18-25	14%
26-35	26%
36-45	31%
46-55	17%
>56	6%
Education	
None	9%
Primary school	9%
Secondary school	73%
Tertiary	9%

Table 5.3. Patient gender, age and education

There were more female MHD patients (86%) than males (14%). From Table 5.3 it is evident the most common age range was between 36 to 35 years (31%), followed by 26 to 35 years (26%), and the least ranges were less than 18 years and more than 56 years with (6%). More than half of the patients were above 36 years of age, indicating that most patients were within the working age group.

The bulk of the patients (73%) had secondary school education. Such patients developed MHD later in their lives. This could be when the patient had completed their schooling and even started working. Nine percent of the patients had primary school education. It is evident many of the patients have formal education. Patients started their schooling careers and either dropped out or abandoned their schooling by their parents, guardians, or caregivers, while some completed their matric. Children who dropped out or were coerced by their parents often did the same grade repeatedly. Caregivers recognised patients as not coping under normal school conditions but did not send patients to any remedial school as there were none in KwaXimba. This accounts for the 9% of patients who only stopped at the primary school level. There are patients who have never attended any schooling facility (9%).

“We did send him to school, but he just was not like the other kids and could not cope and pass; therefore, we made him stop going”. (November 2022; Participant 6)

Caregivers mentioned recognition of the MHD but hoped that the children could learn to read and write. Caregivers find themselves in a predicament where patients are not sent to start their schooling or patient are sent to a normal school within the community, hoping that the patient completes a few grades. This is a clear infringement of the right of the patient. The absence of remedial education or institutions for the disabled renders caregivers and patients helpless. Patients who were born or developed the MHD at a young age did not obtain any education. Remedial schools are not in close proximity and are extremely expensive. Thus, caregivers would have to pay fees if they wanted to enrol their children in those schools. This could prove quite expensive and, therefore, unaffordable to caregivers. The last group of patients reached tertiary institutions (9%).

Caregivers could not provide medical terms for the symptoms of the MHDs. The MHD does not have different names within the Isizulu dialect. However, caregivers could identify the symptoms in patients. The symptoms were used to understand or describe MHDs. From the recognition of symptoms, caregivers would be able to diagnose the patient as suffering from the MHD before seeking another or confirming the diagnosis. Presented below are MHD symptoms noticed by caregivers in patients;

Variables	Total (n=35)
Talking to themselves	
Yes	74%
No	26%
Failing to understand and respond to simple instructions	
Yes	100%
Taking off their clothes	
Yes	9%
No	91%
Violent without any triggering	
Yes	29%
No	71%
Picking and collecting waste	
Yes	14%
No	86%
Failing and repeating the same grade	

Yes	3%
No	97%
Hallucinations	
Yes	40%
No	60%
Talking non-stop	
Yes	3%
No	97%

Table 5.4. MHD symptoms displayed by patients

(i) Talking to themselves

From Table 5.4, it is visible that 74% of patients started talking to themselves as a symptom of the MHD in KwaXimba. Hallucinations linked to seeing things or people with whom one communicates is a common symptom of MHDs. This symptom was often associated with laughing alone. Twenty percent of patients did not talk to themselves as symptoms of their MHD. Patients talking to themselves as a sign of MHD is common, as 74% of patients displayed this symptom.

(ii) Failing to understand and respond to simple instructions

Caregivers indicated that all patients failed to respond to simple instructions. Some patients would ignore the caregiver and be non-responsive. Other patients would respond but in an irrelevant way, with irrelevant information or even with an inappropriate response, indicating failure to understand what was mentioned by the caregiver. The rest of the patients would take long to understand and respond to what was being told to them as displayed in Table 5.4.

(iii) Taking off their clothes

Table 5.4 illustrates that 91% of patients did not take off their clothes unnecessarily within the household or in public. Taking off clothes is not a common symptom of MHDs. Taking off clothes in public is associated with SMHDs (Okello and Ekblad, 2006; Ventevogel et al., 2013). Disregarding societal norms and standards, displaying deviant behaviour is another symptom of MHDs. Taking off one's clothing in public or within the household is an example. Only, 9% of patients took off their clothes or were dressed indecently by revealing too much or inappropriate parts of the body.

(iv) Being violent without any triggering action

MHDs have been associated with violence. However, this study found that 71% of patients have not been violent unnecessarily (Table 5.4). This is when patients randomly attack people by becoming violent towards them. Caregivers noted that 29% of patients have been violent

within the household or community without any triggering or reason to be violent. This violence could either be physical or verbal. Being violent is also associated with SMHDs (Okello and Ekblad, 2006; Ventevogel et al., 2013).

(v) Picking up and collecting waste or rubbish

Table 5.4 shows that 86% of patients did not pick up or collect waste. Constant collecting or picking up waste or rubbish to be carried around in a bag or plastic has been noted as another symptom of MHDs by caregivers. Patients usually carry waste around for a long time as if it were their belongings. This could also fall under unusual behaviour. Such cases were less common than only 14% of patients have ever collected waste and rubbish in their communities.

(vi) Failing and repeating the same grade in school multiple times

Most of the patients did not fail and repeat the same grade numerous times in school. Only 3% of patients enrolled at a regular school in KwaXimba and failed the same grade multiple times until the caregivers decided to withdraw the patient from the school. This was usually because the patient was often the oldest in the class, received bullying or did not want to go to school anymore. In some cases, patients would not display any general symptoms, but once the child repeats the same grade three times or more, the parents or guardian would realise that there is something wrong with the child. These patients would then be removed out of school to stay at home as there were no special needs schools accessible to the households of KwaXimba.

(vii) Hallucinations and talking non-stop

There are other symptoms which patients display due to the MHD. Hallucinations were evident in patients as per Table 5.4 (40%). Patients believed that there were people searching for them and therefore, the patients ran away or went into hiding. In other cases, patients would tell household members someone is calling them and that they need to go. In cases where the patient was employed, the patient would frequently want to go to work and say they are needed in their workplace. A total of 3% of the patient would speak continuously without stopping. Patients would also tell non-ending stories to whoever was willing to listen.

The most common symptom experienced by all MHD patients was failing to understand and respond to simple instructions appropriately and timeously. The second most common symptom was patients talking to themselves, with 74%. The next was the hallucinations option provided by caregivers (40%), which included responding or acting upon hallucinations or things only seen by the patient, the patient talking nonstop and mixing up a conversation, and jumping from topic to topic. Patients also became violent without a cause or reason for the

violence (29%). Patients also collected and picked up waste to carry around for extended periods (14%). In severe cases of MHD, patients would remove their clothing in public (9%). Lastly, repeatedly doing the same grade as patients could not pass with 3%. This graph is a comparative graph showing the different symptoms displayed by patients. Some patients would display more than one symptom hence the multiple responses from caregivers.

5.5. Diagnosis

Variables	Total (n=35)
Family members had MHDs	
Yes	26%
No	74%
Relationship of the family member with MHD to patient	
Father	3%
Mother	3%
Sibling	9%
Grandparent	5%
Uncle or aunt	3%
Cousins	3%
Not applicable (no prior MHD in family)	74%

Table 5.5. History of MHD in family and relationship of the family member with MHD to patient

As illustrated in Table 5.5, 74% (not applicable) of patients did not have any other family member who had suffered from the MHD, as the patient was the initial member of the family. MHDs are infrequently hereditary where they are passed down from generation to generation. This is the case for a family in KwaXimba, where a total of three related households had one or two patients with MHDs. For instance, in one of the households, a mother had the MHD, and a daughter also developed the MHD. Ola (2013) mentioned that caregivers are at risk of developing MHDs because they are related to patients. This indicates that MHD can be hereditary. However, this is not as common as only 26% of households had another family member who have had the MHD prior.

As shown in Table 5.5, the majority of patients did not have a history of MHDs in their families (74%). Approximately 26% of households with patients suffering from MHD had a history of the disorder within the family. In 9% of the cases, the patient's siblings had the MHD. In 6% of the cases, the parents of the patient had the MHD, with the mother (3%) and the father (3%), respectively. The other included grandparents, uncles, aunts, and cousins

who also had the MHD. The table below illustrates the time frame within which caregivers realised the patients had developed the MHD:

Variables	Total (n=35)
First realisation of MHD in patient	
Immediately	88%
After a few days	9%
1-3 months	3%

Table 5.6. First recognition of the MHD in patient

Table 5.6 indicates that caregivers predominantly recognised the MHD immediately (88%) when the patient started showing symptoms of having the MHD. This was often when the caregiver tried to engage with the patient the next morning or on the same day, and the patient failed to respond accordingly. Caregivers (12%) who stated that they noticed the change over time as the symptoms gradually increased. These symptoms started as minor and developed into MHD. This 12% consisted of caregivers who acknowledged the patient having an MHD after a few days (9%) and after 1 to 3 months (3%).

When the patients started showing symptoms of the MHD, the patients started doing random unusual things. These included talking to themselves, shouting, singing too loud for extended periods, and being non-responsive to simple conversations and instructions. Other patients also became violent by either swearing (using vulgar language unnecessarily), fighting with everyone who comes close to them and sometimes even throwing stones at people passing by. The worst-case scenarios included the strangling of household members, stripping naked and running away from home.

“The patient started screaming and saying there were people after him who wanted him dead; therefore, he had to hide from them. However, these people were only seen by the patient.” (November 2022; Participant 9)

“I was called by her employer stating that she was unwell, and I had to go and fetch her” (December 2022; Participant 1)

In cases where the patient was away from home, the caregiver was made aware of the situation and had to assume the caregiving role immediately by bringing the patient home. In most cases, the recognition of the MHD is instant and easily noticeable as patients deviate from social norms. In most cases, the caregiver or any household member would realise something was wrong with the patient and call another household member to also confirm. Upon household

members' agreement that there was something wrong with the patient, initial steps would be sought in seeking help. Except for cases where the MHD was expected within the household or among relatives. The figure below represents the initial steps that were taken by caregivers and patients in seeking treatment for the MHD.



Figure 5.1. Initial steps taken in seeking help for the patient

Most caregivers consider taking the patient to the *Sangoma* the initial route of seeking assistance (49%) and the preferred method. It is common for people living in developing countries to seek traditional assistance in dealing with MHDs (Familia et al., 2013; Nortjie et al., 2016). Taking the patient to the *Sangoma* aimed to find the root cause of the MHD, and then appropriate methods of dealing with it were going to be sought as per advice from the *Sangoma*. The second chosen step of seeking initial help was taking the patient to the *Inyanga* (31%). In households where the MHD was recognised as a similar illness, diagnosis was not sought (11%). Traditional healers are abundant in rural areas in comparison to health care services hence traditional healers are more accessible (Campbell et al., 2008). This was proved by Ae-Ngibise et al. (2010); Kpobi et al. (2014), who found one psychiatrist per 1.4 million people in comparison to 1 traditional healer per 200 people. Furthermore, rural people prefer traditional healers in times of sickness (Sodi et al., 2011; Nortje et al., 2016). Also, medical practitioners in private practice are costly and require payment to be made after the consultation whereas the traditional healer has an agreement with the community of KwaXimba.

Only, 6% of households took patients to the clinic as a first step towards getting assistance, and 3% of patients were taken to a prophet. A prophet is a faith healer. In KwaXimba prophets were associated with Christianity or the Nazareth Baptist church. Traditional and cultural methods are clearly the first or the preferred method of acquiring help for the patient in KwaXimba. This indicates that the use of traditional methods to deal with MHDs is quite common and acknowledged as a viable option. Another contributory factor could be that health care workers impact the experience of patients, thereby influencing the preferred choice for patients (Harris, 2014; Atinga and Esena, 2018). As such, if patients encounter negative experiences in local clinics, they are bound to prefer another route of seeking assistance other than health care.

The *Inyanga* does not ‘*bhula*’ or seek explanations by throwing bones or anything but can sense and find appropriate methods spiritually. Participants who chose to take their loved ones to the clinic initially did know MHDs as just any other illness. However, they also acknowledged that an individual has never been wholly rehabilitated through medicine alone. After caregivers had realised the patient was displaying MHD symptoms, a diagnosis was sought, and initial steps taken are listed below;

Variables	Total (n=35)
First diagnosis	
Professional nurse	6%
Traditional healer	80%
Spiritual healer	3%
Undiagnosed	11%
Steps taken after diagnosis	
Patient started medication	6%
Patient did not start any treatment	9%
Ritual was done for patient	3%
Patient was left at <i>Inyanga</i> ’s house	23%
Patient started using traditional medicine from home	56%
Patients was prayed and started using holy water	3%
Difficulties with obtaining help	
Yes	9%
No	91%

Table 5.7. First diagnosis, steps taken after diagnosis and difficulties in obtaining help

Caregivers were able to recognise the MHD immediately. Caregivers then sought another opinion from either a traditional or cultural person. Approximately 83% of all initial diagnosis

was done by traditional, cultural, or spiritual persons. Majority of this was from traditional healers (80%), inclusive of *Izangoma* and *Izinyanga*. Zuma et al. (2016) defines *Izangoma* as diviners and *Izinyanga* as herbalists. Majority of the caregivers had a high preference for traditional methods for dealing with MHDs. This resulted from, firstly, traditional personnel being plentiful in the community compared to health care professionals. Secondly this could be largely influenced by traditional beliefs about the causes of MHDs. Other caregivers (11%) did not seek any diagnosis after recognising the MHD as they had experienced or seen it before in their families or those close to them.

One adult clinic in KwaXimba provides health care services to a very large community with the inclusion of KwaMkhizwane. This can lead to overcrowding of clinics and people having to wait in very long in ques before receiving assistance. This has been strongly associated with rural clinics. Saraceno et al. (2007); Peck et al. (2014); Burns and Tomita (2015), state that rural clinics are frequently under-resourced and unable to provide appropriate health care services to surrounding communities. As such only 6% of caregivers sought diagnosis from a health care professional. Caregivers also went to spiritual healers (3%). Traditional healers have been known to be more affordable and can even assist with credit (Campbell et al., 2008).

Fifty-seven percent of the patients started utilising traditional medicine and herbs after traditional methods had been sought. This is where the patient was taken to an *Inyanga* or *Sangoma*. A total of 23% of patients were left at the *Inyanga* house to start traditional treatment. Therefore, a total of 80% of the patients started traditional herbs after diagnosis. Indicating that traditional methods of dealing with MHDs are the most common and preferred method in the rural community of KwaXimba. From the undiagnosed patients (11%), 9% did not commence any treatment.

Caregivers elaborated that in such cases, the MHD was recognised by household members due to its hereditary cases in the family. In such cases, assistance was either sought out very late or never. While 3% had a ritual done for them as per the instruction of the traditional healer. The ritual involved the slaughtering of a goat and *ukushweleza* (beg for mercy) from ancestors.

“We were told that our ancestors are not happy with some things hence them letting the patient become sick from wandering spirits; therefore, we had a small ceremony to try and help the patient.” (November 2022; Participant 11)

Only, 6% of patients started taking biomedical medication after diagnosis. This was for patients who sought a diagnosis from professional health care workers at the local clinic. This indicates

that only a fraction of patients start medication timeously. The South African National Department of Health (NDoH) acknowledged that patients with MHDs frequently do not receive treatment (Kahn, 2013). The remaining 3% of caregivers sought religious methods for the MHD. Spiritual healers provided caregivers and patients with spiritual water. The spiritual water was accompanied by a string which was prayed on. This string must be worn on the waist of the patient.

Caregivers elaborated that MHD symptoms usually decrease right after initial steps are taken in seeking help for the patient or no improvement would be achieved at all. After the use of traditional herbs or holy water, patients were usually calmer, more responsive, less violent, and willing to take medication. However, this emotional condition of the patient often did not last, as the patient returned to their original, if not worse, state of the MHD after a short period. Most of the patients did not have any improvement in their state as symptoms came back or continued. Some caregivers mentioned that for some patients' traditional methods did not work at all. However, there were usually explanations associated with no improvement in patients. For both western medicine and traditional medicine, as soon as the patient stopped taking the medication accordingly, symptoms deteriorated, losing any improvement there might have been.

“When the patient started using medication, he stopped having outbursts of laughter, having full-blown conversations alone, but as soon as he stopped taking medication, it all came back.” (November 2, 2022, Participant 27)

When we went to see her at the Inyanga's house, her condition had improved drastically, we spoke to her, and she seemed fine.” (November 2022, Participant 6)

“There was no improvement in patients state.” (November 2022, Participant 14)

Patients who displayed continued improvement continued to take medication accordingly without defaulting. For patients where no improvement was noticeable, the caregiver sought another form of assistance or simply gave up hope after an extended period of using medication.

Most caregivers (91%) did not encounter difficulties in obtaining help for the patient. The caregivers knew where to get desired help and took the patient there as soon as the opportunity presented itself. However, 9% of the caregivers faced challenges in their efforts to obtain treatment for the patient. Challenges encountered by caregivers included the patient running

away from home, the patient being extraordinarily violent, and the patient not wanting to travel with the caregiver.

“He would say I am taking him to the people who are after him.” (November 2022, Participant 9)

In such situations, the caregiver had to ask household members or relatives to come and help in convincing the patient to travel with them. In extreme cases, the patient had to be forced to get into whatever mode of transport organised by the caregiver. This was due to hallucinations of the patient being in danger of being chased.

“The Inyanga we were told about was very far away, so we had to hire a car to take to the Inyanga’s house and back.” (November 2022, Participant 6)

Caregivers often had to pay a neighbour or family acquaintance owning a vehicle to transport the patient to the *Inyanga*’s house. It is worth noting that caregivers who opted for the traditional ways of seeking help rarely went to *Izangoma* or *Izinyanga* in the local vicinity. This is due to mainly issues of privacy. Caregivers preferred someone who knew nothing about them or where they came from. Caregivers believed that a stranger would depend solely on his or her gift to provide diagnosis or treatment methods that must be utilised without any prior knowledge about the patient or caregiver. Payment for such trips was paid by the caregiver out of pocket by caregivers, as these trips were frequently unplanned and emergencies.

All caregivers were affected by the diagnosis of the patient differently. Caregivers had to provide physical, emotional, and financial support to patients. Sudden sickness implied that caregivers had to leave their daily routines and lifestyles to accommodate and provide care for the patient.

“I was really sad for my child; I have seen this happening before to our relatives.” (November 2022, Participant 1)

“I had to assume the role of caregiving immediately.” (November 2022, Participant 9)

“I tried to help the patient, we went everywhere to try and get help, spent time and money on efforts to acquire assistance.” (November 2022, Participant 11)

“It was challenging to see my grandson, who had been a smart young man, turn into someone unrecognisable and a child who needs regular assistance.” (November 2022, Participant 24)

Caregivers who were familiar with the MHD had feelings of hopelessness due to past experiences and exposure to the MHD. Patients continued to suffer from the MHD with persisting symptoms. Patients rarely went back to their original state of mind. As such, caregivers were sadly forced to acknowledge and accept that their son, sibling, parent, grandchild, or niece was not in the same predicament. Other effects on caregivers included worry, concern, uncertainty for the future and heartbreak. According to caregivers, MHDs could either be dealt with quickly and successfully or they become a permanent part of the patient's life. This would now be their way of life, where patients never get rehabilitated.

The immediate assumption of the role of caregiving for the patient was the most common change or effect on caregivers. Assuming this role came with many responsibilities and challenges. Assuming the role of caregiving for the patient includes providing financial, physical, and emotional support (von Kanel et al., 2006; Swartz and Collins, 2019; Anokye, 2018 WHO, 2001; Inogbo et al., 2017; Addo et al., 2018). Caregivers had to stop their lives (daily routines) and take care of the patient, accompanying the patient in efforts to obtain treatment and provide required assistance to patients within the household, which is time-consuming. As such, becoming a caregiver can manifest frustration in the caregiver (Butcher et al., 2001; Swartz and Collins, 2019).

Caregivers elaborated that assistance for patients differs depending on the patient's state, mood and the MHD. The most common form of assistance was with taking medication, food preparation, washing clothes and cleaning for the patient. Caregivers have acknowledged that caregiving can be a moderate to very high burden (Saunders, 2003; Caqueo-Urizar and Gutiérrez-Maldonado, 2006; Vancampfort et al., 2017). Effects on households' data are presented below;

Variables	Total (n=35)
Effect on household	
Unpredictability the MHD	40%
Assuming the role of caregiving	34%
Feelings of distrust and anger	9%
Exclusion of caregivers and households	3%
Not applicable	14%

Table 5.8. Effect on household

From Table 5.8, it is evident that the unpredictability of MHD was acknowledged as one of the most (40%) challenging parts of dealing with patients. At no point can households be sure that

this is the MHD, and it ends here. It could always get worse. Households had to become more understanding of the patient, often letting him or her have their way to avoid any violent incidents. Caregivers mentioned that caregiving could include regularly checking in on the patient, particularly during the day (34%). Mall et al. (2017) and Hailemariam et al. (2017) added that households might be unable to keep social relations reasonable as most of their time and attention is directed towards the patient.

In some households, the effects were not as dire as patients were calm and often quiet or non-responsive (14% not applicable). Such patients often isolated themselves but would respond to simple instructions and be able to perform day-to-day activities for themselves. For patients who had the MHD for a long-time effect on the household was minimal to none, as the household had adjusted and adapted to living with the patient over time. Caregivers occasionally had feelings of anger due to common beliefs about the causes of MHDs (9%). Caregivers mentioned that it is known that wandering spirits are always sent by someone who hates, envies or is just jealous of the patient's or family's achievements. Such beliefs lead to accusations as caregivers often suspected people close to them of sending the wandering spirits causing the MHD. This would create conflict between the caregiver and suspect or within the families. This could potentially become a form of exclusion. Households would minimise or cut relations with those they suspect are responsible for the MHD in the patient. Moahi (2007) and Wankiiri et al. (2013) added that caregivers were sometimes not invited to social gatherings, which would also exclude them. Common beliefs about the MHD could exclude and isolate caregivers, patients, and households from their communities (3%). Traditional beliefs about MHDs often lead to delays in seeking treatment. Below is the time taken by caregivers before seeking medical attention;

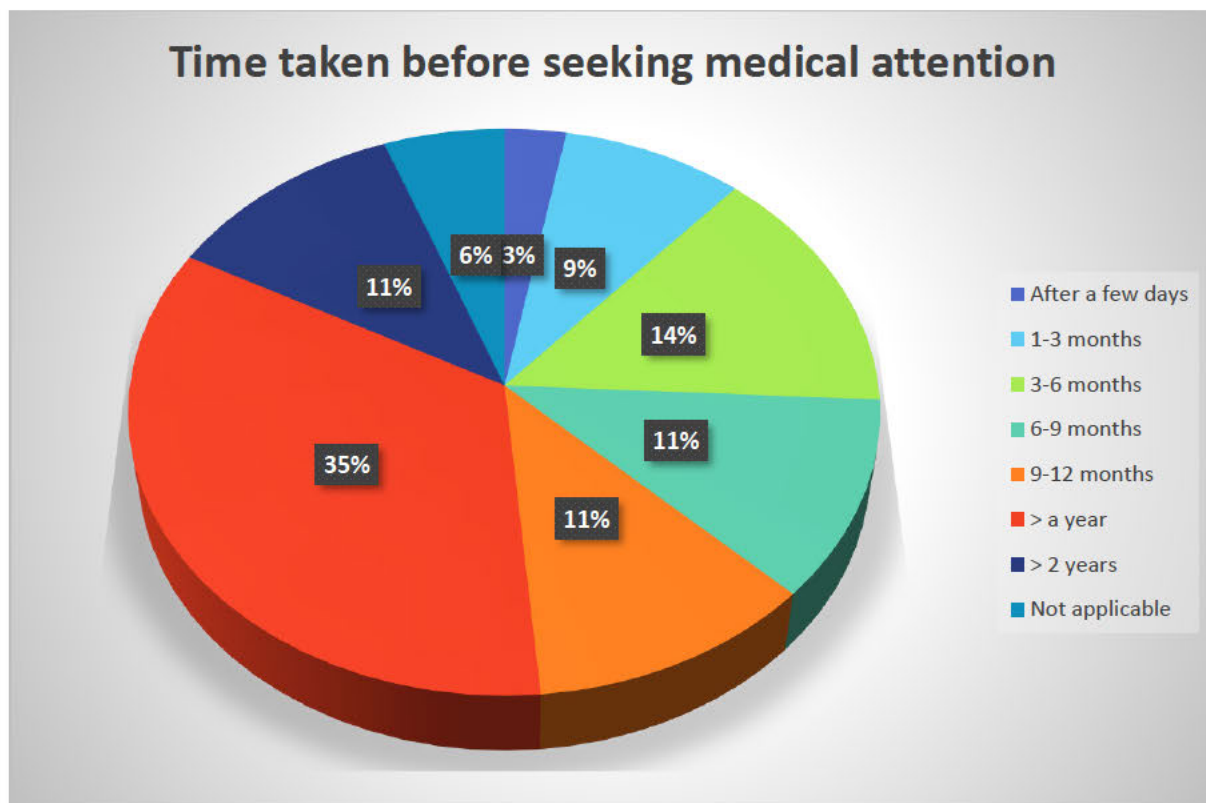


Figure 5.2. Delayed time before seeking medical attention for patient

Delays in seeking medical attention are evident from the data collected and illustrated in Figure 5.2. Close to half of the caregivers (46%) stated that they delayed for over a year before seeking medical attention. This was due to caregivers seeking other forms of treatment before considering medical assistance. Saravanan et al. (2005) and Sorsdahl et al. (2013) mentioned that it is common for caregivers who initially sought out traditional assistance to delay in seeking medical attention. Thirty-four percent of caregivers sought medical attention after a year after the diagnosis of the patient. Another 11% sought medical attention after two years or more. A total of 6% of caregivers stated that they have never sought any medical attention to date (not applicable). Caregivers in KwaXimba argued that medical attention does not work well with traditional medication. Caregivers mentioned that they are always advised to use one treatment form at any given time.

“Traditional medicine must be given time to work on the patient and not rushed” (November 2022, Participant 3)

Such statements clearly indicate that caregivers who initially sought traditional methods of treatment delayed in seeking medical attention as they were still giving the traditional medicine time to ‘work’. Caregivers further elaborated that obtaining tangible results from traditional medicine depended on many variables. The type of ancestors one has (some are slow and take

time to respond while others work quicker). There could be required ceremonies that must be done for the patient or household. According to caregivers the premises of traditional medicine is based on one's ancestors working together with traditional medicine to provide tangible results. Unhappy or slow ancestors do not provide adequate protection for the patient, thus letting the evil spirits have their way with the patient, and no results will be obtained. These beliefs, linked to ancestors, provide a brief understanding or overview of the reasoning behind delays of caregivers and patients prior to seeking medical attention. Caregivers and households were hopeful and patiently waiting for the desired improvement and result from the ancestors. This is common as patients have been known to delay seeking medical attention by up to 3 years (Ganasen et al., 2008; Wang et al., 2007; Spivak et al., 2018). Delaying in seeking medical treatment has been strongly linked to common beliefs about MHDs, providing time for initially sought methods, and fear of humiliation linked to stigma and discrimination (Omenyo, 2006; Twumasi, 1975; Nsereko et al., 2011).

Majority of caregivers (97%) in KwaXimba did not seek medical attention at first instinct or immediately after the realisation that the patient was unwell. Ikwura (2021) argues that caregivers only seek medical attention after traditional methods have failed. Delays in seeking medical attention have been noted to have a negative impact on caregivers, patients, and households. Non-improvement or deteriorating state of patients adds to the burden of disease and caregiving. Delays disempower patients and caregivers. Caregivers continue to have minimal or no time to engage in developmental or income-generating activities as caregiving takes up most of their time. Furthermore, deteriorated states of patients decrease the possibility of rehabilitation and reintegration into society.

Patients with MHDs may run away from home. The table below shows data in relation to such;

Variables	Total (n=35)
Patient away from home	
Yes	26%
No	74%
Location of patient away while away from home	
In communities' households but not at home	11%
Homeless	11%
Constantly travelling by foot	3%
Not applicable (was never away from home)	74%
Time in which patient was away from home	

A few weeks	8%
1 – 6 months	6%
7 – 9 months	6%
1-3 years	3%
Goes away and come back	3%
Not applicable (was never away from home)	74%

Table 5.9. Patient away from home, location of patient and duration of patient being away from home

As illustrated in Table 5.9, the majority of the patients (74%) have not been away from home. For further clarity caregivers who always knew the whereabouts of patients (at *Inyanga's* house) did not consider those patients as lost or away from home. Other patients with MHD have been away from home for different reasons. Some patients would run away from home occasionally, sometimes their whereabouts known or unknown. Other patients would roam around their communities unsupervised. Caregivers mentioned that patients occasionally come back home or may reside in a known location permanently. This could be within the community, in the closest town or in the forest.

Table 5.9 depicts the location in which patients were staying while away from home. Eleven percent of patients were in their communities but did not reside at home. Household members would see the patient in the streets or where patients have randomly chosen to reside in the community. Another 11% of these patients, often travelled by foot to different places. Some of these patients would get picked up by cars belonging to people from the community and bring them back home, but they would leave again. Patients on foot would travel very long distances, stopping and continuing as they wished. Patients who were sleeping or staying in the streets, forests and sleeping wherever they could (open spaces) were 3%; these were the ones considered homeless. The balance of the patients did not leave home (74%) thus referring to as not applicable (Table 5.9).

A total of 26% of patients, however, had been away from home (refer to Table 5.9) for some duration. Eight percent of the patients had been away from home for a few weeks. Caregivers indicated that patients who stay away from home often return home occasionally and then go away again. Six percent of patients were away from home for 7 to 9 months, 3% were away for 1 to 3 months, and another 3% were away for 4 to 6 months respectively. Patients who were away for 1 to 3 years also accounted for 3%, while another 3% went away and came back on their own accord.

5.6. Caregiver perception

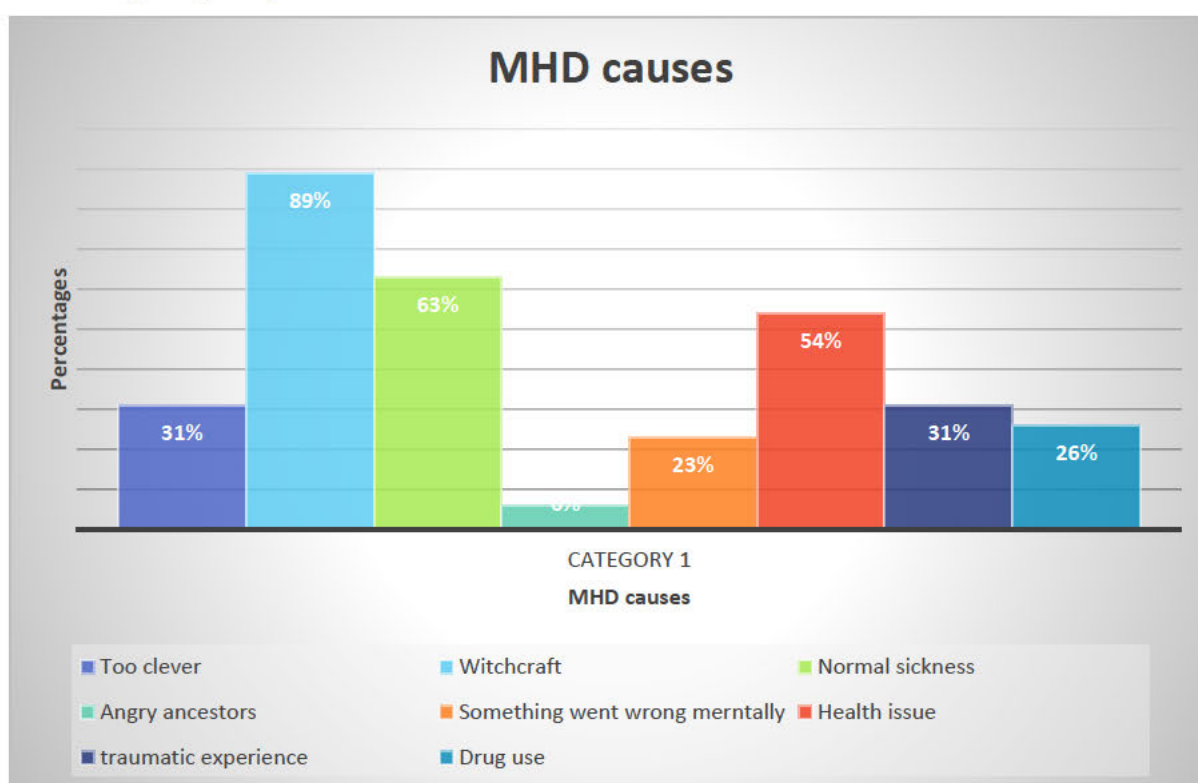


Figure 5.3. Perceived MHD causes

To acquire complete perceptions from caregivers about the perceived causes of MHDs, each caregiver could choose more than one cause (multiple responses). This would indicate not only the case of the caregiver's patient but also include other cases the caregiver might be aware of. Additionally, this provides an opportunity for caregivers to elaborate on their beliefs, past experiences and common traditional beliefs. Caregivers explained that MHDs were different. MHDs from birth or patients that start showing MHD symptoms from a young age were understood to be caused by medical issues. These could be hereditary or just random cases of sickness which required medical attention. Caregivers elaborated that MHDs which developed abruptly or unexpectedly were associated with evil spirits or witchcraft, commonly known as wandering spirits (*izizwe*). It is believed that wandering spirits are sent to a particular individual spiritually, with the aim of driving them to insanity. MHDs which developed gradually over time, were believed to be the cause of hereditary issues, witchcraft, being overly intelligent, drug overuse and traumatic events.

(i) Witchcraft

Witchcraft was believed to be a significant cause of MHDs in KwaXimba. From Figure 5.3, it is visible that approximately 90% of the caregivers believed MHDs to be caused by witchcraft.

Spiritual issues are believed to cause MHDs in non-western cultures, such as witchcraft (Razali et al., 1996; Patel et al., 1997; Sheikh and Furnham, 2000; Suhail, 2005; Ikwuka, 2021). This indicates very firm beliefs in MHDs being caused by evil spirits sent through witchcraft to patients. Similar to this study, Omenyo (2006); Twumasi, (1975); Kpobi and Swartz (2018) found that there was a strong belief that MHDs were caused by spiritual issues associated with the evil or unknown.

(ii) Normal sickness

The believed cause of MHDs being normal sickness (63%) was predominantly associated with cases of having the MHD from birth or developing symptoms from a young age. This was the second-highest perceived cause of MHDs as illustrated in Figure 5.3.

(iii) Health issue

More than half of the caregivers (54%) believed MHDs could be caused by health issues. MHDs believed to be caused by health issues were for patients who have had the MHDs for a very long time or patients born with the MHD. Other cases of health related MHDs could be associated with extended periods of sickness, which could lead to the patient losing their mind (developing the MHD). Caregivers elaborated that these patients often do not have SMHDs.

(iv) Too clever

Caregivers elaborated that patient who were overly intelligent in school and excelling in all academic spheres would ‘sometimes go over the edge’ and start displaying symptoms of MHDs. Caregivers perceived this to be caused by thinking too much. As illustrated in (Figure 5.3), 31% of caregivers believed MHDs could be caused by being intelligent. Caregivers asserted that this type of MHD gradually develops over time either on its own or is compounded by witchcraft related to envy and jealousy.

(v) Drug use

Drug use was believed to be another cause of MHDs. Caregivers elaborated that patient who consume drugs extensively can develop MHDs and start displaying symptoms. Only 26% of caregivers believed MHDs to be caused by drug use.

(vi) Something went wrong mentally

Caregivers mentioned that patients who usually develop the sickness at a later stage are sometimes just random cases of MHDs. This is usually associated with older people. As illustrated in Figure 5.3, 23% of caregivers believed that something could trigger and develop the MHD. This is believed to occur without the influence of any spirits. In different SSA

countries MHDs are also believed to be a “mental disturbance” or the “sickening of the soul” (Okello and Ekblad, 2006).

(vii) Angry ancestors

Caregivers referred to that displeased ancestral spirits who do not offer protection to those who displease them thus leaving those unprotected individuals open to evil attacks from spirits and witchcraft. It makes them vulnerable to evil spirits. Displeased ancestors may also cause responsible individuals or those close to them to be sick. Caregivers elaborated that this action is often to bring attention to ancestor requests and remind stubborn individuals of the importance of respecting ancestor’s wishes. Caregivers mentioned that in such cases, once family members have sought out an explanation for the MHD from a traditional or religious person and conduct what is required of them, the MHD goes away. However, this was not perceived to be common, as only 6% of the caregivers believed MHDs to be caused by angry or displeased ancestors. MHDs also believed to be a form of punishment from a higher power, for instance, God (Waqas et al., 2014). Not maintaining a good relationship with ancestors is another perceived cause of MHDs (Mayston et al., 2020).

The figure below illustrates methods preferred by caregivers for the treatment of MHDs:

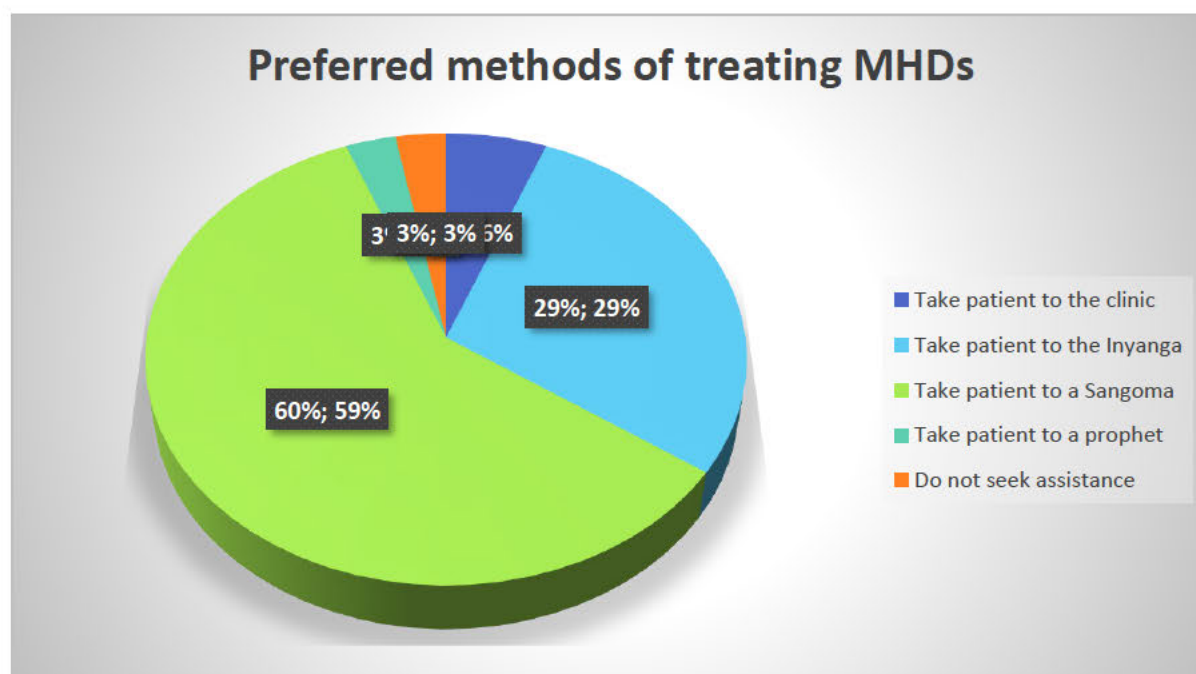


Figure 5.4. Preferred methods of treating the MHD

From Figure 5.4 it can be deduced that most caregivers believed that upon recognition of MHD symptoms in patients, the first route to be taken was to go to the *Sangoma* (60%). The second highest route preferred by caregivers was to take the patient to the *Inyanga* (29%). The two

most preferred methods of treating MHDs in KwaXimba are traditional and cultural methods. Caregiver beliefs about the causes of MHDs highly influence the route taken by caregivers in seeking assistance for patients with MHDs. Majority of the caregivers (89%) believed MHDs to be caused by evil spirits (refer to Figure 5.3). This Figure corresponds with the 60% and 29% of caregivers respectively who preferred traditional or cultural methods of treating patients with MHDs. This increase preference for traditional and cultural methods indicative of high trust for traditional methods. Only 6% of caregivers preferred to take patients to the clinic as a method of dealing with the MHD. This is a very low percentage compared to the first two traditional and most preferred methods of dealing with MHDs. The least chosen options were taking the patient to a prophet with 3% and not seeking assistance with 3%. Caregivers mentioned how they did not seek any assistance as the MHD was common and expected within the family. Table 2.1 from the literature review, clearly illustrates traditional and cultural methods as the most preferred in SSA. This coincides with the findings from this study. This research indicates that caregivers prefer traditional methods of treating MHDs. Below is data showing the use of medical, MHC:

Variables	Total (n=35)
MHD diagnosis by medical professional	
Yes	49%
No	51%
Western medicine dealing with MHDs	
Yes	66%
No	34%

Table 5.10. Diagnosis by medical professional, western medicine, improvement after traditional methods and steps taken for improvement

Table 5.10 shows that caregivers (51%) believed that medical professionals cannot provide the diagnosis for the MHD as medical professionals cannot identify the root cause of the MHD. Caregivers explained that medical diagnoses of MHDs only focused on decreasing the symptoms without revealing or dealing with the root cause. Forty-nine percent of caregivers indicated trust in the diagnosis provided by medical personnel. Such diagnosis was provided in the local clinics for MHDs.

“Nurses can diagnose MHDs in patients, they studied for that, but they cannot deal with the root cause.” (November 2022, Participant 16)

“If you go to the clinics, medical personnel can almost always tell you a diagnosis, except for severe spiritual cases, then they cannot easily identify what is wrong with you.” (November 2022, Participant 1)

It is perceived that dealing with or resolving MHDs can only be done accordingly by *Isangoma*, *Inyanga*, *Umthandazi* or a Pastor. Caregivers explained that this is because medical practitioners cannot understand African spirituality, nor can they address issues of spirituality.

“Medical personnel do provide a diagnosis for MHDs, if its unclear local clinics will send you to the hospital for a better diagnosis.” (November 2022, Participant 31)

Local clinics utilise a transfer system to larger hospitals. This indicates the lack and need for human and medical resources to adequately evaluate, diagnose, and prescribe medication for patients with MHDs. This lack of human and medical resources remains a challenge for many states in SSA (Selamu et al., 2015; Hoeft et al., 2018). Rural health care has been acknowledged to be insufficient and with the most significant treatment gap (Kohn et al., 2004; Alem et al., 2009; Kakuma et al., 2011; Federal Democratic Republic of Ethiopia Ministry of Health, 2012; Patel et al., 2013; Paula et al., 2014; Selamu et al., 2015). KwaXimba is also facing the issue of inadequate MHC resources hence the transferring of patients for diagnosis and medication prescription. There are no doctors in the KwaXimba local clinic. This transferring system of patients from the local clinic to the hospital and back to the clinic before acquiring medication could prove time-consuming and expensive. However, traditional healers are in abundance in KwaXimba, who provide the diagnosis and treatment immediately. This could also influence caregivers to utilise and prefer traditional methods of dealing with MHDs.

Caregivers had doubts about the diagnosis provided by medical personnel due to common beliefs that MHDs are often spiritual and therefore need to be addressed in that manner. Nevertheless, from Table 5.10, caregivers (66%) admitted that taking medication often brings about a noticeable change or improvement in patients. This was also confirmed by caregivers who delayed seeking medical assistance for patients. The rest of the caregivers (34%) did not believe medication could treat or deal with MHDs. According to caregivers, MHDs medical diagnosis can treat MHDs due to health issues, trauma and drug use. However, MHDs believed to be caused by evil spirits cannot be treated medically, as patients with such MHDs do not obtain significant results from taking western medication alone. In most cases, the symptoms subside, and patients and households adapt to their new circumstances and continue living. Western medicine improves the state of MHDs but does not completely rehabilitate the patient.

Phahladira et al. (2019) mentioned that those patients who received medication solely had impairments continuing. Patients with MHDs require evaluation, treatment, and rehabilitation for the effective results (WHO, 2001; Government Gazette, 2002; Angermeyer and Dietrich, 2006; Pereira et al., 2011; Balaji et al., 2012; Wozniak et al., 2015). Patients in KwaXimba never received all three, and therefore, no patient has ever been fully rehabilitated and reintegrated back into their community.

“These things work together because even after seeking diagnosis from Sangomas and Izinyanga, the patient may still require taking medication.” (November 2022, Participant 11)

“I would say that western medicine does provide appropriate help to patients because it is more or less the same for patients who also went the traditional methods. The patient never returns to their original state.” (December 2022, Participant 2)

“With us African families (Zulu), these things are almost always caused by evil spirits, wondering spirits as such medical medicines only treats the symptoms without dealing with the initial cause of the MHD hence little to no improvement.” (November 2022, Participant 35)

Caregivers displayed contradicting views regarding the use of western medicine in dealing with MHDs. Some caregivers believe that western medicine does work as it provides the same outcome as traditional medicines. The outcome was believed to be the same in the sense that patients are never fully rehabilitated or returned to their original state. Other caregivers, however, argued that for any results to be seen, caregivers and patients must seek traditional methods initially to discover the root cause and address that. If not addressed accordingly, caregivers argued that even with western medicine, there would be tangible results.

Caregivers mentioned that they were not aware of cases where an MHD patient has been rehabilitated and reintegrated into their community from taking western medication. MHD symptoms usually subside, and households can coexist with the patient. Phahladira et al. (2019) stated patients who receive medication solely do not get rehabilitated and reintegrated into their communities as impairments tend to continue. For the KwaXimba community, this could be due to the lack of rehabilitation services in the area.

The differentiation was evident in that the cause of the MHD determines which root is taken, which may bring about improvement in the patient. In cases where the patient was born with MHD, it is entirely different; those patients depend more on medical health care to on a daily basis rather than in cases where the person was sent the wondering or evil spirits. The table

below shows the type of improvement obtained in MHD patients after utilising traditional methods.

Variables	Total (n=35)
Improvement after seeking traditional methods	
Yes	71%
No	29%
Measures taken to get improvement	
Patient taken to <i>Inyanga</i> 's house	46%
Patient taken to a <i>sangoma</i>	14%
Patient started using traditional medicine	11%
Not applicable (had no improvements)	29%

Table 5.11. Improvement after traditional methods

African people are rooted firmly in African beliefs and culture (Ezenweke and Nwadiolor, 2013). As such the first instinct when a family member displays symptoms of MHDs is to go to a *Sangoma* or *Inyanga* to find out why the MHD had developed and what can be done to address it. All caregivers (100%) knew of patients with MHDs who had been taken to a *Sangoma* or *Inyanga* to seek assistance. Some of these patients were from KwaXimba, others were far away relatives or just random people or stories known within the community.

As illustrated in Table 5.11, caregivers stated that in some cases, there would be an improvement in the patient's state (71%), but in most cases, symptoms would slowly come back after some time. Only a few patients got rehabilitated and reintegrated into society. In other cases, there would be no improvement, and the patient's state would remain the same if not deteriorate (29%). In exceptional cases, the patient would get better significantly; however, they would not return to their original state of mind entirely as MHD symptoms would persist.

Caregivers indicated that the most common outcome in the community was minor improvement in patients with persisting symptoms. Most caregivers could not provide an example of a patient completely rehabilitated from the MHD.

According to caregivers, there were noticeable improvements in the patient's state or symptoms after seeking traditional or cultural help. Close to half of the patients (46%) were taken to the *Inyanga*'s house to be treated and left to continue with traditional methods of treatment (Table 5.11). Caregivers explained that patients could be left at the *Inyanga*'s house immediately to start treatment. Almost a third of caregivers (29%) had not witnessed any improvement in patients after seeking traditional assistance. Caregivers noted that in some cases, the

improvement was short-lived, and symptoms returned for patients. Fourteen percent of the caregivers mentioned that the patients were taken to a *Sangoma's* house for assistance. Caregivers further elaborated that the *Sangoma* first read bones to find the root cause of MHD. Thereafter guidelines will be provided on what is to be done, and medication will be provided to be taken from the home. After seeking traditional or cultural assistance, 11% of patients used traditional medicine from home.

Caregivers indicated that it could be possible for health care personnel to work together with religious and traditional groups to try and assist people. The table below presents collaborative ways in which traditional healers can collectively treat MHDs.

Variables	Total (n=35)
Collaborative ways for medical and traditional or cultural	
Local clinics can work with the <i>Inyanga</i> for diagnosis and treatment	14%
Local clinics can work with the <i>Inyanga</i> for diagnosis and treatment	37%
Convergence between the MHC services and spirituality inclusive of all traditional, cultural and religious groups	49%
Convergence between the MHC services and spirituality inclusive of all traditional, cultural and religious groups	
Advantages of the collaboration	49%
Increase respect and communication between different health practitioners	54%
Complete rehabilitation of patients	43%
Prevent of deteriorating mental states of patients	3%

Table 5.12. Collaborative ways for medical and traditional or cultural

From Table 5.12, it is evident that most caregivers (49%) would recommend the convergence between MHC services and spirituality inclusive of all traditional, cultural and religious groups. Caregivers did imply and show an understanding that MHDs, like other illnesses, may require a particular type of assistance solely, but this verified once all methods have been sought. As such, if these entities work together, the preferred or most appropriate method for each case can be detected earlier, and patients can get better. In comparison, 37% if caregivers stated that local clinics could work with the *Sangoma* for diagnosis and treatment. Caregivers elaborated that both *Sangomas* and clinics provide diagnosis and medication to be consumed by patients at home. Therefore, there should be synergy between the two. Almost 14% of the caregivers stated that collaboration between local clinics could work with the *Inyanga* for

diagnosis and treatment. Caregivers wanted a general convergence between MHC services and spirituality inclusive of all traditional, cultural, and religious groups. This was due to beliefs that MHDs are different and require different types of assistance. So, the collaboration between various sources would allow the problem to be dealt with from the root cause to the symptoms. This would enable patients to be treated at the root cause.

As illustrated in Table 5.12, more than half (54%) of the caregivers argued that collaboration with these entities would increase respect and communication between different health practitioners. Caregivers pointed out that the biggest issue between traditional and medical workers was patronising and not recognising each other's efforts and contributions toward general health and well-being. According to caregivers, the most significant challenge with such collaboration is that these entities often do not fully recognise each other's potential for the betterment of patients. In most cases, the entities belittle each other, and patients are advised not to seek another form of assistance once one is sought. Forty-three percent of caregivers perceived that the collaboration could lead to the complete rehabilitation of patients. Patients would acquire both spiritual and physical health care, thereby achieving better results in patients. A minimum of 3% of the caregivers believed that the collaboration would prevent the deteriorating states of patients. Caregivers elaborated that patient mental states usually deteriorate due to inadequate assistance. For instance, they were seeking medical attention without traditional methods.

5.7. Community awareness

All caregivers indicated that community members had some form of knowledge about MHDs. Community members could recognise MHD symptoms in patients and often recommend where the caregiver and household could get assistance. Most of these recommendations, however, were primarily based on shared traditional beliefs linking MHDs to spirituality. Particularly for sudden sickness in patients' community members would direct caregivers and patients towards the *Sangoma* or *Inyanga*. As such, it is not the case that community members were utterly oblivious and lacking in mental health literacy. Most community members could recognise MHD symptoms and were aware of the treatment options available for the patient. This assistance was available in two places, the traditional places and the medical and MHC services. Traditional beliefs about the causes of MHDs largely influenced the treatment routes taken.

Another common recommendation was applying for a mental disability grant from SASSA. Caregivers explained that post-diagnosis households were often advised to apply for the disability grant. Applying for this grant meant caregivers and patients had to visit the local clinic for assistance. From the perception and understanding of MHDs by caregivers, common beliefs about MHDs are presented below;

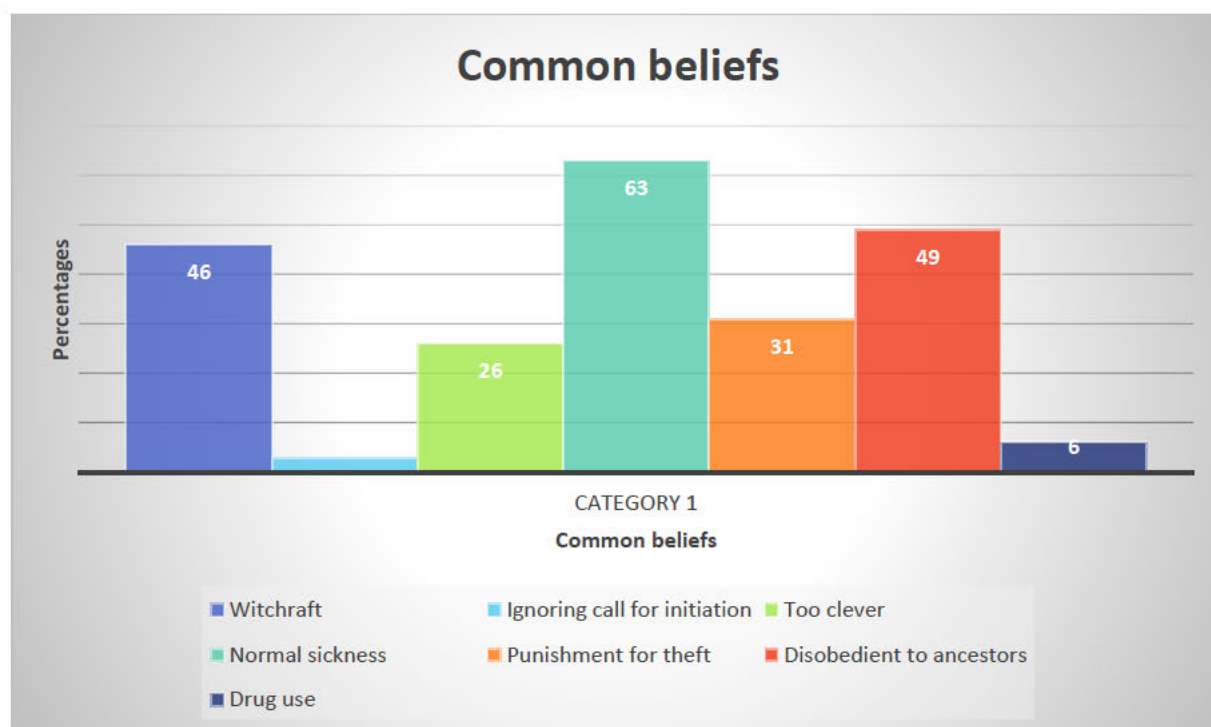


Figure 5.5. Common belief about MHDs

(i) Normal sickness

As illustrated in Figure 5.5, (multiple response) caregivers believed that the community did recognise MHDs as a normal sickness or a health issue like any other (63%). This option was associated with MHDs which develop from a young age or when patients are born with the MHD and those who develop it over time, for example, due to drug overuse.

(ii) Disobedient to ancestors

Mainstream community members do not believe disobedience towards ancestors to be the cause of MHDs (51%). However, this is approximately half of the population, implying that nearly half also believe disobedience towards ancestors is the case for MHDs. Community members generally associate MHDs with issues which put the blame on the patient. Community members believe that when someone is ignorant or oblivious to an ancestor's request, MHDs can befall them for their disobedience. The ancestors may also bring a string of misfortune to that person where they might lose their job, and none of their attempts for

improvement succeed. Nearly half of the caregivers (49%) stated that community members argue that it is not rare for people to get sick with MHDs due to disobedience towards ancestors.

(iii) Bewitched

Bewitching is strongly associated with jealousy and envy from those close to an individual. Communities believe that MHDs are sometimes caused by bewitching (evil spirits sent to patients). As shown in Figure 5.5, 46% of caregivers stated that community members believe MHDs to be caused by bewitching. More than half of the caregivers however did not choose the bewitched options as a perceived potential cause for MHDs.

(iv) Punishment for crimes

As illustrated in Figure 5.5, 31% of community members believe MHDs can be caused by evil spirits sent to patients. Such spirits are sent as a form of punishment for patients who commit theft. Caregivers explained that when an individual steal from you, it is possible to go to a traditionalist and bewitch them as punishment for stealing. Furthermore, caregivers perceive that the MHD is untreatable and permanent in such cases, and the patient cannot get rehabilitated. Caregivers stated that the traditionalist informs you before sending the evil spirits that he or she can only send the evil spirits to the culprit and cannot treat or kick out the evil spirits from the patient. Such MHDs are believed to be uncurable.

(v) Too clever

Beliefs about MHDs being caused by intelligence are common. Caregivers perceived (26%) that Patients known as receiving high grades in school, and high achievers who suddenly become diagnosed with MHDs are believed to be caused by a high intelligence level.

(vi) Ignoring the call for initiation

As shown in Figure 5.5, 3% of caregivers stated that community members believe ignoring the initiation call can cause MHDs. Denial or ignorance of the calling to initiation to become a *Sangoma* in patients could lead to displeased ancestors.

(vii) Drug use

Caregivers (6%) mentioned that the use of drugs for extended periods of time leads to the development of MHDs.

Common beliefs have impacts on caregivers, data of the impacts is provided below:

Variables	Total (n=35)
Impact of common beliefs on caregiver	
Friends and relatives' distance themselves	31%
Not being informed about community announcements	3%
No impacts	49%
Being pitied	11%
Support	3%
Shunned by community	3%
Negative experience by patient	
Yes	60%
No	40%
Effect of negative experience on patient	
Patient did not want to associate	6%
Patient was sad	17%
Patient was violent	9%
Patient was disorientated	3%
Patient did not dwell on negative experience	25%
Not applicable (no negative experience)	40%
Negative experience effect on caregiver	
Yes	60%
Not applicable (no negative experience)	40%
Result of negative experience on caregiver	
Made me very sad for the patient	23%
Felt sorry for the patient	37%
Not applicable (no negative experience)	40%

Table 5.13. Impacts of beliefs on caregiver, negative experience and impact on patient and negative experience impact on caregiver

Common traditional beliefs of society did not have an impact on most caregivers. From Table 5.13, it is illustrated that the community (49%) continued to be civil and treated humanely despite knowledge of the household member having the MHD. The community did not change in any way towards the caregiver. However, those who had a close relationship with the caregiver (31%) tended to distance themselves by distancing themselves or reducing contact. Therefore, social relations decreased by 31% for the caregiver. Some community members displayed feelings of pity towards caregivers (11%) due to the burden of the MHD being carried by caregivers. In rare cases, caregivers experienced being shunned by community members (3%). Caregivers elaborated that this was often caused by community members partly blaming the patient or caregiver for the MHD. This was when the patient committed a crime, and the caregiver knew and did nothing to rectify the patient. In such cases, the community would not sympathise and let the caregiver deal with the situation alone. Another 3% of caregivers were

not informed about community issues or events. This is another way social relation in terms of kinship ties and networks decrease for the caregiver, which may isolate and burden the caregiver. Of the remaining caregivers, 3% chose others and specified that some community members would support them and try to suggest people who can help them.

Caregivers have stated that community members do not usually mistreat patients within the community. Community members know the patients from a young age and often sympathise with patients and their households. From Table 5.13, it can be deduced that 40% of the community does not mistreat the patient due to the MHD. However, due to the believed causes of the MHD, speculations may begin to surface. For example, suppose a patient is suspected of committing a crime and suddenly gets diagnosed with the MHD. In that case, community members will assume it is punishment for a crime and, in that case, do not sympathise. Such reasoning accounts for the 60% of patients who have had negative experiences within the community due to the MHD.

The most common form of negative impact on patients was when community members would treat the patient as retarded or foolish. Community members sometimes treat patients as children, instructing to conduct various activities without any form of remuneration. This may lead to feelings of anger and resentment for the patient and caregiver.

“People take advantage of patients; for instance, people usually hire patients to do their lawn or cut down some trees in their back yard and tend to underpay patients, which saddens me.” (November 2022, Participant 1)

“Patient was chased away from a family gathering in the community.” (November 2022, Participant 21)

“People sometimes do not want to sit with or speak to the patient.” (December 2022, Participant 33)

In some cases, community members employ patients and do not compensate patients for their time and efforts. Thus, the caregiver must step in, and this may lead to conflict. There are cases where the patient has been bullied (specifically in shebeens), and the patient cannot fight back or stand up for themselves. Patients have also been called names or given degrading nicknames. Infrequently people do not want to socialise or talk to the patient as members might believe patients are retarded and cannot hold conversations. Others might not want the stigma which might come with being associated with a patient suffering from MHD.

There have been cases where the patient has been accused of stealing when they did not, people find it easier to blame the patient, and then the caregiver is obligated to make payment. This is done to avoid payment towards the patient. Participants who voted no sometimes further explained that the community is not hostile to the patient and would rather avoid them than anything else. All these negative experiences are clearly premised on negative beliefs about MHDs. This indicates there is a need to increase mental health literacy within KwaXimba eThekweni Municipality, KZN and SA as well.

Patients encounter different negative experiences in different areas, which have impacts on them. As illustrated in Table 5.13, 40% of the patients did not experience negativity. Twenty-six percent of the patients did not dwell on the negative experience. This did not have a significant impact on the patient. This was either due to the patient not understanding the context or severity of the negative experience or the patient recovering from the experience. The negative experience saddened 17% of patients, and 9% were very angry and wanted to retaliate violently. Six percent of patients did not want to associate with community members, while 3% were disorientated in KwaXimba. Negative impacts may cause patients to withdraw from everyone, react negatively or lead to depression as patients may feel unworthy of inhumane treatment.

Caregivers who knew of patients having negative experiences in the community were affected by that incident. As depicted in Table 5.13, a total of 60% of caregivers were affected by the negative experience. The remaining 40% of caregivers were not affected in any way, as they did not know of the patient ever experiencing anything negative in the community of KwaXimba. It is evident from Table 5.13 that some patients (40%) in the community had no negative experiences. Twenty three percent of caregivers believed that the negative experiences of the patient often brought feelings of sadness and heartache for caregivers (23%). Caregivers were saddened for the patient because they could observe and understand that some members of the community were taking advantage of the patient. If the behaviour became persistent, caregivers ended up feeling angry or even confronted the individual responsible for this experience of the patient in the community (37%). This may lead to bad relations between the caregiver and community members, thereby reducing social relations.

All beliefs and impacts on caregivers and patients are due to the poor mental health literacy in KwaXimba, data on poor mental health literacy is provided below;

Variables	Total (n=35)
Causes for poor mental health literacy	
No available platform to teach the community	14%
Instilled beliefs about MHDs	72%
Explanations for the MHD from religious leaders justifying common beliefs	3%
Lack of education	11%
Increased mental health literacy improve treatment of patients within the community	
Yes	91%
No	9%
Type of improvement in the treatment due to awareness	
Humane treatment	37%
Less discrimination	9%
Less stigmatisation	11%
Assistance of patients in public	43%
Ways to improve mental health literacy	
Posters at the local clinic	31%
Television and Radio	60%
Taught in school	9%

Table 5.14. Causes for poor mental literacy, potential for improving mental literacy and ways of improving mental literacy

Caregiver responses linked to community mental health literacy were strongly associated with the question “*knowledge like what?*” This indicates that caregivers believe that the community have the necessary information about MHDs. The researcher had to elaborate on what would be different if the community understood MHDs as a medical issue that could be addressed adequately with medication. After clarification from the researcher, 91% of the caregivers indicated that increased awareness about MHDs could lead to improved treatment of patients within the community.

“People do not understand them in the sense of it sometimes just being a medical condition; people always believe there is an underlying reason or causation that maybe the family does not want to acknowledge or want to deal with.” (December 2022; Participant 7)

Caregivers thereafter acknowledged that, in most cases, people understand MHDs within the frame of evil spirits. As such, despite a possible understanding of MHDs being a medical condition, the stigma attached to the disorders would remain hence the 9%. Nevertheless, caregivers noted that community members often felt pity and treated people with other medical

conditions respectfully. Therefore, most of the caregivers, therefore, noted that informed community members would treat patients with MHDs better.

From Table 5.14, it is evident that providing assistance and help to patients in public was the most common option for caregivers (43%). Indicating that patients often do not get assisted if in public. The other specific option, with 37%, included recognising and treating patients as equal human beings. Not taking advantage of patients, decreased mocking or ridiculing and common decency towards patients. Caregivers indicated that humane behaviour towards patients was important. Approximately 20% (9% decreased discrimination and 11% decreased stigma) of the caregivers indicated that improved awareness of MHDs would lead to decreased discrimination and stigmatisation of patients.

Table 5.14 illustrates that a total of 72% of caregivers indicated that instilled beliefs about MHDs cause a lack of awareness. Instilled beliefs are traditional or cultural beliefs about MHDs are common within the community. Therefore, it is challenging to convince people who believe they are adequately informed about MHDs to think otherwise and be willing to learn. No platform is available for informing the community about MHDs (14%). Caregivers noted that communities are more informed about other medical conditions such as diabetes, asthma and HIV. This is due to information dissemination about such conditions being dispersed and common. Information about such conditions is available on social media, in newspapers, on television and in local clinics. Lack of education, particularly for the older generation, was identified as another barrier towards increased knowledge about MHDs (11%).

MHDs, however, are not as common or spoken about as much. Explanations about the root causes of MHDs provided by religious people also contribute to the lack of awareness (3%). Lack of awareness about MHDs has been recognised in research, where other illnesses such as HIV/AIDS have received more attention; hence patients and communities are informed (Weller, 2006; Saxena et al., 2007; UNAIDS, 2010; Saxena and Setoya, 2014; WHO, 2019). As such, the treatment of such illnesses has improved drastically as patients know where to go for appropriate health care, and medication adherence is also high, leading to improved results (Gray et al., 2015; Geffen, 2017). The main challenge is that MHDs are continually given less attention (fewer resources), leading to minimal chances of access to psychiatric services (Davis et al., 2019).

“The easiest way to teach people about an illness is to show on television; in these shows, people watch a lot like uZalo” (December 2022 Participant 33)

Caregivers indicated that the fastest and probably easiest way to increase mental health literacy was through televising MHDs and through the radio (60%). Caregivers explained that many people watch television shows and this would propagate the message about MHDs.

Caregivers had an understanding that the community needs to be more informed about MHDs, and there is an urgency to educate communities for educating communities. Radio was another recommended platform for increasing mental health literacy. Caregivers elaborated that older people in their communities continue to listen to the radio. These were excellent options provided by caregivers as almost every household in SA has a television or a radio. Popular shows such as uZalo are watched by approximately ten million South Africans (Dube, 2022). Gurung et al. (2017 and Davids et al. (2019) argued that the vital opportunity for destigmatising MHDs in rural areas was to educate rural communities. This would not only lead to early detection and treatment of MHDs but will eventually lead to improved results in patients (Fekadu et al., 2016). Thereafter patients have the possibility of being reintegrated into the communities.

Caregivers stated that the community could be informed more about MHDs in clinics. All community members have gone to the local clinic. Therefore, hanging up posters about MHD may increase mental health literacy (31%). Caregivers also mentioned how learners could be taught in schools about the MHD (9%), similarly to the way HIV and AIDS were taught. Caregivers stated that discrimination will decrease if the youth are well informed about MHD. More information should also be made available in a local clinic. Therefore, increased awareness could be brought by making information available to the public on different platforms that people utilise or come into contact with.

“People can always be taught better, especially in terms of understanding MHDs as a medical disease.” (November 2022, Participant 7)

Caregivers mentioned that the community strongly associates MHDs with spirituality and that impacts how patients are treated. According to caregivers, if the community understood MHDs as typical diseases like TB or HIV and AIDS, then the manner in which patients are treated could improve. Caregivers acknowledged that in most cases, patients are treated humanely, and harmful incidents are not common; however, there is room for improvement.

5.8. Access to social services



Figure 5.6. Available social services for patients

(i) Social workers

All caregivers stated that they were aware of social welfare offices. Caregivers can travel to these offices to request assistance. Offices are in a nearby town Pinetown, a neighbouring community Inchanga and PMB. Caregivers can utilise public transport to get to these offices. Each area has a designated social worker who provides welfare services. There are no welfare offices in KwaXimba. Social workers who assist the community are from the Pinetown or Inchanga offices. Caregivers mentioned that at some point, social workers used to come to the traditional court to provide the community with services. Therefore, despite caregivers stating that social workers are available in social welfare offices, accessibility might be challenged due to accessibility, affordability and difficulties in travelling with the accompanied patient.

(ii) SASSA offices

All caregivers stated that access to social welfare services such as SASSA was the most utilised service due to its availability and accessibility. In SSA, some countries offer disability grants to patients suffering from MHDs, SA is one of those countries. The grant is meant to provide financial support to patients perceived as vulnerable and more exposed to shocks and stress, particularly due to poverty (Filmer, 2008; McClain-Nhlapo, 2007; Mitra and Sambamoorthi, 2006; Edusei et al., 2017). Caregivers stated they had access to SASSA offices to apply for or renew the different grants. The offices are always open except for holidays and weekends.

Caregivers indicated that only one trip to the SASSA offices is often efficient and adequate to complete the application for the grant. After that, a month passes, and the caregiver can collect the grant. SASSA offices, however, are also located in Pinetown and PMB. Caregivers elaborated that their applications are processed through the Pinetown offices. Similar challenges may arise here, accessibility, affordability, and difficulties in travelling with the accompanied MHD patient.

(iii) Community health care workers

All caregivers indicated having knowledge of community health care workers in KwaXimba. Caregivers mentioned that community health care workers change after a certain duration, which often leads to caregivers not knowing who has assumed the position. Majority of caregivers (74%) indicated that community health care workers have been available to help in the past. Community health care workers come to people's homes from time to time to assist. The balance of the caregivers (26%) stated that they knew there was an appointed community health care worker, but they did not know who that was and could not access any assistance from them.

(iv) NGOs

Six percent of caregivers indicated receiving assistance from people entering the area. These people, however, are not focused on the caregivers and their plight rather on people experiencing poverty in the community. These groups of people are interested in philanthropy as they come with food parcels or stamps, clothing, and school uniforms for children. Caregivers indicated not knowing and needing to know where exactly these people come from (institution). Approximately, 94% of caregivers stated that no NGOs in KwaXimba provide aid to them.

(v) Religious organisation

Caregivers elaborated religious organisations are one of the places where patients are predominantly supported and received. As such, caregivers regard attending church with patients rehabilitating. As illustrated in Figure 5.6, 26% of caregivers regarded religious organisations as a social service. Patients receive prayers within the church. A caregiver elaborated that the eChibini church has a program for patients with mental disability, where patients can stay to receive continuous prayers. Patient can go home at any time.

Available health care services data is presented below;

Variables	Total (n=35)
Distance to nearest clinic	
<500 m	9%
2-5 km	3%
6-10 km	60%
11-15 km	28%
Mode of transport to the clinic	
Taxi	88%
Walking	6%
Own transport	6%
Frequency of clinic visits	
Once a month	46%
Once in 3 months	9%
Twice a year	3%
Only when unwell	42%

Table 5.15. Distance to the clinic, mode of transport to the clinic and clinic visit frequency

KwaXimba is a large area. therefore, the distance to the clinic was different for caregivers. KwaXimba has two clinics, one in the Bhobhonono community and the other in Number 9. The clinic in Bhobhonono is specifically for children, whether immunisation or just common influenza. The clinic in Bhobhonono is made up of a few containers used as consultation rooms with professional health workers. All caregivers, however, had to go to the clinic in Number 9, which serves as the primary community clinic. As illustrated in Table 5.15, majority of the caregivers (60%) travelled approximately 10 minutes which is 6 to 10km. Second is caregivers travelling for 10 to 15 minutes, which was 11 to 15km (28%). Third is the travel for under 500m with 9%, and lastly was 2 to 5km (3%),

Caregivers who lived close to the clinic could reach the clinic by walking. The rest of the caregivers used public transport to get to the clinic. Caregivers could not provide precise distances in kilometres but rather how much time it took to use public transport. Analyses are done based on the mode of transport, travelling 1km per minute. Therefore, the clinic is located approximately 10km away from caregiver households. All caregivers utilised the local government clinic, which offers health care services free of charge. According to Neelyand and Ponshunmugam (2019), the majority of South Africans utilise public sector health care services. This can be linked to the poverty characterising rural areas (Bettenhausen et al., 2021). As such rural people have limited resources (Neelyand and Ponshunmugam, 2019).

From Table 5.15, it is evident that the most common mode of transport used by caregivers to travel to the clinic was taxis (88%). Only 6% had their mode of transport or private vehicles.

Caregivers who lived close to the clinic and walked amounted to 6% as well. Caregiver car ownership or caregiver households with cars, therefore, fall below 6%. KwaXimba is characterised by poverty; therefore, the low percent of car ownership coincides with other data. An image of the most common mode of transport utilised by caregivers is provided below:



Plate 5.10. The most common mode of transport in KwaXimba, eThekweni Municipality, the quantum taxi

From Table 5.15, it is evident that most of the caregivers went to the clinic once every month (46%). This was often to collect medication for themselves or for the patient. Some caregivers indicated they only go to the clinic when they feel unwell (42%). Other caregivers only visited the clinic once in 3 months (9%). These caregivers could collect their medication elsewhere and only went to the clinic for the drawing of blood. The other caregivers are estimated to go to the clinic at least twice a year (3%). None of caregivers have indicated never going to the clinic or just going once a year. Caregivers also clarified that other household members go to the clinic to collect medication for the caregivers thus caregivers do not frequently travel to the clinic.

All caregivers indicated travelling more than 50 km to the nearest hospital. Caregivers thus chose the other specific option and clarified. Caregivers explained that they take more than one taxi to reach the hospital. The nearest hospitals mentioned were the St Mary's Hospital (known as Marianhill), the Northdale Hospital and the Ederne Hospital. These three are the most common referral hospitals for patients from the KwaXimba local clinic.

Taxis, the most utilised mode of transport, collect caregivers from their bus stops to the taxi rank (in number. 9). Caregivers estimated this to be about a 10-minute drive, approximately

10km. From the taxi rank caregivers, then get into a taxi going to Pinetown or PMB, taking approximately 30 to 45 minutes. This is about 30 to 45 kilometres in distance. Once in Pinetown or PMB, caregivers take another taxi to the hospital. Trips to St Mary's Hospital and Northdale take about 15 minutes, while the Ederne Hospital is further. The last trip to the hospital, therefore, takes approximately another 15km. In total, caregivers, therefore, travel 10 km going to the taxi rank, 30 to 45km to Pinetown or PMB and then 15km to reach the hospital. According to caregivers, the nearest hospital is approximately 55 to 60km from KwaXimba.

However, caregivers with their own mode of transport indicated travel for about 45 to 60 minutes to reach the nearest hospitals, which is about 45 to 60km in distance. The only difference when travelling with the different modes of transport is duration, cost, and time. Data on the mode of transport and hospital visits is presented below:

Variables	Total (n=35)
Mode of transport to hospital	
Taxi	94%
Own transport	6%
Frequency of travel to the nearest hospital	
Once or twice	20%
For emergencies	54%
When they say so in the clinic	26%

Table 5.16. Table showing mode of transport to hospitals

All caregivers utilise private or public transport to reach the hospital. Ninety-four percent (94%) of the caregivers travelled with public transport as taxis to reach hospitals. The rest of the caregivers (6%) utilised their own mode of transport. These could be vehicles from caregiver households or hired private vehicles.



Plate 5.11. KwaXimba, eThekweni Municipality, KZN taxi rank

This could be associated with the economic conditions in KwaXimba, where the majority live just above the poverty line. Poverty is still very prominent in this area. Hence the lack of car ownership in the community and the high utilisation of public transport.

Caregivers go directly to the hospital in extreme cases such as labour (54%). Caregivers indicated that they have only gone to the hospital when the clinic transfers them to the hospital (26%). According to caregivers, trips to the hospital are infrequent. Caregivers have only gone once or twice to the hospital with patients with the MHD (20%). However, caregivers did indicate that they have been to the hospital more than once or twice but for other reasons, such as a household member in labour, a bad injury, or to see relatives who have been admitted. Some caregivers have been to the hospital for their sicknesses and ailments.

Caregivers indicated that the first point of acquiring medical attention is the local clinic, therefore, most of the trips to the hospital are after the patient has been given the transfer letter from the local clinic to the hospital. Once the caregiver has identified the MHD in the patient, the caregiver then takes the patient to the clinic. The clinic will then transfer the patient to the nearest hospital for further diagnosis and prescription. The transfer of patients and caregivers to hospitals indicates no available psychiatric specialists within the local clinic. This may be due to the minimal amount dedicated to mental health expenditure by the DoH, where only 8% of the health expenditure is used in certain districts (Aloshore et al., 2019:2; WHO, 2013; Vancampfort et al., 2017). The deficient expenditure dedicated to the mental health sector is the main challenge in SSA as countries such as Botswana dedicate only 1% (WHO, 2013; Vancampfort et al., 2017), and Ghana only 3.4% (Ministry of Health, 2013). SSA countries dedicate 2.1% to MHC (WHO, 2021:54). This indicates the sector's neglect as minimal is dedicated to mental health. This could explain the need for more psychiatric services in KwaXimba as patients can only collect medication from the local clinic. There are no specialists in the community. Once the prescription is provided, the patient and caregiver are sent back to their local clinic to collect medication. This is the first trip to the hospital taken by patients and caregivers. The patient will then collect medication monthly from their local clinic in number 9.

All caregivers indicated having no knowledge of special needs schools equipped to deal with MHDs in KwaXimba. The nearest school caregivers mentioned was KwaThintwa School for deaf students, located in Cato Ridge.

KwaThintwa is located approximately 13km from KwaXimba taxi rank, a 17 minutes' drive. This school is not dedicated to learners with MHDs and only focuses on children with a hearing impairment.

All caregivers indicated that the special school nearest to them was for the children with a hearing impairment and not equipped to deal with MHDs. None of their patients attended this school. Patients who studied went to regular schools in the area. Outcomes of attending the special needs schools are, therefore, not applicable to all caregivers. Access to social workers and community health care workers is presented below:

Variables	Total (n=35)
Contact with social worker	
Yes	17%
No	83%
Contact with community health care worker	
Yes	20%
No	80%
Health care worker assistance	
Assistance with caregiving for patient	14%
Assistance with health care	6%
Not applicable (never received assistance)	80%

Table 5.17. Contact with social worker, contact with community health care worker and health care worker assistance

As shown in Table 5.17, most of the caregivers (83%) have never been in contact with social workers regarding the patient with MHDs. Some of the caregivers had been in contact with and received assistance from social workers concerning other matters, not that of the patient with the MHD.

“Social workers from Inchanga have been to my house; however not much assistance was received, had a disagreement patient was present, and it got physical, and they never came back.” (November 2022, Participant 1)

Only 17% of caregivers indicated having interactions with caregivers from Inchanga offices. However, these were very brief meetings, and no significant help was obtained.

All caregivers were not in contact with social workers about the patient --concerning their MHD. According to caregivers, social workers tend to follow and assist more in cases involving children and orphans. If one takes the initiative and goes to their offices in Pinetown or Inchanga, they will assist you but not follow up. In cases involving children, social workers

are known to even request to see end-of-the-year results and may come to their home occasionally.

From Table 5.17, it can be seen that majority (80%) of caregivers had never had a visit from a community health care worker. Twenty percent of caregivers indicated that a community health care worker had been to their house at some point in time in the past. Community health care has been recognised and aims to be accessible to many caregivers. The position of being a community health care worker often changes from one person to the next, due to the employment being limited to a specific period. As such, at some point, the caregiver loses any communication with the community health care worker as they do not know who it is at that time.

There is a mobile clinic which comes on Thursdays for parts of KwaXimba located the furthest away from the local clinic in number nine. This is when community health workers are most visible as they assist with registration on the mobile clinic. Other community health care workers assist in creating a relationship between community members and whatever assistance may be required.

Some of the caregivers do not even know who the community health care worker is. Caregivers (80%) indicated they had yet to receive significant assistance from community health care workers in KwaXimba.

“The community health care worker used to come to my house and just provide assistance to the unwell individual, by either helping the patient eat and take their medication.” (November 2022, Participant 7)

“Community health care workers also remind households when to fetch treatment and encourage adherence to treatment.” (November 2022, Participant 3)

Caregivers (20%) stated that assistance from community health care workers was received at some point. The 20% consisted of 14% assistance with caregiving patients (bathing and feeding), and 6% was health-related (administering medication). This assistance was often received during home visitations. However, this assistance often stopped when a new person filled the position. According to caregivers, different people resume the position of community health care workers over time. Some community health care workers are effective and do house visits. According to caregivers, community health care workers visit households and inform the clinic, social worker or counsellor of households which needs intervention.

All caregivers were aware that there is a disability grant available for patients suffering from MHDs.

“The disability grant is a non-contributory, means-tested cash transfer available on a permanent or temporary basis to people deemed unfit to work due to functional impairment and who do not have sufficient other means of support.” (Gabrielle, 2013:2).

Caregivers knew about the disability grant from different people or found out in different ways. As shown in Table 5.17, most caregivers found out through relatives (inclusive of family members) about the disability grant (51%). When family members and relatives recognise the MHD in the patient, they often recommend that the caregiver apply for a disability grant. Another 26% of caregivers had been informed about the disability grant by friends or people close to them. The rest of the caregivers indicated that they knew someone getting the disability grant (23%). Knowledge of the disability grant was widespread within the community, hence all caregivers in KwaXimba knew about it. The case in KwaXimba is different from other SSA countries where knowledge of such assistance in respect to the disability grant and other forms of grants are scarce (Mitra, 2010; Abdille and Mbataru, 2019). In KwaXimba all caregivers indicated knowing the mental disability grant. The disability grant was R1860 as of 2019 (Western Cape Government, 2019). Data pertaining to the disability grant is found below that they are aware of the:

Variables	Total (n=35)
Knowledge of the disability grant	
Relatives	51%
Friends	26%
Someone I know was getting it	23%
Patient collecting the disability grant	
Yes	80%
No	20%
Duration of collecting disability grant	
1-3 years	9%
4-6 years	17%
7-10 years	14%
>10 years	40%
Not applicable (does not collect grant)	20%
Number of times disability grant has been renewed	
Never	29%

1-3 times	20%
4-6 times	11%
7-10 times	17%
>10 times	3%
Not applicable (does not collect grant)	20%
Grant assistance to patient	
Grant provides help to the patient with clothes and food	69%
Used by patient at their own discretion	11%
Not applicable (does not collect grant)	20%
Grant assistance to household	
Traditional rituals	6%
Patient's child needs	14%
Household needs	40%
Groceries	14%
Does not assist household	6%
Not applicable (does not collect grant)	20%
Challenges with mental disability grant	
Yes	11%
No	69%
Not applicable (does not collect grant)	20%

Table 5.18. Disability grant information and assistance

In SA, if an individual is in a situation where they cannot work for longer than six months due to a disability, that person can apply for a disability grant (SASSA, 2009; Western Cape Government, 2019).

From Table 5.18, it can be deduced that majority of caregivers (80%) collect the disability grant for patients. This was the majority of the patients with MHDs. Only 20% of caregivers indicated not collecting the disability grant. Caregivers who did not collect the disability grant stated a lack of required documents, such as the identification document (ID) or a recent patient diagnosis. Patients who did not have the required documents have often tried to reach out for the assistance of social workers. Patients not collecting the disability grant were aware of it but did not have proper identification documents or medical certificates or had difficulties travelling with the patient due to the MHD. Therefore, they could not apply for the grant.

This grant is significant for households with patients and caregivers, as caregivers cannot engage in income-generating activities (Ntsayagae et al., 2019). This grant becomes a source of income for households who are compromised as caregivers cannot secure another means of income due to the responsibilities of caregiving.

Most caregivers could not provide when the patient started collecting the disability grant. Caregivers, however, were able to estimate the number of years. From Table 5.18, it is evident that many patients had been collecting the grant for more than ten years (40%). Nine percent of patients have been collecting the grant for six and eight years respectively. Other patients had collected the grant for four years (6%) and nine years (6%) respectively. The rest of the patients (3%) had been collecting the grant for 5 years, 3 years, 2 years and just over a year respectively.

Approximately 17% of patients had been collecting the grant for five years or less. A further 23% had collected the grant for 6 to 10 years. This indicates that patients are not getting rehabilitated and require the renewal of their disability grant. The grant is meant to support people with disabilities (McKenzie and Hanass-Hancock, 2017). Most of the patients (40%) had been collecting the grant for more than ten years, indicating that the MHD has been a part of the patient's life for more than a decade without getting rehabilitated.

According to the SASSA documents, the mental disability grant is provided for six months, after which it must be renewed. However, that is only the case for some of the patients in KwaXimba. Some caregivers have never undergone the process of renewing the grant despite collecting it for an extended period (31%). However, caregivers failed to differentiate between a mental disability grant and a disability grant. The mental disability grant is renewed every six months upon confirmation from a medical professional. However, the disability grant is never renewed unless it is time for everyone to renew their cards or their grant, which occurs approximately once in 10 years. As such, patients do not require an evaluation and have only gone once in their lifetime or a few times, depending on how long they have been collecting the grant. For 20% of the patients, grant renewable was not applicable as these patients did not collect the disability grant. Fourteen percent of the caregivers had renewed the grant eight times, 9% of the caregivers had renewed it twice, 6% of the caregivers had renewed it once, another 6% three times as well as another 6% four times respectively.

A dependency relationship may have developed between patients, caregivers and collecting the disability grant. This might lead households to resist engaging patients with rehabilitation due to the possibility of the grant being amended. For poor households losing a household income will have detrimental effects.

From Table 5.18, it is evident that most of the caregivers (69%) use the disability grant to purchase food and clothes for the patient. Twenty percent remain not applicable as these

patients do not collect the disability grant. While 11% of patients use the disability grant at their discretion. Caregivers complained that in cases where the patient takes the disability grant, it is usually spent with or by friends in local shops and taverns. Caregivers who collect the grant utilise it for household needs and wants. This includes groceries, clothing, electricity or travelling with the patient when necessary. Patients are unemployed and unemployable, thus, the disability grant becomes their source of income contribution to the household. The grant is collected monthly at the beginning of the month.

“It depends on what needs are there for that time. I may buy food, clothes, pay for funeral cover and stokvels.” (November 2022, Participant 7)

“After going to collect the money, I usually give him some of the money to buy whatever he wants.” (November 2022, Participant 16)

Therefore, this money contributes towards all household financial needs in KwaXimba, eThekweni Municipality, KZN. The grant covers different aspects in different months, focusing mainly on food and clothing. As indicated above in Table 5.18, the disability grant is used to cover different household financial expenses. This grant assists with household expenses including purchasing electricity tokens, paying for stokvels, funeral covers, travelling to the hospital with patients (40%) and clothing purchases. The grant assistance with household groceries which account for 14%. For patients with children, the disability grant may be used to pay for the creche, transport, clothing, pocket money and other needs (14%). Caregivers stated that at local government schools, they do not pay school fees as schools are free. According to Edusei (2017) and Wrights (2015), the grant covers household needs, improves living standards, and fills financial gaps such as school fees. Six percent of assistance was for contributing towards the conduction of ceremonies or cultural rituals within households.

Six percent of caregivers perceived that the disability grant does not assist the household of KwaXimba. Also, 20% of the caregivers mentioned that the patients do not collect the disability grant (not applicable). In such cases, the patient uses the money at his discretion and does not contribute towards household expenses.

Caregivers indicated that the application, collection, and renewal of the disability grant is predominantly a straightforward process. Therefore, the majority of the caregivers (69%), as depicted in Table 5.18, do not experience any challenges when applying, collecting and renewing the disability grant. As such, only 11% of caregivers indicated that they had experienced challenges with the disability grant. In addition, caregivers mentioned the

difficulty when travelling to the hospital to obtain the letter in respect to renewing the grant. As the patient is not easy to travel with. The patient must be present with the caregiver whenever the letter is provided. The letter is then taken to SASSA offices to apply for the grant renewal.

“Sometimes I wish he didn’t collect the disability grant because it does not assist the household in any way, and he will come back here to ask for food.” (November 2022, Participant 29)

In this case, the caregiver showed concern for the patient in that the disability grant is wasted with friends, usually purchasing alcohol for short or temporary enjoyment. During this time, the patient is seen with friends and spends money with and on friends. This was a challenge for the caregiver as the patient would often come back to eat and utilise other household necessities, Yet the patient does not contribute to the household.

5.9. Providing care

Variables	Total (n=35)
MHD caregiver training	
Yes	20%
No	80%
MHD caregiver training duration	
> an hour	17%
Over a couple of days	3%
Not applicable (never received training)	80%
Contents of training	
How to assist patient take medication	17%
How to help patient with day-to-day activities	3%
Not applicable (never received training)	80%

Table 5.19. Caregiver training, duration and content

From Table 5.19, it is evident that majority caregivers (80%) did not have any training in respect to providing care for patients with MHDs. Thus, caregivers provided care for patients based on common knowledge, performing associated responsibilities in the form of trial and error if experience and knowledge were not available. In contrast, 20% of the caregivers had received elementary training or instructions. Nurses would explain how to administer the medication to patients and recommend methods caregivers can try if patients hesitate or resist taking the medication.

Of the 20%, 17% of caregivers had their training for less than an hour. Professional nurses provided brief training and guidelines for caregivers during consultations in the local clinic,

usually for approximately 10 to 15 minutes. Three percent of the caregivers indicated they continuously received training from a community health care worker over time on different days.

Table 5.19 shows that 17% of caregivers received training at the local clinics from professional nurses. Caregivers were informed about medication administration and how to encourage patients to take their medication. Information from the community health care worker included how to accommodate the patient, administer medication, assist with needed activities (such as assistance with bathing) and live with the patient (3%). Assistance required by patients is presented below:

Variables	Total (n=35)
Patient requires assistance with everyday activities	
Yes	63%
No	37%
Assistance required for everyday activities	
Taking medication	11%
Patient laundry	26%
Cleaning and cooking for patient	26%
Does not require assistance	37%
Assistance provided in caregiver's absentia	
Yes	63%
No	37%
Person assists patient in caregiver absentia	
Caregiver's child	17%
Patient sibling	37%
Available household member	9%
Not applicable (no assistance given)	37%

Table 5.20. Assistance is required by patient with everyday activities

Everyday activities include bathing, eating, making the bed, doing laundry, cleaning, getting dressed and preparing meals. Most patients (63%) require assistance performing all or some of the daily activities. The most common assistance was doing laundry, cleaning, and preparing patient meals. The remaining 37% of patients do not require assistance with daily activities.

For routine visits to the clinic, hospital or SASSA offices to apply or renew the disability grant caregivers have to accompany the patient. Patients often need the caregiver to diffuse the situation by being patient, caring and understanding regarding mood swings or the use of vulgar

language. Caregivers stated that patients need constant emotional support, consisting of patience, understanding, general support, and encouragement in doing tasks. Caregivers indicated that patients do not want to be treated like children or in a way that makes them feel inferior or belittled, making them angry or irritated when they are undertaking tasks.

All caregivers assist patients in one form or the other. As depicted in Table 5.20, 26% of patients require assistance with cleaning and preparing meals. Twenty-six percent need assistance with doing laundry. Caregivers doing laundry, cooking, and cleaning the patient's room was listed as the patient's most common form of assistance. Caregivers indicated that in some cases, the patients can do their laundry, but caregivers are often unsatisfied and prefer to do these activities for the patients.

“The patient can bath and dress, but I prefer to do their laundry and do spring cleaning in their room occasionally. The patient can wash her clothes, but in an unsatisfactory manner, therefore, I step in.” (November 2022, Participant 16)

“Whoever cooks in this house dishes up for everyone. Patients never cook but are cooked for and come to collect their food.” (November 2022, Participant 8)

MHD patients remain disabled and dependent on caregivers for assistance with daily tasks due to MHD impairments. The MHD keep patients mentally disabled and dependent on caregivers for assistance with ordinary tasks. This resembles children and old people's relationship with those who care for them. In as much as patients can perform these activities by themselves, they need assistance in undertaking tasks appropriately. Therefore, caregivers' step in for patients to look presentable to the public. Caregivers cook, or other household members cook and dish up food for everyone, including the patient. Cooking and cleaning were a shared household responsibility compared to doing laundry, which remains primarily the caregiver's responsibility for the patient. Frequently, patients take medication independently, and only 11% of patients are assisted by caregivers. Caregivers assist these patients in different ways as patients can perform simple everyday activities.

Caregivers are often at home or near the household. Caregivers are usually not at home during the day, and during this time, any household member who is available assists the patient if needed. Caregivers have someone who assists patients in their absentia (63%). Caregivers are never away from home for extended periods thus, can assist the patient whenever needed. As shown in Figure 5.20, 37% of caregivers do not have anyone to assist the patient in their

absence as caregivers are available most of the time. This comprises of assistance with ordinary tasks such as meal preparations.

Caregivers elaborated that anyone available or in the household when the patient needs assistance provides that assistance to the patient. Assistance may be provided by any household member (9%) to the patient. Patients' siblings also assist the patient (11%) in caregiver's absence and lastly, the caregiver's child may aid the patient. The caregivers perceive that 86% of the patients require medication. The Figure 5.7 below depicts the person responsible for collecting medication for MHD patients. The Figure 5.7 below illustrates the individual responsible for collecting patient medication:

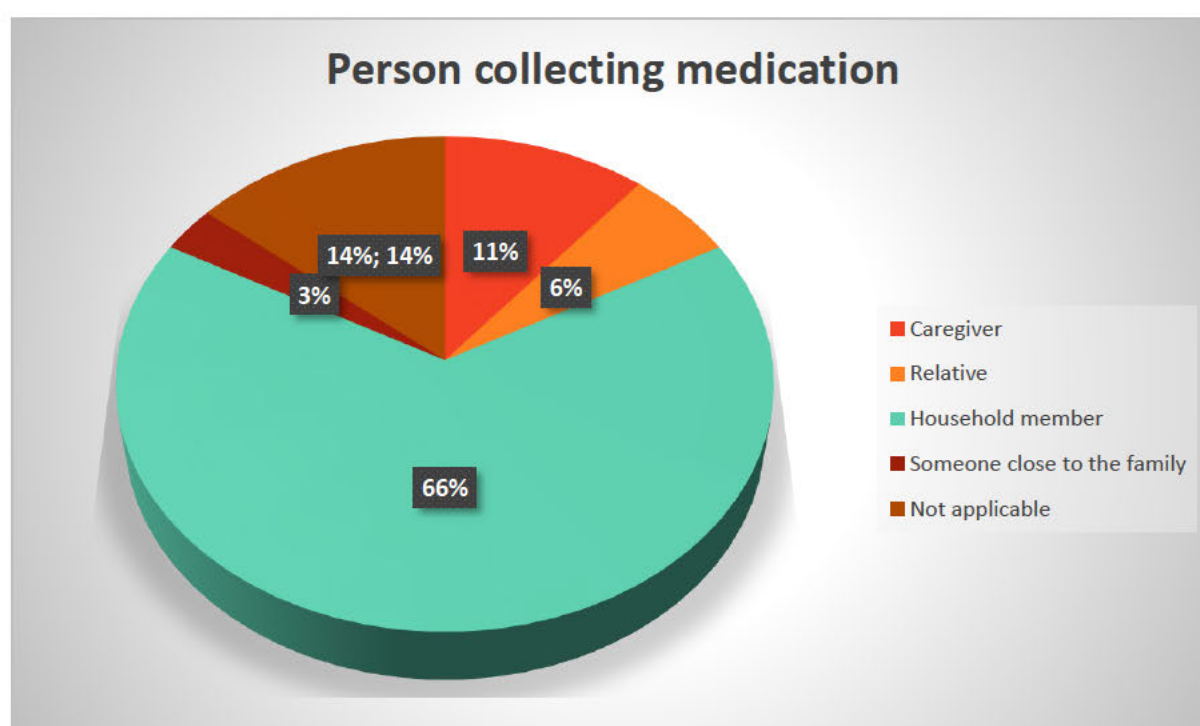


Figure 5.7. Person responsible for patient medication collection

Caregivers mentioned how households have stopped collecting medication for patients. The caregivers provided a reasoning such as that the patient would often default on medication. Caregivers stated that patients defaulted from medication for different reasons despite noticeable improvement in the patient's mental state. Hailemariam et al. (2017) argued that patients do not want to take medication despite improving MHDs symptoms. This seems to be the case in KwaXimba as caregivers acknowledged that medication improves patients' states, but patients continued to default.

Collecting medication from the local clinic was a shared responsibility within the households, as illustrated in Figure 5.7. The figure above illustrates medication was collected by the

household member (66%), a relative (6%) or someone close to the family (3%). Caregivers who collected the medication amounted to 11%. Collecting medication was quick and convenient as long as the patient's card was with the person collecting the medication. Location and medication compliance data are available in the table below:

Variables	Total (n=35)
Location for collecting medication	
Clinic	86%
Not applicable (does not collect medication)	14%
Assists patient with taking medication	
Caregiver	26%
Patient can take medication on their own	40%
Household member available	17%
Community health care worker	3%
Not applicable (does not collect medication)	14%
Patient compliance with taking medication	
Yes	20%
No	66%
Not applicable (does not collect medication)	14%
Reason for patient non-compliance with taking correct dosage of medication	
Patient does not want to take the medication	26%
Sometimes patient is not at home	17%
Depends on the mood of the patient	9%
Patient lies about taking medication	6%
Believed pills are poisonous (hallucinations)	9%
Not applicable (does not collect medication)	34%
Improvement in patient's state	
Yes	14%
No	72%
Not applicable (does not collect medication)	14%

Table 5.21. Location for collecting medication, patient assistance, compliance with medication and improvement

Not all patients take medication for MHDs. Therefore, as illustrated in Table 5.21, 86% of patients require medication, while 14% do not require medication. This indicates caregivers' acknowledgement that medication can make an impact and lead to improvement in the patient's state. A range of reasons could account for caregivers believing that patients do not require medication. Which could be based on shared traditional beliefs, loss of hope for improvement in patients, and experience with MHDs and MHDs that do not have significant symptoms.

However, this is not the case, as all MHDs need to be treated accordingly with the appropriate medication. All medication was collected from the local clinic in KwaXimba Number 9. Table 5.21 clearly depicts that 86% collected medication in the local clinic. The remainder 14% was for patients who did not collect medication.

Most patients can do a lot independently and require minor assistance with certain things. As such, 40% of patients can take medication on their own. Patients who are assisted in taking medication either by a caregiver (26%) or by any household member (17%) are usually just provided with water in a cup and a tablet. Caregivers stated that in some cases, they have to lie to patients and say the medication is for something else rather than MHDs. The negative connotations attached to MHD lead to resistance to taking medication. The other specific option (3%) was the occasional assistance of patients by community health care workers to take the medication. However, this has only happened twice in one household of KwaXimba.

Compliance with medication appears to be a challenge in KwaXimba. Many patients do not take the medication as instructed (66%). This percentage consists of different groups of patients. Some patients do not want to take the medication at all. Other patients have defaulted and stopped taking medication, while others only take the medication when they feel it is suitable. Only 20% of the patients comply and take their medication accordingly.

From Table 5.21, 26%, of patients are non-compliant due to not wanting to take medication. Seventeen percent of patients were often not at home during the day and therefore, could not take their medication. Nine percent of patients only took medication on the days they feel are suitable to them. Fourteen percent included patients who lie to caregivers about taking medication, hallucinate that they are being poisoned or someone is trying to kill them with the medication. In some cases, patients would explain that they do not like the effect medication has on them and would, therefore, not take it.

The not applicable percentage was 34%, accounting for the patients who do not take medication at all which means medication is not collected (14%) for them and the compliant patients (20%). There seems to be a high correlation between patients who can take medication independently and defaulting. Caregivers indicated that in most cases, they are unaware that the patient has stopped taking the medication until they find the medication hidden, untouched or thrown away.

Caregivers elaborated that improvement in patient's state depended on continued medication intake. Caregivers have noticed an improvement in the patients when taking medication, but

patients frequently default which stops any improvement. From Table 5.21, the majority of the MHD patients (72%) did not have any noticeable improvement at the time of data collection. It is important to note that the 'taking of medication' does not equate to compliance but rather just the collection of medication which is frequently not consumed. Caregivers who assisted the patient with taking medication argued that there was a significant improvement in the patient's state due to continued medication intake. A total of 14% of caregivers had noticed an improvement in the patient's state. Other caregivers mentioned how there was improvement when patients were taking medication. However, symptoms returned after patients defaulted, diminishing any improvement to be achieved.

A total of 86% of patients are supposed to be collecting medication from the local clinic. However, only 14% of the 86% have improvements after taking medication due to continued medication intake. Therefore, only 14% of patients remained compliant with medication. This is a minimal percentage of medication compliance.

As illustrated in Figure 5.32, 6% of patients became less violent. Caregivers mentioned that medication usually made patients calmer. Another 6% of patients had improved independence. Patients could clean, do their laundry, and bathe themselves. Patients who stopped talking to themselves (associated with hallucinations) were 3%. Decreased hallucinations were explained as a significant improvement, as it leads to an overall improvement in patients. Patients who hallucinate can become violent, run away from home, and talk to themselves. A decrease in all these symptoms leads to better patients. Improvement differed in patients. Caregivers noted that sometimes patients would reduce roaming around unsupervised, become more helpful around the home whilst requiring decreased assistance from caregivers. Unfortunately, a large percentage of the patients displayed no improvement in their mental condition even after taking medication, a result of the non-compliance. As depicted above, 86% of patients are still in the same state of the MHD with no improvement despite any treatment sought.

Most caregivers chose the option of no improvement in patients for different reasons. In some cases, patients improved for a while but then declined and returned to their original state, as patients defaulted, and symptoms continued. None of the patients had been fully rehabilitated or close to normal and reintegrated back into their communities, including the ones that had been compliant with medication. This outcome of minor to no improvement despite taking medication agrees with what (Phahladira et al. 2019) argued impairments continued for patients

who take medication solely even if they comply. The duration of patients taking medication is found below:

Variables	Total (n=35)
Period of patient taking medication	
1-3 years	6%
3-6 years	23%
6-9 years	31%
>10 years	23%
Not applicable (does not collect medication)	17%

Table 5.22. Duration of patient taking medication

Caregivers could not state the exact date the patient started taking medication but could estimate the number of years or the duration of the patient taking medication. As shown in Table 5.22, the most common number of years was 6 to 9 years, with 31% of patients taking the medication. Secondly were patients taking the medication for more than ten years (23%) who had developed the MHD long ago or from an early age. Patients taking medication for 3 to 6 years also had 23% and only 6% of patients had been taking medication for 1 to 3 years. This increase from 14% to 17% for patients not taking medication (not applicable) is due to 3% of caregivers indicating that medication was only collected once. The patient did not want to take the medication.

MHDs have been associated with violence, data pertaining to patient violence is presented below:

Variable	Total (n=35)
Patient violence	
Yes	46%
No	54%
Form of violence	
Throwing stones and outbursts	25%
Patient hit or strangle strangers	3%
Patient hit or strangle household member	6%
Patient destroys things within the household	9%
Patients hit or strangle caregiver	3%
Not applicable (patient not violent)	54%
Circumstances around violent incident	
Patient becomes violent unprovoked	14%
Patient becomes violent when they need to take medication	3%

Patient becomes violent if they do not understand something	3%
Patient becomes violent if you touch their belongings	12%
Hallucinations	14%
Not applicable (patient not violent)	54%

Table 5.23. Patience violence and circumstances around violent incident

Table 5.23 shows that more than half of the patients, 54% were not violent. These patients never had violence as a symptom of the MHD. A total of 46% of caregivers had experienced some form of violence from patients.

The above Table 5.23, accounts for patients who displayed any form of violence, which comprised of 46% of the patients. Table 5.23 shows that the most common type of violence consisted of throwing stones and outbursts (26%). Patients would throw stones at people or children passing by their households. Patients also had random outbursts of anger which led to shouting, screaming, threatening, and swearing. These are the most common forms of violence from patients. Patients have also been known to destroy things within the home (9%). This was usually when patients were angry due to a misunderstanding or hallucinations. Patients have also been violent towards other household members (6%). Caregivers who had experienced violence towards themselves from patients were 3%. This was when the patient hit or strangled the caregiver or household member.

MHDs have been associated with patients being violent hence the associated stigma. In KwaXimba caregivers indicated that patients are rarely violent without cause. Less than 15% of patients have become violent without cause or due to hallucinations (14%).

“He often believes there are people after him and will be on his guard and sometimes even violent to strangers coming into the home stead.” (November 2022, Participant 24)

“He gets angry very easily and may start swearing at the individual.” (November 2022, Participant 35)

“When people mock her or call her crazy, she gets furious and may start a fight with those people.” (December 2022, Participant 1)

Patients also become violent when their belongings are touched or taken away from them (12%). Caregivers mentioned how patients with MHDs are possessive of their belongings. Patients also become violent due to misunderstandings or when the caregiver or someone is trying to get the patient to engage in something he or she dislikes. Three percent of patients

become violent when they need to take medication, while another 3% become violent due to misunderstandings or when a patient does not understand something. The balance was violent incidents linked to hallucinations.

Illustrated below in Figure 5.8 are the challenges experienced by caregivers of patient suffering from MHDs:

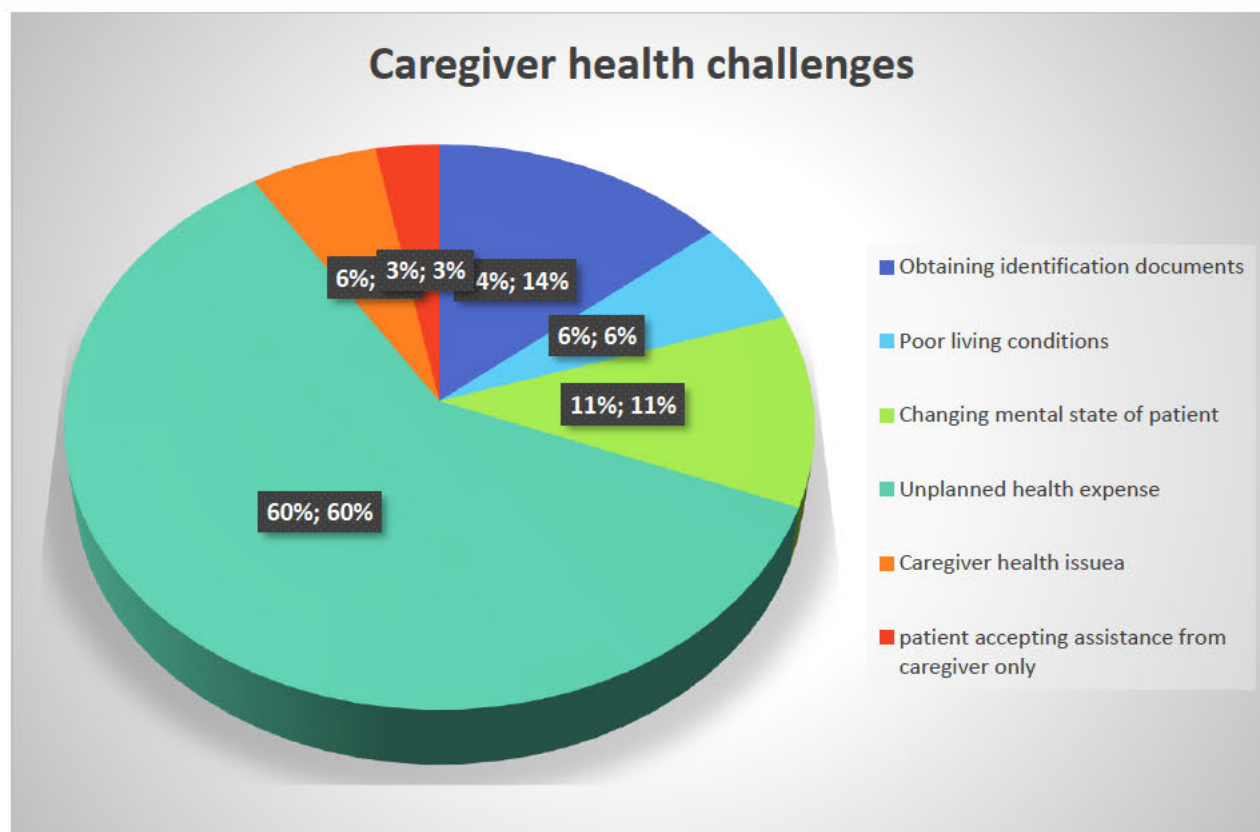


Figure 5.8. Caregiver health issues

“Ukugulelwa kuyabiza” when someone you are responsible for is sick, it becomes expensive (December 2022, Participant 3).

Caregivers explained that when someone suddenly gets sick within the household, that leads to unexpected expenses for the household (60%). Caregivers added that whether medical health care or traditional help is sought, expenses are bound to occur. Caregivers often explained how significant amounts of money had been utilised to acquire assistance for the patient. All travelling fees were paid for by the caregiver. Caregivers explained that they rarely relied on one traditional healer. Caregivers would seek two or three consultations with different traditional healers before accepting the truthfulness of the diagnosis and associated causes and

routes to be taken. As noted, caregivers opted to utilise traditional healers far away from their homes, thereby increasing transportation costs.

“Traditional healers tell you what you need to do alongside traditional medicine, which requires additional money.” (December 2022, Participant 12)

According to caregivers, traditional healers often inform the caregiver of what must be done before the patient starts traditional medication. This could be a ceremony or *inhlambuluko* (when the family comes together to speak the truth about past issues which might have divided the family). The ceremony requires a lot of money, inclusive of money for the chickens, goats or cows, alcohol (traditional and brewed) and food for whoever will be there for the ceremony, at the basic level. This process is done before seeing results or improving the patient’s state. The traditional healer also charges for all consultations. Majority of caregivers mentioned how providing care for patients with MHDs was associated with many challenges. Caregivers had challenges obtaining important documents for patients, which were necessary for acquiring assistance (14%).

“I have tried but failed to obtain an identity document for the patient, and that remains a challenge for me as it means the patient cannot even get the disability grant.” (November 2022, Participant 1)

Caregivers pointed out that some of the patients do not have identification documents, and this becomes a challenge, as caregivers cannot apply for the disability grant for patients. Providing care for the patient can be very challenging due to changing moods and reactions of patients (11%). Caregivers mentioned that the patient will be calm and understanding, however, on a bad day, the patient can become quite verbally abusive. The researcher experienced such in one of the households, where the patient was vulgar, and the caregivers asked the researcher to leave the household and come back some other time.

“Patient is very moody. On a good day, the patient will be calm and perform whatever on their own. On a bad day, the patient will be irritable, use vulgar, and chases everyone away. On such days we just let the patient be.” (December 2022, Participant 6)

Caregivers also mentioned poor living conditions (6%) as many people are living in the household. Caregivers mentioned that having the patient live with them, where the entire family shares a house or rondavel, becomes challenging as patients may not be understanding or behave indecently in front of other household members.

“We are a lot, and therefore it becomes congested.” (November 2022, Participant 1)

Caregivers stated that one cannot estimate how a patient will react to something similar. Patients, therefore, need caregivers to adjust to their constantly changing moods and needs. This means the caregiver must always be available emotionally and physically to assist patients despite their challenges or personal issues.

Caregivers mentioned having other illnesses for which they take medication, among other personal challenges. Caregivers mentioned how it can be hard explaining to patients that the caregiver is unavailable, unable to assist and not well enough. Understanding and communication between caregivers and patients is another challenge. It becomes a problem as the patient needs the caregiver to be completely available and supportive whenever the need arises. Caregivers had to reduce engaging with other activities as patients may require assistance while caregivers are away. Caregivers indicated that household members are often around to assist the patients; however, they prefer to assist patients themselves if it is serious. Patients also prefer to be assisted by caregivers and usually have a closer relationship with caregivers (3%). This places an added responsibility on caregivers. As such, the patient may reject assistance from other household members and wait for the caregiver. The Table 5.24 below shows psychiatric access for patients with MHDs in KwaXimba:

Variables	Total (n=35)
Psychiatric evaluation of patient	
Yes	80%
No	20%
Frequency of psychiatric evaluation	
Never	14%
Yearly	6%
Prior to grant renewal	26%
Once or twice	54%
Psychiatric evaluation location	
Hospital	86%
Not applicable (no psychiatric evaluation)	14%
Mode of transport to psychiatric evaluation	
Taxi	83%
Private vehicle	6%
Not applicable (no psychiatric evaluation)	11%
Cost of travelling to psychiatric evaluation	
R100-R200	29%
R200-R300	54%

Used private vehicle	6%
Not applicable (no psychiatric evaluation)	11%
Cost of travelling paid by caregiver	
Yes	55%
No	34%
Not applicable (no psychiatric evaluation)	11%

Table 5.24. Accessing psychiatric assistance for patient

According to caregivers' patients rarely get evaluated psychologically. This evaluation is usually conducted by professional nurses at the hospital through consultation. As depicted in Table 5.24, 80% of patients have received a psychiatric evaluation. Majority of the caregivers (80%) indicated that patients only went once to the clinic and hospital for psychiatric evaluation and never went back. This evaluation was usually conducted at the initial stages of medical diagnosis. Moreover, 20% of patients have never received a psychiatric evaluation. This 20% consists of the 14% of patients who have never sought medical assistance and 6% where patients who decided to stop during the process.

Caregivers stated that patients underwent psychiatric evaluation when medical assistance was sought. This evaluation, however, was moderate as health professionals interviewed patients. Table 5.24 shows that more than half of the caregivers (54%) have only gone once or twice with the patient to the clinic and the hospital. A total of 26% of patients receive psychiatric evaluations before grant renewal. Years may pass before patients require another evaluation when SASSA has instructed all grants to be renewed. Caregivers mentioned that this is because every time patients with MHDs require to renew their grant, a letter from professional health personnel is needed. Some patients had never sought medical treatment, thus, psychiatric evaluation was not conducted (14%). According to caregivers, it is due to never considering going to the clinic or patients not wanting to start or continue with the process. Only 6% of caregivers indicated that the patient receives an annual psychiatric evaluation, which is also done for patients who need to renew their grant after a couple of months. This indicates that patients with MHDs collect different types of disability grants. Other caregivers have to renew the grant frequently compared to others.

All caregivers indicated that their initial point of interaction with health professionals was at the local clinic. Table 5.24 shows that 86% of patients received a psychiatric evaluation at the hospital. Complete diagnosis and prescription for MHD patients were provided at the hospital, to which patients were transferred from the local clinic in KwaXimba.

The mode of transport used by caregivers and patients for travelling to the hospital for psychiatric evaluation is public transport in the form of taxis. As illustrated in Table 5.24, the majority of the caregivers (83%) utilised taxis. Only 6% of the caregivers indicated utilising a private vehicle with the patient. The use of public transport by caregivers may be due to households not owning private vehicles and cannot afford to hire private vehicles. Utilising public transportation implies that one must display human, decent, and general understanding and acceptable public behaviour. This might be challenging for patients with MHDs. As such, caregivers would rather not travel with patients to avoid humiliation or any adverse treatment towards patients in public spaces. It is important to note that some caregivers started acquiring medical assistance, psychiatric evaluation and stopped at some point for various reasons.

Poor people cannot afford to own cars, use private vehicles, or even get an uber as finances are very low. SA rural areas such as KwaXimba are often customised with poverty (Cheteni et al., 2019). The use of public transportation may also be linked to poverty. The challenge of poverty became pronounced after the apartheid regime which initialised the market economy in SA (Cheteni et al., 2019).

As illustrated in Table 5.24, more than half of the caregivers (54%) indicated utilising R200 to R300 when travelling with patients to the hospital. This amount is inclusive of both the caregiver and patient's bus fare. The bus fare from KwaXimba to Pinetown is R120 inclusive of a return. The bus fare from Pinetown to the hospital can range from R80 to R100 inclusive of a return. The total travelling cost is therefore around R220 for both. This excludes any meals the patient and caregiver may require during this trip. Hospital visits usually take about 7 to 8 hours of the day. Caregiver and patient must wake up early and leave their households around 6 am, if not earlier. This would place them in Pinetown around 7:30 am. The caregiver and patients would then take the taxi to the hospital, placing them at the hospital around 8:30 am. Hospitals are usually filled to capacity, so patients and caregivers leave the hospital at around 12 pm at the earliest. Travelling back home would take another two and a half hours, meaning the caregiver and patient would arrive home around 14:30pm to 3:00 pm. During this time, the caregiver and patients would have needed something to eat.

Twenty nine percent of caregivers and patients paid between R100 to R200 when utilising taxis to reach the hospital. The decrease in transportation costs was associated with patients who went for psychiatric evaluation a long time ago. Nearly 55% of other caregivers spent R200 to R300 for transport when going to the hospital. Caregivers who indicated utilising less for

travelling to the hospital elaborated that they had not been to the hospital in a long time thus, the bus fare was cheaper back then. Caregivers who used the bigger amount have been to the hospital this year or a few years ago. The other specified, 6% of patients, were caregivers who utilised private transport to get to the hospital.

In relation to the caregivers, all initial medical assistance was paid for by caregivers, however, for second trips to the hospital for MHD patients, the taxi fare is taken from the disability grant to cover both the patient and caregiver. If the grant was utilised for other household necessities, the fare may come from the caregiver or other household sources of income. As shown in Table 5.24, the caregiver paid solely for all travelling costs in more than half (55%) of the cases. These were often unplanned and led the caregiver to borrow money where necessary. The remaining 34% of caregivers who travelled with patients stated that the fees were not paid by caregiver. Reasons for patients not receiving psychiatric evaluation are provided below:

Variables	Total (n=35)
Reason for patients not receiving psychiatric evaluation	
Very difficult to get patient to travel with caregiver	6%
Patient does not want to be evaluated	3%
Negative experience with medical staff	8%
Stubbornness of patients	3%
Not applicable (no psychiatric evaluation)	80%

Table 5.25. Reason for patient not receiving psychiatric evaluation

Table 5.25 illustrates the different reasons for patients not receiving psychiatric evaluation. Out of the 20% of patients who do not receive a psychiatric evaluation, 8% had negative experiences. Clinic staff may reprimand patients for defaulting on medication, this leads to patients not wanting to return to the clinic. Six percent of patients are challenging to travel with, making travelling to the hospital extremely difficult. Hospitals are far from KwaXimba implying that caregivers and patients must take two or more modes of transport to reach the hospital. This can prove challenging for caregivers as patients may have symptoms which lead to a lack of public decency. Patients and caregivers dealing with MHDs in rural areas face more challenges in accessing MHC as rural areas lack psychiatric services (Murray and Keller, 1991; Gale and Lambert, 2006; Yellowlees et al., 2008; Saraceno et al., 2007; Shah et al., 2009; Smalley et al., 2010; Willcox et al., 2015; Hoeft et al., 2018; Hughes et al., 2019). Therefore, caregivers prefer to avoid travelling with the patient. Three percent of patients do not want to be evaluated, while another 3% remain stubborn. Caregivers complained that patients are very stubborn and will only do what they want and when they want to do it.

Caregivers who have never gone for a psychiatric evaluation for their patients had reasons for not taking patients, such as never considering such. None of the caregivers had tried to take the patient to a specialist to evaluate the patient. This could be linked to affordability issues, specialists are often expensive and therefore not an option for rural caregivers. Therefore, caregivers take patients to the local clinic and sometimes are transferred to the local clinic. Since, it is the local clinic only transport fees are incurred. Caregivers mentioned that hospitals might request for a R30 fee for registering and make the health card for the patient at the hospital, except for caregivers who are collecting pension. However, this is the only fee paid at the hospital.

5.11. Access to rehabilitation programmes

Variables	Total (n=35)
Awareness about rehabilitation	
Yes	94%
No	6%
Awareness about rehabilitation made by	
Local clinic staff	3%
Relative or friend	3%
General knowledge within community	94%
Available rehabilitation program	
Yes	97%
No	3%
Accessible rehabilitation program	
Yes	3%
No	97%

Table 5.26. Awareness, availability and accessibility of rehabilitation

All caregivers were aware of rehabilitation institutions. However, from Table 5.26, 94% of caregivers were aware of and understood rehabilitation. Caregivers indicated that they are aware of the numerous psychiatric facilities in PMB and the possibility of the patient getting rehabilitated. However, the understanding of caregivers when it comes to MHDs differs concerning rehabilitation. Some caregivers were utterly unaware that patients could get rehabilitated, reintegrated into their communities and be able to work. For instance, caregivers were particularly unaware that rehabilitation could occur within their communities. This indicates the absence of collaboration between MHC services and caregivers. Patel (2015), however, argued that collaboration between caregivers and MHC services was vital for improved and effective treatment of patients. There are no rehabilitation programs in KwaXimba for patients with MHDs, therefore, no community rehabilitation plans are in place.

Caregivers understood rehabilitation in terms of mental health facilities which detained patients. A total of 6% of caregivers were unaware of rehabilitation or that the patient could get rehabilitated, reintegrated and be completely independent of care. Some caregivers firmly believed that patients could never get rehabilitated and reintegrated however, MHD symptoms could decrease.

From Table 5.26, 94% included general knowledge in the community. Therefore, caregivers could not pinpoint who precisely informed them as this was regarded as standard and general information within the community. According to caregivers' information about rehabilitation facilities was common, and everyone knew of rehabilitation. However, there is a significant barrier to understanding rehabilitation among caregivers. Caregivers would mention awareness of mental health institutions in PMB but not recognise such institutions as MHC facilities for the rehabilitation of patients. These institutions were perceived merely for the detainment of patients with SMHDs. This explains the 6% of caregivers who were unaware of rehabilitation (refer to Table 5.26) but had knowledge of the mental institutions.

Local clinic staff informed 3% of caregivers about rehabilitation, and relatives or friends informed another 3%. The caregivers displayed a lack of knowledge about rehabilitation. Caregivers were under the impression that rehabilitation (decreasing symptoms) took place within institutions, as patients could be forced to take medication while having access to health workers all the time. Community rehabilitation programs were a foreign concept to caregivers in KwaXimba. Caregivers acknowledge that patients could be in a much better condition due to medication adherence, where symptoms would decrease to a minimum or cease. However, patients being involved in programs that may prepare them for employment was new information. Another area for improvement was the strong belief of caregivers that patients would not reach that stage where they could be employable. Past experiences of caregivers and others around them had instilled in caregivers the belief that MHDs are a permanent state where the patient cannot be reintegrated into the community.

Caregivers stated they had never been exposed to such programs, and despite being doubtful, caregivers stated they would be willing to put their patients through such community programs. According to caregivers, the most common form of rehabilitation was that of psychiatric institutions in PMB. All caregivers were aware that patients could be taken to live in these institutions.

However, caregivers believed the worst cases of MHD patients went there (SMHDs). The understanding of rehabilitation for caregivers was very minimal. Caregivers acknowledged that patients would receive medication within these institutions, not to rehabilitate and reintegrate patients back into their communities but to keep them under control. Rehabilitation aims to enable patients to live a fulfilling life by engaging physically, socially, emotionally and most intellectually with everything around them (Chaturvedi, 2020).

There are a few rehabilitation facilities in PMB that caregivers were aware of. These are mental health institutions. As illustrated in Table 5.26, approximately 97% of caregivers stated that there is an available rehabilitation facility in PMB. However, there are no institutions within KwaXimba. There are also no known programs, or community rehabilitation plans that caregivers were aware of. Three percent of caregivers did not know about available rehabilitation programs.

From Table 5.26, most caregivers argued that the PMB mental health rehabilitation facility is not accessible (97%). The application process for patients to be accepted at the institution is very complicated and lengthy. Caregivers indicated that they had knowledge of this strenuous application process and did not attempt, as many have been turned down.

“They only take those who are really sick.” (November 2022, Participant 5)

Caregivers elaborated that such facilities are recognised in the community but are strongly associated with SMHDs. These were perceived to be for patients who were a danger to the community, their households or themselves. Only 3% of caregivers indicated that the rehabilitation facilities in PMB are accessible. This is due to the caregiver having applied, and the patient was accepted to stay in the institution. The Table 5.27 below shows patient rehabilitation involvement:

Variables	Total (n=35)
Patient involvement in rehabilitation program	
Yes	3%
No	97%
Patient Rehabilitation program location	
In a psychiatric facility	3%
Not applicable (never involved in rehabilitation)	97%
Patient Rehabilitation program duration	
1-6 moths	3%
Not applicable (never involved in rehabilitation)	97%

Outcome of engagement with rehabilitation program	
Patient was able to understand simple instruction	3%
Not applicable (never involved in rehabilitation)	97%

Table 5.27. Patient involvement with rehabilitation

From Table 5.27, it is evident that the majority (97%) of patients were never involved with any rehabilitation programs. Only 3% of patients have been involved or part of a rehabilitation program.

The 3%, depicted in Table 5.27, of patients who have been part of rehabilitation by staying in mental health institutions were those of severe cases. Caregivers elaborated that the patient was getting worse, and the patient's state was deteriorating rapidly; hence the household and caregiver decided to send the patient to the mental health institution. The caregiver had applied and underwent the acceptance process, after which the patient was admitted. The process, however, is lengthy, and at the end, the patient is also examined to see if the patient meets the requirements to be accepted into the facility.

Table 5.27 shows that only 3% of patients had been in the mental institution, and this was for a duration of 1 to 6 months. The patient, however, was released from this institution shortly after their admission. Caregivers elaborated that the institution stated that the patient was getting rehabilitated and was ready to complete their rehabilitation in their community. The patient, therefore, spent approximately six months within the institution and was then released to complete their rehabilitation program within their community. Patients, however, only continued to take medication for a while and then defaulted to taking them back to worsening symptoms of the MHD. Caregivers elaborated that strict instructions are provided that patients should continue to take medication correctly, however, once patients are back in their communities' caregivers struggle to keep patients adhering to medication.

Caregivers noted that symptoms had decreased drastically upon the patient's arrival (3%, as shown in Table 5.27). The patient was able to communicate and understand simple instructions. The patient's state had improved drastically (3%) as shown in Table 5.27 and the patient was not violent or talking to themselves. The patient, however, did not adhere to the medication as prescribed a few months after their release from the institution. This led to a deteriorating state of the patient. In addition, the caregiver mentioned that the patient received negative comments from community members, such as being called crazy. This discouraged the patient from adhering to medication. Community members were aware that the patient had been in the

mental health facility and brought that up in conversations when the patient was around. There were recreational and community activities that the patient could still engage with in KwaXimba community, and that information is provided below:

Variables	Total (n=35)
Availability of recreational activities	
Yes	66%
No	34%
Recreational activities patient engages in	
Sport	9%
Shopping	26%
Going to church	11%
Not applicable (not engaging in recreation)	54%
Availability of community activities	
Yes	63%
No	37%
Community activity patient engages in	
Cultural gatherings	46%
Going to church	17%
Not applicable (not engaging in community activity)	37%

Table 5.28. Availability of recreational and community activities

There are no recreational activities in KwaXimba designated for patients with MHDs. However, patients engage in recreational within the community, usually with the supervision of caregivers. As illustrated in Table 5.28, 66% of caregivers had engaged in recreational activities with patients or patients engaged with the activities independently. However, 34% of caregivers stated that there were no recreational activities for patients with MHD or which patients could engage with.

Engagement with recreational activities of patients was done through going to town or sports. From Table 5.28, it is evident that 26% of caregivers travel to town with patients, usually for grocery shopping for the household. Caregivers do their shopping or monthly groceries with patients whenever necessary. Caregivers indicated that during these trips, caregivers usually get something to eat at any restaurant in town (for example Kentucky Fried Chicken (KFC)) with patients. Caregivers go to different stores with patients in Pinetown, sometimes to buy clothes for themselves or the patient. Eleven percent of the caregivers mentioned going to the beach with patients who remain under their supervision whilst swimming. Some caregivers

attend church with patients. Which serves as a recreational activity for both patients and caregivers.

Nine percent of caregivers stated that patients could watch soccer games in the community. One of the caregivers elaborated that the patient had been playing for a football team at some point.

There are no community activities designated for patients with MHDs in KwaXimba. However, 63% of caregivers elaborated that patients engage with regular community activities as everybody else. The remaining 37% of patients do not engage in any community activities. This may be due to a lack of interest from the patients, absence of community activities for patients and stigma associated with MHD hence discrimination of patients when engaging with ordinary community activities.

Cultural gatherings are common in KwaXimba occurring at least once a month. As illustrated in Table 5.28, 46% of caregivers stated that patients attend cultural gatherings. This could be a cultural gathering in which the entire household was invited to. The patient then goes to the gathering with other household members. In some cases, patients go to community cultural gatherings on their own. In most gatherings, the patients are treated humanely, with or without their household members. Patients are served food and allowed to sit and drink like other community members. For patients who isolate themselves in these gatherings, food is brought to them, and then they are left alone. This indicates that community is familiar with people who suffer from MHDs. As such, patients are welcome in gatherings and treated as community members and guests, hence they are provisioned with food and drinks.

Caregivers who chose the other indicated that they sometimes go to church with patients, which would be regarded as a community activity. Community members meet up in church for spiritual purposes, promoting socialisation. Patients who do not attend cultural gatherings usually stay home and prefer being alone or with their household members. Caregivers also pointed out that sometimes they do not want patients to attend these (unless they are related) due to past negative experiences within the community.

“The patient does attend gatherings, but I prefer for her to go to gatherings within our family or those of relatives.” (November 2022, Participant 1)

“The patient attends cultural gatherings whenever he feels like, invited or not.” (November 2022, Participant 10)

Another 17% of caregivers attend church with patients. Patients are also welcome and treated with the understanding of the MHD within their communities. MHDs are understood as the possession of evil spirits within the church, which need to be cast out of the patient.

NGOs frequently provide different types of assistance to surrounding communities. The table below presents data on NGOs in KwaXimba:

Variables	Total (n=35)
NGOs in community	
Yes	9%
No	91%
Assistance from NGOs	
Yes	23%
No	77%
Form of assistance from NGO	
Food parcels and clothing	23%
Not applicable (no assistance)	77%

Table 5.29. Presence and assistance of NGOs within the community

“There are organisations which help the community, but I am unsure if they are NGOs, sometimes providing food and clothes for the poor.” (December 2022, Participant 1)

As shown in Table 5.29, 91% of caregivers did not know NGOs within KwaXimba. The uncertainty of caregivers about the presence of NGOs could indicate two issues. One is that there are no NGOs in the community, and two is that existing NGOs are not active or assisting the community. This is a challenge for caregivers as NGOs have been known to provide aid and help ease the burden for caregivers in other areas (Lund et al., 2013). The deinstitutionalisation of patients with MHDs requires them to be monitored closely within their communities (Robertson and Makgoba, 2018) with the assistance of NGOs. The working together of MHC and NGOs is important to avoid another tragedy, such as the Isidimeni tragedy, where 144 patients died after being sent back to their communities (IDurojaye, and Agaba, 2018; Kabagambe, 2019). This tragedy resulted from patients being sent back into communities without the necessary support structures in place, such as NGOs. Closely monitoring patients in communities requires caregivers, health workers and NGOs to work together. The absence of NGOs in KwaXimba presents a problem for patients who might be discharged from the mental facilities in PMB. Only 9% of caregivers had knowledge of existing NGOs.

Caregivers have received assistance but were unsure if these were from an NGO or random groups of people who help in the community, often, this assistance was not specifically for the patient but for poor households. From Table 5.29, 77% of caregivers had yet to receive any form of assistance from NGOs in KwaXimba. Only 23% of caregivers had received assistance however, this was due to households falling under the poor within the community and not because households had patients with MHDs.

“There are also a group of white people who sometimes call those who are poor to come and take food parcels, especially around Christmas time.” (December 2022, Participant 1)

In other countries, NGOs have been very helpful to caregivers. BasicNeeds in Ghana, Kenya, Tanzania and Uganda and other community-based rehabilitation (CBR) has assisted caregivers while trying to alleviate poverty for households with patients suffering from MHDs (Raja et al., 2012; Lund et al., 2013; Asher et al., 2016; Tirfessa et al., 2019). The absence of NGOs assisting caregivers in KwaXimba indicates that the burden of caregiving is carried by caregivers solely on their own without any assistance. From Table 5.29, it is evident that most of the caregivers (77%) did not receive any form of assistance from NGOs. For caregivers who received assistance from NGOs (23%), it was clothing and food parcels for poor households.

In addition, caregivers, getting patients into the mental facility is nearly impossible. Mental facilities are known to take the worst cases of MHDs. Only 6% of caregivers had tried to put their patients in mental facilities, and 3% succeeded. Other caregivers did not try sending their patients to rehabilitation facilities. This was influenced by common beliefs that patients are mistreated in such facilities. This was a common comment from caregivers. Caregivers only spoke of the difficulties in enrolling patients into mental health facilities when asked about the lack of rehabilitation. This is due to caregivers not knowing about community-based rehabilitation programs.

5.12. COVID-19 impacts

Variables	Total (n=35)
COVID-19 has impacted patient	
Yes	11%
No	89%
Ways of COVID-19 impacts patient	
Lockdown imposed caused frustration on patient	11%
Not applicable	89%
COVID-19 impact on caregiver	
Yes	51%

No	49%
Ways of COVID-19 impacts caregiver	
Loss of income due to lockdown	3%
Disruption of normal household routines	3%
Had to manage household while providing care for the patient	3%
Became stressed due to uncertainty of living	20%
Bans on travelling, wearing of masks, controlled numbers of people in spaces and operating hours of offices	22%
Not applicable (no COVID-19 impact)	49%

Table 5.30. COVID-19 impact on patient

COVID-19 did not have a significant impact on patients. This may be due to patients spending the majority of their time in the local area of KwaXimba or within their home. As illustrated in Table 5.30, 89% of patients were unaffected or impacted by COVID-19. Only 11% of patients were impacted by COVID-19, mostly due to lockdown and restrictions.

From Table 5.30, it is shown that COVID-19 did not impact 89% of patients. Patients are unemployed and do not travel frequently, therefore, the lockdown restrictions on unnecessary travelling did not affect patients. Patients do not travel into areas or spaces which require the wearing of face masks. As such, the lockdown and COVID-19 restrictions did not impact patients. For patients who happen to travel, they seemed annoyed due to wearing masks when going into social spaces. Patients often wander around the community and continue to do so during the lockdown.

Only 11% of patients were affected by COVID-19, these effects were due to the lockdown restrictions. The expected effect was that of the closure of the selling of alcohol. Some of the patients spend their days in local shops and spazas, the closure of many shops and local shebeens meant patients have nowhere else to be besides their homes. This led to patients' frustration, which led to the whole household's frustration. Some patients also like to wander around, the absence of people in social spaces led to confusion and frustration, particularly when patients were chased away from public spaces.

Table 5.30 shows that more than half of the caregivers (51%) were impacted by COVID-19. Caregivers experienced the impacts of COVID-19 primarily when caregivers had to travel or engage in activities outside of their homes. In the initial lockdown, caregivers indicated that the SA army forces were seen patrolling the streets of KwaXimba ensuring that people were in their homes and not roaming the streets. It became an issue for caregivers who were mainly at home when they needed to go to the community gardens and church gatherings. As no one was

allowed to be engaged in unnecessary travelling even within their communities. Other caregivers were not impacted by COVID-19 (49%). Caregivers unaffected by COVID-19 were primarily unemployed and spent most of their time at home.

From Table 5.30, it is evident that the majority of the caregivers were not impacted by COVID-19 (49%). Many caregivers are unemployed, meaning the unnecessary travel ban did not affect caregivers. Twenty-three percent of caregivers were affected by COVID-19 regulations. Caregivers would only take short trips within KwaXimba. These trips included clinic visits, community gardens, church gatherings and going to the local shops, predominantly done by children from the household. The COVID-19 pandemic, however, did make even the short trips tedious due to things like social distancing and a limited number of people being allowed in at a time in places such as the local clinic or places of worship.

Caregivers mentioned that this tedious process was not an issue for the local clinic solely, going grocery shopping also became a challenge. The main issue mentioned was long queues outside food stores. Caregivers elaborated that when going to Pinetown or PMB to purchase food, new processes were being followed. Food stores allowed a limited number of people inside, leading to long queues outside the stores. This meant caregivers could be standing in this line for hours specifically because caregivers usually do food and groceries around the same time after collecting disability grants.

Caregivers added that the lockdown meant that most household members were at home all the time. This led to frustration due to several issues. Food got depleted quicker, especially as children were not attending school. Simple issues such as which TV programme to watch could lead to a disagreement.

“Having all household members at the house all day every day also became a challenge, the groceries finished up quicker than the normal time, children for one eat so many times in one day.” (December 2022, Participant 1)

Caregivers stated that household members were often home daily due to the lockdown. This meant that household resources were increasingly used more hence the groceries were getting depleted quicker than usual. Children, for example, are at school for most of the day and only return home in the afternoon to eat, do their homework and go to bed. Due to the lockdown, children were at home all day, eating as many as five times a day. Groceries getting finished earlier meant that caregivers or heads of households had to acquire additional money to purchase more food before the household source of income arrived. By the time the grant or

additional source of income arrived, caregivers already had a debt to pay. The income was therefore decreased before even attempting to cover household financial expenses. A total of 20% of caregivers became stressed due to the uncertainty related to the COVID 19 pandemic. Caregivers argued that their stress levels, therefore, increased due to debt accumulation and food insecurity within households. This was particularly difficult for caregivers to control as patients and children often need to understand that household resources are getting overused, leading to insufficiency.

Loss of income from selling beadwork in Durban impacted 3% of caregivers. Another 3% was impacted as patient care increased due to increased time spent at home by patients. Lastly, another 3% was impacted as household routines changed. More household members were at home for extended periods of time, leading to a few issues, some of which are mentioned above.

Caregivers indicated that in some cases, it seemed like the patient's symptoms were deteriorating. Patients would have outbursts more frequently, and misunderstandings leading to arguments or conflicts.

During the pandemic SASSA provided a relief grant for South Africans up to the amount of R350, data pertaining to this grant is provided in the Table 5.31 below:

Variables	Total (n=35)
Received relief grant	
Yes	49%
No	51%
Reasons for caregivers not receiving the relief grant	
Disqualified due to employment	11%
Disqualified due to other grants	28%
Grant pending for months	3%
Did not get approved	9%
Not applicable (receives grant)	49%
Relief grant benefits	
Has become an extra source of income	34%
Assists in buying household groceries	14%
Not applicable (does not receive grant)	51%

Table 5.31. Patient received relief grant

The SA government introduced the relief grant at the commencement of the lockdown to assist South Africans as restrictions were introduced (SONA, 2020). The relief grant was designed

to assist South Africans financially as people could not work, trade or engage in income-generating activities which required people to travel or be outside their homes. The relief grant could be collected by the unemployed and people living in poverty. As illustrated in Table 5.31, 49% of caregivers received the relief grant, while 51% did not. The grant was R350 for each individual. It is important to note that in addition to the relief grant, which most South Africans could apply for, all other grants received additional funds for six months of the lockdown restrictions. Therefore, all people collecting any grant in SA received this grant (SONA, 2020). Caregivers indicated that they did receive these additional amounts with the disability grant, pension and child welfare grant.

Approximately 49% of caregivers received the relief grant. All South African citizens could apply for the relief grant, but a criterion specified people who could and those who could not obtain the grant. Many caregivers did not collect the grant as they were already collecting other grants (28%). An amount of up to R400 was added to all grants during the initial lockdown in SA. Only people who were not collecting any grants were approved for the relief grant. According to caregivers, if you have an income, SASSA could identify and disqualify you, therefore, 11% of caregivers did not obtain the grant due to employment. Some caregivers applied and were declined for differing reasons (9%). In contrast, the other caregivers declined (3%), while for others, the grant would be pending for months (3%) respectively. Some caregivers elaborated that they did not apply for the relief grant as they knew they would not get approved according to the criterion (3%). Other caregivers indicated they applied, but their applications were declined (6%). The status of the application could be checked on a phone with access to the internet.

As depicted in Table 5.31, the relief grant became an additional source of income for their households (34%). This money could be used within the household to cover any expenses arising or added towards ordinary household expenses. Other caregivers (14%) specified that the money was used to buy household groceries, contributing to food. This grant therefore assisted in different household expenses, relieving some of the financial stress on households. Access to services was also affected during the COVID-19 pandemic and lockdown measures. Below is data on access to services:

Variables	Total (n=35)
Access to social services during COVID	
Yes	77%
No	23%

Challenges experienced due to COVID	
Yes	71%
No	29%

Table 5.32. Access to services during COVID-19 lockdown

From Table 5.32, it can be deduced that 77% of the caregivers faced challenges in accessing social services during the COVID-19 lockdown. The caregivers mentioned that access to some restrictions. According to caregivers, access to health care services became a challenge. Furthermore, caregivers complained about the process followed in local clinics.

“During the lockdown, going to fetch medication or just going to the local clinic became a tedious process. From registration at the gate, masks, sanitising frequently, queues outside the clinic, filling in forms to waiting outside for long as the clinic only allowed a certain number of people inside at a time.” (November 2022, Participant 6)

Caregivers indicated that clinic visits became tedious and time-consuming. The processes being followed due to COVID-19 restrictions led to increased time spent at the local clinic. This meant caregivers could not engage in other activities as more time was spent at the local clinic. Moreover, the caregiver was away from home for a longer duration than normal.

Another challenge was going to the SASSA offices. The change in routine and SASSA processes became a challenge for caregivers.

“COVID changed everything; even SASSA changed how they worked; different days were set for different groups of people. I once travelled to their offices only to be told that this was not the day for disability grants, and I must come back another day.” (November 2022, Participant 33)

According to caregivers, disability grants did not require renewal for some time, as the government extended all grants during the lockdown's initial stages. Patients continued to receive grants until restrictions were eased. However, this was when the SASSA offices dedicated different days to different groups of grant collectors. For instance, Monday and Tuesday are specifically for social grants, pensions and disability grants also have different days. Caregivers indicated that this knowledge was often discovered once they arrived with patients at the SASSA offices. This was a challenge because caregivers often did not have money set aside for return trips, and being told to come back another day became a challenge for them. In cases where caregivers had the money, it was used up in the first trip, and then

caregivers had to borrow money for the second trip on the correct day. Only 23% of caregivers stated that there were no challenges in accessing social services.

Table 5.32 shows that 71% of the caregivers experienced challenges due to COVID-19, while 29% of the caregivers indicated that COVID-19 has not directly impacted them. This is due to caregivers being unemployed and always at their household. Therefore, restrictions on travelling and social spaces such as restaurants did not impact them. Caregivers mentioned that many community activities, such as going to the temple or church, were restricted. Community cultural gatherings were also restricted. The worst, according to caregivers, was that of funerals. As the night vigils were banned, caregivers complained that many of their loved ones were buried without them being present. These were dear friends, sisters or aunts who lived far away from them.

The caregivers perceived that meeting with other people for instance in the church assisted them a lot. Caregivers perceived that at church they felt at ease and were revived. Caregivers elaborated that this helped them a lot even when going through difficult situations, the church was a place in which they could vent or just gain hope by listening to others preach. According to caregivers, grant renewals were put on hold during the lockdown. All grants continued until the restrictions eased. As such, caregivers were not required to travel to hospitals for psychiatric health care services. Therefore, access to psychiatric services was not disturbed in any way. Other caregivers do not receive psychiatric services, and this question was inapplicable to them.

5.13. Suggestions

Variables	Total (n=35)
Suggestions	
Special disability services	54%
School for the disabled	6%
Injections	23%
Active health care workers	11%
Collaboration between traditional and health care	6%

Table 5.33. Suggestions

Caregivers suggested that the government find should innovative ways to make applying for a disability grant easier. Caregivers suggested that this can be achieved through special disability services being made available (54%). Caregivers mentioned how they had struggled to acquire identification documents for some of the patients thus, would like the Department of Home

Affairs to allow them to get these documents without standing in these long queues. The department of Home Affairs comes to provide their services to the KwaXimba community. However, their primary focus is on learners in grade 12. Also, caregivers would like the department of Home Affairs to prioritise themselves and their patients. The reason being with the assistance from social workers, it is possible to acquire the required documents for patients efficiently.

“Offices where patients can receive help easier such as Identification Documents or even applying for the SASSA grant as it is often hard to travel with the patient using public transport.” (November 2022, Participant 12)

Offices which provide assistance to the public should have special access for those with disabilities. It should be a quicker process to obtain documents for those with disabilities. Another 23% of caregivers stated that regular injections should be made available for patients, as the injections keep patients calm and in an improved state. In addition, caregivers stated that they wish the mental health staff could provide injections for patients, which help keep the patients at home and not wander around. Caregivers mentioned how it remains challenging for patients to adhere and not default from taking their medication.

“Government can come up with an injection as a medication because patients default a lot and get worse; it is hard to convince them to take medication.” (November 2022, Participant 15)

Caregivers stated that the community health workers should be helping them at the household level and provide regular check-ups (11%).

A local school for special needs children should be available for learners with disabilities (6%). Caregivers mentioned how it remains challenging for patients to adhere and not default from taking their medication. Caregivers stated that they wish the mental health staff could provide injections for patients, which help keep the patients at home and not wander around.

Medical health practitioners should let patients use traditional medicines alongside their medicines (6%), in most cases, patients are told to stop with traditional medicines and focus solely on western medicines. Professional staff should also encourage patients to seek traditional assistance because traditional practitioners do encourage patients and their families to seek medical care, specifically if the patient is not improving with traditional methods.

The caregivers had few recommendations. This is due to limited education, limited understanding of MHDs medically, and caregivers succumbing to living under poverty with

little to no opportunities for development. For KwaXimba, caregivers living with patients who are never rehabilitated has become normal. Therefore, caregivers do not see the need for more MHC services. Caregivers also seemed hesitant to believe that patients can be rehabilitated and reintegrated into their communities.

5.14. Interview with key informant

An interview was conducted with the king of KwaXimba. The king was the key informant for this research. King Mlaba is a community resident. The role of the king is to lead the people by maintaining or ensuring peaceful living within the community (King Mlaba, 2022).

5.14.1. Role of the king

The king is responsible for the people. The king serves as the high court of the area, where any disputes can be resolved. The king prioritises the community's welfare, ensuring community members live in harmony with one another. Land allocations are also conducted by the king. If anyone wants land in KwaXimba, they have to request land from the king. If community members have disputes or disagreements, a case can be lodged with izinduna. If the case cannot be resolved, it then proceeds to the king's court. The king, however, does not deal with disputes or crimes involving blood or killing. Such issues must be reported to the police. The king must be informed if someone wants to start any community development initiatives. All other projects in relation to the community development (sport programme, pre-school) or business ventures (hardware store, park) a request must be sent to the king.

5.14.2. Community characteristics

KwaXimba used to be a very rural area, after many people moved here from KwaNyavu it started becoming more and more populated. Today it is like a village, and it is such a large community. The king elaborated that this beautiful and fertile land enables the people to rear livestock and engage in farming.

5.14.3. Access to health care

KwaXimba has a local clinic which is understaffed. Over the years, community members have continuously complained about the poor service offered at the clinic. Upon consultation with nursing staff from the clinic, the nurses raised the issue of being understaffed. This is exacerbated by that some of the nurses from the clinic are taken to the children's clinic in Bhobhonono. Community members have mentioned that they sometimes travel to the clinic in KwaNyavu under king Mdluli. This is a neighbouring community; the clinic is in number 2. As such, the area lacks health care services. Nurses have elaborated that community members

often fail to understand that there are different types of health care workers who perform different duties. Community members expect all health staff at the clinic to assist without understanding roles and responsibilities. Nurse responsibilities however are different depending on the type of qualification each nurse has obtained. As such the community lack health care human resources.

5.14.4. Access to MHC

The issue of MHD has been acknowledged for a long time. According to the king, people develop MHDs, and the community continues to live with them. The king also acknowledged a few available mental health facilities in PMB to which caregivers send their patients too. MHDs are not a common issue in KwaXimba, however people understand the illness as it has existed within the community.

“There is a local clinic in KwaXimba with professional health care workers, we also have a variety of traditional healers, and there are MHC facilities in Pietermaritzburg which is close to us.” (King Mlaba, December 2022).

As such it depends on the family in terms of which route, they wish to take in helping their sick family member. However, there are places people can go to acquire help for MHDs. The king of KwaXimba, shares similar beliefs and perceptions than that of caregivers. These beliefs link the causes of MHDs to supernatural or spiritual factors. The mentioning of traditional healers when dealing with MHDs indicates a belief in that MHDs can be treated with traditional methods. This is associated with beliefs that there is a traditional or cultural causation behind the MHD.

Some people just randomly become sick with the MHDs, for others, it is a hereditary illness and for others its linked to their spiritual issues. Responses from the king seemed to resemble those of caregivers in terms of linking MHDs to spirituality. Traditional beliefs pertaining to MHDs remain consistent in KwaXimba, despite the acknowledgement of MHDs needing medical attention.

The king recognises the need for services specifically tailored for the disabled within the community and acknowledges that such services are lacking. The king stated that there are no services available in KwaXimba, for patients suffering from MHDs besides the local clinic which offers all health care services. The only facilities available are the mental institution in a nearby town which is PMB. These include the Town Hill Mental Hospital, Pietermaritzburg Mental Health Society, Fort Napier Hospital to mention a few. According to the king families

from KwaXimba, can take their patients to these institutions if the need arises. In addition, the king mentioned how all services do not discriminate and are accessible to all community members.

There are community health workers employed by the community of KwaXimba who are responsible for looking after the unwell in this community. Such community workers are required to go from house to house, providing assistance with any household issue. Community health workers are therefore expected to also assist caregivers with whatever assistance they may require. Community health workers should have knowledge of which houses have patients who require caregiving.

Every year the Department of Home Affairs comes to KwaXimba, to assist people with identity documents. This program can be extended to provide assistance to caregivers where they have a day specifically for them, or the workers can go to households with patients with disabilities. Caregivers of patients with MHDs can also receive special attention in the local clinic.

The king acknowledges the presence of numerous NGOs within the community. However, none of these NGOs are focusing on patients with MHDs. The king added that there are community gardens which have received donations from NGOs within the community. For instance, such groups have been provided with fencing material for community gardens. Such groups then request land from the king to start these community gardens. Tractors have been provided to help those groups initiate their community gardens. The king added that there are other NGOs within the community of KwaXimba, but their impact on the community is unknown.

The king perceives that there are no special need schools in KwaXimba. There are no opportunities or programs tailored for patients with MHDs in the community. However, patients can engage with other community programs as they wish.

There are no community programs aimed at helping patients with MHDs, either with rehabilitation or just assistance. Rehabilitation is only offered in PMB institutions. Patients can collect medication from the local clinic to help relieve them of their symptoms of the MHDs. Patients therefore have two services available to them, which is the local clinic and the community health care workers. According to the king, rehabilitation occurs within institutions where patients are provided with all the support and released once they are rehabilitated. The king displayed a lack of knowledge in terms of rehabilitation of patients. The king believed

that patients could be rehabilitated within the institutions and did not have knowledge of community rehabilitation. There should be programs within the community to assist patients once they are out of the mental institutions. The king shared a similar perception with caregivers in regard to rehabilitation occurring adequately within mental institutions.

The spirit of Ubuntu is common in African communities. From the king's the spirit of Ubuntu still exists in KwaXimba. The king states that there are instances where communities still support each other in times of need. For instance, men still proceed to dig graves for households with deceased persons. People still come together to support each other in happy and difficult times. According to the king, the people of KwaXimba, coexist with patients who have MHDs peacefully within the community. This is a symbol of Ubuntu as discrimination is minimal towards patients. The king believes that it is the same spirit of Ubuntu, which can be used to educate people about MHDs and inform them about community programs. Ubuntu can also be used as a tool against stigma and discrimination within the community to decrease negative connotations linked to MHDs.

5.15. Chapter summary

All data collected in KwaXimba, from caregivers for patients with MHDs has been presented, analysed and discussed in this chapter. The results indicate that the community lacks MHC services. The area has two clinics, none of which can diagnose and prescribe for patients with MHDs. Patients and caregivers are transferred to the nearest hospital for complete diagnosis and prescription of appropriate medication. There are no rehabilitation programs in the area or activities designated for patients. The three types of assistance available to caregivers and patients are medication from the local clinic, community health care workers and the SASSA disability grant. Strong beliefs of MHDs being caused by evil spirits or cultural factors influence the preferred method of help for caregivers. Most caregivers chose the cultural or traditional route in seeking help. There is a lack of understanding among caregivers about rehabilitation and the reintegration of patients into the community post-MHDs.

Chapter 6 Summary, Recommendations and Conclusion.

6.1. Introduction

The previous chapter provided an analysis of the data collected from caregivers of patients with MHDs in KwaXimba, eThekweni Municipality, KZN. This research aimed to explore the awareness, knowledge and perceptions about mental health disorders, the challenges, and opportunities available for rural caregivers and to analyse accessibility and availability of MHC services for patients with mental health disorders and their caregivers in rural communities of KwaXimba. The data was collected through the administration of questionnaires to 35 caregivers and an interview with one key informant. The data has been analysed through SPSS version 28 and elaborated upon in the previous chapter. This chapter thus focuses on key findings. Thereafter, the key findings are summarised, reviewed through the literature and the conceptual framework. The research objectives are reintroduced to assess if they have been met. In addition, this chapter provides recommendations and concludes the entire research.

6.2. Summary of key findings

The key findings are presented below in relation to literature and research objectives.

6.2.1. To explore caregivers' perception on the causes of mental health disorders in patients within KwaXimba eThekweni Municipality, KZN.

Evil spirits are strongly believed to be the cause of MHDs in KwaXimba, (89%). Traditional beliefs which link MHDs to evil spirits are common in many non-western cultures (Razali et al., 1996; Patel et al., 1997; Sheikh and Furnham, 2000; Suhail, 2005; Ikwuka, 2021). KwaXimba is dominated by the Zulu people with strong beliefs in ancestors and spirituality. Ancestors (viewed as potent guardians of the living) are believed to provide protection, blessing and guidance (Mekoa, 2020). As such, indigenous people such as Zulus rely on traditional healers to provide explanations for tragedies, unfamiliar and unordinary events. Traditional healers provide clarification of tragedies, sudden or uncurable diseases and unexplainable events alongside guidance for which actions should be taken or which traditional practices should be conducted. Therefore, clarification of the root cause for MHDs is sought from traditional healers. Knowledge, experiences, and beliefs influence an individual's perception. Therefore, caregiver perceptions in KwaXimba are influenced by the Zulu culture, traditional beliefs, and experiences.

Evil spirits believed to be the underlying or root cause of MHDs are often from witchcraft or a form of punishment. In KwaXimba the most common spirits believed to cause MHDs were

izizwe (wondering spirits). Caregivers believed that wandering spirits were sent to the patient by an enemy or someone who envies the patient, hence the sudden sickness. However, there was a clear distinction between MHDs believed to be caused by spirituality and those caused by other factors, such as health-related issues. The caregivers perceived, sudden sickness with MHD indicates witchcraft. Witchcraft is believed to be a common cause of MHDs in non-western cultures (Razali et al., 1996; Patel et al., 1997; Sheikh and Furnham, 2000; Suhail, 2005; Ikwuka, 2021). In cases where the MHD was expected due to hereditary reasons or developed from a young age, causes were perceived as unrelated to witchcraft. MHDs are believed to be caused by the following in KwaXimba witchcraft (89%), normal sickness (63%), health issues (54%), being too intelligent (31%), trauma (31%), drug use (26%), something went wrong mentally (23%) and angry ancestors (6%).

Majority of the caregivers perceived MHDs as the result of witchcraft. This prominent belief in MHDs being caused by spirits does not solely focus on witchcraft but also on disobedience, neglect and ignorance of cultural practices leading to angry ancestors. Ancestors, however, are not regarded as evil but rather as guardians of those on earth whose fury is inflamed by human actions. Approximately 65% of caregivers indicated that MHDs are a sickness, and another 54% stated that they are a health issue which needs medical attention. Despite such high percentages of caregivers indicating that MHDs are caused by health factors, only 6% of the caregivers utilised health care as the initial step for treating patients with MHDs. The need to seek medical attention was not crucial to the majority of the caregivers in KwaXimba. Additionally, many of the patients do not consume medication, inclusive patients who have sought medical attention. This is due to patients defaulting or medical attention had never been sought. Caregivers mentioned that medication often led to decreased symptoms in patients, however, adherence to medication was minimal. This may indicate how caregiver perceptions have a strong influence on the use of medication.

The firm belief displayed by caregivers that patients can never get rehabilitated is supported primarily by caregiver efforts to treat MHDs traditionally without success. Caregivers have never been exposed to community-based rehabilitation programs, however, caregivers were adamant that patients cannot get rehabilitated and reintegrated back into their communities. Issues of mental health literacy exist, however, such statements from caregivers indicate that strong beliefs in traditional methods (which have not been successful) have led caregivers to perceive that no other methods can therefore achieve the rehabilitation of patients.

Furthermore, the need for medical attention is strongly associated with the application for the mental disability grant. Many caregivers went to the local clinic to apply for the mental disability grant rather than for health care reasons. Medical assistance was therefore often sought for the mental health disability grant rather than dealing with the MHD. Caregivers explained that a medical certificate is required pertaining to the mental disability grant. This is further confirmed by caregivers for not attending psychiatric evaluation for years until the caregiver needs to renew the disability grant. In addition, caregivers who have not renewed the disability grant in a long time, these patients have not been to the clinic for matters pertaining to MHD for many years. Despite medical attention being sought by caregivers in KwaXimba, adhering to medication is not prioritised which hinders its potential. This is largely attributed to the firm beliefs of MHDs being caused by spirituality.

Moreover, traditional methods were the most preferred method of dealing with MHDs, as 83% of caregivers' initial step was going to a *Sangoma* or *Inyanga*. A total of 60% of caregivers preferred taking patients to a *Sangoma*, while 23% preferred the *Inyanga*. Approximately, 85% of caregivers in KwaXimba, opt for the traditional method of dealing with MHDs. This could be linked to the 89% of caregivers who indicated the causation of MHDs could be spirituality. Only, 6% of caregivers preferred medical methods of taking patients to the clinic. Preferring to take patients to the clinic was often associated with hereditary cases of MHDs.

Delays in seeking medical attention for MHDs are linked to beliefs that MHDs are caused by evil spirits, which require adequate time to be dealt with traditionally. Furthermore, caregivers allocate a minimum of three months to several years before seeking medical attention. It is common for patients to delay seeking MHC services by up to three years (Ganasen et al. 2008; Wang et al., 2007; Spivak et al., 2018). This is due to the belief that traditional methods need to be provided with sufficient time before seeking another form of treatment. Seeking another form of treatment is often done after traditional methods fail to yield the desired results. The MHDs have progressed very much in the patient by this time, which makes it more challenging to treat. Saravanan et al. (2005) and Sorsdahl et al. (2013) conferred that caregivers who seek traditional methods usually delay seeking MHC services.

Caregiver perceptions shaped by culture, beliefs and experience influence preferred methods of treating MHDs, seeking medical attention, adherence to medication and the perceived potential of rehabilitation. The perceptions of caregivers are crucial to the rehabilitation of

patients due to caregivers being responsible for decision-making on utilised methods of treatment for patients.

6.2.2. To identify the socio-economic conditions of caregivers looking after patients with mental health disorders within KwaXimba eThekweni Municipality, KZN..

The caregiving role in KwaXimba was assumed mostly by women (94%). The majority of caregivers were above 46 years of age (77%), indicating the role is often assumed by the older generation. This might be due to time-consuming caregiving, leaving caregivers with limited time to socialise (Mall et al., 2017; Hailemariam et al., 2017). In KwaXimba 77% of caregivers were direct family members to patients. Caregiving is predominantly assumed by relatives or friends who provide care for patients with chronic or disabling conditions without the expectation of remuneration (Pearlin et al., 1990; Family Caregiver Alliance, 2006). A total of 77% of caregivers were heads of households. Majority of caregivers completed high school (46%), while 17% had preschool education to none. Almost half of the caregivers were single (46%), widows (28%) and married (20%). More than half of the caregivers were unemployed (54%), while 29% were pensioners. Put together, 83% of caregivers had no formal income besides the SASSA grant, indicating poor economic and living conditions.

Formally built housing (mostly rondavels) was common in KwaXimba (71%). The second most common type of dwelling was RDP houses (23%) and lastly, 6% lived in traditional houses. However, almost every household has an RDP house within the yard, which may not be considered the main dwelling but is utilised by household members. RDP houses are part of government strides to address the socio-spatial inequalities of the colonial era (Narsai et al., 2013; Mashwama et al., 2018; Thakur et al., 2019). Unemployed or households with a household income of less than R3500 monthly qualify for the RDP houses (Gryling, 2009; Mashwama et al., 2018). Significant households with RDP houses indicate that household income for the majority was below R3500 monthly when applying for the RDP houses. These households are considered low-income households. High unemployment compounded with the high dependence on grants as well as the significant presence of RDP houses within the community all indicate people experiencing poverty within KwaXimba.

In KwaXimba most households had more than seven members (69%). In 40% of the households, all household members were dependents implying that dependents made up most of the household members. This places even greater pressure on caregivers and heads of households, of whom more than half were unemployed. Unemployed South Africans often depend on SASSA grants (Modi et al., 2006). The highest household primary source of income

for caregivers was the mental disability grant (74%) followed by pension, which was 29%, wages were 23%, and remittances (17%). The mental disability grant is unique to SA, as access to such grants in other SSA countries remains limited (Mitra, 2010; Abdille and Mbataru, 2019). The mental disability grant is collected by 80% of caregivers, for 74% of which the disability grant is the main source of household income. Thus only 6% of those who collect the mental disability grant have alternate income regarded as the main source of household income.

In KwaXimba 66% of caregiver households lost an income due to the MHD. Caregivers frequently lose sources of income after the assumption of caregiving due to decreased time in income-generating activities (Addo et al., 2018). Frequently no changes were made to the household to accommodate the patient (31%). Changes could prove expensive, and households did not have the financial ability.

Approximately 86% of caregiver households in KwaXimba, utilise pit latrine toilets. Msweli and Ngobese (2013) stated that KZN continues to have limited access to water and sanitation. This could indicate the lack of availability of water in KwaXimba, and that most households are living in poverty or just above the poverty line. All caregivers were South African and utilised the isiZulu dialect. All caregivers indicated having access to key services such as water, electricity and health care. However, all these key services had challenges. Water was often unavailable, electricity led to load-shedding issues and theft and was not readily available for extended periods of time. Health care services was available and accessible at the local clinic for minor illnesses such as headaches, rash, stomach aches, flu and collecting of medication. For all other complicated illnesses, community members needed to travel to PMB, Catoridge and Pinetown to see a doctor or the nearest hospital. Half of the caregivers (50%) had health issues for which medication was collected from the local clinic.

Only 6% of caregivers utilised private vehicles accompanying patients for hospital appointments, indicating that the majority utilised public transport. Majority of the caregivers (94%) utilised public transport in the form of Quantum taxis from KwaXimba. This could be linked to issues of poverty in KwaXimba. High unemployment, dependence on SASSA grants, the high number of households qualifying for RDP houses, and lack of car ownership indicate that poverty is predominant. The use of pit latrines, water trucks carrying water and the use of various types of energy sources indicate minimal development and poor access to services, which are general characteristics of many rural areas in SA (Schatz et al., 2011).

6.2.3. To critically analyse caregiver perceptions about traditional beliefs, stigma, and the experiences of caregivers of patients suffering from mental health disabilities.

In KwaXimba MHDs are predominantly believed to be more than regular illnesses and usually have an underlying root cause. An overwhelmingly 89% of caregivers believed MHDs to be of spiritual causes, mostly associated with evil. Traditional beliefs strongly associate MHDs with evil spirits in many non-western cultures (Razali et al., 1996; Patel et al., 1997; Sheikh and Furnham, 2000; Suhail, 2005; Ikwuka, 2021). Caregivers thus seek a deeper understanding of the MHD from traditional healers. Omenyo (2006), Twumasi (1975) and Kpobi and Swartz (2018) also found that MHDs were strongly associated with evil spirits. This explains the high preference for traditional methods amongst caregivers.

Initial steps taken to seek diagnosis by caregivers included taking the patient to a *Sangoma* (49%) or to an *Inyanga* (31%). Therefore, the preferred method of initial steps is traditional for most caregivers (80%). *Sangoma*'s and *Izinyanga* are believed to provide explanations for underlying factors leading to MHDs. According to caregivers, the best way of dealing with MHDs was taking the patient to a *Sangoma* for treatment (60%) or the *Inyanga* (29%). Caregiver perceptions and beliefs influence the route taken in dealing with the MHD. Sodi et al. (2011) and Nortje et al. (2016) note that it is common for rural communities to prefer traditional methods when dealing with sickness. Thus, it is not surprising that the majority of caregivers of rural KwaXimba, prefer traditional methods for treating the MHD.

According to caregivers punishment for crime through MHDs is untreatable. This is done by an individual from whom items were stolen, usually by traditional healers of Indian descent. However, wandering spirits are treatable. Spirits can be forced to evacuate a patient's body leading to decreased or seizing symptoms of the MHD. A total of 71% of caregivers noticed an improvement in patients after traditional methods. Such a high percentage of caregivers noting improvement after seeking traditional methods encourages other caregivers also to seek traditional methods. High percentages of improvements also instil knowledge of traditional methods working and achieving desired improvements most of the time hence their continued preference and utilisation.

To acquire a better understanding of the perceptions of caregivers with regard to MHD causes, caregivers could choose more than one possible cause. As such, even caregivers whose patients had MHD due to health reasons continued to choose evil spirits as a cause. Thus, traditional beliefs of MHDs being caused by evil spirituality are mutual within the community. This indicates that in KwaXimba MHDs are still predominantly perceived as spiritual diseases

compared to health issue. Hence the preferred method is going to traditional healers who communicate with the spiritual world. Caregivers argued that even if the MHD patient does not get rehabilitated and reintegrated into their community, however, dealing with the root cause may prevent other family members from also developing the MHD.

For caregivers who recognised MHDs as a health issue, delays in seeking health care services were still common. Caregivers had experienced the MHD in their family or household, for which traditional and health care services were sought, achieving little to no improvement. Therefore, caregivers delayed in seeking any form of assistance for the patient. Additionally, caregivers elaborated that seeking treatment often proved costly. Caregivers lacked the understanding that MHDs could deteriorate if not treated promptly and appropriately. However, this was for minority of the patient as most of the caregivers sought traditional assistance for patients immediately.

Caregivers did not prioritise medical attention for patients with MHDs. The disregard for services in KwaXimba, could be due to varying factors. Firstly, the abundance of traditional healers within the community and in almost every African community. Caregivers preferred traditional healers not from KwaXimba, due to beliefs that households would not want their ‘business’ known to someone in close proximity. This also minimises the chance of other community members having knowledge of their consultation outcomes.

Same-day consultations with traditional healers were an added advantage. According to caregivers there was less waiting time in *Inyanga*’s or *Sangoma*’s home compared to the local clinic, and this was due the *Inyanga* having less patients to service. Another advantage was that patients at the traditional healer were more understanding of patients with MHDs. This indicates that discrimination and stigma were less prevalent in traditional settings when compared to western health care settings. Overcrowding of the local clinic was identified as a challenge towards accessing health care services. Overcrowding of local clinics is common in SA because most South Africans utilise public health care (Neelyand and Ponshunmugam, 2019). This could explain the low 6% of caregivers who went to the clinic to acquire assistance for the patient with the MHD. Rural clinic frequently provides health care services with limited resources, rendering their service provision poor (Saraceno et al., 2007; Peck et al., 2014; Burns and Tomita, 2015). Caregivers elaborated that going to the local clinic guaranteed a transfer to the nearest hospital for a complete diagnosis and prescription. In contrast, a complete diagnosis was provided by the traditional healer and medication was provided in one place. The time

spent by caregivers before seeking medical attention is another indication of health care service not being a priority for caregivers. Most of the caregivers waited for more than a year before seeking medical attention (34%), while 11% waited for more than two years, and 6% never sought any health care services. Delays in seeking health care services were associated with traditional methods requiring extended periods to work and should not be rushed. Delays in seeking health care services were due to extended periods in which caregivers still had hopes for improvement in patients after seeking traditional assistance. This indicates firm beliefs in traditional medicine for MHDs from caregivers.

MHC had disadvantages which discouraged caregivers. Negative connotations within the community linked to MHD medication led to mistrust and hesitation in patients. Caregivers struggle with patients to continuously take their medication, despite knowledge of medication decreasing symptoms. Caregivers, however, elaborated that even when patients take medication, impairments tend to continue. This is because MHDs require more than medication for complete rehabilitation and reintegration of patients into their communities. Collectively psychiatric evaluation, medication and rehabilitation produce the best results for MHDs (WHO, 2001; Government Gazette, 2002; Angermeyer and Dietrich, 2006; Pereira et al., 2011; Balaji et al., 2012; Wozniak et al., 2015). However mental health literacy is a challenge in this regard. Caregivers further indicated beliefs that medical professionals could not provide a complete diagnosis of the MHD (51%), while 34% believed western medicine could not deal with MHDs adequately. Mistrust for MHC services also influences and causes a delay in seeking medical attention.

Nevertheless, most caregivers sought health care services at some point. This was often done not to acquire medication to treat the MHD but rather as a way to obtain the mental disability confirmation letter required in the SASSA grant application. Only 6% of caregivers sought health care services as their preferred method or initial steps in dealing with the MHD. However, 80% of caregivers collect the disability grant, indicating that 80% of caregivers have been to the local clinic to seek health care services. This contradicts the perceptions and strong beliefs of caregivers that MHDs are caused by evil spirits and should therefore be dealt with traditionally. Furthermore, all caregivers indicated that they are aware of the SASSA disability grant. High poverty in KwaXimba is another influential component. Caregivers need the SASSA grant as a source of income for households.

Traditional beliefs about the cause of MHDs influence the treatment method caregivers seek. Firm traditional beliefs of MHDs being caused by evil spirits lead the majority of the caregivers towards traditional healers. Knowledge of MHD patients whose symptoms decreased after utilising traditional methods continues to instil beliefs and trust for traditional pathways of treating MHDs. The abundance of traditional healers, immediate diagnosis and provision of traditional medication is an added advantage compared to the local overcrowded clinic. The swift consultation providing the diagnosis and treatment of MHDs in one consultation and location (*Inyanga's* or *Sangoma's* place) also discourages patients from following the medical route. This is due to the medical process of diagnosis being lengthy. Moreover, continued impairments in patients despite taking medication render medication insufficient in dealing with MHDs. The lack of MHC and biomedical knowledge about MHDs leads to caregivers making informed decisions leading to delays or even never seeking medical assistance.

Caregivers indicated increasing trust for traditional methods in dealing with MHDs, despite caregivers also indicating that MHDs are rarely cured completely from traditional methods. This may also be influenced by some of the caregivers having knowledge of patients who have been completely rehabilitated from traditional methods in comparison to not receiving knowledge of patients getting rehabilitated from MHC. However, this is due to the lack of rehabilitation programs in KwaXimba. An example of NGOs that could facilitate patients' rehabilitation and reintegration into their communities.

6.2.4. To identify the accessibility of mental health care services for patients with mental health disorders in KwaXimba eThekweni Municipality, KZN.

Services available within KwaXimba, include schools, library, post office, police station and local clinic. Access to social services was argued to be good.

The only available health care service is the local clinic. This is because community members stated that they could access essential services such as the library, post office and police station. Furthermore, caregivers stated that access to SASSA offices was good.

The KwaXimba, local clinic provides health care services to a large community, leading to poor service provision. This may be due to most South Africans utilising public health care (Neelyand and Ponshunmugam, 2019), which the KwaXimba local clinic is a part of. The clinics work with a limited number of professional health care workers.

Therefore, there is a limited number of nurses who can assist community members and provide health care services adequately. The large community leads to overcrowding at the clinic

leading to extended time being spent at the clinic. Health care services in rural areas remain inadequate, causing a high treatment gap (Kohn et al., 2004; Alem et al., 2009; Kakuma et al., 2011; Federal Democratic Republic of Ethiopia Ministry of Health, 2012; Patel et al., 2013; Paula et al., 2014; Selamu et al., 2015). There is a second clinic in KwaXimba, however, it only provides health care services to children, thus, all other health care issues are dealt with at the local clinic. According to King, community members have been known to travel to KwaNyavu, a neighbouring community, to acquire health care services, as service provision is better. Rural people frequently have limited resources (Neelyand and Ponshunmugam, 2019). One of the biggest challenges pertaining to health care service provision in SSA is the inadequate health care workers (Maphumulo and Bhengu, 2019).

All caregivers who went to the local clinic with patients stated that they were transferred to the nearest hospital for a complete diagnosis. KwaXimba local clinic does not have the personnel to provide a complete diagnosis of the MHD and transfers patients. Caregivers and patients, therefore, have to travel long distances to the nearest hospital, which is costly, time-consuming and inconvenient.

Caregivers elaborated that it is usually challenging to travel with the patient utilising public transport, as patients may fail to behave with common decency, causing caregivers embarrassment and shame. Public transport is the most common form of transport (94%). Once a complete diagnosis has been provided at the hospital, the caregiver then collects medication from the local clinic monthly. If the diagnosis could be provided at the local clinic, caregivers would only need to take one taxi to the local clinic, where they may be surrounded by familiar people. The cost of travelling long distances to acquire health care services are often unaffordable for caregivers.

The preferred method of dealing with MHDs in KwaXimba was traditional methods. This could be due to two reasons, firstly, the availability and accessibility of traditional healers within the community. Secondly would be the perceptions and beliefs about the causation of MHDs. Caregivers complained of the local clinic being overcrowded, thus providing poor service. The King also confirmed this, who stated that community members had been known to travel to the next community kwaNyavu, under King Mdluli to access better health care services. All these factors can influence the method caregivers seek, rendering traditional methods preferable.

There are no NGOs in KwaXimba, which provide services to caregivers and patients with MHDs. Caregivers did not indicate knowledge of NGOs within their community, however, the King stated otherwise. According to the King, there are NGOs however, they do not provide assistance to caregivers and patients with MHDs.

There are no special schools in the area. Most patients developed the MHD later on in their lives, however, for patients who had the MHD at an earlier stage, there were no educational programs for patients. Caregivers either sent patients to the local school, where they did not thrive and were forced to drop out. Other caregivers have yet to try to enrol their children in the local schools.

The lack of a special needs school excludes patients with MHDs from any form of education and any possibility of being employable and independent.

Furthermore, no rehabilitation facilities or programs exist within the area. The implication is that for patients who have obtained any form of education, that education is lost. Without rehabilitation for patients, impairments continue, which means patients never reach a state of rehabilitation with the possibility of generating an income for themselves. This means patients depend on the SASSA disability grant for their entire lives. Additionally, caregivers must also provide care for the rest of the patient's life.

Therefore, the burden of caregiving is a lifetime commitment for caregivers in KwaXimba. This could be disheartening to caregivers, as caregiving requires financial, physical and emotional support for patients (von Kanel et al., 2006; Swartz and Collins, 2019; Anokye, 2018 WHO, 2001; Inogbo et al., 2017; Addo et al., 2018).

The only form of rehabilitation caregivers had knowledge of was mental health facilities in PMB. This indicates a lack of knowledge in terms of community rehabilitation. Research has acknowledged the lack of awareness about MHDs compared to other diseases such as HIV and AIDs (Weller, 2006; Saxena et al., 2007; UNAIDS, 2010; Saxena and Setoya, 2014; WHO, 2019). The mental health sector has moved from institutionalisation towards community rehabilitation programs, often pioneered by local NGOs. The lack of such programs in KwaXimba, indicates the absence of the possibility of community rehabilitation. The lack of NGOs which also render services to caregivers and patients is another challenge for community rehabilitation. The case of Esidimeni was a lesson learnt in the mental health sector (Durojaye and Agaba, 2018). Therefore, for successful community rehabilitation, many community

sectors need to be informed and engage with rehabilitation initiatives. This is far-fetched for the community of KwaXimba.

The lack of access to MHC services in KwaXimba is a challenge for caregivers, which places a greater burden of caregiving on caregivers. The burden of caregiving is different for caregivers but has been acknowledged as being moderate to extremely high (Saunders, 2003; Caqueo-Úrizar and Gutiérrez-Maldonado, 2006; Vancampfort et al., 2017). The lack of knowledge amongst caregivers about possible rehabilitation programs within their community is another challenge to overcoming the burden of caregiving in KwaXimba and improving access to MHC services. Argued that in knowledgeable communities, treatment is sought timeously, and defaulting from medication is low, leading to improved results for MHDs (Gray et al., 2015; Geffen, 2017). Developing countries, such as SA, continuously dedicate an extremely low percentage of their health expenditure to MHC (WHO, 2021). On average, SSA dedicates 2.1% of their health expenditure towards MHC (SSA (WHO, 2021:54), while SA dedicates approximately 8% in certain districts (Aloshore et al., 2019:2; WHO, 2013; Vancampfort et al., 2017).

The COVID-19 pandemic did not have a significant impact on caregivers and patients. Caregivers were predominantly unemployed, therefore, restrictions on travelling did not have an impact on them. Patients similarly do not travel frequently, thus, the lockdown did not have a significant impact. Caregivers elaborated that they applied for the relief grant, however, some did not receive it as they collected other grants or did not qualify. The R350 from the relief grant provided financial stability to households where caregivers qualified for the grant. Caregivers mentioned that services were available but frequently inaccessible due to restrictions. Restrictions limited the number of people who received any service, leading to extended waiting periods to acquire a service.

This could lead to inconvenience as caregivers may not acquire service promptly and have to return the following day, which can also prove costly. The uncertainty surrounding the pandemic caused worry and concern for the future of caregivers.

6.2.5. To provide recommendations for the improvement of mental health care policies.

6.2.5.1 Caregiver recommendations

(i) Coping mechanism MHD medication

Negative connotations associated with MHD medications negatively influence patients leading to defaulting from medication. MHD medication is perceived to be worse than the actual

disorder, and patients who take the medication are often ridiculed or viewed as worst-case scenarios of madness. Patients, therefore, default from medication to avoid association with these negative connotations. This is a problem because the patient may lose any form of improvement which might have been achieved to that point. Symptoms may also return worse than the initial symptoms and the patient's state debilitates. Patients believe that when they default, they will avoid being ridiculed or perceived as 'crazy', however, the opposite usually occurs. Patient symptoms increase, which may appear as confirmation that the patient has the MHD.

Therefore, caregivers stated that communities need to be informed about MHD medication being a solution and have their perceptions changed. Increased mental health literacy could increase patient adherence to medication leading to improved standards of living due to decreasing symptoms. Caregivers acknowledge that MHD medication does lead to an improvement in the patient's mental and overall state. Defaulting of patients may increase responsibilities associated with caregiving for the patient as symptoms increase or worsen. Patients may need more assistance compared to when they were taking treatment. Therefore, the burden of caregiving increases for caregivers when patients default from medication. This adds to already difficult circumstances where access to MHC services is scarce, unavailable, inaccessible or non-existent.

(ii) Social workers

Disagreements have been noted to become physical between patients and social workers. Physical altercations between patients and social workers lead to decreased trust and reduced communication from caregivers. Caregivers indicated that social workers could be helpful in acquiring documentation and even applying for SASSA grants. Caregivers stated that social workers should become more engaged with their households and MHD patients. Social workers have been known to provide assistance to abused, orphans, child-headed or very poor households. Caregivers argued that if social workers were more involved, all patients would have proper documentation, such as Identity Documents and also collect the disability grant. Households which collaborate with social workers have received or collected food parcels from time to time, and caregivers would like such opportunities. Caregivers elaborated that social workers then focus on the entire household rather than the patients, as such involvement of social workers would imply more assistance for their households.

(iii) Injections

According to caregivers, patients do not like taking medication. Patients get irritated when it is time to take medication, as it is a continuous everyday activity. Patients who take medication are more calm, responsive and spend more time at home. Patients who default or do not take medication usually spend very little time at home, which worries caregivers. Caregivers thus recommended that patients should get injected with medication. Patients get injections at the local clinic occasionally, usually around the time to collect or renew the disability grant. Caregivers pointed out that after the injection, patients are calm, more responsive and able to travel by utilising public transportation. Caregivers thus recommended that patients get these injections more regularly to allow improved living for patients and households. Additionally, caregivers believe that patients would stay at home, require less assistance and be more responsive if injections were provided regularly.

6.2.5.2. Mental health literacy

Caregivers acknowledge that the community needs to gain knowledge of MHDs compared to other illnesses. Patients occasionally face discrimination in the community, and some community members may choose to avoid having any contact with patients. This may go as far as avoiding or ignoring patients completely. This may also be due to fear. Community members understand MHDs in different ways and therefore react to patients differently. Caregivers believed that patients would receive better treatment if communities were better informed about MHDs. This can be referred to in cases where patients are treated as children or with limited intellectual capacity. For instance, patients may get employed within the community and not receive the appropriate compensation after the job is completed. Community members, therefore, take advantage of patients, which will not be done to another patient with any other illness besides the MHD. Caregivers argued that the best way to inform the public about MHDs was through televising the illness. This is an excellent way of informing people without discriminating against those lacking education or poverty. Most households in SA have television and radio, which would spread the information quicker. This can be done through popular shows such as uZalo, and MuVhango (which utilise the native language). This is important as discrimination and stigma exist in rural areas where posters and educative programs might not yield wanted outcomes due to lack of education.

KwaXimba leadership need to be more informed about services required by patients with MHDs. The king did not recommend any initiatives which could rehabilitate patients. Caregivers do not believe that patients can be rehabilitated and reintegrated into their society.

Caregivers confidently believed that MHDs are mostly incurable, therefore, patients either get better after attempts or never get better. This indicates a lack of mental health literacy among caregivers, hence none of the caregivers recommended a rehabilitation program. Caregivers gave recommendations of temporary solutions or assistance to render the MHDs more accommodated rather than initiatives to make patients independent. Caregivers have accepted the assumed role of caregiving as a permanent circumstance. As such, caregivers from KwaXimba could not recommend a rehabilitation program, they did not believe to be achievable or have knowledge of.

6.2.5.3. Research recommendations

A. Increase community and caregiver mental health literacy

Caregivers recommended that patients receive frequent injections, which keep them calm and decrease their unsupervised roaming within the community. This serves as a coping mechanism for caregivers. Patients being calm and spending more time at home implies that caregivers have more time to engage in activities other than caregiving. However, the injection does not aid in patients' rehabilitation but serves as solely a coping mechanism. Three things influence this recommendation. Firstly, caregivers seek to decrease the caregiving burden upon themselves, and secondly, caregiver's instinct is to shelter and protect patients. Lastly is poor mental health literacy in caregivers. Caregivers had reasonable doubts about the rehabilitation and reintegration of patients into their communities. Caregivers had never seen a patient suffering from MHDs get rehabilitated, reintegrated and gain independence with necessary support structures such as NGOs. Therefore, the only point of reference for caregiver's perceptions and understanding of MHDs and their treatment is based on traditional methods, past experiences, lack of awareness and the lack of psychiatric services in KwaXimba. Caregivers must be literate about mental health to participate and engage with relevant stakeholders actively. Educating caregivers about MHDs and its rehabilitation holds the potential for caregivers to provide mental health literate recommendations in KwaXimba.

Increasing community awareness or mental health literacy is essential for two reasons. Firstly, increased MHD awareness decreases stigma and discrimination against patients and caregivers. Allowing patients more dignity, increased public assistance, and adherence to medication leads to overall improved states of the MHDs. Improvement in MHD patient state empowers patients to take and engage with available opportunities without hesitation due to fear of stigma or discrimination. Secondly, the burden of caregiving decreases on caregivers. Improved states of patients lead to less assistance being needed by patients, providing caregivers with time to

engage in other activities. In this way, caregivers have opportunities to invest in their personal development and engage in income-generating activities, leading to the empowerment of the caregiver.

Increased mental health literacy is not solely for decreasing stigma and discrimination against patients (improved treatment) but also to end self-stigma. MHD patients often accept derogative and discriminative terms associated with their illness, changing their perspective of themselves. Self-stigma hinders patients from challenging the status quo (Mugisha et al., 2019).

A similar challenge was observed with caregivers. Due to past experiences and traditional knowledge, caregivers have reasonable doubt about the potential of CBR and the reintegration of patients. Caregivers had limited access to information, leading to poor mental health literacy. This hindered caregivers from challenging the status quo. Caregivers thus focused their attention on coping mechanisms rather than rehabilitative strategies for themselves, patients and their households.

B. Strengthening of local institutions

It is important to acknowledge all institutions that provide support to pinpoint areas for improvement to achieve sustainable livelihoods (Scoones, 1997). The church or religious organisations in KwaXimba appear to be a strength. Religious organisations are common and act as a coping mechanism for caregivers. Caregivers and patients engage with these institutions for spiritual support and enlightenment. Therefore, religious organisations need to be included in strategies and initiatives taken to assist caregivers and patients in KwaXimba. Religious organisations such as churches have been known to provide assistance to households faced with burdens of sickness and caregiving (Campbell et al., 2008).

C. Decreasing vulnerability of households

Increased household members who cannot engage in income or developmental activities have increased dependence on SASSA grants (Mthethwa and Wale, 2023). Households in KwaXimba display high dependence on SASSA grants. This is due to the high unemployment amongst caregivers, the high number of household dependents, and poverty. Mthethwa and Wale (2023) state that households with more than one source of income have low vulnerability. As such, households with one source of income remain vulnerable to stress and shock, possibly falling into abject poverty if the income is decreased. The SASSA grants act as a safety net for the community of KwaXimba; however, high dependence on the grant and in cases where the grant is the only means of income vulnerability remains high. The high dependence becomes a

weakness for caregivers and their households. Mental health programs and initiatives should have strategies to assist households in generating other sources of income. This could be through training caregivers and patients to utilise their assets to generate an income.

D. Participation of patients in their rehabilitation

Patients suffering from MHDs are central to MHC and should be prioritised in all rehabilitation plans. As such, this research recommends that caregivers and patients need to be part of MHC. This involvement, however, needs to be treated with caution. Drew et al. (2011); Gruskin et al. (2012), and Abayney et al. (2017) mentioned that MHD patients have an intellectual disability which hinders them from adequate involvement with issues relating to MHC service provision. This research raises two points against this point. Firstly, if patients have the necessary support structures to enable their rehabilitation and reintegration into society, their cognitive or intellectual abilities improve drastically. As such, those patients can provide valuable insights. Secondly, caregivers need to be included as much as patients. Caregivers have experience and knowledge of systems that work to assist patients and decrease symptoms. The equal inclusion of patients and caregivers can thus provide the needed insight for MHD-related services.

E. Employment of non-specialists

Rural areas have challenges of lacking services, development and MHC resources. Training and employing rehabilitated patients from rural communities is a plausible solution (Rathod et al., 2015). This would increase the number of MHC workers within the community, increasing patient access. Rehabilitated patients relate to and understand MHD challenges and circumstances better than anyone. Therefore, rehabilitated patients could provide the needed services adequately and sufficiently. This would further encourage patients and caregivers to engage with rehabilitation programs. Rural patients and caregivers would find it easier to relate to and engage with people from their communities suffering from the MHD. Employing rehabilitated patients could also prove less expensive for the mental health sector (Kakuma et al., 2011). CBR, increased mental health literacy and support to patients and caregivers provided by rehabilitated patients have been advocated for, particularly in undeveloped and resource-lacking areas (Mari et al., 2009; Vancampfort et al., 2017).

F. Introduction of physical exercise

This recommendation is particularly suitable in rural areas SSA due to the minimal resources required to execute. MHD patients can exercise or play sports within their communities utilising a ball, rope and open spaces. This is particularly suitable for resource-lacking contexts

such as KwaXimba. The involvement of caregivers could further prove beneficial in this instant. If caregivers are informed that engaging their patients in exercise activities could be beneficial. Caregivers could also assist patients in the absence of physical therapists. However, this requires the training of caregivers and household members. Physical exercise must become mental health's primary focus, particularly in PHC (Vancampfort et al., 2017).

6.3. Inferential and comparative data

Table 2.1 focuses on the traditional beliefs and preferred method of treating MHDs in SSA. Tabulated in 2.1 were different studies which showed very strong beliefs in supernatural causes and a strong association between spirituality and MHDs. This data provided a clear picture of local community understandings about MHDs and how this actually influenced the treatment that was sought. Escalating belief in supernatural or spiritual cases was directly linked to seeking traditional or spiritual treatments to deal with the MHD. Drawing from these studies it was evident that KwaXimba was soundly following the same pattern. The reason being there was an increasing belief in supernatural and spirituality linked to MHDs. Therefore, such many caregivers sought traditional and spiritual means of acquiring help for their patients. Table 4.1. tabulated results from different studies conducted in similar settings to KwaXimba. It is clearly evident that there are major similarities between the findings such as provide the case studies and the current study focusing on KwaXimba as well. Caregiver challenges in providing care for the patients that are significantly similar such as unemployment of patients, reliance on social grants, required assistance with food preparation, bathing and personal hygiene. The lack of resources in rural areas makes caregiving even more for rural caregivers in SSA. In addition the other challenges affecting caregivers were financial, social and stigma related.

6.4. Conceptual reflections

The research adopted two conceptual frameworks to understand the perceptions, challenges and access to mental health services in KwaXimba, for caregivers with patients suffering from MHDs. The first was the sustainable livelihood approach, and the second was Ubuntu. Key findings from the research will be evaluated in regard to the conceptual framework below.

6.4.1. Sustainable Livelihood Approach

The SLA places emphasis on rural community contexts. It is pinned upon rural community engagement and participation in all projects, development initiatives and service provision. The SLA argues for rural community members to be acknowledged and included as active stakeholders in all decision-making processes. This is due to the in-depth knowledge of the

rural community, its challenges and the resources possessed by community members. As such, their contributions towards programs or initiatives within their communities are crucial. Therefore, patients and caregivers should be recognised as stakeholders in relation to MHC services in KwaXimba. The SLA has been utilised in this study to understand the manner and caregiver coping strategies with the burden of caregiving. This was conducted by investigating which methods have been adopted by households and caregivers in providing care for the patient with MHD.

The SLA is premised on five capitals which are elaborated on below:

6.4.1.1. Human capital

In this research, human capital refers to the “knowledge, skills, experience and health” of caregivers. The majority of caregivers (63%) had completed secondary school education, implying a good understanding of fundamental life skills in terms of knowledge. Caregivers mentioned making beadwork, engaging in community gardens and obtaining certificates from short courses. Caregivers utilise all these skills to generate an income or contribute towards financial capital. However, most caregivers were unemployed, thus, their knowledge and skills were not being utilised efficiently. Caregiver experiences revolved around providing care for their patients suffering from MHDs. Caregiving was often a shared responsibility within the household, however, the caregiver provided most of the work. The shared responsibilities included collecting medication, preparing food, and cleaning the patient’s room. Available household members undertook these activities for the patient in the presence or absence of the caregiver. Households may adopt this strategy to decrease the burden of caregiving upon one individual who is the caregiver.

Additionally, human capital includes good health for caregivers. Most caregivers were not disabled. Nonetheless, a significant percentage of caregivers had health issues. The health of caregivers is important to enable adequate care for patients. If a caregiver is unwell or fails to care for themselves, the caregiving level will depreciate.

Poor mental health literacy in KwaXimba indicated a limited understanding of MHDs medically. Poor mental health literacy has hindered caregivers from providing recommendations about community rehabilitation services. Doubt from caregivers that MHD patients could get rehabilitated and reintegrated into their communities emphasises the lack of awareness about MHDs. The lack of awareness has led to poor recommendations which cannot enable rehabilitation and reintegration but rather continued existence under the same or slightly

improved conditions. This lack of knowledge has disempowered caregivers, leaving patients with consistent, if not deteriorating, MHD symptoms. The responsibility of caregiving thus becomes a permanent, time-consuming role leading to caregivers not having time to engage in income-generating or self-development initiatives. Providing care for the patient can thus become a passed-on responsibility if the caregiver dies, leading to possible stagnation of household members' lives.

6.4.2.2. Financial capital

Financial capital denotes all streams of income for caregiver households for this research. More than half of the caregivers (54%) were unemployed and without any form of wages or salary. In KwaXimba there was high dependence on SASSA grants which were the main source of income. Eighty-six percent collected a SASSA grant, 80% collected a disability grant, and 29% collected a pension also provided by SASSA. The grant is often utilised towards basic household needs without focusing on a particular individual. This may be for purchasing food, the electricity token, paying funeral insurance, school fees and other household needs. "People who receive the social security benefits in SA tend to be dependent on them for their survival" (Gabrielle, 2013:10). The grant provides financial support forming part of the household's financial capital.

The high unemployment rate and dependence on the SASSA grant in KwaXimba, indicate poor economic conditions. Other sources of household income included wages, remittances and the selling of products or beadwork, which also contributed towards the generation of household financial capital.

6.4.2.3. Social capital

Social capital includes relations of caregivers with their community for this research. Caregivers mentioned that they do not experience stigma or discrimination within their communities, however, patients have encountered such. This has led to strained relationships between the caregiver and community members who discriminate against patients. Traditional beliefs about the causes of MHDs have also led to stranded social relations. Caregivers distance themselves from people they suspect of bewitching patients and causing the MHD. This leads to caregiver isolation, and decreasing social networks, which may assist the caregiver. Ultimately this can lead to caregiver households being stranded and isolated, receiving minimal to no community support.

The lack of rehabilitation programs or CBR in KwaXimba indicates that patients and caregivers do not receive the necessary psychiatric and emotional support. There are no support groups within the community to also provide support to patients and caregivers.

6.4.2.4. Natural capital and physical capital

All caregivers in KwaXimba, had ownership of the land for their homestead. Caregivers who were heads of households had the land registered under their names or spouses. Other caregivers were living on family land or their parent's land. All housing belonged to households. The Umsunduzi River going through KwaXimba, is a common pool resource for the community utilised by all members. The river is a water source for the community, particularly as water is often unavailable from community-installed taps. Water trucks deliver water regularly, but this process has its challenges. As such, the community utilises water from the Umsunduzi River for activities such as doing laundry. The same applies to open land spaces where community members can leave their livestock to graze.

Almost all caregiver households in KwaXimba had RDP houses. These could not generate an income for households but were physical assets for the caregivers and their households. KwaXimba has two clinics, a police station, a post office, a few schools, and a majority of tarred roads and community halls. All RDP houses came with water tanks. All households had access to electricity. Therefore, KwaXimba, has a good infrastructure.

6.4.3. Community strengths and weaknesses

The community pool resources (uMsunduzi river and vacant land) are utilised by the community for different activities. The uMsunduzi River is a water source for households, community gardens and livestock. The vacant land is also utilised for community gardens and livestock rearing. These natural capitals serve as strengths for the community, enabling the community to engage in activities which sustain their livelihoods. KwaXimba, has a police station, post office, schools, two clinics and community halls, which service the whole community if needed and therefore serve as strengths. Community members only need to travel a little to acquire these services as they are available locally. The SASSA grants act as a safety net for the majority of the community. This grant is a definite source of income which can be utilised during times of vulnerability and shocks. Households are thus certain that the grant will assist with the purchasing of basic needs such as food on a monthly basis without fail. The high regard for traditional beliefs in KwaXimba, eThekweni Municipality, KZN, encourages Ubuntu within the community. This has led to decreased discrimination against patients and caregivers despite the existing poor mental health literacy. Traditional beliefs enable caregivers

and patients to seek traditional care pathways for MHDs timeously, which may lead to patient improvements. However, traditional beliefs also become the community's weakness. Delays in seeking medical attention for MHDs are largely attributed to traditional beliefs pertaining to the causes. This can disempower patients and caregivers where MHD symptoms are consistent or deteriorating.

The unavailability of water from community-installed taps leads to increased time spent collecting water from water trucks or the uMsunduzi River. Caregivers thus have less time to provide care or engage in other activities, and collecting water can take time and effort. KwaXimba, is located far from the developed area with hospitals, social welfare offices and other services. Community members thus require money to travel and be able to access these services. KwaXimba is a congested community within a rural area. Increased populations lead to increased inequalities within the community which may lead to social exclusion or isolation of the poorer households. This may be exacerbated by better-off households forming relations with similar families due to shared characteristics.

The limited financial capital of poor households in KwaXimba, presents a weakness. Limited financial capital implies that human, natural and physical capital cannot be increased for households. Such households are, therefore, a continued cycle of poverty. The lack of NGOs within the community suggests that multilevel partnerships between the public and private sectors are impossible. The SLA focuses on such partnerships to enable sustainable livelihoods for communities. NGOs have further been acknowledged as important stakeholders for CBR within rural communities. Without these private stakeholders, the rehabilitation of MHD patients in KwaXimba, is a distant possibility. As such, caregivers have developed strategies to accommodate and live with patients within their households.

The firm belief that MHDs are caused by spirituality can be linked to indigenous knowledge systems, which are common in rural areas. The utilisation of indigenous knowledge systems is often sustainable.

Caregivers mentioned going to religious gatherings such as church with patients. According to caregivers, the church was a faith-based organisation where patients were regarded as sick, possessed, and in a situation out of their control. As such, patients and caregivers are perceived as individuals requiring emotional support. Going to church was, therefore, a coping mechanism for caregivers. Caregivers did not have to worry about discrimination whilst at 'church'. Religious organisations thus served as a strength for caregivers. Religious

organisations are plentiful in KwaXimba. This provides caregivers with options and choices about which church is most supportive. Religious organisation, therefore, plays a significant role in the lives of caregivers and patients. Caregivers elaborated that church members would often pray for the patient and also encourage the caregiver. This brought back hope for the caregiver due to beliefs such as God would intervene and reassurance that they had the strength to continue providing care as God trusted them with the patient.

6.4.2. Ubuntu

Ubuntu as a conceptual framework was introduced and discussed in chapter three. Ubuntu refers to the African notions of people being interdependent within a community (van Breda, 2019; Sambala et al., 2020). An individual is not recognised as a human without dependence and living in harmony with others (Turaki, 2006; Letseka, 2012). The community of KwaXimba has displayed Ubuntu amongst each other and those in need. In KwaXimba immediately after the patient starts showing symptoms of MHDs, community members recommend where help may be acquired for the patient. This indicates genuine concern, compassion and willingness to assist caregivers who may find themselves in situations where a household member has developed the MHD. In this way, the caregiver is informed where assistance for the patient may be acquired, and hopefully, the patient will be rehabilitated.

Caregivers stated that patients had been known to go to local ceremonies, with or without the invitation. Patients have been provided with food and drinks in these ceremonies in KwaXimba. This indicates that community members recognise the MHD as a challenge or sickness for the patient, which does not rid them of their dignity or humanity. Patients are treated with mutual respect. Sambala et al. (2020) argued that through Ubuntu, community members treat the patient with kindness and the same way they would like to be treated if ever in a similar situation. This further indicates a lack of fear of patients from community members, despite MHDs being associated with violence (Okello and Ekblad, 2006; Ventevogel et al., 2013). This further adds to the community acting with Ubuntu towards patients. Caregivers in KwaXimba should have mentioned being excluded by not getting invitations to community ceremonies due to their caregiving role. This indicates that community members sympathise with caregivers and do not discriminate against caregivers. This contradicts what Moahi (2007) and Wankiiri et al. (2013) argued that caregivers may be excluded from social gatherings by not sending invitations to their households.

There have been cases where a patient had wandered off and was recognised by a community member very far away from home, and community members have brought the patient back. This indicated sympathy and care for the patient and the entire household. It can be concluded that community members are open to patients and provide assistance where possible without request. This is a gesture of kindness on the part of the community member, indicating a way of life still premised on Ubuntu. Ramose (2002) and Mabovula (2011) mention Ubuntu to include showing kindness to those who might seem insignificant within the community. Ubuntu exists in KwaXimba as patients have been brought back home after wandering off or getting lost, despite patients being unable to contribute positively to the community.

According to caregivers, most of the community lives in harmony with patients. Community members do not bother or engage with patients unnecessarily by letting them be. This indicates that community members understand the MHD and do not randomly mistreat the patient. Caregivers stated that the community understands that MHDs are caused by different things. Patients with MHDs believed to be a medical condition or developed by patients from a young age receive better treatment from the community. This is because community members have known patients to have MHD for a long time and, in most cases, have grown up with the patient developing some form of relationship.

Caregivers indicated that discrimination towards patients in KwaXimba, is not a significant challenge. Community members have seen MHDs at some point in their lives; it is not shocking or alarming when someone develops an MHD. However, shared beliefs that MHD is occasionally being caused as a punishment for crimes may impact how patients believed to have MHDs due to such factors are treated. In such cases, the community does not sympathise with the patient. Such cases, however, are not as expected, therefore, most patients receive humane treatment from their communities. The community of KwaXimba, has displayed high levels of Ubuntu in numerous ways.

6.5.. Conclusion

This chapter has focused on the key findings of this research, reviewing the data against the overarching framework. The research objectives were reintroduced to ascertain if the research objectives had been met. Most of the caregivers were unemployed, collected different SASSA grants, with many dependents and had RDP housing in their homestead. This is an indication of poverty within the community. Nonetheless, KwaXimba is adequately serviced as water and electricity infrastructure is present. However, accessibility is a challenge as the community

frequently does not have water and electricity due to load-shedding. Health care is available in under-resourced facilities leading to poor health service provision. There are no health specialists or doctors in KwaXimba patients must travel to the nearest hospital for a complete diagnosis. MHDs are not rare KZN community members can recognise MHDs. Caregivers recognised the symptoms and sought out diagnoses from traditional healers. Traditional healers were the preferred method of dealing with MHDs in KwaXimba. This community is deeply rooted in traditional and cultural beliefs, and traditional healers are abundant.

Traditional healers are known for providing and solving health-related problems hence their high reliance on and trust in MHDs. Mental health literacy was average for caregivers. Caregivers were able to recognise MHDs and aware of where to acquire assistance depending on the preferred choice. Preferred routes of dealing with MHDs were premised on shared beliefs about the causes of the MHD. The majority believed MHDs to be the cause of spirituality gone wrong hence the preferred route of spirituality. Caregivers did not prioritise MHC services for patients. There were significant delays before seeking MHC services for patients, while others never sought MHC. Defaulting patients from the medication was very high within the community. According to caregivers taking medication resulted in decreased symptoms, but impairments continued, and patients never got rehabilitated. This is due to the lack of rehabilitation within the community. Patients require psychiatric evaluation, medication and rehabilitation for a chance to lead an everyday life. KwaXimba only provides one of these three requirements, hence patients never show significant improvement despite seeking MHC services.

The main objective for caregivers to obtain MHC services was to apply for the application of the SASSA mental disability grant. This is the only time patients receive psychiatric evaluation in hospitals. Caregivers were oblivious to MHDs being treatable and patients being reintegrated into their communities. Knowledge of community rehabilitation programs was non-existent among caregivers. Indicating that mental health literacy is still lacking. There are no special schools or facilities to accommodate those with disabilities. Furthermore, none of the NGOs provide services to caregivers and patients with MHDs. The rehabilitation and reintegration of patients into society in KwaXimba remain unfamiliar with the community.

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Appendix 1 (Questionnaire Survey English)



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Caregiver perception regarding mental health disorders, living conditions and access to psychiatric programs: a case study of KwaXimba, eThekweni District Municipality, KwaZulu Natal, South Africa.

Research survey: Household structured questionnaire

Date: ____/____/____

Village: _____

Please tick the appropriate boxes and answer the longer questions where necessary. Multiple responses are allowed where indicated.

1. Carer demographic personal details

1.1 Gender

1. Female	
2. Male	

1.2. Age

1. 18-25 years	
2. 26-35 years	
3. 36-45 years	
4. 46-55 years	
5. 56-65 years	
6. >65 years	

1.3. Are you the head of the household?

1. Yes	
2. No	

1.3.1 If not, who is the head of your household?

1.4. Nationality

1. South African	
2. Zimbabwean	
3. Nigerian	
4. Mozambiquan	
5. Other (specify)	

1.5. Home language

1. English	
2. IsiZulu	
3. Xhosa	
4. Afrikaans	
5. Other (specify)	

1.6. Disability

1. Yes	
2. No	

1.5.1 If yes, what disability do you have? _____

1.7. Education

1. None	
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2. Level 1 (preschool)	
3. Level 2 (std 6/grade8)	
4. Level 3 (std 8/grade 10)	
5. Level 4 (std 10/grade 12)	
6. Level 5 (diploma or degree)	
7. Other (specify)	

1.8. Marital status

1. Single	
2. Married	
3. Widow	
4. Separated	
5. Living with partner	

1.9. Occupation

1. Unemployed	
2. Domestic	
3. Shop assistant	
4. Professional	
5. Business owner	
6. Trader	
7. Pensioner	
8. Other (specify)	

1.10. Do you suffer from any health issues?

1. Yes	
2. No	

1.10.1 If yes, what health issues do you suffer from?

1.11. Relationship to mentally ill patient

1. Mother	
2. Father	
3. Grandparent	
4. Relative	
5. Guardian	
6. Sibling	
7. Other (specify)	

2. Household background information

2.1. Type of dwelling

1. Formal house that is owned by you	
2. Traditional house that is owned by you	
3. Shack (informal housing)	
4. RDP Housing	
5. BNG Housing	
6. Other (specify)	

2.2. Number of people living in this household

1. 2	
2. 3	
3. 4	
4. 5	
5. 6	
6. 7	
7. 8	
8. 9	
9. 10	
10. >10	

2.3. How many of the household members depend on you to provide for them?

1. All	
2. None	
3. 1	
4. 2	
5. 3	
6. 4	
7. 5	
8. 6	
9. 7	
10. 8	
11. 9	
12. 10	
13. >10	

2.4. Do you have immediate access to water?

1. Yes	
2. No	

2.4.1. If not, how far do you have to travel to access water?

1. <500 m	
2. 0-1 km	
3. 2-5 km	
4. 6-10 km	
5. 11-15 km	
6. 16-20 km	

2.5. Main sources of energy within this household (tick as many sources of energy that you use in your home)

1. Electricity from public supply	
2. Gas	
A3.Paraffin	
4.Wood	
5. Coal	
6. Candles	
7. Dung	
8. Other (specify)	

2.5.1 Do you ever have any challenges with these forms of energy?

1. Yes	
2. No	

2.5.2. If yes, what are the challenges?

2.6. What type of sanitation does your dwelling have?

1. Septic tank	
2. Chemical toilet	
3. Pit latrine	
4. Bucket toilet	
5. Other (specify)	

2.7. Household main sources of income

1. Pensions	
2. Money sent home	
3. Wages	
4. Sell produce/products for income	
5. Disability grant	
6. Assistant from relatives	

7. Assistant from friends	
8. Other (specify)	

2.8. Has the household lost any source(s) of income since the patient had the mental illness?

1. Yes	
2. No	

2.8.1. If yes, kindly elaborate on the loss of that income?

2.9. Did you make changes to your household to accommodate the mentally ill patient?

1. Yes	
2. No	

2.9.1. If yes, elaborate on these changes.

3. Mentally ill patient details

3.1. Gender

1. Female	
2. Male	

3.2. Age

1. >18	
2. 18-25	
3. 26-35	
4. 36-45	
5. 46-55	
6. >56	

3.3. Education

1. None	
2. Primary school	
3. High school	
4. Tertiary	
5. Special needs school	
6. Other (specify)	

3.4. Does the patient suffer from a mental health disorder?

1. Yes	
2. No	

3.4.1. If yes, kindly identify the type of mental health disorder the patient has.

3.5. What symptoms does the patient display because of the mental health disorder?

1. Talking to themselves	
2. Failing to understand and respond to simple instructions	
3. Taking off their clothes	
4. Being violent without any triggering action	
5. Picking up and collecting waste or rubbish	
6. Failing and repeating the same grade in school multiple times	
7. Other (specify)	

4. Diagnosis

4.1. Has any other member of your family had a mental health disorder before?

1. Yes	
2. No	

4.1.2. Kindly identify the relationship of the mentally ill family member to the patient with the mental health disorder.

1. Father	
2. Mother	
3. Grandparent	
4. Sibling	
5. Other (specify)	

4.2. When did you realise something was wrong with the patient mentally?

1. Immediately	
2. After a few days	
3. 1-3 months	
4. 3-6 months	
5. 6-9 months	
6. 9-12 months	
7. > a year	
8. 2 years or more	

4.2.1 Please explain what happened during this period?

4.3. What was your first step in seeking help for the patient?

1. Patient was taken to the local clinic	
2. Patient was taken to a Sangoma	
3. Patient was taken to an Inyanga	
3. Patient was taken to a Pastor	
4. Patient was taken to a Prophet	
5. Did not seek diagnosis	
6. Other (specify)	

4.3.1. Identify who was the first person to tell you that the patient was suffering from a mental health disorder.

1. Medical doctor	
2. Professional nurse	
3. Traditional healer	
4. Spiritual healer	
5. Relative	
6. Other (specify)	

4.4. What were the initial steps taken after diagnosis?

1. Patient started using medication	
2. Patient was transferred to a hospital for psychiatric evaluation	
3. Patient was taken to a psychiatric facility	
4. Performed a ritual on patient	
5. Patient was left at Inyanga house for treatment	
6. Patient was left at Sangoma house for treatment	
7. Patient was taken to a Sangoma to start initiation	
8. Patient started using traditional herbs	
9. Patient was prayed for and started using holy water	
10. Sought medical assistance after patient did not show improvement from traditional methods	
11. Other (specify)	

4.4.1. What was the outcome of these steps?

4.5. Was it difficult to obtain care for the mentally ill patient in the initial stages?

1. Yes	
2. No	

4.6. Did the diagnosis have an effect on you as you are the caregiver?

1. Yes	
2. No	

4.6.1. If yes, please elaborate on the effect it had on you as the caregiver.

4.7. Did the diagnosis have an effect on the household?

1. Yes	
2. No	

4.7.1. If yes, please elaborate on the effect it had on the household.

4.8. How long did you take before seeking medical assistance?

1. Immediately	
2. After a few days	
3. 1-3 months	
4. 3-6 months	
5. 6-9 months	
6. 9-12 months	
7. > a year	
8. 2 years	
9. >2 years	

4.9. Has the patient ever been away from home due to the mental disorder?

1. Yes	
2. No	

4.9.1. If yes, for how long was the patient away from home?

1. A few weeks	
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2. 1 – 3 months	
3. 4 – 6 months	
4. 7 – 9 months	
5. 10 – 12 months	
6. 1-3 years	
7. > 3 years	
8. Other (specify)	

4.9.2. Identify where the patient resided during this time

1. In a mental institution	
2. In the community but not at home	
3. In the streets (homeless)	
4. Do not know	
5. Travelling by foot from one place to another	
6. Other (specify)	

5. Caregiver perception

5.1. Identify the cause of mental health disorders

1. Evil spirits	
2. Witchcraft	
3. Angry ancestors	
4. Being too clever	
5. Something went wrong mentally	
6. Health issue	
7. Traumatic experience	
8. Other (specify)	

5.2. What do you think is the best way to deal with mental health disorders?

1. Take the patient to the nearest clinic	
2. Take the patient to a Sangoma	
3. Take the patient to an Inyanga	

4. Take the patient to a Pastor	
5. Take the patient to a Prophet	
6. Take the patient to a mental institution	
7. Other specify	

5.3. Do you think the medical practitioner can assist the patient adequately with mental health disorders?

1. Yes	
2. No	

5.3.1. If not, why do you think the medical practitioner cannot assist the patient adequately with mental health disorders ?

5.4. Are you aware of anyone who has dealt with mental health disorders in traditional or cultural ways?

1. Yes	
2. No	

5.4.1. If yes, was there an improvement in the patient's condition?

1. Yes	
2. No	

5.4.2. If yes, kindly elaborate on what steps were taken traditionally or culturally for the patient to get better?

1. Patient started initiation to be a Sangoma	
2. Patient was taken to a Sangoma to find out the root cause of the mental illness	
3. Patient was taken to a Inyanga and left there for treatment	
4. A ceremony was done for the patient	
5. Patient was taken to a religious person to be assisted	
6. Other (specify)	

5.5. Do you think there is a way in which mental health care services can be merged with traditional or cultural ways of dealing with mental health disorders?

1. Yes	
2. No	

5.5.1. If yes, identify ways in which mental health care services can work collaboratively with traditional or cultural healers?

1. Local clinics can work with the Inyanga for diagnosis and treatment	
2. Local clinics can work with the Sangoma for diagnosis and treatment	
3. Local clinics can work with religious organisation for diagnosis and treatment	
4. Other (specify)	

5.6. Identify advantages whereby mental health care services can work collaboratively with traditional or cultural healers?

1. Prevent deteriorating state of patients as medical assistance would be sought timeously	
2. Complete rehabilitation of patients as the mental health disorder would be dealt with in numerous ways	
3. Increased understanding of mental health disorders leading to decreased stigma	
4. Increase respect and communication between medical, cultural and religious organisations	
5. Increase rate of adherence and continuation with medication as all parties will support its use	
6. Other (specify)	

6. Community awareness

6.1. Do you think the community understands what mental health disorders are?

1. Yes	
2. No	

6.1.1. If not, why does the community not understand what causes mental health disorders?

6.2. What are the most common beliefs about mental health disorders?

1. The patient has been disobedient to ancestors	
2. The patient has been bewitched	
3. The patient was too clever	
4. The patient does not want to start initiation to be a Sangoma	
5. It is a normal sickness like any other	
6. Other (specify)	

6.3. What impacts do those common beliefs have on you ?

1. Getting shunned by the community	
2. Friends and relatives distancing themselves	
3. Not getting invited to social gatherings	
4. Not being informed about anything in the community	
5. Being pitied by the community	
6. Had no impact on caregiver	
7. Other (specify)	

6.4. Has the patient ever experienced negativity from the community?

1. Yes	
2. No	

6.4.1. If yes, kindly elaborate on the negative experience.

6.4.2. Did this negative experience affect the mentally ill patient?

1. Yes	
2. No	

6.4.2.1. If yes, how did this negative experience affect the mentally ill patient?

1. Patient did not want to associate with the community	
2. Patient became sad	
3. Patient became violent	
4. Patient was disorientated	
5. Patient chose to move away	
6. Other (specify)	

6.4.3. Did this negative experience affect you as the caregiver?

1. Yes	
2. No	

6.3.4.1. If yes, how did this negative experience affect you as the caregiver?

1. Had to protect patient by keeping them home	
2. Had to provide care for a longer period of time so that patient was never alone	
3. Had to explain to the that the community are not aware of mental health disorders	
4. Made me very sad for the patient	
5. Had to relocate patient from the community	
6. Other (specify)	

6.5. Do you think the community would treat patients better if they understood or had more knowledge on mental health disorders?

1. Yes	
2. No	

6.5.1. If yes, do you think the community would treat the patient differently?

1. Assist them in public if patient needs assistance	
2. Not stigmatise the patient	
3. Not make fun of the patient	
4. Not discriminate against the patient	
5. Other (specify)	

6.6. What causes the lack of awareness or knowledge about mental health disorders in the community?

1. No available platform to teach the community	
2. Instilled beliefs about mental health disorders	
3. Explanations for the mental health disorder from Sangomas or Inyanga justifying common beliefs	
4. Explanations for the mental health disorder from prophet or religious leaders justifying common beliefs	
5. Other (specify)	

6.7. How can the community have a better understanding of mental health disorders?

7. Access to social services

7.1. List the social services that are available for the mentally ill patient?

1. Community health care workers	
2. Social workers	
3. NGOs	
4. SASSA offices	
5. Other (specify)	

7.1.1 How does the social service(s) chosen above help you?

7.2. How far away is the nearest clinic?

1. <500 m	
2. 0-1 km	
3. 2-5 km	
4. 6-10 km	
5. 11-15 km	
6. 16-20 km	

7.2.1. What is the mode of transport to the nearest clinic?

1 Taxi	
2 Walking	
3 Own transport	
4 Ambulance	
5 Other (specify)	

7.2.2. How often do you have to travel to the nearest clinic?

1. Once a month	
2. Once in 3 months	
3. Twice a year	
4. Once a year	
5. Only when I feel unwell	
6. Never	
7. Other (specify)	

7.3. How far is the nearest hospital?

1. <500 m	
2. 0-1 km	
3. 2-5 km	
4. 6-10 km	
5. 11-15 km	
6. 16-20 km	
7. Other (specify)	

7.3.1. What is the mode of transport to the nearest hospital?

1 Taxi	
2 Walking	
3 Own transport	
4 Ambulance	
5 Other (specify)	

7.3.2. How often do you have to travel to the nearest hospital?

1. Once a month	
2. Once in 3 months	
3. Twice a year	
4. Once a year	
5. Only when I feel unwell	
6. Never	
7. When they say so in the clinic	

7.4. Is there a special needs school in the area for mentally ill patients?

1. Yes	
2. No	

7.4.1. If yes, has the mentally ill patient attended the special needs school in the area.

1. Yes	
2. No	

7.4.1.1. If yes, what was the outcome of that?

7.5. Have you ever been in contact with a social worker in matters concerning the mentally ill patient?

1. Yes	
2. No	

7.5.1 If yes, kindly explain the circumstances regarding the meeting with the social worker?

7.6. Do you still maintain contact with the social worker?

1. Yes	
2. No	

7.6.1. If not, please provide reasons as to why you do not maintain contact with the social worker.

7.7. Have community health care workers been to your house?

1. Yes	
2. No	

7.7.1. If yes, what assistance did you receive from the community health workers?

7.7.2. What was the outcome of that assistance provided by the community health workers?

7.8. Do you know about the mental disability grant for mentally ill patients?

1. Yes	
2. No	

7.8.1. If yes, how did you find out about the disability grant?

1. From social media	
2. From the community health care worker	
3. From the social worker	
4. From friends	

5. From relatives	
6. Other (specify)	

7.9. Does the mentally ill patient collect the disability grant?

1. Yes	
2. No	

7.9.1. If yes, elaborate on how you applied for the disability grant for mentally ill patient.

7.10. How long has the patient collected the disability grant?

1. < 6 months	
2. over a year	
3. 2 years	
4. 3 years	
5. 4 years	
7. 5 years	
8. 6 years	
9. 7 years	
10. 8 years	
11. 9 years	
12. 10 years	
13. >10 years	

7.11. How many times has the disability grant been renewed for the mentally ill patient?

1. never	
2. once	
3. twice	
4. 3 times	
5. 4 times	

6. 5 times	
7. 6 times	
8. 7 times	
9. 8 times	
10. 9 times	
11. 10 times	
12. >10 times	

7.12. How does the disability grant provide help to the mentally ill patient?

1. Used to buy clothes and food for the patient	
2. Used to travel to clinic or hospital	
3. Used to buy medication for the patient	
4. Patient is not at home and does not benefit	
5. Used by patient at their own discretion	
6. Other (specify)	

7.13. How does the disability grant provide help to the household?

Used to buy household groceries	
Used to assist with household need (eg. electricity)	
Used to pay for school fees	
Used to help the patient's child	
Other (specify)	

7.14. Have you experienced any challenges with the disability grant for the mentally ill patient?

1. Yes	
2. No	

7.14.1. If yes, please explain these challenges.

8. Providing care

8.1. Have you had any training on how to provide care to the patient with mental illness?

1. Yes	
2. No	

8.1.1. If yes, please list by whom the training was provided?

8.1.2 How long was this training for?

1. > an hour	
2. Few hours	
3. a day	
4. A few days	
5. < 1 week	
6. A month	
7. Other (specify)	

8.1.3. Please list what you were taught in this training.

1. How to assist patient take medication	
2. How to help patient with day-to-day activities	
3. How to understand patients	
4. How to handle stressful situations for the patient	
5. Other (specify)	

8.2. Does the mentally ill patient require assistance with day-to-day activities?

1. Yes	
2. No	

8.2.1. If yes, please elaborate on these activities.

1. Eating	
-----------	--

2. Bathing	
3. Getting dressed	
4. Taking medication	
5. Getting in or out of bed	
6. Other (specify)	

8.3. Do you have assistance with the patient when you are away?

1. Yes	
2. No	

8.3.1. If yes, who helps the patient in your absentia.

1. Caregiver's child	
2. Patient sibling	
3. Neighbour	
4. Friend	
5. Relative	
6. Patient's child	
7. Other (specify)	

8.4. Does the mentally ill patient require medication?

1. Yes	
2. No	

8.4.1. If yes, who is responsible for the collection?

Caregiver	
Relative	
Friend	
Household member	
Neighbour	
Other (specify)	

8.4.2. Where is the medication collected from?

1. Clinic	
2. Hospital	
3. Brought to the household	
4. Other (specify)	

8.5. Who is responsible for helping the mentally ill patient when taking the medication?

1. Caregiver	
2. Patient can take medication on their own	
3. Household member available	
4. Friend	
5. Relative	
6. Other (specify)	

8.6. Does the mentally ill patient comply with the required dose of medication?

1. Yes	
2. No	

8.6.1. If not, why does the patient not take the required dose of medication

1. Patient is away from home	
2. Patient refuses the medication	
3. Sometimes patient is not at home	
4. Depends the mood of the patient	
5. Other (specify)	

8.7. For how long has the mentally ill patient been collecting medication?

1. 1-3 months	
2. 3-6 months	
3. 6-9 months	
4. 9-12 months	
5. 1-3 years	
6. 3-6 years	
7. 6-9 years	

8. >10 years	
9. Other (specify)	

8.9. As the sole caregiver do you see an improvement in the state of the mentally ill patient?

1. Yes	
2. No	

8.9.1. If yes, what was the improvement?

1. Patient is no longer violent	
2. Patient is able to help themselves with day-to-day activities	
3. Patient can understand and respond to simple instructions	
4. Patient no longer talks to themselves	
5. Patient no longer takes their clothes off	
6. Patient can hold a normal conversation	
7. Patient is attending and passing in school	
8. Other (specify)	

8.10. Is the mentally ill patient physically violent?

1. Yes	
2. No	

8.10.1. If yes, please elaborate on the severity of the physical violence.

1. Patient hit or strangle the caregiver	
2. Patient destroyed things within the home	
3. Patient hit or strangle household member	
4. Patient hit or strangles anyone trying to touch him or her	
5. Patient hit or strangle community members	
6. Other (specify)	

8.10.2. Kindly choose circumstances around the physical violent incident.

1. Patient becomes violent unprovoked	
2. Patient becomes violent when you touch him or her	
3. Patient becomes violent when they need to take medication	
4. Patient becomes violent if they do not understand something	
5. Patient becomes violent if you touch their belongings	
6. Other (specify)	

8.11. What other challenges do you face as a caregiver for a mentally ill patient?

9. Access to psychiatric help

9.1. Does the patient receive psychiatric evaluation?

1. Yes	
2. No	

9.1.1. If not, why does the patient not receive psychiatric evaluation?

1. Patient ran away from home	
2. Psychiatric evaluation facility is too far away	
3. Psychiatric evaluation facility is unavailable	
4. Very difficult to get patient to travel with caregiver	
5. Patient does not want to be evaluated	
6. Too expensive to get psychiatric evaluation	
7. Other (specify)	

9.2. How often does the mentally ill patient receive psychiatric evaluation?

1. Never	
----------	--

2. Once a month	
3. Once in 3 months	
4. Once in 6 months	
5. Yearly	
6. After a couple of years	
7. Prior to grant renewal	
8. Other (specify)	

9.3. Identify where the mentally ill patient receives psychiatric evaluation?

1. Local clinic	
2. Hospital	
3. Private facility	
4. Psychiatric facility	
5. Other (specify)	

9.4. What mode of transport is being used to reach the mental health facility for psychiatric evaluation?

1. Taxi	
2. Foot	
3. Bus	
4. Private vehicle	
5. Other (Specify)	

9.5. How much does it cost to travel with the patient to the mental health facility for their psychiatric evaluation?

1. < R50	
2. R50 – R100	
3. R100-R200	
4. R200-R300	
5. R300-R400	
6. R400-R500	
7. Above R500	

8. No cost	
9. Other (specify)	

9.6. Are the travelling fees paid by you?

1. Yes	
2. No	

9.6.1. If not, who pays for the travelling fees?

10. Access to rehabilitation programmes

10.1. Have you ever been informed about rehabilitation programs?

1. Yes	
2. No	

10.1.1. If yes, who informed you about the rehabilitation programs.

1. Community health care worker	
2. Social worker	
3. Local clinic staff	
4. Social media	
5. Relative or friend	
6. Other (specify)	

10.1.2. What was this rehabilitation programs?

10.2. Is there a rehabilitation programme available to the mentally ill patient?

1. Yes	
2. No	

10.3 Is there a rehabilitation programme accessible to the mentally ill patient?

1. Yes	
2. No	

10.4. Has the mentally ill patient been involved in any rehabilitation program?

1. Yes	
2. No	

10.4.1. If yes, where did the mentally ill patient engage with the rehabilitation program?

1. In a local NGO facility	
2. Had to travel to the rehabilitation program	
3. Within the community	
4. In a psychiatric facility	
5. In the local clinic	
6. In the nearest hospital	
7. Other (specify)	

10.5. How long was the patient part of the rehabilitation program?

1. A few days	
2. A few weeks	
3. 1-6 months	
4. 6-12 months	
5. Over a year	
6. More than 2 years	
7. Still ongoing	

10.6. What was the outcome from the engagement of the patient with the rehabilitation programme?

1. Patient was able to understand simple instruction	
2. Patient was able to continue with studies	

3. Patient was able to seek employment	
4. Patient was able to take care of themselves	
5. Patient was able to socialise	
6. Patient was able to help around the household	
7. Other (specify)	

10.7. Are there any recreational activities available for the mentally ill patient?

1. Yes	
2. No	

10.7.1. If yes, list the recreational activities.

1. Sport	
2. Shopping mall	
3. Park	
4. Singing or dancing	
5. Other (specify)	

10.7.2. Explain the manner in which the mentally ill patient engages with these recreational activities?

10.8. Are community activities available for the mentally ill patient?

1. Yes	
2. No	

10.8.1. If yes, list the community activities.

1. Community Garden	
2. Community contests	
3. Community clean-up or recycling	

4. Free courses	
5. Cultural gatherings	
6. Other (specify)	

10.8.2. Explain the manner in which the mentally ill patient engages with these activities?

10.9. Are you aware of any non-governmental organisations in the area?

1. Yes	
2. No	

10.10.1. Have you received any assistance from the non-governmental organisation?

1. Yes	
2. No	

10.10.2 If yes, what help have you received from the non-governmental organisation in your area?

10.11. Please comment on the lack of rehabilitation in your area.

11. COVID-19 impacts

11.1. Has the COVID-19 had an impact on the patient?

1. Yes	
2. No	

11.1.1. If yes, choose the impact of the COVID 19 pandemic on the mentally ill patient?

1. Worsening symptoms	
2. Limited access to health care services	

3. Lockdown imposed caused frustration on patient	
4. No psychiatric evaluation	
5. Limited access to rehabilitating activities	
6. Other (specify)	

11.2. Has the COVID-19 pandemic affected you as the caregiver?

1. Yes	
2. No	

11.2.1 How has the COVID-19 pandemic affected you as the caregiver?

1. Increased time for caregiving as patient's symptoms deteriorated	
2. Loss of income due to lockdown	
3. Disruption of normal household routines	
4. Had to manage household while providing care for the patient	
5. Became stressed due to uncertainty of living	
6. Developed new sickness	
7. Other (specify)	

11.3. Have you received the COVID-19 relief grant?

1. Yes	
2. No	

11.3.1. If not, why have you not received the COVID-19 relief grant?

1. Did not apply for it	
2. Does not qualify for it due to employment	
3. Does not qualify for it due to another grant	
4. Did not get approved	
5. Other (specify)	

11.3.2. If yes, how has the COVID-19 relief grant assisted you?

1. Has become an extra source of income	
2. Assists in buying household groceries	
3. Assists in school fees	
4. Assists in taking better care of the patient	
5. Has become the main source of income	
6. Other (specify)	

11.4. Has the COVID 19 pandemic had an impact on your access to social services?

1. Yes	
2. No	

11.4.1. If yes, how has the COVID 19 pandemic had an impact on your access to social services?

11.5. Has the COVID 19 pandemic had an impact in your access to psychiatric services?

11.6. Have you had any other challenges because of the COVID-19 pandemic?

1. Yes	
2. No	

11.6.1. If yes, kindly explain these challenges.

12. Suggestions

12.1. List ways in which government can contribute positively to patients with mental health disorders.

12.2. What other form of assistance can be made available for patients?

12.3. What other form of assistance can be made available for caregivers?

12.4. Do you have any other recommendations in relation to mental health disorders?

12.5. Are there any other recommendations you would like to add in relation to mental health disorders?

12.6 Are there any other information you would like to add in relation to mental health disorders?

Thank you for participating.

Appendix ii (Questionnaire in IsiZulu)



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Caregiver perception regarding mental health disorders, living conditions and access to psychiatric programs: a case study of KwaXimba, eThekweni District Municipality, KwaZulu-Natal, South Africa.

Ucwaningo: Imibuzo elungiselwe inkulumo mpendulwano

Usuku: ____/____/____

Indawo: _____

Kucelakala ufake uphawu lokuvuma emabhokisini alungisiwe uphinde uphendule imibuzo emide layikhona. Ukuphendula kaningi kumbuzo owodwa kuvumelekile.

1. Imininingwane yomnakekeli wesiguli

1.1 Ubulili

1. Owesifazane	
2. Owesilisa	

1.2. Iminyaka

1. 18-25	
2. 26-35	
3. 36-45	
4. 46-55	
5. 56-65	
6. >65	

1.3. Ingabe wuwe umnikazi walelikhaya?

1. Yebo	
2. Cha	

1.3.1. Uma kungesiwe umnikazi, ingabe ubani?

1.4. Ubuzwe

1. Ungum-South African	
2. Ungum Zimbabwean	
3. UngumNigerian	
4. Ungum Mozambiquan	
5. Obunye (chaza)	

1.5. Ulimi lasekhaya

1. Isilungu	
2. IsiZulu	
3. Xhosa	
4. Isibhunu	
5. Olunye (chaza)	

1.6. Ukukhubazeka

1. Yebo	
2. Cha	

1.5.1. Uma unako ukukhubazeka, yikuphi? _____

1.7. Imfundo

1. Awukaze uye nhlobo esikoleni	
2. Izinga loku- 1 (ekhreshi)	

3. Izinga lesi- 2 (ibanga le- 6/grade8)	
4. Izinga lesi- 3 (ibanga le- 8/grade 10)	
5. Izinga lesi- 4 (ibanga le- 10/grade 12)	
6. Izinga lesi- 5 (uneziqu zemfundo ephakeme)	
7. Okunye (chaza)	

1.8. Ngokomshado

1. Awushadile/shadelwe	
2. Ushadile/ shadelwe	
3. Umfelokazi	
4. Wehlukanisile	
5. Uhlalisene	

1.9. Umsebenzi

1. Awusebenzi	
2. Emakhishini	
3. Usiza estolo	
4. Wenza umsebenzi owufundele	
5. Ungusomabhizinisi	
6. Uyahweba	
7. Uhol impesheni	
8. Okunye (chaza)	

1.10. Sikhona isifo onaso?

1. Yebo	
2. Cha	

1.10. Uma unaso, isiphi leso sifo?

1.11. Ubudlelwano bakho nesiguli

1. Umama waso	
2. Ubaba waso	
3. Ukhulu/ umkhulu	
4. Isihlobo	
5. Umnakekeli nje	
6. Niyelamana	
7. Okunye (chaza)	

2. Imininingwane yasekhaya

2.1. Uhlobo lwezindlu

1. Indlu yamabloksi yakho	
2. Indlu yodaka yakho	
3. Umjondolo	
4. Indlu yomxhaso	
5. Uhlobo lwe BNG	
6. Okunye (chaza)	

2.2. Abantu abahlala layikhaya

1. 2	
2. 3	
3. 4	
4. 5	
5. 6	
6. 7	
7. 8	
8. 9	
9. 10	
10. >10	

2.3. Bangaki kubona abondliwayo?

1. Bonke	
2. Akekho	
3. 1	
4. 2	
5. 3	
6. 4	
7. 5	
8. 6	
9. 7	
10. 8	
11. 9	
12. 10	
13. >10	

2.4. Ninawo amanzi egcekeni?

1. Yebo	
2. Cha	

2.4.1. Uma engekho egcekeni, nihamba indlela engakanani uma niyowakha amanzi?

1. <500 m	
2. 0-1 km	
3. 2-5 km	
4. 6-10 km	
5. 11-15 km	
6. 16-20 km	

2.5. Indlela enithola ngayo amandla okukhanyisa (ungakhetha okuningi)

1. Ugesi kamasipala	
2. Igesi	

3. Upharafini	
4. Niyatheza	
5. Amalahle	
6. Amakhandlela	
7. Ubulongwe	
8. Okunye (chaza)	

2.5.1. Zikhona izinkinga enibhekana nazo kuloluhlobo lwamandla okukhanyisa?

1. Yebo	
2. Cha	

2.5.2. Uma zikhona izinkinga, iziphi?

2.6. Uhlobo lwendlu yangasese?

1. Itanki eli- septic	
2. Eliflashwayo	
3. Elomgodi	
4. Ebhakedeni	
5. Okunye (enaba)	

2.7. Indlela efaka imali ekhaya

1. Impesheni	
2. Imali ethunyelwayo	
3. Umholo womqashi	
4. Imali yezandla zakho	
5. Impesheni yokukhubazeka	
6. Usizo oluvela kubangani	
7. Usizo oluvela kwizihlobo	
8. Okunye (chaza)	

2.8. Kungabe ikhona yini indlela yokufaka imali ekhaya enilahlekele njengoba kunomuntu ongaphilile ngokwengqondo?

1. Yebo	
2. Cha	

2.8.1. Uma ikhona indlela elahlekile, chaza ukuthi loko kusishintshe kanjani isimo sasekhaya?

2.9. Likhona yininushintsho enalwenza ekhaya ukuze niphilisane nesiguli

1. Yebo	
2. Cha	

2.9.1. Uma lukhona, bhala ngalolo lushintsho

3. Imniningwane yongaphilile ngengqondo

3.1. Ubulili

1. Owesifazane	
2. Owesilisa	

3.2. Iminyaka

1. >18	
2. 18-25	
3. 26-35	
4. 36-45	
5. 46-55	
6. >56	

3.3. Ifundo

1. Akakaze aye esikoleni	
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2. Wgcina emazingeni aphansi	
3. Wagcina emazingeni aphakeme	
4. Ezikhungweni zemfundo ephakeme	
5. Esikoleni sabakhubazekile	
6. Okunye (chaza)	

3.4. Ungakwazi ukusho igama lohlobo lokuphazamiseka kwengqondo lwesiguli

1. Yebo	
2. Cha	

3.4.1. Uma kunjalo, chaza ukuthi isiguli sinaluphi uhlobo lokuphazamiseka kwengqondo

3.5. Iziphi izimpawu anazo ophazamiseke ngokwengqondo

1. Wayekhuluma yedwa	
2. Ukuhluleka ukuqonda nokuphendula inkulumo elula	
3. ukukhumula izingubo	
4. Ukuba nodlame singekho isidingo	
5. Ukuhambe ucosha udoti	
6. Ukuphinda izinga elilodwa eskoleni kaningi	
7. Okunye (chaza)	

4. Ukuqondakala kwesifo

4.1. Ukhona yini phambili emndenini oke wangaphila ngokwengqondo?

1. Yebo	
2. Cha	

4.1.2. Bahlobene kanjani lona owayengaphilile ngokwengqondo nalophazamisekile

1. Ubaba	
2. Umama	
3. Umkhulu/ ugogo	

4. Bayalamana	
5. Okunye (chaza)	

4.2. Nabona nini ukuthi lomuntu akasaphilile ngokwengqondo?

1. Eqala nje ukugula	
2. Emva kwezinsukwana	
3. Izinyanga e- 1-3	
4. Izinyanga e- 3-6	
5. Izinyanga e- 6-9	
6. Izinyanga e- 9-12	
7. Emva konyaka	
8. Emva kweminyaka e-2 kuyaphezulu	

4.2.1. Kucelakala uchaze ngokwenzeka ngalesi sikhathi?

4.3. Iziphi izinyathelo enazithatha nisafisa ukuthola ukuthi isiguli sinani?

1. Isiguli sayiswa emtholampilo	
2. Isiguli sayiswa esangomeni	
3. Isiguli sayiswa enyangeni	
4. Isiguli sayiswa kumfundisi/umprofethi	
5. Azikho izinyathelo ezathathwa	
6. Okunye (chaza)	

4.3.1. Imuphi umuntu owanazisa kahle ukuth isiguli sigula ngokwengqondo.

1. Udokotela wesilungu	
2. Umhlengikazi	
3. Inyanga/ sangoma	
4. Umthandazi / umfundisi	
5. Isihlobo	
6. Okunye (enaba)	

4.4. Iziphi izinyathelo zokuqala enazithatha emva kokwazi ngokugula?

1. Isiguli saqala ukusebenzisa imshanguzo	
2. Isiguli saqhubelwa esibhedlela ukuze sihlolisiswe	
3. Isiguli sayiswa ekhaya labagula ngengqondo	
4. Kwenziwa umsebenzi othile ksiwiguli	
5. Isiguli sahanjiswa esangomeni ukuze silashwe	
6. Isiguli sahanjiswa enyangeni ukuze silashwe	
7. Isiguli saqala ukuthwasa	
8. Isiguli saqala ukusebenzisa amakhambi esintu	
9. Isiguli sathandazelwa sasebenzisa iziwasho	
10. Kwafuneka usizo lwezempilo emva kokuth ungabi khona umehluko memva kokusebenzisa amakhambi esintu	
11. Okunye (chaza)	

4.4.1. Kwaba imuphi umphumela walezo zinyathelo?

4.5. Kwakunzima yini ukutholela isiguli usizo ekuqaleni kokugula?

1. Yebo	
2. Cha	

4.6. Ukwaziswa ngokuthi isiguli sigula ngokwengqondo kwaba nomthelela kuwena?

1. Yebo	
2. Cha	

4.6.1. Uma wabakhona, kwaba namuphi umthelela kuwena?

4.7. Ukwaziswa ngokuthi isiguli sigula ngokwengqondo kwaba nomthelela ekhaya?

1. Yebo	
2. Cha	

4.7.1. Uma wabakhona, kwaba namuphi umthelela ekhaya?

4.8. Kwakuthatha iskhathi esingakanani ngaphambi kokuba ufuna usizo lwezempilo?

1. Kuqala nje ukugula	
2. Emva kwezinsukwana	
3. Izinyanga e 1-3	
4. Izinyanga e 3-6	
5. Izinyanga e 6-9	
6. Izinyanga e 9-12	
7. Ngaphezu konyaka	
8. Ngaphezulu kwemnyaka e -2	

4.9. Kwake kwenzeka wangahlala ekhaya ongaphilile ngokwengqondo?

1. Yebo	
2. Cha	

4.9.1. Kwaba isikhathi esingakanani engahlali ekhaya?

1. Amasonto ambalwa	
2. Izinyanga e 1-3	
3. Izinyanga e 4-6	
4. Izinyanga e 7-9	
5. Izinyanga e 10-12	
6. Unyaka o-1 kuya kwe-3	
7. >3	
8. Okunye (chaza)	

4.9.2. Ungachaza ukuth wayehlalaphi lona ogulayo ngalesi sikhathi

1. Engaweni yabagula ngokwengqondo	
2. Emphakathini kodwa hhayi ekhaya	
3. Emgwaqeni	
4. Asazi	

5. Elope ehamba ngezinyawo izindawo ezahlukene	
6. Okunye (chaza)	

5. Ngokomnakekeli

5.1. Ngokwakho yini edala ukugula ngokwengqondo?

1. Umoya omubi	
2. Ubuthakathi	
3. Abaphansi abathukuthele	
4. Ukuhlakanipha kakhulu	
5. Into eyenzeka engqondwen yomuntu	
6. Isimo sezempilo	
7. Isigameko esamushaqisa kakhulu	
8. Okunye (chaza)	

5.2. Iyiphi indlela obona ukuth ifaneleke kakhulu ukubhekane nesifo sokugula ngokwengqondo?

1. Ukumyisa emtholampilo	
2. Ukumyisa esangomeni	
3. Ukumyisa enyangeni	
4. Ukumyisa kumfundisi	
5. Ukumyisa kumprofethi	
6. Ukumyisa ekhaya labangaphilile ngokwengqomndo	
7. Okunye (Chaza)	

5.3. Ngokucabanga kwakho izindlela zokwelapha zesilungu zingakwazi yini ukuthola umsuka ziqondisise ukugula ngokwengqondo ngokuphelele?

1. Yebo	
2. Cha	

5.3.1. Uma kungenjalo, yin indaba ukholelwa ekutheni abazempilo ngeke bakwazi bebedwa ukuthola umsuka baqondisise ukugula ngokwengqondo?

5.4. Ukhona yini umuntu omaziyo owake welapha ukugula ngokwengqondo ngezindlela zesinto?

1. Yebo	
2. Cha	

5.4.1. Uma kunjalo, lwaba khona yini ushintsho kogula ngokwengqondo?

1. Yebo	
2. Cha	

5.4.2. Uma lwabakhona ushintsho, yiziphi izinyathelo ezathathwa ukuze lube khona ushintsho?

1. Isiguli waala ukuthwasa esangomeni	
2. Isiguli wayiswa esangomeni kuyobhulwa umsuka wokugula ngokwengqondo	
3. Isiguli wayiswa enyangeni ukuyokwelashwa	
4. Isiguli senzelwa usiko oluthile	
5. Isiguli sayiswa kumuntu wezenkolo ukuze sithole usizo	
6. Okunye (chaza)	

5.5. Ngokucabanga kwakho ikhona yini indlela ekungeziwa ngayo ukuth kuhlenganiswe izindlela zokwelapha zesintu nezesilungu ukuze kulapheke ukungaphili ngokwengqondo

1. Yebo	
2. Cha	

5.5.1. Uma kunjalo, veza ukuthi iyiphi indlela abezempilo abangasebenzisana ngayo ngabesintu?

1. Abasemtholampilo bangabambisana nenyanga ukuze kulashwe isiguli	
2. Abasemtholampilo bangabambisana nesangoma ukuze kulashwe isiguli	
3. Abasemtholampilo bangabambisana nabezenkolo ukuze kulashwe isiguli	
4. Okunye (chaza)	

5.6. Ngokubheka kwakho ikuphi okuhle okungaphuma ekutheni kuhlenganiswe lezi zindlela zokwelapha?

1. Kunganqaba ukubhebbhetheka kokugula uma usizo lwezempilo lutholakale ngesikhathi	
2. Ukwelulama kwabaphazamisekile nghokwengqondo ngoba izifo zengqondo zilashwa ngokufanele	
3. Ukuqondisisa ukuthi kuyini ukuphazamiseka ngokwengqondo kungenza ukuthi kwehle ukucwaswa kwabagulayo	
4. Kunganyuka izinga lokubambisana phakathi kwezempilo, ezamasiko kanye nezenkolo	
5. Ukunyuka kwezinga leziguli lokugcina imlandelo yezempilo ngenxa yokusekwa kwaloko izinhlangothi zonke	
6. Okunye (chaza)	

6. Ulwazi lomphakathi

6.1. Ngokucabanga kwakho umphakathi unalo yini ulwazi ngokuthi kuyini ukungaphili ngokwengqondo?

1. Yebo	
2. Cha	

6.1.1. Uma kungenjalo, kungani umphakathi ungenalo ulwazi ngokuphazamiseka kwengqondo?

6.2. Iziphi izinkolelo ezijwayelekile emphakathini ngokugula ngokwengqondo?

1. Isiguli asifuni ukulalela abaphansi	
2. Isiguli sithakathiwe	
3. Isiguli besihlakani phe kakhulu	
4. Isiguli asifuni ukuyothwasa	

6.3. Imuphi umthelela ezinawo lezi zinkolela kwisiguli nawe njengomnakekeli waso?

1. Ukuxhwaswa umphakathi	
2. Izihlobo nabangani baziqhelelanisa	
3. Ukungamenywa emcimbini	
4. Ukungaziswa ngalutho olwenzeka emphakathini	
5. Ukudatshukelwa umphakathi	
6. Akubanga namthelela	
7. Okunye (chaza)	

6.4. Kwake kwenzeka ukuthi isiguli sithole ukungaphatheki kahle emphakathini ngenxa yokuthi asiphilile ngokwengqondo?

1. Yebo	
2. Cha	

6.4.1. Uma kwake kwenzeka, kucelakale uchaze.

6.4.2. Kwaba nawo yini umthelela kwisiguli ukungaphatheki kahle emphakathini

1. Yebo	
2. Cha	

6.4.2.1 Kwaba namuphi umthelelo kwisiguli ukungaphatheki kahle emphakathini?

1. Isiguli sasingasafuni ukuhlanganyela nomphakathi	
2. Isiguli saphatheka kabi	
3. Isiguli saba nodlame	
4. Isimo sokugula kwesiguli sabhebbhetheka	
5. Isiguli sakhetha ukuhamba endaweni	
6. Okunye (chaza)	

6.4.3. Kwaba yini nomthelela kuwena ukungaphatheki kahle kwesguli?

1. Yebo	
2. Cha	

6.4.3.1. Kwaba namuphi umthelelo kuwena ukungaphatheki kahle emphakathini

1. Kwafanela isiguli sigcinwe ekhaya ukuze sivikeleke	
2. Kwaphoqa ukuthi sande isikhathi sokunakekela isiguli ukuze singeke sibe sodwa	
3. Kwafanele ngichazele isiguli ngokucwaseka kwaso nokungaqondisis komphakathi	
4. Kwangiphatha kabi kakhulu	
5. Kwafanele sithuthe isiguli emphakathini	
6 Okunye (chaza)	

6.5. Uma ubheka umangase umphakathi ube nolwazi ngokuphazamisek kwengqondo ungasiphatha kahle isiguli

1. Yebo	
2. Cha	

6.5.1. Iziphi mhlawumbe izinto obona ukuth zingashintsha ekuphathekeni kwesguli emphakathini?

1. Isguli singasizakala uma sidinga usizo emphakathini	
2. Ngeke sisakuthola ukucwaseka isiguli	
3. Ngeke kusahlekiswa ngesiguli	
4. Ngeke sisahlukumezeka isguli emphakathini	
5. Okunye (chaza)	

6.6. Yini ocabanga ukuth idala ukuthi umphakathi ungabi nolwazi ngokuphazamiseka kwengqondo?

1. Ukungabi khona kwendawo ezofundisa umphakathi	
2. Izinkolelo zakudala ngokugula ngokwengqondo	
3. Izincazelo ezivela kwabesintu ngokugula ngokwengqondo	
4. Izincazelo ezivela kwabezenkolo ngokugula ngokwengqondo	
5. Okunye (chaza)	

6.7. Yini engenziwa ukuze umphakathi ufundiseke ngezifo zokungaphili ngokwengqondo?

7. Ukuthola izinsiza

7.1. Iziphi izinsiza azitholayo ongaphilile ngokwengqondo?

1. Onompilo	
2. Osonhlalakahle	
3. Abasizi abazimele	
4. Amahhovisi aka SASSA	
5. Okunye (chaza)	

7.1.1. Lezizinsiza ezingenhla ingabe zikunika luphi usizo?

7.2. Ukude kangakanani umtholampilo oseduze?

1. <500 m	
2. 0-1 km	
3. 2-5 km	
4. 6-10 km	
5. 11-15 km	
6. 16-20 km	

7.2.1. Kuhambeka kanjani uma niya emtholampilo?

1. Amatekisi	
2. Kuhanjwa ngezinyawo	
3. Imoto encane	
4. Nge ambulansi	
5. Okunye (chaza)	

7.2.2. Kufanele uye nini emtholampilo

1. Kanye ngenyanga	
2. Kanye ezinyangeni e 3	
3. Kabili ngonyaka	
4. Kanye ngonyaka	
5. Uma ngingaphilile kuphela	
6. Nhlobo	
7. Okunye (chaza)	

7.3. Sikude kangakanani isibhedlela esiseduze

1. <500 m	
2. 0-1 km	
3. 2-5 km	
4. 6-10 km	

5. 11-15 km	
6. 16-20 km	

7.3.1. Kuhambeka kanjan uma kuyiwa esibhedlela

1. Amatekisi	
2. Kuhanjwa ngezinyawo	
3. Imoto encane	
4. Nge ambulansi	
5. Okunye (chaza)	

7.3.2. Kufanele uye kangaki esibhedlela

1. Kanye ngenyanga	
2. Kanye ezinyangeni e -3	
3. Kabili ngonyaka	
4. Kanye ngonyaka	
5. Uma ngingaphilile kuphela	
6. Nhlobo	
7. Uma kushiwo emtholampilo	

7.4. Sikhona isikole sabakhubazeke ngokwengqondo esiseduze?

1. Yebo	
2. Cha	

7.4.1. Uma sikhona, useke wafunda yini kusona ongaphilile ngokwengqondo?

1. Yebo	
2. Cha	

7.4.1.1. Kwaba imuphi umphumela waloko?

7.5. Nake naxhumana nosozonhlala kahle mayelane nodaba longaphilile ngokwengqondo?

1. Yebo	
2. Cha	

7.5.1 Uma nake naxhumana, chaza ukuthi kwakwenzenjani nize nixhumane?

7.6. Nisaxhumene mnamanje naye usonhlala kahle?

1. Yebo	
2. Cha	

7.6.1. Uma kuwukuthi anisaxhumani, isiphi isizathu esidala loko?

7.7. Wake wafika unompilo ekhaya?

1. Yebo	
2. Cha	

7.7.1. Uma ake afika, iluphi usizo enake naluthola kunompilo?

7.7.2. Ikuphi okwaba umphumela walolosiza enaluthola kunompilo?

7.8. Ninalo yini ulwazi ngempesheni yokukhubazeka ngokwengqondo?

1. Yebo	
2. Cha	

7.8.1. Nanithole kanjani ngempesheni yokukhubazeka ngokwengqondo

1. Kwizinkundla zokuxhumana	
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2. Kunompilo	
3. Kuzonhlalakahle	
4. Kwizihlobo	
5. Kubangani	
6. Ukhona esimaziyo owayeyihola	
7. Okunye (chaza)	

7.9. Ongaphilile ngokwengqondo uyayihola impesheni yokukhubazeka ngokwengqondo?

1. Yebo	
2. Cha	

7.9.1. Chaza ukuthi iziphi izinto okumele uzenze noma ezenziwayo ukuze uthole impesheni yokukhubazeka ngokwengqondo

7.10. Sekuytisikhathi esingakanani isiguli sihora lempesheni?

1. Ngaphansi kwezinyanga ezi-6	
2. Sekuphele unyaka	
3. Iminyaka ezi -2	
4. Iminyaka ezi-3	
5. Iminyaka ezi-4	
7. Iminyaka emi-5	
8. Iminyaka eyi-6	
9. Iminyaka eyi-7	
10. Iminyaka eyi-8	
11. Iminyaka eyi-9	
12. Iminyaka eyi-10	
13. Iminyaka engaphezu kwe-10	

7.11. Seniyivuselele kangaki le mpesheni?

1. Asikaze	
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2. kanye	
3. kabili	
4. kathathu	
5. kane	
6. kahlanu	
7. kasthupha	
8. kaskhombisa	
9. ka -8	
10. ka -9	
11. ka -10	
12. ngaphezulu kwe-10	

7.12. Imusiza ngayiphi indlela lempesheni ongaphilile ngokwengqondo?

1. Ithenga izingubo zokugqoka nokudla	
2. Kugitshelwa ngayo makuyiwa emtholampilo noma esibhedlela	
3. Ithenga ismhanguzo yesiguliu	
4. Isiguli asikho ekhaya asisizakali ngalemali	
5. Uyazisebenzisela yena ngokwakhe	
6. Okunye (chaza)	

7.13. Isiza ngani lempesheni ekhaya?

1. Ithenga ukudla kwasekhaya	
2. Ithenga izidingo zasekhaya (ugesu)	
3. Ikhokhela izingane ezikoleni	
4. Isiza ingane yesiguli	
5. Okunye(chaza)	

7.14. Zikhona izinkinga enake naba nazo ngalempesheni

1. Yebo	
2. Cha	

7.14.1. Uma zake zabakhona, iziphi lezo zinkinga?

8. Ukunakekela ogulayo

8.1. Zikhona yini izimfundiso owake wazithola ngokunakekela ongaphilile ngokwengqondo?

1. Yes	
2. No	

8.1.1. Uma zikhona owazithola, ubani owayekufundisa?

8.1.2. Zathatha isikhathi esingakanani lezi zimfundiso?

1. Ngaphansi kwehora	
2. Amahora ambalwa	
3. Usuku	
4. Izinsuku ezimbalwa	
5. Ngaphansana kweviki	
6. Inyanga	
7. Okunye (chaza)	

8.1.3. Chaza ukuthi ikuphi owakufundiswa kulezi zimfundiso

1. Ukusiza isiguli sithathe imshanguzo	
2. Ukusiza isiguli nezinto ezenziwa nsukuzonke	
3. Ukukwazi ukuqonda sesiguli	
4. Ukukwazi ukumela izimo ezinzima zesiguli	
5. Okunye (chaza)	

8.2. Ongaphilile ngokwengqondo uyadinga yini ukuthi umsize ukwenza izinto zansukuzonke?

1. Yebo	
2. Cha	

8.2.1. Uma edinga, iziphi izinto adinga kuzona

1. Ukudla	
2. Ukugeza	
3. Ukugqoka	
4. Ukuthatha imshanguzo	
5. Ukuvuka nokungena embhedeni	
6. Okunye (chaza)	

8.3. Ukhona okusizayo ngokunakekela isiguli uma ungekho?

1. Yebo	
2. Cha	

8.3.1. Uma ekhona okusizayo, chaza ngokuth ungubani lona, usiza kanjan

1. Ingane yomnakekeli	
2. Olamana nesiguli	
3. Umakhelwane	
4. Umngani	
5. Isihlobo	
6. Ingane yesiguli	
7. Omunye (chaza)	

8.4. Ikhona imshanguzo ethathwa ongaphilile ngokwengqondo?

1. Yebo	
2. Cha	

8.4.1. Uma ikhona, ubani oyilandayo imshanguzo?

1. Umnakekeli	
2. Isihlobo	
3. Umngani	
4. Ilunga lomndeni	
5. Umakhelwane	
6. Omunye (chaza)	

8.4.2. Itholakala kuphi imshanguzo yongaphilile ngokwengqondo

1. Emtholampilo	
2. Esibhedlela	
3. Siyalethelwa ekhaya	
4. Okunye (chaza)	

8.5. Ubani osiza ongaphilile ngokwengqondo ngokuyithatha imshanguzo?

1. Umnakekeli	
2. Isguli siyazithathela imshanguzo	
3. Okhpna ekhaya uyamsiza	
4. Umngani	
5. Isihlonbo	
6. Omunye (chaza)	

8.6. Ingabe uyidla ngendlela efanelekile imshanguzo ongaphilile ngokwengqondo?

1. Yebo	
2. Cha	

8.6.1. Uma kungenjalo, kungani ogulayo engathathi imshanguzo ngokufanelekile?

1. Isiguli asikho ekhaya	
2. Isiguli asifuni ukuthatha imshanguzo	
3. Kwesinye isikhathi usuke engekho ekhaya	
4. Kuyangokuthi isiguli sizizwa kanjani	
5. Okunye (chaza)	

8.7. Sekuyisikhathi esingakanani ethatha imshanguzo ongaphilile ngokwengqondo?

1. Izinyanga 1-3	
2. Izinyanga 3-6	
3. Izinyanga 6-9	
4. Izinyanga 9-12	
5. Iminyaka 1-3	

6. Iminyaka 3-6	
7. Iminyaka 6-9	
8. Ngaphezu kwe 10 lemyaka	
9. Okunye (enaba)	

8.9. Njengomuntu onakekela ongaphilile ngokwengqondo lukhona yini ushintsho olubonayo kwisiguli?

1. Yebo	
2. Cha	

8.9.1. Uma lukhona iluphi loloshinstho?

1 Ogulayo akasenalo udlame	
2. Ogulayo useyakwazi ukuzenzela izinto zansuku zonke	
3. Ogulayo useyakwazi ukuzwa alandele imiyalelo	
4. Ogulayo akasakhulumi yedwa	
5 Ogulayo akasakhumuli izingubo	
6. Ogulayo useyakwazi ukuxoxa intesile	
7. Ogulayo useyafunda esikoleni futhi uyaphumelela	
8. Okunye (chaza	

8.10. Ingabe ungumuntu onodlame yini ongaphilile ngokwengqondo?

1. Yebo	
2. Cha	

8.10.1. Uma kuke kwenzeka abe nodlame, kucelakale uchaze ukuthi lube njani loludlame

1. Ogulayo washaya noma akinye umnakekeli	
2. Ogulayo wabulala izinto ekhaya	

3. Ogulayo washaya noma wakinya umuntu wasekhaya	
4. Ogulayo washaya noma wakinya ozama ukumnthinta	
5. Ogulayo washaya noma wakinya Ilunga lomphakathi	
6. Okunye (chaza)	

8.10.2. Kwakwenzenjani aze abe nodlame ongaphilile ngokwengqondo

1. Ogulayo uvele abe nodlame kungenzakale lutho	
2. Ogulayo uba nodlame uma umthinta	
3. Ogulayo uba nodlame makufanele athathe imshanguzo	
4. Ogulayo uba noidlame makukhona ingakuzwisisi kahle	
5. Ogulayo uba nodlame makuthintwa izinto zakhe	
6. Okunye (chaza)	

8.11. Iziphi ezinye izingqinamba obhekana nazo ekunakekelenin umuntu ongaphilile ngokwengqondo?

9. Ukuthola usizo lwengqondo

9.1. Wake wahlolwa ingqondo ogulayo?

1. Yebo	
2. Cha	

9.1.1 Uma kungenjalo, yini edala loko?

1. Ogulayo wabaleka ekhaya	
2. Indawo ehlola ingqondo ikude kakhulu	
3. Ayikho indawo ehlola ingqondo esiyaziyo	
4. Kunzima ukuhamba nogulayo	

5. Ogulayo akafuni ukuhlolwa ingqondo	
6. Kuyabiza kakhulu ukuthola ukuhlolwa kwengqondo	
7. Okunye (chaza)	

9.2. Uya kangaki kohlolwa ingqondo?

1 Akakaze ahlolwe	
2. Kanye ngenyanga	
3. Kanye ezinyangeni ezi-3	
4. Kanye ezinyangeni ezi-6	
5. Kanye ngonyaka	
6. emva kweminyaka	
7. Njalo masizovuselela impesheni	
8. Okunye (enaba)	

9.3. Wayehlolwaphi ingqondo ongaphilile ngokwengqondo?

1. Emtholampilo	
2. Esibhedlela	
3. Endaweni ekhokhelwayo	
4. Endaweni yabagula ngokwengqondo	
5. Okunye (chaza)	

9.4. Iyiphi indlela enihamba ngayo uma eyohlolwa ingqondo ongaphilile ngokomqondo?

1. Amatekisi	
2. Ngezinyawo	
3. Ngebhasi	
4. Ngemoto encane	
5. Okunye (enaba)	

9.5. Kuyimalini ukugibela nesiguli usiyisa lasihlolwa khona ngokwengqondo

1. Ngaphansi kwa- R50	
2. R50 – R100	

3. R100-R200	
4. R200-R300	
5. R300-R400	
6. R400-R500	
7. Ngaphezulu kwa - R500	
8. Kumahhala	
9. Okunye (chaza)	

9.6. Kungabe lemali isuke iphuma kuwe

1. Yebo	
2. Cha	

9.6.1. Uma ngabe ingaphumi kuwe, isuke iphumaphi?

10. Izinhlelo zokuvuselela noma ukululamisa

10.1. Wake weza ngezinhlelo zokuvuselela noma ukululamisa ongaphilile ngokwengqondo?

1. Yebo	
2. Cha	

10.1.1. Uma wazi, ubani owakwazisa ngalezi zinhlelo?

1. Unompilo	
2. Usezonhlalakahle	
3. Abasemtholampilo	
4. Ezinkundleni zokuxhumana	
5. Umngani noma ishlobo	
6. Okunye (chaza)	

10.1.2. Chaza kabanzi ngalezi zinhlelo?

10.2. Likhona uhlelo lokuvuselela noma lokululamisa ongaphilile ngokwengqondo emphakathini?

1. Yebo	
2. Cha	

10.3. Likhona uhlelo lokuvuselela noma lokululamisa angafinyelela kulo ongaphilile ngokwengqondo?

1. Yebo	
2. Cha	

10.4. Wake waba ingxenye yohlelo lokuvuselela noma ukululamisa ongaphilile ngokwengqondo?

1. Yebo	
2. Cha	

10.4.1. Uma ake aba ingxenye yaloluhlelo vchaza ukuthi loku kwakwenzeka kuphi nendawo.

1. Kwinhlangano ezimele endaweni	
2. Kwafanele sihambe siye endaweni yokululamiswa	
3. Khona emphakathini	
4. Endaweni yabagula ngokwengqondo	
5. Emtholampilo	
6. Esibhedlela esiseduze	
7. Okunye (chaza)	

10.5. Ongaphilile ngokwengqondo waba ingxenye yaloluhlelo lokuvuselela noma ukululamisa isikhathi esingakanani?

1. Izinsukwana	
2. Amasonto ambalwa	
3. Izinyanga e 0-3	
4. Izinyanga e 6-12	
5. Ngaphezulu konyaka	
6. Ngaphezulu kwemnyaka e 2	
7. Namanje usayingxenye	

10.6. Kwaba imuphi umphumela wokuthi ongaphilile ngengqondo abe yingxeny yohlelo lokuvuselela noma lokululamisa?

1. Ogulayo wayeseqonda imiyalelo elula	
2. Ogulayo wakwazi ukuqhubeka afunde	
3. Ogulayo wakwazi ukufuna umsebenzi	
4. Ogulayo wakwazi ukuzinakekela	
5. Ogulayo wayesekwazi ukuhlala nabantu	
6. Ogulayo wayesekwazi ukusiza ekhaya	
7. Okunye (chaza)	

10.7. Zikhona izinto ezichithisa isizungu ezenziwayo zabantu abangaphilile ngokwengqondo ezikhona?

1. Yebo	
2. Cha	

10.7.1. Uma zikhona, iziphi lezozinto?

1. Ezemidlalo	
2. Ukuya ezitolo	
3. Ukuya epaki	
4. Ukucula nokudansa	
5. Okunye (chaza)	

10.7.2. Uke azenze kanjani ongaphilile ngokwengqondo?

10.8. Zikhona yini izinto zabantu abangaphilile ngokwengqondo kwizinto ezenziwa emphakathini?

1. Yebo	
2. Cha	

10.8.1. Uma zikhona, iziphi lezozinto.

1. Izivande zomphakathi	
2. Imcintiswano yomphakathi	

3. Ukuhlinwa komphakathi	
4. Ukufunda kwamahhala ephakathini	
5. Ukuhambela imicimbi	
6. Okunye (chaza)	

10.8.2. Uke abe ingxenye yazo lezozinto kanjani ongaphilile ngokwengqondo?

10.9. Zikhona yini izinhlangano ezizimele emphakathini?

1. Yebo	
2. Cha	

10.9.2. Likhona usizo enake naluthola kuzona lezo zinhlangano?

1. Yebo	
2. Cha	

10.9.3 Uma lukhona usizo, kucelakala uchaze ngalolo sizo.

10.10. Uma engakaze abe ingxenye, phawula ngokungabi khona kwalezi zinhlelo emphakathini.

11. I-COVID-19

11.1. Ingabe i- COVID-19 ibile yini nomthelela kongaphilile ngokwengqondo?

1. Yebo	
2. cha	

11.1.1. Uma ibile nomthelela, chaza ngalowo mthelela?

1. Ukubhebbetheka kokugula	
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2. Ukungakwazi ukuyobona abezempilo njengokujwayelekile	
3. Ukuvalwa thaqa kwezwe kwadala ukukhathazeka kogulayo	
4. Ukungahlolwa kwengqondo	
5. Ukungakwazi ukuthola usizo lwezokululamisa njengenjwayelo	
6. Okunye (chaza)	

11.2. Ingabe i- COVID-19 ibile nomthelela kuwena njengomnakekeli womuntu ogulayo?

1. Yebo	
2. cha	

11.2.1. Ikulethele luphi ushintshi njengomnakekeli

1. Kwanda isikhathi sokunakekela ogulayo njengoba izimpawu zokugula zabhebbhetheka	
2. Kwalahleka indlela eletha imali ekhaya ngenxa yokuvalwa thaqa kwezwe	
3. Kwaphazamiseka indlela ekuhlezi kwenzeka ngayo izinto ekhaya	
4. Kwafanele nginakekele ikhaya ngibe nginakekela nesiguli	
5. Ngaba nokukhathazeka ngenxa yokungazi ukuth ikusasa lisiphatheleni	
6. Ngaqalwa ukugula okusha	
Okunye (chaza)	

11.3. Ingabe uyitholile yini imali yesbonelelo se COVID-19?

1. Yebo	
2. cha	

11.3.1. Uma ungayitholanga, ingaba kudalwa yini loko?

1. Angizange ngiyi aplayele	
2. Ngangingabalwa kwabazoyithola	

3. Angiyitholanga ngenxa yokuhola enye impesheni	
4. Angizange ngiphumelele ekutheni ngiyithole	
5. Okunye (chaza)	

11.3.2. Uma usitholile ingabe sikusize ngani isibonelelo?

1. Sibe indlela engeziwe efaka imali ekhaya	
2. Sisize ekuthengeni ukudla kwasekhaya	
3. Sisize ekukhokheleni izingane esikoleni	
4. Sisize ekunakekeleni ogulayo kancono	
5. Sibe iyonandlela yokuth kungene imali ekhaya	
Okunye (chaza)	

11.4. Ibile yini nomthelelo I COVID-19 ekutholeni izinsiza

1. Yebo	
2. Cha	

11.4.1. Ingabe yimuphi lowomthelela ekutholeni izinsiza?

11.5. Ingabe i-COVID-19 ibile yini nomthelela ekutholeni usizo lwabangaphilile ngokwengqondo?

11.6. Ingabe zikhona yini izingqinamba esezandile ngenxa ye COVID-19?

1. Yebo	
2. cha	

11.6.1. Uma zikhona kucelakala uchaze kabanzi ngalezi zingqinamba.

12. Imibono

12.1. Bhala izindlela uhulumeni angasiza ngazo kubantu abangaphilile ngokwengqondo.

12.2. Iluphi olunye usizo noma izinsiza ezinganikezwa iziguli?

12.3. Iluphi olunye usizo noma izinsiza ezinganikezwa abanakekelayo?

12.4. Ikuphi okunye ongakuphawula makuza kwisifo sokungaphili ngokwengqondo

12.5. Kukhona yini okunye ongathanda ukukuphawula mayelana nokungaphili ngokwengqondo?

12.6. Kukhona yini ongathanda ukukunezela phezu kwengxoxo esibe nayo namhlanje?

Siyabonga ukuthi ube ingxenye yalolucwaningo.

Appendix iii (Key informant interview schedule)



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4000

HSSREC Research Office
University of KwaZulu-Natal
Research Office: Ethics
Govan Mbeki Centre

Caregiver perception regarding mental health disorders, living conditions and access to psychiatric programs: a case study of KwaXimba, eThekweni District Municipality, KwaZulu-Natal, South Africa.

Research Semi-structured interview questions for the chief

Date: ____/____/____

Village: _____

1. Do you live in KwaXimba?

2. What is your role in KwaXimba?

3. What is your responsibility for the KwaXimba community?

4. How would you describe KwaXimba?

5. Can you identify aspects that the community of KwaXimba is lacking?

6. How would you describe mental health disorders among the community of KwaXimba?

7. What services do you think are available for mentally ill patients in KwaXimba?

8. What do you perceive is the root cause of mental health disorders in KwaXimba?

9. Can you identify any strategies to assist the caregivers of KwaXimba?

10. Are you aware of any Non-Governmental Organisations within the community of KwaXimba?

11. Can you identify the role of Non-Governmental Organisations within the community?

12. Are there any special needs schools in KwaXimba?

13. What opportunities are available for patients with mental health disorders in KwaXimba?

14. Are you aware of rehabilitation programs in KwaXimba?

15. Are you aware of the purpose of rehabilitation programs in respect to mentally ill patients?

16. Are you aware of the spirit of ubuntu within the KwaXimba community?

17. How will the spirit of ubuntu assist in destigmatising mental health disorders?

Appendix iv (Informed consent form in English)



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Informed consent to participate in research

Caregiver perception regarding mental health disorders, living conditions and access to psychiatric programs: a case study of KwaXimba, eThekweni District Municipality, KwaZulu-Natal, South Africa.

You are being invited to consider participating in the research project conducted by Zenelise Mbambo, a Master of Science in Geography and Environmental Management student at the University of KwaZulu-Natal, Westville campus. Your participation in the study is voluntary. Before agreeing to participate, please read the information below and ask questions about anything you do not understand.

PURPOSE OF THE STUDY

The study aims to investigate the challenges faced by caregivers of patients with mental health disabilities, the social (relations with the community) economic (household income and financial) conditions and what the community understands mental health disorders to be in the rural area of KwaXimba, eThekweni Municipality.

PROCEDURES

If you volunteer to participate in this study, you will be asked to do the following:

1. Find a place suitable for yourself and researcher to administer the questionnaire.
2. Both the participant and carer will be expected to keep all COVID-19 regulation (keeping social distance (being far from each other), wearing a mask for the entire time, avoiding any touching by all means, sanitizing hands before and after interview).
3. The participant will be expected to sign the informed consent form.
4. The participant will be expected to answer the structured interview questions in relation to the study's topic.

The questionnaire/interview will take approximately 45-60 minutes of your time.

POTENTIAL RISKS AND DISCOMFORTS

There are no potential or known risks and anything that might make the participant uncomfortable during participation in this study. The study will strictly go through the questionnaires with caregivers of patients with mental health disorders only, at no point will the patient or person living with the mental illness be required to answer or be present or part of the research.

CONFIDENTIALITY

The researcher will keep participant information private and protected, no details of who the participants are will be published or shared with the public at any point. The participants will sign the informed consent form which will hold the researcher responsible for protecting the identities (details of who the participants are) until the end of the research. If a participant can be identified by the position they hold in society, that individual will be made aware of such a situation and asked to be a participant fully aware of that. All the information (data) collected from the from the administration of questionnaires and interview will be kept at the University of KwaZulu Natal for 5 years before being disposed. All data will be saved in student folders which only the student has access to as it requires a personal password to access.

PARTICIPATION AND WITHDRAWAL

Taking part in this study is voluntary and participants have the right to withdraw or stop the administration of the questionnaire or interview at any point in time without any negative results. Participants also have the right to not answer any questions they may feel uncomfortable with. There are no direct benefits (any form of payment or rewards) from participating in this research.

IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about this research, please contact supervisor Dr. Nkomo at (031) 260 1149 or co-supervisor Dr. Desai at (031) 260 2955 or Zenelise Mbambo at [REDACTED].

INFORMED CONSENT FORM

I _____ (full name and surname of participant) have read and understood the above about the nature of this research project and consent (agree willingly) to participate in the research project.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without negative results.

I hereby also provide consent to audio-record my interview YES ☐ NO ☐

If applicable, I understand that I may be able to be identified by my position and I give my consent for my position to be linked to my responses. YES NO ☐ N/A ☐ ☐

Printed name of participant

Signature of participant

Date

Signature of witness

Date

Appendix v (Informed consent form in IsiZulu)



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Research Office: Ethics
Govan Mbeki Centre

Ifomu lokuvuma ukuya yingxeny yocwaningo

Caregiver perception regarding mental health disorders, living conditions and access to psychiatric programs: a case study of KwaXimba, eThekweni District Municipality, KwaZulu-Natal, South Africa.

Uyamenya ukuba ube yingxeny yocwaningo lweriseshi eyenziwa uZenelise Mbambo, owenza iziqu zakhe ze Master of Science in Geography and Environmental Management enyuvesi yaKwaZulu Natali, e Westville Campus. Ukuba yingxeny yalolucwaningo kungokuzithandela. Ngaphambi kokuba uvume ukuba yingxeny, uyacelwa ukuba ufundisise loku okubhalwe ngezansi futhi ubuze lapho ungazwisisi khona.

Inhloso yocwaningo

Lolucwaningo lwenziwa ngenhloso yokubhekisisa nokuphenya ngezingqinamba ezibhekana nabantu abanakekela abantu abangaphilile ngokwengqondo ezindaweni zasemakhaya, isimo sempilo yasemakhaya abo kanjalo nezingqinamba ababhekana nazo emiphakathini abaphila kuyo yakwa Ximba, phansi kukamasipala waseThekwini.

Okuzokwenzeka

Uma uvuma ukuba yingxeny yalolucwaningo, uzocelwa ukuba wenze lokhu okulandelayo:

1. Thola indawo elungele ukuthi kwenzeke inkulumo ngxoxo.
2. Nobabili wena ovumile nomcwaningi kulindeleke ukuth niyilandele yonke imigomo ye COVID-19 (ngokuth nishiye iskhala phakathi kwenu esingange metre, ukuhlamba izandla nge sanituizer ekuqaleni nasekugcineni, ukugwema ukuthintana ngakho konke nokugqoka i musk ize iphele inkulumo ngxoxo).
3. Kuzolindeleka ukuth usayine ifomu lokuvuma ukuba yingxeny yocwaningo.
4. Kuzolindeleka ukuth uphendule imibuzo elungiswe umcwaningi engocwaningo.

Inkulumo ngxoxo izothatha iskhathi esingangemizuzu engama 45 kuya kwengama 60 esikhathini sakho.

Okungaba ingozi noma kudale ungakhululeki

Akukho nokukodwa okuzodala ukuthi ube sengozini noma ungakhululeki ngokuba ingxenye yalolucwaningo. Ucwano ngoluzokhuluma nomuntu onakekela lona ongaphilile ngokwengqondo kuphela, akadingeki ndawo lona ongaphilile ngokwengqondo.

Ukugcinwa kobunini

Umcwaningi uzobuvikela ubunini bakho ovumile ukuba yingxenye yocwaningo, imininingwane yakho ayizovela ezindaweni azobhala kuzo umcwaningi. Ukusayina ifomu lokuvuma kuyambophezela ukuth afihle imininingwano yakho umcwaningi. Uma kukhona osesikhundleni esingamveza ukuthi ungubani isicelo sokuthi avezwe uzosisayina. Lonke ulwazi oluzoqoqwa kulezi zinkulamo ngxoxo luzogcinwa enyuvesi yaKwaZulu Natali iminyaka emi 5 ngaphambi kokuba lulahlwe ngendlela efanelekile.

Ukuba yingxenye nokuyeka

Ukuba yingxenye yalolucwaningo kungokuthanda, akukho ngempoko. Osevimile ukuba yingxenye unelungelo lokusho uma esefuna ukuyeka ngaphandle kokuthi enzekelwe utho olubi. Uma kukhona umbuzo ongakhululekile ukuwuphendula unelungelo lokungawuphenduli. Ayikho inzuzo etholakalayo ngokuba yingxenye yalolucwaningo.

Ongabathinta ngocwaningo

Uma unemibuzo noma izikhalazo ngocwaningo ungathinta uSupervisor ongu Dktl. Nkomo kule nombolo (031) 260 1149 noma u Dktl. Desai kule nombolo (031) 260 2955 noma umcwaningi uZenelise Mbambo kule nombolo [REDACTED].

Ifomu lokuvuma

Mina _____ (igama lakho nesibongo) ngifundile ngaqondisisa okubhalwe ngenhla ngase ngiyavuma ukuba yingxenye yalolu cwano ngoluzokhuluma.

Ngiyavuma ukuth ukuba yingxenye kwami kulolucwaningo kungokuthanda kwami futhi ngingayeka yinoma inini ukuba yingxenye ngaphandle kokwenzekelwa okubi.

Ngiyavuma ukuthi umcwaningi aqophe inkulamo ngxoxo yethu **YEBO** ☐ **CHA** ☐

Uma kwenzeka, ngiyaqonda ukuth kungenzeka ngikhombeke ngenxa yesikhundla sami futhi ngiyavuma ukuth izimpendulo zami zingaqondaniswa nami **YEBO** ☐ **CHA** ☐
AKUNGITHINTI ☐

Igama nesibongo loyingxenye

Ukusayina koyingxenye

Usuku

Ukusayina kongufakazi

Usuku

Appendix vi (Ethical clearance letter)



10 October 2022

Zenelise Nosipho Mbambo (216003895)
School Of Agri Earth & Env Sc
Westville Campus

Dear ZN Mbambo,

Protocol reference number: HSSREC/00004742/2022

Project title: Caregiver perception regarding mental health disorders, living conditions and access to psychiatric programs: a case study of KwaXimba, eThekweni District Municipality, KwaZulu-Natal, South Africa.

Degree: MSc

Approval Notification – Expedited Application

This letter serves to notify you that your application received on 12 September 2022 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

This approval is valid until 10 October 2023.

To ensure uninterrupted approval of this study beyond the approval expiry date, a progress report must be submitted to the Research Office on the appropriate form 2 - 3 months before the expiry date. A close-out report to be submitted when study is finished.

HSSREC is registered with the South African National Research Ethics Council (REC-040414-040).

Yours sincerely,



Professor Dipane Hlalele (Chair)

/dd

Humanities and Social Sciences Research Ethics Committee

Postal Address: Private Bag X54001, Durban, 4000, South Africa

Telephone: +27 (0)31 260 8350/4557/3587 Email: hssrec@ukzn.ac.za Website: <http://research.ukzn.ac.za/Research-Ethics>

Founding Campuses:  Edgewood  Howard College  Medical School  Pietermaritzburg  Westville

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