

Social Policy and Public Health

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Patient Perceptions and Experiences of Public Healthcare Services in the Presence of a Healthcare NGO: A Qualitative Study in Moutse Valley, Sekhukhune, Limpopo, South Africa

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This thesis has been written as a study assignment under the supervision of an Utrecht University teacher. Ethical permission has been granted for this thesis project by the ethics board of the Faculty of Social and Behavioral Sciences, Utrecht University, and the thesis has been assessed by two university teachers. However, the thesis has not undergone a thorough peer-review process so conclusions and findings should be read as such.

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Abstract

Background: The public healthcare system in South Africa grapples with limitations that hinder comprehensive patient care. Moutse Valley, located in the Sekhukhune district of Limpopo, presents an intriguing scenario where Ndlovu Care Group (NCG), an NGO, initially played a crucial role in bolstering healthcare services during the HIV epidemic. As HIV prevalence waned, the provision of NCG assistance shifted to private channels which were no longer free of charge. Research questions: This study seeks to explore the perceptions and utilisation patterns of public healthcare services among residents of Moutse Valley, Sekhukhune district, Limpopo, South Africa. Additionally, it aims to investigate the influence exerted by the presence of NCG on the perception of public healthcare services within this context. Methods: In semi-structured interviews, community members of Moutse Valley were engaged to discuss predisposing, enabling, and needs factors in line with the Andersen model of healthcare utilisation. Results: The study involved 31 participants who were all residents of Moutse Valley at the time of the study. Foremost among the barriers to healthcare utilisation were factors such as limited biomedical knowledge, preference for alternative healing methods, concerns about the quality of public healthcare, transportation issues, and financial constraints. Moreover, comparisons between publicly provided services and the privately funded healthcare by NCG were common, contributing to dissatisfaction with public services. Conclusion: This study sheds light on barriers to accessing public healthcare in Moutse Valley, uncovering quality of care, traditional practices, disease stigma, financial constraints, and transportation issues as key challenges. The presence of NCG's privately funded services has influenced dissatisfaction with public healthcare. Moreover, the Andersen model's application and adaptation underscores the influence of historical factors and highlights the role of NGOs in bridging healthcare gaps. While limitations exist, addressing these issues is imperative given rising disease burdens and healthcare challenges.

1 Table of Contents

1 Table of Contents	3
2 Introduction	5
2.1 Problem Description and Research Questions	5
2.2 Scientific and Social Relevance	7
2.3 Interdisciplinarity	8
2.4 Overview of Existing Research and Theoretical Approach	8
2.4.1 Limpopo's Disease Burden	8
2.4.2 Anderson Model of Health Service Use	9
2.4.3 Predispositioning Factors	10
2.4.4 Enabling Factors	12
2.4.5 Needs Factors: Historical and Contextual	14
3 Research Methods	16
3.1 Design and Procedures	16
3.2 Participants and Recruitment	16
3.3 Variables of Interest and Operationalisation	17
3.4 Data Analysis	18
3.5 Ethical Aspects	18
4 Results and Discussion	20
4.1 Demography of the Participants	20
4.2 Predispositioning Factors	20
4.2.1 Biomedical Knowledge	20
4.2.2 Beliefs and Traditions	22
4.2.3 Disease Stigma	24
4.3 Enabling Factors	25
4.3.1 Financial Status	25

4.3.2 Quality of Care	26
4.3.3 Accessibility	28
4.4 Perceived Needs Factor	30
4.4.1 Comparisons with NCG	30
4.4.2 Gratitude	31
5 Conclusion	33
6 References	35
7 Appendices	40
7.1 Abbreviations	40
7.2 Code Tree	41
7.3 Interview Transcript	42
7.4 Participant Information Letter	48
7.5 Consent Statement	53
7.6 Pharma Ethics Approval Letter	54

2 Introduction

2.1 Problem Description and Research Questions

While visitors wait in front of a ward of Philadelphia hospital in Moutse Valley to visit their loved ones, chickens roam through the high grass that grows all over the property grounds. Outdoor corridors connect the ward buildings of the hospital, and the hot sun reflects on rubbish that is scattered in corners outside. The security person in front of the ward yawns, and it is quiet. When going through the buildings of the hospital, no doctors or nurses are to be seen. Many patients are waiting to collect their files in the reception room, but service seems to be rather slow, only one person is handing out files from large shelves that are behind him. This slow pace is also present at a clinic in Ntwane, Moutse Valley, where patients go for primary care needs. A cat walks through the hallway of the clinic - as a protection against snakes, the staff say - and there are some culms on the floor. After waiting for about an hour, only two patients have gotten consultation, and many are still waiting. It is a Friday afternoon and already past 3pm, so the clinic closes soon. Some patients might have to come back on Monday.

This is the reality of public healthcare in rural Limpopo, South Africa in 2023. While many things in South Africa have changed since apartheid ended in the 1990s, healthcare standards remain an issue until today. In the era of apartheid, black population hospitals were described to be similar to prisons by patients due to the inadequate care provided. After spending some time in these facilities, patients would often desire to get out due to the lack of sufficient care (Apartheid Museum, 2023). Nowadays, while most citizens use the state-funded, public healthcare services, only a small, wealthy part of the population can afford high-quality, privatised healthcare. Nationwide, about 71% of the South African

population uses public services (Kelly et al., 2019; Rensburg, 2021), even though these services are underfunded and do not have the capacities to provide quality care for most of their patients (Rensburg, 2021). Government spending on public healthcare per individual was about twelve times less than what health insurance plans for privatised care cost per individual in South Africa (Stats SA, 2017; IFC, 2022). Additionally, Limpopo was one of the provinces that had below-average healthcare funding in 2015 and 2016 (Stats SA, 2017; Phillips, 2017).

Historically, Limpopo is a province which three of the "homelands" or "Bantustans" used to be located in during apartheid, when white people displaced black people into designated areas for racial segregation purposes (Stats SA, 2017; Phillips, 2017). Even though the Bantustans no longer exist, Limpopo remains South Africa's poorest province with an adult poverty rate of 67.5% (Stats SA, 2019). Therefore, upon examining the historical records and statistical information of Limpopo, it is likely that its population does not have adequate access to healthcare. This inaccessibility is also known as *underutilisation* of healthcare services, and was defined by Fetterolf (1999) as "not receiving full range of necessary services because of barriers with access to services, underprescription of services".

What makes this phenomenon unique in the communities of Moutse Valley in Limpopo is that public healthcare services were not always the norm. During the *human immunodeficiency virus* (HIV) epidemic in early 2000s a *non-governmental organisation* (NGO) called *Ndlovu Care Group* (NCG) provided privately funded healthcare services to the local citizens free of charge (NCG, 2021). Over the years, NCG established a multitude of programs to foster development in the communities of Mouse Valley. However, nowadays, the majority of NCG healthcare services are not provided free of charge anymore, as the management of the HIV epidemic has improved. Some of NCG's programs today still include

medical consultations for enrolled members of the programs: for example, in their *Ndlovu Nutritional Unit* (NNU) program, malnourished children are entitled to medical care from NCG's medical centre.

This case presents a thought-provoking circumstance: a community where certain individuals directly encountered the healthcare challenges of apartheid and the HIV epidemic, were initially granted access to privately funded medical services during the height of HIV disease burdens. However, they were subsequently compelled to return to underfunded, public healthcare. When assessing healthcare utilisation, this case can offer a unique patient perspective on the intertwinement of state-funded healthcare and the impact of a NGO.

This poses two questions: 'How do residents of Moutse Valley, Sekhukhune district, Limpopo, South Africa, perceive and utilise public healthcare services?', and 'What impact does the presence of NCG have on the perception of public healthcare services in this context?'

2.2 Scientific and Social Relevance

Unravelling the reasons behind the underutilisation of healthcare services in the specific context of Limpopo holds the potential to enhance accessibility and quality of care, thereby significantly impacting public health outcomes in the region. Despite the considerable challenges stemming from limited funding, little research has been dedicated to investigating this issue within the bounds of Limpopo. While insights from studies conducted in other parts of South Africa offer valuable insights, it is imperative that future policies and interventions are tailored to the unique local landscape. These initiatives must encompass not just biomedical aspects, but also consider cultural and socio-economic dynamics that deeply influence health behaviours.

Given South Africa's notable health inequalities and the high disease burden in Limpopo (Gyekye & Akinboade, 2003), this study could contribute to a broader

understanding of health disparities in other contexts on global scale. Moreover, it has the potential to provide direct input which could serve as a basis for policy making in Moutse Valley. Collaborating between NCG and local government health departments could foster more effective ways to address healthcare needs, using insights from this specific situation. Local stakeholders could tailor interventions and policies where required. Additionally, the collected data has the potential to offer valuable guidance to healthcare clinics to improve accessibility of healthcare services across the community, through the identification of potential barriers.

This study stands as a representative example of a larger phenomenon. Importantly, it highlights a significant divide in South African society, emphasising the need for efforts that ensure all citizens have equal access to healthcare. The findings presented in this study can contribute to the broader goal of enabling every individual to realise their fundamental right to quality healthcare.

2.3 Interdisciplinarity

An essential facet of this study lies in its interdisciplinary approach, which merges insights from different domains regarding the issue at hand. This combination of diverse perspectives from fields such as public health, social policy, economics and anthropology has significantly enriched the study's comprehensiveness. When different fields of knowledge are combined, a full understanding of why people experience healthcare barriers is achieved. This shows how various factors influence individuals' decisions. Collaboration across disciplines highlights the potential for innovative solutions to complex issues.

2.4 Overview of Existing Research and Theoretical Approach

2.4.1 Limpopo's Disease Burden

Considering the lower-than-average healthcare expenditure that Limpopo receives, one might conclude that the services are underutilised due to a constrained prevalence of

diseases. To answer the research questions, there is evidence in the existing literature that this concept can be dismissed. While the disease burden of communicable disease has significantly decreased over the last decade, the overall disease burden remains substantial in Limpopo (Achoki et al., 2022). Just over a decade ago, HIV was the main driver of South Africa's disease burden and killed millions of citizens (Rhele & Shisana, 2003; Bradshaw et al., 2016). Rates of infection and mortality linked to HIV have shown a decline and this trend persists, because of the availability of antiretroviral therapy (ART) and HIV awareness campaigns (UNAIDS, 2023). Meanwhile, non-communicable diseases (NCDs) like cardiovascular diseases, respiratory illnesses, cancer, diabetes and mental illness are on the rise in South Africa (Samodien et al., 2021). Half of the South African population are overweight or obese, and this trend is expected to increase in the next decades (Boachie, 2022). With obesity standing as a significant risk factor for NCDs (WHO, 2023), an increase in the NCD burden can be expected. Particularly in Limpopo, while NCD prevalence is increasing, the province also has one of the highest proportions of disease-adjusted life years (DALYs) attributed to communicable, maternal, neonatal, and nutritional diseases in comparison with the other South African provinces (Achoki et al., 2022). Hence, a demand for healthcare services exists in Limpopo, and additional factors must be considered to comprehend the reasons for the underutilisation of these services.

2.4.2 Anderson Model of Health Service Use

While the literature regarding underutilisation of healthcare services in the Limpopo province is scarce, existing literature focusing on other regions in South Africa nevertheless provides important insights into the most prominent barriers explaining underutilisation in different healthcare sectors. Several reasons that explain underutilisation from different healthcare sectors could be identified. The Andersen Model of Health Service Use provides a systematic framework with which to structure such factors (Chen & Gu, 2022), and it stands

out as one of the most commonly employed frameworks for examining the factors connected to patient utilisation of healthcare services (Phillips et al., 1998). In the Andersen Model, three different components are distinguished which identify determinants that influence an individual's utilisation of healthcare services. Depending on these determinants, a health behaviour can be predicted and improvements to the individual's situation can be made. In order to fit the scope of this research, the model was adapted and simplified.

2.4.3 Predispositioning Factors

The first component of the model describes health beliefs and the demographics of an individual, calling them predispositioning factors (Chen & Gu, 2022). These factors encompass the intrinsic attributes and inclinations of individuals, which influence their inclination to seek healthcare. For instance, gender, age, health knowledge and beliefs or a certain cultural upbringing may predispose an individual toward seeking healthcare (Chen & Gu, 2022).

In the context of Moutse Valley, existing literature has shown that one individual factor which may be significant in utilising healthcare is the biomedical knowledge of an individual. If an individual does not know how to interpret certain symptoms, they may not seek out healthcare services. For example, Maimela and colleagues (2018) found that residents of Limpopo were often unaware of symptoms of NCDs, so they also did not know they needed medical treatment. Mental illness was often associated with witchcraft rather than a biomedical source (Bila & Carbonatto, 2022), and knowledge on different types of cancers also seemed to be rather inadequate (Bhuiyan et al., 2022; Ramathuba & Ngambi, 2018). Cultural beliefs influence the view on biomedical healthcare services. In a study where pregnant women from rural Limpopo were asked if they would visit antenatal care services, many responded that they would be "bewitched" by enemies if they did so (Mulondo, 2020). They claimed that because of their beliefs, they were not allowed to disclose their pregnancy

early on, and some women only made use of the healthcare services in their last trimester (Mulondo, 2020). In a similar study, a participant stated she would not make use of healthcare services because having a male present while a woman is giving birth would be against her cultural beliefs (Nesane et al., 2016). In another study regarding HIV antibody counselling and testing in Limpopo, a participant asserted that undergoing HIV testing was unnecessary as they believed that biomedicine had no capacity to cure acquired immune deficiency syndrome (AIDS); only traditional medicine could do so (Mambanga et al., 2016). Other research conducted in Limpopo inquired whether participants had utilised *Tuberculosis* (TB) testing facilities either prior to or subsequent to diagnosis. Seventy-five percent of the participants stated that they had gone to faith healers after diagnosis, rather than the medical healthcare services (Matakanye et al., 2021). For specific health concerns like influenza, measles, mumps, fever, snake bites, or diarrhoea, rural communities in Limpopo also expressed that there was no need for healthcare service use. These health issues were addressed by traditional practices and a health-conscious lifestyle (Rankoana, 2012). For example, traditional health practitioners administer indigenous plant medicines in order to immunise against certain diseases (Rankoana, 2012).

Apart from biomedical knowledge, disease stigma can be seen as another predispositioning factor in the model. Stigma has the potential to hinder individuals from accessing healthcare services. This hindrance does not only arise from external discrimination due to their illness, but also from the internalisation of this stigma, causing individuals to perceive feelings of guilt or shame because of their disease (Rüsch et al., 2005; Møller & Erstad, 2007).

In South Africa, HIV stigma has been studied extensively. Healthcare services are avoided by individuals because of the fear of testing positive (Adeagbo et al., 2019). Fear of testing positive does not only stem from individual struggles such as the irreversible nature of

the virus, the physical suffering and the fact that it can be lethal (Madden et al., 2020), but rather from the societal perception of why an individual has HIV and the behaviour that is associated with a positive status (Treves-Kagan et al., 2015). People living with HIV experience discrimination and prejudice which often expands into all areas of their lives (Manganye et al., 2013). For instance, stigma can result in extreme social exclusions, going as far as being rejected by family members, or family members refusing to consume food prepared by an individual with HIV (Airhihenbuwa et al., 2009). Having HIV is associated with irresponsibility, and people living with HIV are often blamed for contracting the virus and infecting others (Manganye et al., 2013). Research shows that HIV-positive women are mostly stigmatised, and that sexual promiscuity is associated with being infected with HIV (Yuh et al., 2014). These stereotypes and judgements can stem from a lack of education and knowledge about the disease (Manganye et al., 2013; Gilbert & Walker, 2002), and cannot easily be eradicated (Treves-Kagan et al., 2015). Furthermore, not only the perceptions of patients play a role here, healthcare professionals often treat patients with HIV differently from the other patients and some lack knowledge on transmission of the disease (Delobelle et al., 2009; Chambers et al., 2015). Apart from HIV, other diseases in South Africa are stigmatised as well, even though most are not studied as extensively as HIV stigma. Stigma around TB in South Africa had shown a decline; however, with the emergence of the HIV epidemic, TB became stigmatised once more due to its frequent linkage with being HIV positive (Wallace et al., 2018). For example, research has indicated that stigma related to TB has been recognised as a hindrance to accessing occupational health units (Sommerland et al., 2017). Furthermore, mental disorders also face stigmatisation in South Africa due to inadequate mental health awareness, which acts as a deterrent preventing individuals from seeking treatment (Sorsdahl & Stein, 2010; Egbe et al., 2014).

2.4.4 Enabling Factors

Enabling factors encompass the resources and tools that facilitate or hinder an individual's ability to access healthcare. Examples for this could be the availability of transportation to the healthcare facility, the financial situation of an individual or perceived quality of care of the healthcare service that is provided (Chen & Du, 2022).

The latter is a crucial determinant because if people believe that the care they receive is of high quality, they are more likely to utilise healthcare services. This perception can include factors such as the competence of healthcare providers, the cleanliness and modernity of facilities, the responsiveness of staff, and the overall patient experience (WHO, 2020). In the literature, the issue of quality of care frequently emerged as a barrier to the utilisation of healthcare services in the Limpopo province. Waiting time was often criticised to be very long in healthcare facilities, which then resulted in poor patient care because of time pressure (Nesane et al., 2016; Masemola, 2021). Patients said they have to clear up an entire day, and that lengthy administrative procedures at the clinics would take up a lot of time (Nesane et al., 2016). Furthermore, shortages in medication and personnel contribute to the criticism of the quality of care, and clinics sometimes have to open late and close early, simply because there is not enough staff (Douglas et al., 2021; Delobelle et al., 2009; Masemola, 2021). This also contributes to the long waiting times for patients (Douglas et al., 2021). However, even in situations where clinics are operational and patients have interactions with healthcare providers, research on chronic disease care indicated that there are instances when medical personnel lack comprehensive training and expertise in managing these health conditions effectively (Maimela et al., 2018). Similar observations were noted in the case of nurses tending to HIV patients, with a recognised need for enhanced training to bolster their capabilities in delivering high-quality care to patients (Delobelle et al., 2009). Moreover, an investigation into physiotherapy services in Limpopo revealed that language barriers posed challenges in both the provision and receipt of care (Maphosa, 2022).

The theme of accessibility was a recurring topic in the literature as well. Research highlighted inadequate infrastructure in Limpopo as a prevailing issue. Additionally, the distance to healthcare facilities occasionally acted as a barrier for patients, who faced challenges of time constraints and limited transportation means (Douglas et al., 2021; Nesane et al., 2016; Maphosa, 2022).

As outlined in the Problem Description (2.1), a significant portion of Limpopo's population lives in poverty, and only a mere five percent have health insurance (CMS, 2020). Viewed through the lens of an enabling factor, this suggests that scarce financial resources can pose a barrier to accessing healthcare services unless they are offered free of charge.

2.4.5 Needs Factors: Historical and Contextual

The third component of the Andersen model, "Needs," pertains to individuals' inclination toward healthcare services (Chen & Gu, 2022). This stems from their personal evaluation of their health and functional status (perceived need) as well as medical practitioners' evaluations of patients' health conditions and care necessities (evaluated need) (Chen & Gu, 2022). The perceived need influences specific care-seeking actions, while the evaluated need dictates the nature and extent of medical interventions administered by healthcare professionals (Chen & Gu, 2022). Due to the scope of the study and constrained avenues for consulting medical professionals and obtaining patient data, the model was adjusted to concentrate solely on perceived patient needs. Moreover, in light of the specific case in Moutse Valley, additions were integrated that the original Andersen model does not address. Given the NGO's presence in Moutse Valley, it becomes essential to evaluate the implications of an NGO on the perception of patient needs.

Literature on public health NGOs in South Africa shows that they play a crucial role by addressing gaps in the healthcare system and enhancing the accessibility and quality of healthcare services for marginalised populations (Nxumalo et al., 2013). Through various

initiatives such as community outreach programs, health education campaigns, and provision of essential medical services, NGOs have contributed to raising awareness about available healthcare resources and promoting positive attitudes towards seeking medical assistance (Humphries at al., 2011). Scholarly works propose that the additional assistance extended by NGOs, particularly in the realm of healthcare, can maximise sustainable benefits for the healthcare system when these NGOs collaborate closely with the national or municipal health department (Pillay, 2022). This collaboration ensures that NGO interventions and projects align harmoniously with the department's policies and optimise their impact (Pillay, 2022).

3 Research Methods

3.1 Design and Procedures

To address the research questions, semi-structured interviews were used to gather insights from Moutse Valley community residents. While most of the questions adopted a qualitative approach through open-ended questions, a few incorporated quantitative elements such as closed-off questions to enhance comprehension of demographics and overarching patterns. This methodology was chosen to get a detailed insight into a small number of participants' perception of healthcare. Additionally, interviews ensured privacy for each participant and made participation accessible for illiterate individuals. In order to eliminate language barriers, the interviews were conducted in the local languages English, Sepedi and isiZulu, with help of social and community workers of NCG. An interview transcript in English is attached in the *appendix* (7.3). Whenever participants felt more comfortable communicating in languages other than English, a community worker would be present during the interview to facilitate translation between languages.

The qualitative essence of this study can be regarded as an asset in comprehensively grasping the intricacies surrounding the underutilisation of healthcare services in Moutse Valley. This approach aids in highlighting the drivers contributing to this matter. While the outcomes may not be applicable in a statistical universal sense, this case offers valuable theoretical insights that could potentially be extended to similar contexts.

3.2 Participants and Recruitment

Participants for this study needed to fulfil certain criteria: they needed to be 18 years or older and be a resident of one of Moutse Valley's communities in Sekhukhune district. For recruitment, the researcher actively engaged in NNUs' meetups, events aimed at providing meals to undernourished children and educating caregivers about child nutrition and other relevant parenting subjects. This method was agreed upon after consulting with employees of

NCG to recruit participants, and for the researcher to get access to the community in a safe way. Furthermore, entering the community through a trusted institution like NCG also helped participants to feel more comfortable during interviews.

Having a community or social worker present did not only help with the literal translation of the interviews, but also enhanced the research with interesting insights of translation of the social context by the social or community worker. Participation in the interviews was entirely voluntary, and participants were not coerced into joining. However, a drawback of this recruitment approach lies in the potential for participants to perceive indirect pressure to partake. To counteract this potential bias, an information letter was read to them before participation, explicitly assuring them of no negative consequences for abstaining and affirming that their relationship with the community worker would remain unaffected by their decision. Verbal consent was sought if participants chose to participate. Initially, the study's details and the contents of the informed consent forms were explained, followed by a query about allowing electronic recording of interviews for those who agreed. Once consent for recording was obtained, participants were again asked for consent on recording before the interview questions commenced. The decision to refrain from using written consent was made due to potential literacy challenges and potential hesitancy to sign documents.

A strength of this sampling and recruitment method was that data from the local context could be gathered, which may be different from other regions in Limpopo or South Africa. A weakness can be seen in the fact that the sampling was not randomised and only opinions of those who are willing to participate are represented in the results.

3.3 Variables of Interest and Operationalisation

In *overview of existing research and theoretical approach* (2.4), the themes that emerged from existing literature included biomedical knowledge, health beliefs and

traditions, disease stigma, quality of care, accessibility, financial status and the influence of an NGO on the public healthcare system. While only focusing on these themes would force a preconceived result, questions including these themes were asked. On top of this, there were open questions where participants could answer more freely to get a more detailed and open insight in how people perceive healthcare and what their attitudes are towards it.

3.4 Data Analysis

All interviews were transcribed with help of software, and manually where software could not understand the South African accent. For the analysis, an integrated coding approach was used. This approach retains the benefits of inductive coding and line by line analysis, but also allows certain new codes and themes to develop. Themes identified in the literature also helped and guide this process. Furthermore, the entire research was guided by experts, namely the internship and thesis supervisors, in order to ensure credibility. Results were shared at University of Utrecht with the thesis supervision team in order to defend the Master thesis. Data dissemination to the local community was coordinated by Moderator Morongwa Magongoa and the NCG community engagement team. The findings may be subsequently communicated to the *Limpopo Department of Health*, aiming to provide feedback to local authorities concerning the research subject.

3.5 Ethical Aspects

To uphold research ethics, the researcher consistently reiterated to each participant that they were under no obligation to answer questions and could decline participation without encountering adverse repercussions. To assure this, the instruments were pre-tested with local social and community workers before commencing data collection, and their feedback on question phrasing and consent forms was sought. The researcher took measures to prevent any form of coercion among participants, ensuring that their decision to participate or not had no impact on the roles of social or community workers.

Considering that some interview topics, such as disease stigma or exposure to certain diseases could be sensitive in the South African context, all questions were phrased as openly as possible, to not purposefully evoke negative emotions. Moreover, a small sample size might raise ethical concerns since it may not accurately reflect the genuine viewpoints of local residents. However, to gain profound insights into certain local perceptions, a limited sample size was the practical choice. This limitation was acknowledged when analysing the data.

Additionally, the researcher collaborated with NCG, establishing a mutual vested interest in the success of this research. Consequently, the researcher exercised particular caution to avoid imposing any outcomes and focused only on analysing data-driven findings, irrespective of whether they proved beneficial to the research objectives or the NCG.

4 Results and Discussion

4.1 Demography of the Participants

Thirty-one individuals participated in the study and allowed to be recorded during their interviews. Participants had varying levels of English, meaning that twenty-three interviews could be conducted in English, and for eight interviews a healthcare worker was present to translate English into Sepedi or isiZulu and vice versa. Participants' ages ranged between 19 and 71 years old, with an average of 33 years and a median of 30 years. Two participants chose not to disclose their gender, all other participants identified as female. Twenty-six of the participants culturally identified as being Sepedi, two identified as Sotho, one identified as isiZulu, one as Setswana and one as Tsonga. Only two participants stated that they were married, two were widowed and all others were unmarried. All participants were residents of the Moutse Valley, from four different communities. Fifteen lived in Marapong, eight lived in Thabakhubedu, six in Phooko and two in Elandsdooring at the time of the interview. Eighteen participants said they were Christian, ten affiliated with traditional beliefs, two did not have a religion and one participant stated she was Agnostic.

4.2 Predispositioning Factors

4.2.1 Biomedical Knowledge

Participants in the study were asked if they could connect symptomatics to a specific disease or illness when they felt sick or had pains in their body or mind. Almost all participants indicated that usually they would not know and would seek out help at the clinic, sometimes they would consult family members before. In order to better understand the level of biomedical knowledge, participants were asked about six different diseases that community healthcare workers and social workers from NCG had described to be very common in the community. These diseases included cancer, COVID-19, HIV, mental

disorders, *sexually transmitted infections* (STIs) and TB. Almost all participants only had limited knowledge regarding the causes of these diseases.

When asked about the cause of TB, participants who answered often associated working with dust or cement as the cause, others mentioned drinking alcohol as the cause. Knowledge on the cause of cancer was low, although some participants mentioned drinking alcohol as a risk factor. Interestingly, in one community, Phooko, several participants stated that they had heard that putting coins in one's bra could cause cancer. When asked to elaborate, one participant said that she was not sure why, but that it was a local rumour. The cause for mental disorders was often associated with stress, but also ancestral reasons. The cause for COVID-19 was unknown by most participants, and some questioned the existence of the disease. Even though knowledge on biomedical causes of HIV and STIs was low, many participants were aware of how HIV and STIs are transmitted and how they can be prevented. Commonly, participants answered "having sex without protection and mix of *blood*" as the cause of HIV. This wide-spread knowledge could be linked to the campaigns which NCG established in the community. The campaigns were still visible in the streets of the communities, there were big signs with slogans like "Men with balls play it safe, tata no chance". After speaking with staff of the Ndlovu Medical Centre, it became clear many resources for HIV management had been brought to the community. From free testing, free education, free condoms and free counselling for those affected as well as their family members, everything was taken care of. HIV counsellors told stories about how they had managed to eradicate stigma in families and made people accept the status of themselves or their loved ones. And even though nowadays, many resources of the campaign are part of NCG's privatised healthcare, some are still accessible in the community. For instance, at the NNUs, caregivers get education on HIV and other STIs. Even in this small sample, it shows that health literacy campaigns can have a strong effect.

4.2.2 Beliefs and Traditions

Furthermore, regardless of religious beliefs, in the sample, almost all participants claimed that they would use the public clinic or hospital as their primary healthcare provider when they got sick. Only one participant who said to not get sick often mentioned relying on prayer before considering any alternative assistance. This discovery is intriguing because scepticism toward the medical system or religious convictions commonly hinder healthcare access in South Africa (Moll, 2021), yet these factors do not appear to be applicable within the context of Moutse Valley. This underscores the significance of healthcare facilities within the Moutse Valley region, emphasising the necessity for their effective operation and adequate provision of care. Acknowledging that within this community sample, distrust was limited and participants displayed a willingness to engage with healthcare services is important to highlight. This recognition holds importance as distrust towards such facilities is often difficult to overcome in communities (Moll, 2021).

Most of the participants in the study said they were either Christian or believed in African traditional religion. Christianity and traditional religions blend together in South Africa, so someone may consider oneself a Christian, and also believe in ancestral healing practices done by the *Sangomas*, the traditional healers. Even though clinics were the primary point of contact when healthcare services were needed, Sangomas were often used as secondary care services. Headaches or mental health problems were cited as health concerns for which participants reported seeking assistance from Sangomas, as these concerns frequently carried associations with ancestral issues. A participant also claimed she would go to Sangomas when she simply felt uncomfortable at the clinic because of the nurses' attitudes:

"Yeah, I am trying to use traditional medicine cause I don't want to go to the clinic. [...] I mean like a headache, for that I would rather go to traditional. Last time there was even this

problem of my vagina. I don't know it's a rash or something? [...] Yeah, itching. So I'm wondering, what can I do, cause I don't want to go to the clinic. Then I bought the garlic. But I didn't know what it was [the symptoms]. I didn't want to talk to anyone to ask what is going on. Then I bought garlic, and I chopped it and put it in hot water. And then I steamed my vagina with that. I felt like it was better. And even now, it's still itching, but not that much." This finding is intriguing as it shows the intertwinement of cultural health beliefs with the structural issues of the public healthcare system. While there is a willingness to visit public healthcare services, the attitudes of nurses can be identified as a barrier, leading participants to find traditional healing methods more appealing.

Most participants who elaborated on Sangoma healing practices mentioned undergoing treatments that involved consuming a concoction similar to herbal tea or applying steam infused with this herbal blend to a specific body part, occasionally containing dead snakes. Furthermore, Sangomas would throw bones from deceased animals and interpret the arrangement they formed. This allowed them to provide participants with information regarding their ancestral heritage and offer guidance on dispelling curses or spells that might have been cast upon them. When inquired, participants frequently expressed contentment with the care provided by Sangomas, despite its cost *(See section 4.3.1 for further details).* Waiting times at the Sangomas were short and Sangomas were described to be friendlier than nurses at the clinics.

Prophets at church were not as popular as Sangomas in the participant sample, but some individuals said they would go to prophets for advice. From a healthcare perspective, prophets seemed to be part of psychiatric care, and would guide people in crisis and listen to their problems. Since there are no psychiatrists or psychologists in Moutse Valley, Sangomas and prophets seem to take over the role and facilitate mental healthcare services to some extent.

Complementary and alternative medicine (CAM), the phenomenon of combining different approaches to healthcare, is common in South Africa (Peltzer, 2009). The use of traditional healing methods is not just about addressing physical symptoms but also about fostering a sense of connectedness with one's heritage, ancestors, and the natural world (Peltzer, 2009). The integration of traditional healing practices within the broader healthcare system can be complex (Peltzer, 2009). There are ongoing discussions about how to bridge the gap between biomedical healthcare and traditional healing, ensuring that patients have access to safe and effective treatments while respecting cultural beliefs and practices (Hollenberg, 2007).

4.2.3 Disease Stigma

In the sample, most participants said that they had never experienced or witnessed discrimination because of any disease. Some participants even highlighted that they or their family members are openly HIV-positive, and elaborated that HIV is not something one should be ashamed of.

Among the limited number of participants who disclosed encountering discrimination, they further explained that the discrimination was targeted specifically at their HIV-positive status. A 19-year old mother said her mother had insulted her and blamed her for contracting HIV at such a young age because of her promiscuity. Another participant opened up about her family situation, where a sibling with positive HIV status was excluded in the household by another sibling: *"She doesn't want to share a cup with her, and she doesn't want her child to play with that baby because her mother is sick."*

One participant explained that in the clinic, nurses had judged patients who were HIV-positive, and that sometimes, information about an individual's status was even shared on social media. NCG social workers shared accounts explaining that HIV was extremely stigmatised in the past, and that comparatively, incidences of HIV related stigmatisation or discrimination are rather rare. Other stories from NGC social workers revealed that in the past, there were extreme cases where parents of disabled children killed their children because Sangomas had claimed the children were cursed. While over the years, disease stigma in Moutse Valley has drastically decreased, it is not entirely eradicated. Therefore, while this might not be universally applicable, the information implies that for certain individuals, stigma could potentially still serve as a barrier hindering access to healthcare services.

4.3 Enabling Factors

4.3.1 Financial Status

Only three of the participants were employed at the time of the interview, and only one participant relied entirely on her salary from her occupation. All other participants relied entirely or partly on government grants. The majority of participants specifically indicated that these grants were allocated as child grants, which during the time of the interviews, ranged between R 480 and R 500 per child per month. This range was affected by an increment on April 1, 2023. On average, participants had two children, which was also the median of the sample. Consequently, the majority of participants had a monthly income of R 1000 through child grants (after the increment). Only one participant in the study claimed they had health insurance, namely medical aid, all other participants said they entirely relied on free healthcare services or had some out of pocket healthcare expenses. Interestingly, although the cost of a session with a Sangoma ranged, approximately R 300 fell at the midpoint of this spectrum. Notably, when considering that most participants indicated child grants as their sole source of income, averaging R 1000, the expense of R 300 for a Sangoma consultation appears proportionally high. This observation could once more indicate the formidable strength of belief in Sangoma practices (*See section 4.2.2*).

4.3.2 Quality of Care

Almost none of the participants were entirely satisfied with the healthcare services in Moutse Valley. The clinic in Marapong was often the focus of these complaints because participants in the three communities used this facility the most. Some comments were directed at the clinic in Ntwane. Almost all participants referred to the only hospital in the region, Philadelphia hospital, whenever they made comments about a hospital.

Many different themes emerged from the data, with participants revealing discontent across a range of issues regarding the care they received. Primarily, attitude from healthcare workers towards patients was criticised. This was consistent in the hospital and clinics, participants often said that nurses were rude and did not care for the patients' needs. While not all participants perceived the nurses to be rude, those who did were prompted to provide further insight. One participant conveyed that nurses at the clinic simply did not believe her when she recounted her symptoms. Another participant revealed that there was no confidentiality in clinic settings, nurses would openly talk about patient information in the corridor where patients wait for consultation. In the hospital, a 30 year old, unmarried participant was being yelled at by a nurse while giving birth:

"Yoh, she [the nurse] was so rude. So rude. She said to me 'You are still young, why did you get pregnant at your age?' [...] She said 'I didn't tell you to go there and sleep with him, why did you get pregnant?' And she said 'Stand still, don't move around.' She said a lot of things. And while I was in pain. [...] The time I was in labour, she stood there. I was in pain, screaming, and she just stood there and said to me 'Shut up! Shut up! You're making noise!'."

The participant further explained that she was not given any painkillers and only received sufficient care after the baby was born. Another participant raised concerns about staff shortages, which she linked to the negative attitude exhibited by certain nurses at

Philadelphia hospital: "And find more staff. We understand that money is not there for paying many nurses or many doctors, but if they can improve to make sure that clinics and hospitals, those people don't work long hours, I think it would be better. Because if you're dealing with many people, believe me, you're going to be depressed yourself, then take out the stress to the patient, then it's become a problem."

When participants talked about their experiences when visiting the clinic, medicine seemed to be an important part of the treatment participants were getting. When asked, participants often could not indicate which kind of medicine they were receiving for specific symptomatics. Yet, the presence or absence of medicine was considered as a means to judge if the clinic visit had been successful. Participants often reported that medicine was not available at the clinic, but it was unclear which medicine was the focus of these statements. Apparently, nurses often split up doses of medication, and would then distribute a certain number of tablets from a blister to regulate the availability of medication for longer. One participant reported she had not received her medication in a month, while breast feeding her newborn. Later in the interview, she revealed that she was HIV-positive and the medication she was usually given was ART. Not receiving medication at the clinic or at the hospital can be quite dramatic for community members of Moutse Valley because the only available alternative to receive medicine is at the private pharmacy. With most participants in this sample relying on government grants for their survival, spending money on medication is often not an option. The specific participant who was not receiving her ART at the time also seemed unaware of how crucial the treatment was for her, highlighting the avoidable, physical harm that insufficient healthcare and unavailability of medication can exacerbate.

Waiting time and general availability of healthcare was criticised specifically in the context of the clinics. The average waiting time participants described exceeded two hours, while some described they would have to wait an entire day. Participants described they

would have to journey to the clinic early in the morning since clinics operated on a first-come first-serve base. Appointments for certain days could be made, but without specification of time. Opening or closing hours of the clinics were uncertain, and participants stated that healthcare workers often disappeared during their lunch break for extensive amounts of time. Another complaint that was stated frequently was that participants found clinics and the hospital dirty, outdated and dysfunctional. In the clinic in Marapong, there was no running water and therefore the toilet was not working, while patients endured long waiting hours as described above. Cats were seen at the clinics, and sometimes floors were dusty or covered in hay. The hospital had chickens roaming outside the wards, and a participants stated: *"They can change the environment of the hospital. Especially start to be clean as much as they can. When you speak about health, you speak about cleanliness. So if the department is not clean itself, that's a problem. That one must change."*

Apart from cleanliness, issues regarding dysfunctionality were described by another participant: "Maybe they should provide a good service for the patients. Let's talk about Philadelphia. They lack generators. Now, if there's loadshedding, they say the generators are short, and if patients who are using the machines, it becomes a problem, people are dying." South Africa has a ongoing problem with scheduled power outages, commonly referred to as "Loadshedding" (Eskom, 2023). External electricity generators are supposed to bridge the gaps in the electricity supply, and failure of such generators in hospital settings poses an extreme flaw in healthcare delivery, putting patients lives at risk.

4.3.3 Accessibility

Participants described that they either walked or took the only public transport option available in the area - namely taxi buses - to the clinics or the hospital. Most participants described that taxi buses would cost R 30 per person for a trip to the nearest clinic and back. While healthcare services by themselves can be accessed free of charge, transport to the

facilities can bear hidden costs. Therefore, in the case of Moutse Valley, accessibility of healthcare is intertwined with the financial opportunities of an individual (See section 4.3.1). In other words, this means that if an individual cannot afford R 30 for transportation costs, they are simply unable to access the healthcare facility. Especially participants from Thabakhubedu saw accessibility as a barrier in their healthcare experience. Thabakhubedu is furthest away from the other communities, and does not have its own clinic. Should residents of this community require urgent medical attention, they rely entirely on their ability to afford public transportation or depend on assistance from fellow community members for transportation.

Access to the only hospital was also limited. A participant claimed that only one ambulance serves the entirety of Moutse Valley, and numerous participants recounted instances where ambulances failed to arrive or experienced extreme delays. A woman shared a story about how she nearly delivered her baby in a taxi bus due to the absence of an ambulance, making it to the hospital just in time for the delivery.

Another commonly described way to access healthcare facilities, especially the clinics, was walking. Participants stated that walking to the clinic would usually take them about one to two hours each way. Because of the first-come first-serve system at the clinics, those who walked often had to leave their houses very early in the morning, when it was still dark. Some women stated they did not feel safe, especially when they went to the clinic by themselves: *"Walking alone, it was safe before. It was safe, but nowadays, oh my God, things have changed. [...] Crime is too high. Maybe people have been raped, ambushed, killed. You never know what's going to happen to you if you get to the bush."*

Walking in groups was perceived as a safer option, leading many participants to express that walking would not be an issue if they were accompanied by others, even in the dark.

4.4 Perceived Needs Factor

4.4.1 Comparisons with NCG

One of the stories deemed particularly impactful and shared during this research involved a NCG community healthcare worker who recounted the experience of a friend who lost her infant in a public hospital. The woman had arrived at the hospital experiencing contractions, but was told by the nurses at the maternity ward that she was not in labour yet. Consequently, she gave birth on the hospital lawn, tragically resulting in the baby's passing. Merely a few kilometres away from the hospital lies NCG's mostly privatised medical centre, where nowadays, having two patients in one day was considered "busy" by one of the healthcare professionals there.

As outlined throughout this paper, history and context are crucial determinants to understand experiences within a healthcare system, including the perceived need of a patient to seek care. Assessing one's own health and the ability to estimate when professional help is needed, including the scope professional aid has to offer, must take into account comparative healthcare experiences an individual has had. Because of NCG's presence and involvement in Moutse Valley over the last three decades, community members have had access to elevated healthcare standards facilitated by dedicated healthcare professionals and funding comparable to that of privatised healthcare. Presently, NCG's medical centre no longer provides care free of charge and operates similarly to other private clinics or hospitals. Nevertheless, the residents of Moutse Valley were previously granted access to this privately-funded care, and from an etic viewpoint, transitioning back to rely on the public healthcare system may feel regressive and disappointing to some. One could even call it a demoralisation, or a disillusion in their healthcare experience. In the sample of the study, not all participants were old enough to experience NCG in times when it still operated as a public HIV clinic, but children who were enrolled in the NNU program are eligible to have consultations (accompanied by their caregivers, the participants of this study) with doctors from NCG free of charge. Therefore, all participants of the study had at some point witnessed the direct comparison between privately funded and public healthcare. healthcare personnel at NCG medical centre recounted an anecdote about the clinic's past, during the HIV epidemic, when queues extended down the street, attracting individuals from distant communities who travelled long distances only to use NCG's services. NCG's healthcare services did not only empower the community of Moutse Valley and save many lives, but the findings of this study also suggest NCG's presence indirectly made residents more critical in what they would set as their standard of care. In response to a question about improving the public healthcare system, a participant in the study captured the emic perspective by stating that "clinics must be more like Ndlovu". Especially within the context of South Africa, a nation marked by historical segregation, the case of Moutse Valley suggests that the true perceived healthcare need does not only call for general improvements in healthcare delivery, but also a broader theme, namely equality. In other words, findings of this study suggest that residents of Moutse Valley perceive public healthcare services in a comparative manner, knowing the private type of healthcare offered behind closed doors.

4.4.2 Gratitude

Despite all the issues participants were describing, some participants also expressed gratitude for the clinics and the hospital, since having some type of healthcare facility is better than to have none at all. Even though this mentality was not shared by all participants, and there is a perceived need for better service, it is an intriguing finding that some participants could also still see the efforts that were already being made. When asked what participants liked about the clinics and the hospital, *"sometimes the service is good"* was a common answer. Also, when asked if there was anything participants wished for, in order to meet their healthcare needs, interestingly the most common answer was about the healthcare

professionals' attitude, rather than other issues with the services. From a policy standpoint and in the pursuit of enhancing the existing healthcare landscape in Moutse Valley, the priority should be an inquiry into the underlying causes of the staff's demeanour. Given the discussion on inadequate healthcare funding outlined in section 2.1, addressing challenges that may not be entirely or directly linked to funding should take precedence.

5 Conclusion

This study has brought to the surface which possible barriers the public healthcare system poses for residents of Moutse Valley. Overall, quality of care seems to be the biggest issue, specifically, patients demand nicer attitudes from nurses and more effective clinics. Other findings could identify predispositioning factors, such as little biomedical knowledge, traditional healing practices and disease stigma as barriers when accessing healthcare services. Furthermore, enabling factors, such as limited financial resources and lack of transportation to healthcare facilities hindered participants to accessing healthcare services. While some participants were grateful for the services that were functional, the exposure to privately-funded, yet freely accessible care provided by NCG is very likely to be part of the reason for the dissatisfaction with public services.

As an exploration of the findings within the framework of the Andersen model of healthcare utilisation reveals, it becomes apparent that this model, while valuable, may not fully account for historical factors like apartheid and the societal divide between private and public healthcare services. The presence of NGOs in the healthcare landscape warrants further exploration to assess their integration within the existing system, thereby aiding in the realisation of South Africans' right to healthcare.

Acknowledging the limitations of this study, it is important to highlight that the scope did not encompass a comprehensive exploration of critical issues such as funding challenges and potential corruption. The demographic profile also excluded men and or employed people, potentially impacting the ecological validity.

In conclusion, healthcare issues in Moutse Valley must urgently be addressed, given the projected increase in disease burdens including pandemics, antibiotic resistance, climate change-related health concerns, and the surge in NCDs (Samodien et al., 2021; WHO, 2020; WHO, 2021; WHO, 2023). The study underscores the pressing need for a transformative

healthcare reform that is responsive to the evolving healthcare landscape and sensitive to historical disparities, providing equitable and quality healthcare for all.

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7 Appendix

7.1 Abbreviations

AIDS	Acquired immune deficiency syndrome	
ART	Antiretroviral therapy	
CAM	Complementary and alternative medicine	
COVID-19	Coronavirus Disease 2019	
DALY	Disease-adjusted life year	
HIV	Immunodeficiency virus	
NCD	Non-communicable disease	
NCG	Ndlovu Care Group	
NGO	Non-governmental organisation	
NNU	Ndlovu Nutritional Unit	
STI	Sexually transmitted infection	
ТВ	Tuberculosis	

7.2 Code Tree

Factor \rightarrow		Theme \rightarrow	Code
1.	$Predispositioning \rightarrow$	Biomedical knowledge \rightarrow	• HIV
			• TB
			• Cancer
			• STI
			• Mental illness
			• COVID-19
		Traditional beliefs \rightarrow	• Faith healers (Prophets)
			• Traditional healers (Sangomas)
		Disease stigma \rightarrow	• HIV stigma
2.	Enabling \rightarrow	Financial status \rightarrow	• Government grant (child grant)
		Quality of care \rightarrow	• Attitude of healthcare professionals
			• Availability of medication
			• Waiting time
		Accessibility \rightarrow	• Public transport
			• Walking
			• Lack of ambulances
3.	Needs \rightarrow	Presence of NCG \rightarrow	• High expectations towards public sector
		Gratitude	

7.3 Interview Transcript

Interview Transcript version 2.0, 24.03.2023/English Qualitative Study in Moutse Valley, Sekhukhune, Limpopo, South Africa.

Semi-structured Interview Transcript

Exploring Willingness of South Africans to seek out Public healthcare Services: Asking open-ended questions (Qualitative Study) in Moutse Valley, Sekhukhune, Limpopo, South Africa

The transcript has been reviewed and been approved by the thesis supervisor and social workers and head of research from Ndlovu Care Group before data collection.

Personal Information:

1.1. Age

18-25
26-35
36-45
46-55
56-65
66 and above

Unknown

1.2. Gender

- □ Female
- □ Male
- \Box Choose not to disclose

1.3. I identify with:

- □ Sepedi
- □ Ndebele
- 🗌 IsiZulu
- □ Tsonga
- 🗆 Venda
- □ other:
- 1.4. Which languages do you speak fluently?
 - 🗆 English
 - □ Sepedi
 - □ Ndebele

- 🗆 IsiZulu
- □ Tsonga
- U Venda
- □ other:

1.5. I live in

- □ Bloempoort
- □ Elandsdooring
- □ Thabakhubedu
- □ Marapong
- D Phooko
- □ Ntwane
- □ Krkvosfontein
- 🗆 Moteti
- □ Newtown
- □ Other

1.6. Are you currently employed?

- □ Yes
- 🗆 No

1.7. What is your main source of income?

- \Box My own salary
- □ My partner's salary
- Government grand
- □ Other.....
- 1.8. Are you married?
 - □ Yes
 - 🗆 No
- **1.9.** What is your religion? (multiple possible)
 - □ Christian
 - 🗌 Islam
 - □ African Traditional Religion
 - □ None
 - □ Other

1.10. Do you have children?

□ Yes

🗆 No

1.10a. If so, how many?

1.11. When you feel sick, where do you usually go for help first?

- Dublic hospital (Philadelphia hospital)
- \Box Local clinic
- □ Private doctors
- □ Traditional Healer
- □ Faith Healer
- □ Family or Friends
- \Box I don't ask for help
- Other.....

1.11a. Why do you go elsewhere (other than Philadelphia)?

1.12. How do you pay for healthcare?

- □ Medical aid (insurance)
- \Box Private funds
- \Box I only use free services
- □ Other.....

Questions:

Knowledge

2.1. When you feel sick, have pains or something is unusual with your body or your mind, do you know which disease it might be?

2.2. When you feel sick, have pains or something is unusual with your body or your mind, and you do not know what might be wrong, how do you usually obtain information about it?

Cultural Beliefs and Traditions

3.1 What is your opinion of traditional healers?

3.1a. In case you go to traditional healers, which services do they provide in regards to your health?

3.2. What is your opinion of faith healers?

3.2a. In case you go to faith healers, which services do they provide in regards to your health?

<u>Accessibility</u>

(Before answering this section, check what they answered about which healthcare service they go to)

3.1. Do you find the Philadelphia hospital accessible?

Yes
No
Other.....

3.1a. If you go to Philadelphia hospital, how do you get there and back?3.1b. If no: Are there other reasons apart from transport that hinder you from visiting Philadelphia hospital? If so, which ones?

3.2. Do people at the Philadelphia hospital speak your language?

□ Yes

🗆 No

3.2a. If not, how do you communicate with the hospital staff?

Quality of Care (this focuses on public healthcare services only)

4.1. What is your opinion of your Philadelphia hospital or other public clinics?

4.2. How often have you been to the Philadelphia hospital in the last year? / When was the last time you went to the hospital?

4.3. If you go to Philadelphia hospital, which healthcare needs do they meet for you? / Which services do they provide for you?

- 4.4. How have staff members in Philadelphia hospital treated you?
- 4.5. How would your healthcare experience ideally be?
- **4.6.** How long do you usually have to wait at the hospital before you get treated/ served?
- **4.7.** What do you like the most and the least about the hospital?

4.7a. Please explain why

4.8. When you need medication, how and where do you get it?

- **4.9.** How often do you get medication?
- **4.10.** Is getting medication easily accessible for you?

<u>Stigma</u>

5.1. Which of the following diseases have you been exposed to in your life? (This means either you or someone close to you has or has had it or them.)

- □ Tuberculosis (TB)
- □ Cancer
- Sexually Transmitted Infections (STI)
- □ Human Immunodeficiency Virus (HIV)
- ☐ Mental illness (like depression, anxiety, trauma)
- Coronavirus disease 2019 (COVID-19)
- □ other

5.1a. Which one(s) has or have impacted your life or the life of someone you're close to the most?

- TB
 Cancer
 STI
 HIV
 Mental illness (like depression, anxiety, trauma)
 COVID-19
- □ other

5.1b. Please explain how.

5.2. Have you ever been tested or screened for any of the diseases above? (You do not have to disclose if you tested positive or negative)

YesNo

5.2a. If so, which ones?

TB
Cancer
STI
HIV
Mental illness (like depression, anxiety, trauma)
COVID-19
other

5.3. From the previous disease, are there any you would not be comfortable seeking help for if you had symptoms?

5.3a. If so, why?

5.4. Have you or someone close to you experienced discrimination because of the above mentioned diseases?

Yes
No
5.4a. If so, where/ by whom and what was your or their experience?

5.5. What do you think is the cause of people getting a disease? (ask for each disease individually below)

5.5a. TB 5.5b. Cancer 5.5c. STI 5.6d. HIV 5.7e. Mental illness 5.8f. COVID-19 5.9g. Other.....

Overall Opinion

6.1. How do you feel about the healthcare system in Moutse?

6.2. Is there anything you wish for your healthcare needs to be met?

7.4 Participant Information Letter

Participant Information version 3.0, 30.03.2023/English Qualitative Study in Moutse Valley, Sekhukhune, Limpopo, South Africa

Participant Information for Participation in (social) Scientific Research

Exploring Willingness of South Africans to seek out Public healthcare Services: Asking open-ended questions (Qualitative Study) in Moutse Valley, Sekhukhune, Limpopo, South Africa

30th March 2023

The Participant information letter will be read out for the participants and if needed translated into their language with the help of a social or community worker.

1 Introduction

Dear Sir, Madam,

Through this letter we would like to ask your permission to participate in the study "Exploring Willingness of South Africans to seek out Public healthcare Services: Asking open-ended questions (Qualitative Study) in Moutse Valley, Sekhukhune, Limpopo, South Africa".

2 Aims: This research aims to understand how public healthcare services in Moutse Valley are perceived, and what can be improved. This is student research and the outcome of this research will be used for the researcher's master thesis.

3 How the research will be done (Design/implementation of the research)

The Design of the study is as follows: community members of Moutse Valley are asked interview questions regarding their perception of healthcare services, and which actions they usually take when feeling sick. The questions will be analysed by the researcher with help of computer software.

4 Background research

Research has shown that public healthcare services are not always accessible for patients and that the quality of care is often not sufficient in South Africa. Little is known about this in the specific local context of Moutse valley. On top of this, in this region, other healing practices are popular and there is stigma or knowledge differences concerning some diseases.

5 Sharing of what the study finds out (Publication of Findings)

Results will be shared at University of Utrecht with the thesis supervision team in order to defend the Master thesis. Data sharing with the local community will be coordinated by Moderator, Morongwa Magongoa and the Ndlovu Research Centre's community engagement team. Results may be shared with the Limpopo Ministry of Health later on in order to give feedback to local authorities regarding the research topic.

6 What is expected of you as a participant

Participating in the study means that the researcher with help of a Ndlovu social or community worker will ask you questions regarding the topic stated above. You can either answer the questions or decide to skip them. The questions will address the following themes regarding healthcare services in Moutse valley: Accessibility, quality of care, cultural beliefs and traditions, knowledge differences and stigma regarding certain diseases. Apart from that, there are no other tasks you as a participant have. The interview will take about 30-40 minutes and will only be performed once per participant. Apart from that, there are no other tasks you as a participant, which could be psychologically straining.

7 Recording

In order for the researcher to translate and analyse the interviews, they will be recorded on a recording device. Once they have been conducted, they will be transferred to a secure virtual environment and only the researcher will be able to access them. The social or community worker who was present during your interview will help the researcher with translation at a later stage, but no third party will have access to the recordings. You will be asked if you consent to a recording before it starts, and once again in the beginning of the recording before the interview starts.

8 Possible advantages and disadvantages of the study for you as a participant

You will not be compensated financially or in any other way for your time and effort. Regardless whether you participate in the study or not, no disadvantage in the relationship with Ndlovu community health workers will result from your decision. If for any personal reason you do not feel comfortable participating, no one will convince you to do so.

9 Confidentiality and processing of your data

This study requires us to collect some personal data from you to understand demographic differences of the answers. Personal data, such as contact information, will be stored separately from the research data itself and kept only as long as necessary. The computer on which the personal data is stored is secured to the highest standards and only researchers involved have access to this data. The data itself is also secured by means of a security code.

See also the RDM support website for example sentences:

Informed consent for data sharing - Research Data Management Support - Utrecht University (uu.nl). If you have difficulties accessing the website because you have no internet access or can't read in English language, the social or community worker in your interview will assist you in finding this information.

All potential locator and/or potential participant identifier data will be de-identified to protect the identification of every participant.

Personal data, such as questions about your political affiliation, religious beliefs, sexuality or other special personal data, we need in order to be able to keep the research questions. We never ask for more of this data than is necessary to answer the specific question. Nor are you required to answer these questions.

The survey data itself (without your contact information) will be retained for a minimum of 10 years. This is according to the appropriate guidelines of the Universities of the Netherlands (formerly VSNU).

10 Voluntary participation

Participation in this study is voluntary. You may withdraw from the study at any time, without giving any reason and without any adverse consequences for you.

11 Contact address for questions and/or complaints

If you have questions or comments about the study, you can contact Morongwa Magongoa, reachable via mmagongoa@ndlovu.com.

If you have an official complaint about the study, please send an email to the complaints officer at <u>klachtenfunctionaris-fetcsocwet@uu.nl</u>.

The social or community health worker who will be there during the interview can assist you with contacting either of the two contacts given above.

12 Privacy questions

If you have any questions about the processing of your personal data, please direct them to privacy@uu.nl. Please also refer to UU's general privacy statement: Privacy statement University of Utrecht - Organization - Utrecht University (uu.nl)

You can read more information about privacy on the website of the Authority.

The social or community health worker who will be there during the interview can assist you with reaching the site mentioned above should you have any issues doing so.

If, after reading this information letter, you decide to participate in the study, please verbally consent to the researcher.

Kind regards, Line Asbahr

Table 1. Elements according to SAGCP, 2020.

Trial involves <i>research</i>	Not applicable (not a trial).
<i>Purpose</i> of the trial	Not applicable (not a trial).
<i>Treatment(s)</i> and probability of receiving each	Not applicable (no treatment received).
<i>Procedures</i> , including all invasive procedures	Asking interview questions. No invasive procedures.
Participant's <i>responsibilities</i>	Answering questions, with option to skip questions or opt out at any point.
Experimental aspects of trial	Not applicable.
Reasonably foreseeable <i>risks</i> or <i>inconveniences</i>	No risks. Inconveniences: Questions may trigger unpleasant memories and may feel psychologically straining for some participants.
Reasonably expected <i>benefits</i> - also if no intended clinical benefit	No benefits.

<i>Alternative</i> procedures or treatments available and their important potential benefits and risks.	Not applicable.
Compensation & treatment for trial-related <i>injury</i>	Not applicable.
<i>Payment</i> for participating in the trial.	(Not a trial). Participants who take part in the interviews will not be financially compensated.
Anticipated expenses	No expenses.
<i>Voluntary</i> participation & right to refuse participation / withdraw without penalty or loss of benefits otherwise entitled to.	Participants can withdraw at any time if they no longer want to participate without facing any penalty or disadvantage. There is no loss of benefits.
<i>Direct access</i> to original medical records without violating confidentiality	Not applicable, no medical records are involved in the study.
Confidentiality	All interviews and associated records are only accessible to the researcher and are confidential. Interviews are held in enclosed rooms for privacy of the interviewee. All records of interviews are stored in a secure, password protected virtual environment. A community healthcare worker may be present during the interview for translation, but is not allowed to talk about any of the information the participants shared in the interviews. No participant information can be shared, only the researcher has access.
Informed of <i>new information</i> that may affect willingness to continue participation	Not applicable.
<i>Contacts</i> for information regarding trial, rights of trial participants and trial-related injury.	Not applicable (not a trial). Contact information regarding general questions or complaints and privacy questions about the study can be found under point 11 and 12.
Circumstances and/or reasons for <i>termination</i> of participation.	As long as participants fulfil the requirement to be 18 years or above, there is no reason for termination of a participant.
Expected <i>duration</i> of participation.	About 30 minutes. This depends on how much participant engages in the questions.
Number of participants involved.	Researcher aims for 30 participants. This

	depends on how many participants are willing to be interviewed at Nutritional Units.
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7.5 Consent Statement

Consent Statement version 2.0, 24.03.2023/English Qualitative Study in Moutse Valley, Sekhukhune, Limpopo, South Africa

Consent Statement

The consent statement will be read out for the participants and if needed translated into their language with the help of a social or community worker.

I hereby declare that the community or social worker has read the information letter regarding the research "Exploring Willingness of South Africans to seek out Public healthcare Services: Asking open-ended questions questions (Qualitative Study) in Moutse Valley, Sekhukhune, Limpopo, South Africa" and agree to participate in the study."

Confidentiality All potential locator and/or potential participant identifier data will be de-identified to protect the identification of every participant.

This means that I agree to:

participation in the study
 collection of my contact information
 collection of special personal data, namely: religious beliefs, source of income

Date: Name: Verbal consent to participate:

"I agree that research data collected for the study may be published or made available, provided my name or other identifying information is not used."

"I understand that the research data, without any personal information that could identify me (not linked to me), may be shared with others."

"I consent that the interview will be recorded electronically so the researcher can translate and analyse it. I understand that no one apart from the researcher and the social or community worker present will have access to this recording."

7.6 Pharma Ethics Approval Letter



PO Box 786, Irene, 0062, Gauteng, Republic of South Africa • 123 Amkor Road, Lyttelton Manor Ext 3, Centurion, 0157 Tel: +27 087 230 8460 • Fax: +27 12 664 7860 • E-mail: marzelle@pharma-ethics.co.za Website: www.pharma-ethics.co.za

12 April 2023

EMAILED

Dr A. Nel Ndlovu Research Centre Plot 1140 Elandsdoorn Limpopo 0470

Fax:

Dear Dr Nel,

PROTOCOL: N/A

EXPLORING WILLINGNESS OF SOUTH AFRICANS TO SEEK OUT PUBLIC HEALTH CARE SERVICES: A QUALITATIVE STUDY IN MOUTSE VALLEY, SEKHUKHUNE, LIMPOPO SOUTH AFRICA

ETHICS REFERENCE NO: 230312345

RE : EXPEDITED REVIEW

The above-mentioned Protocol was reviewed by the Pharma-Ethics Independent Research Ethics Committee Members by means of expedited review, and CONDITIONAL APPROVAL was given for the Investigator to participate. This letter certifies that all conditions were met to the satisfaction of the committee and constitutes the FINAL Ethics approval. Please refer to the attached schedule for a list of documents reviewed and investigators approved.

The study has been accepted as complying to the Ethics Standards, based on FDA, ICH GCP and the Declaration of Helsinki guidelines. The Ethics Committee (IRB) granting this APPROVAL is in compliance with the Guidelines for Good Practice in the Conduct of Clinical Trials in Human Participants in South Africa (2020), Ethics in Health Research: Principles, Processes and Structure (2015), ICH Harmonised Tripartite Guidelines E6: Note: for the Guidance in Good Clinical Practice (CPMP/ICH/135/95) and FDA Code of Federal Regulation Part 50, 56 and 312.

This approval is valid for a period of ONE YEAR. The Ethics Committee is to be supplied with a STATUS REPORT on the progress of the study at least ONCE A YEAR after which the study will be reviewed for annual re-approval. The FINAL REPORT on the outcome of the Study must be submitted upon study completion. Please refer to Pharma-Ethics Standard Operating Procedures for more information regarding applications, amendments, annual re-approval, SAE reporting etc.

The above has been noted for the Ethics Committee information and records.

unforkins

Regards,

Marzelle Haskins cn=Marzelle Haskins, o=Pharma-Ethics, email=marzelle@pharma-ethics.co.za, c=ZA l attest to the accuracy and integrity of this document Centrurion 2023.04.12 12:54:06 +02'00'

MRS MARZELLE HASKINS For and on behalf of Pharma-Ethics

