

Title

A qualitative exploration of the enablers and challenges that mothers of children with disabilities experience in accessing primary healthcare in Lwandle

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March 2023

Declaration

By submitting this research assignment, I declare that the information in this document is my own original work, unless explicitly otherwise stated. I have not submitted this research assignment in full or a partial part thereof in order to obtain a qualification.

Marcia Torres

March 2023

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Dedication

This dissertation is dedicated to my husband and my three daughters who have always been a source of strength, solace and support.

I am grateful for all the encouragement and assistance you have given me during this time period of completing my dissertation. Special thanks to Zoe, you have been a light on my path.

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Abstract (In English)

Introduction

Children with disabilities do need special protection and proper healthcare. The purpose of this study was to gain an insight into the experiences of mothers of children with disabilities on accessing primary healthcare in Lwandle. The main objectives were to identify the enablers and challenges that influenced this healthcare access for their CWD.

Methods

This study had a qualitative approach to answer the research question. Six mothers of children with disabilities, recruited through total population sampling, participated in the research. In-depth data was gathered by face-to-face interviews which were audio recorded. Data was transcribed and analysed through thematic analysis.

Findings

Findings of this study highlight six themes which are: Living in the water, Alone and isolated, I am struggling, Spirituality, Helpful healthcare professionals and Family and neighbours. The demands of caring and the mental health challenges that mothers of CWD experience have an impact on accessing PHC for their children. However, spirituality provides mothers with strength and together with caring healthcare professionals and family, these were identified as enablers to PHC access.

Conclusion

It is critical to also provide the mothers of CWD with optimal care together with their CWD, and the creation of a contextually relevant, multidimensional support system is important going forward to improve health outcomes for CWD.

Abstract (In Afrikaans)

Inleiding

Kinders met gestremdhede het spesiale beskermings en gesondheidsorg nodig. Die doel van hierdie studie was om insig te kry oor die ondervindings van moeders en hulle kinders met gestremdhede, om toegang tot primere gesondheidsorg in Lwandle te hê. Die hoof doel was om die bemagtigers en uitdagings te identifiseer wat toegang tot hierdie gesondheidsorg beïnvloed vir hul kinders met gestremdhede.

Metode

Hierdie studie het 'n kwalitatiewe benadering om die navorsings vraag te beantwoord. Ses moeders van kinders met gestremdhede was gewerf deur totale bevolkingsteekproef-neming en het deelgeneem in die navorsing. In-diepte data was versamel deur aangesig tot aangesig onderhoude met klank opname geneem. Data was getranskribeer en ge-analiseer deur tematiese ontleding.

Bevindings

Bevindinge van hierdie studie lig ses temas uit naamlik: Lewe in die water, Alleen en geïsoleerd, Ek sukkel, Spiritualiteit, Hulpvaardige Gesondheidsorg Personeel en Familie and bure. Die eise van versorging en geestesgesondheid uitdagings wat moeders van kinders met gestremdhede ondervind het 'n impak op toegang van primere gesondheidsorg saam hul kinders. Spiritualiteit verskaf aan moeders krag en saam met sorgsame gesondheidsorg personeel en familie is hierdie instaatstellers tot die toegang van primere gesondheidsorg.

Gevolgtrekkings

Dit is krities om ook die moeders van kinders met gestremdhede tesame hulle kinders, optimale gesondheidsorg te voorsien. Die skepping van 'n kontekstueel relevante, multlidimensionele ondersteunings stelsel is nooddadig om gesondheid uitkomst te verbeter vir kinders met gestremdhede.

Glossary of Terms

Disability

Disability can include impairments, limitations in activities, and/or participation restriction in any area of life, resulting from interactions between a person with health conditions and contextual factors such as the environment or personal factors (WHO, 2001)

Children With Disabilities (CWD)

CWD includes persons below the age of 18 years of age with either a mental, intellectual, physical, and sensory impairment that prevents their complete and adequate participation in society (WHO, 2007)

Primary Health Care

The World Health Organization defines Primary Health Care (PHC) as an approach to address mental, physical, and social health and wellbeing of a person, providing healthcare throughout the life of a person (De Maeseneer et al., 2020).

Access to healthcare

Access to healthcare refers to the ease with which people can obtain the healthcare needed (Nunez et al., 2021)

Caregivers

A caregiver is a person who cares for another person who has difficulties in completing day to day tasks in life and therefore need assistance or supervision because of an illness or disability (Xia et al., 2020)

Community Orientated Primary Care (COPC)

COPC has been described as a continuous process whereby PHC is provided to a specific community based on the needs assessments of this community, the integration of PHC services and public health (Ajudua et al., 2022)

Acronyms and Abbreviations

PHC- Primary Health Care

CWD -Children with disabilities

CRPD - Convention on the rights of people with disabilities

WHO- World Health Organization

UNICEF- United Nations International Children Emergency Fund

CHW- Community Health Worker

COPC- Community Orientated Primary Care

UNHS- Universal New-born Hearing Screening

NPO- Non-profit Organization

FQOL- Family Quality of Life

HRQOL- Health Related Quality of Life

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Chapter 1: INTRODUCTION

1.1 Background of this study

Globally disability is a public health and communal concern (World Health Organization , 2011). Children with disabilities (CWD) are marginalised globally and do face health challenges and unfavourable health outcomes (Asim , 2022). Discrimination and disadvantage towards CWD are further worsened by poverty, the lack of vital services and a hostile and non-inclusive environment (Makwela et al., 2022), despite the Convention on the Rights of Persons with Disabilities (CRPD) Article 17 emphasizing that people with disabilities have the right to respect for physical and mental integrity on the same and equal basis as other people (Minkowitz, 2007).

Disability can include impairments, limitations in activities, and/or participation restraint in any facet of life, resulting from interactions between a person with health conditions and contextual factors such as the environment or personal factors (WHO, 2001). CWD includes persons below the age of 18-years of age with either a mental, intellectual, physical, and sensory impairment that prevents their total and appropriate participation in society (WHO, 2007).

Disabilities in children are conditions that impact and influence the development of children into adulthood (Mathye & Eksteen, 2016). Disabilities in children are common in both high- as well as low-income countries. The aetiology of disability in children is caused by prenatal, perinatal, and postnatal factors (Mathye & Eksteen, 2016). Sometimes a cultural and metaphysical lens is used to understand disability, based on various contexts. The understanding of disabilities within the African context have been linked with beliefs and retribution such as the "will of God or witchcraft" (Mathye & Eksteen, 2016).

Having a child with a disability is difficult for families and results in adaptations that have to be made within the family, and as a result, the parents face limitations in their lives. Families of children with disabilities often face economic challenges, lack of knowledge in terms of access to relevant information, negative behaviour from society, a reduction of participation in social activities, and tension within the family (Kucuk et al., 2018).

The mothers' quality of life of children with disabilities is lower compared with mothers of generally developed children. Although there was no difference in the mothers' resilience of both groups of children, (Fereidouni et al., 2021) mothers of CWD experience higher death anxiety and state-trait anxiety than mothers of children without disabilities. Study results from Turkey reveal that having a child with a disability increases the psychological burden of these mothers (Koca et al., 2019) who provide care to their children.

Limited research has been carried out related to caregivers of children with disabilities (CWD) from low-to-middle-income countries (LMIC) (Hepperlen et al., 2021). Previous research from Zambia highlights the challenges experienced socially and emotionally by caregivers in areas in low resource areas (Hepperlen et al., 2021). The studies pinpoint that although there are policies that stipulate the provision of services for people with disabilities, such services are often poorly executed or not prioritized. Therefore, due to inadequate services, nongovernmental organisations sometimes implement supportive interventions to people with disabilities and to people who care for them (Geiger, 2012). This deficiency in the provision of adequate services for CWD further compounds the challenges of access to healthcare for this population.

1.2 Problem Statement and rationale of study

It is estimated by the World Health Organization (WHO) that over one billion people globally live with a disability, and 80% live in developing countries (Asa et al., 2022).

The United Nations International Children's Emergency Fund (UNICEF) states that the incidence of disability in childhood is high, with 150 million documented children with disabilities globally (Aduagna et al., 2020). In Africa, a significant percentage of the child population is born with disabling conditions due to various reasons (Moodley, 2021). In South Africa, Statistics South Africa (Stats SA) indicates that approximately 2 870 130 (7.5%) of the population are living with a type of disability. Of this data documented, CWD constitute approximately 25% (718 409) of people living with disabilities (Stats SA 2014:63).

Families of children with disabilities (CWD) experience observable challenges when compared with families without CWD (World Health Organization, 2011). Access to healthcare and rehabilitation services for children with a disability (CWD) is important to

improve their health and wellbeing. However, it was documented that access to these services, especially in developing countries with limited resources, is still restricted (Asa et al., 2022) and even worse in rural areas.

In South Africa, especially in the rural areas, caregivers, who are mostly the mothers of CWD, experience challenges in accessing healthcare for their children with hearing impairments (Khoza-Shangase 2019). Many rely on government-funded health facilities and must travel long distances to access healthcare services, and sometimes face inappropriate healthcare services (Vergunst, 2016; Khan et al., 2020). This may have an indirect effect on the family, as the parents are at risk of losing their employment because of their time away from work (Slemming & Balton, 2016).

These challenges were evident in a study conducted in Khayelitsha, a low resource area in South Africa, which revealed how parents and caregivers of children with intellectual disabilities struggled to access healthcare services for their children (Mkabile et al., 2019). Due to these barriers, the mothers have developed skills that contribute to agency building, so they became activists and fight for the interests of their CWD (Ebrahim et al., 2014), building a resilience to sustain caregiving. The resilience and sustained capacity of the mothers in providing long-term care to their children is critical for the wellbeing of their children with disabilities (Bourke et al., 2022). Improved access to healthcare begins with examining the enablers and challenges they experience (Makwela et al., 2022) which this study aimed to explore. The context is presented below.

1.3 Context

The study context is Lwandle, which means “ocean” in Zulu, a South African indigenous language. Lwandle is a township in Strand, about 40 km from Cape Town. Situated between Somerset West and Gordons Bay, Lwandle has a total area size of 1.21km². The population size is 19,818, i.e., 16,414,63 per km² (Mutero et al., 2018). There are 6562 households in this area of which 83% are isiXhosa speaking, 4% Afrikaans speaking, 3% Sesotho speaking and 3% speak other languages (Mutero et al., 2018).

Masincedane Community Service (NPO) implements all-inclusive community-based healthcare services in Lwandle. Community Health Workers (CHWs) under the management

of nursing coordinators visit and support their clients in the community. The healthcare services in this area are aligned with the Community Orientated Primary Care (COPC) approach. Within the South African context, COPC depends on teams of community health workers who are managed by nursing coordinators. Each team is responsible for a designated area of households (Ajudua et al., 2022).

1.4 Motivation and Positioning the Researcher

The Convention on the Rights of Persons with Disabilities (CRPD) pinpoints that it is the right of everyone to have access to good quality healthcare (Shakespeare, 2018). Disability is not only a health issue, but also a social and economic issue (Shakespeare, 2018) and children with disabilities require sustained care to help them to thrive (Makwela et al., 2022). Access to healthcare is foundational to the attainment of all other rights. Therefore, an understanding of factors that influence access to healthcare for mothers of CWD is important and can potentially support the provision of adequate care for CWD.

The researcher is employed by Masincedane Community Service and has observed mothers of CWD in Lwandle struggling daily with little support. The experience of working with community health workers also informed the researcher that these mothers often face stigma and negative behaviour from the community towards their children with disabilities. These mothers often struggle to attend their appointments at healthcare facilities with their CWD. Because of this, the researcher became curious as to why some mothers were absent at the health facilities on some days and began to explore the experiences of mothers in this area related to accessing primary healthcare for their CWD. This will help healthcare professionals at the clinics to gain insight on how best to support mothers and to improve access to healthcare and wellbeing for their CWD in Lwandle.

1.5 Significance of Study

The South African Constitution protects the rights of all children to have equitable access to quality healthcare services (Hendricks, 2014) and it is important within this study to identify the enablers and challenges that mothers of CWD experience in order to ensure equitable access to quality healthcare in Lwandle for them and their children. This will hopefully contribute to increased knowledge on improved health outcomes and wellbeing for CWD.

Governments focus less on children with disabilities, and this affects the quality of healthcare services that are given to them (Adujna et al., 2020). There is little to no research done on access to healthcare for CWD and mothers' experiences of access to healthcare for their CWD in Lwandle. For health professionals, understanding the experiences of mothers in accessing healthcare for their children is vital to improve programmes for mothers and their CWD. Early hearing detection and intervention (EHDI) for children in South Africa, for example, is not extensive and the shortage of resources is a challenge (Khoza-Shangase, 2019). Understanding the experiences of mothers will address this gap and contribute to a more comprehensive and relevant outcomes from early hearing detection and intervention (EHDI) research.

Adujna et al., (2020) assert that studies in this area are deficient, thereby pinpointing the requirement for more research to investigate ways of improving the experiences of accessing healthcare for CWD. This study seeks to address this gap by exploring the experiences of mothers accessing healthcare with their CWD. After this study is completed, the researcher aims to be able to recommend strategies to improve mothers' experiences of accessing healthcare with their CWD.

1.6 Theoretical Framework and Methodology

The Health Access Livelihood Framework (ACCESS), informed by the human rights approach, is the theoretical framework for this research. This framework is comprised of five inter-related dimensions of access to healthcare which are namely: accessibility, availability, affordability, acceptability and adequacy (Visagie et al., 2016). The questions on the interview guide were based on the theoretical framework mentioned above to determine challenges and enablers of mothers in accessing healthcare for their CWD.

1.6.1 Study methodology

This study is a qualitative descriptive study, aligned to the transcendental phenomenological paradigm. This is because the researcher wanted to explore the understanding and lived experience of a phenomenon, the phenomenon being access to primary healthcare services in Lwandle. This methodology helped the researcher to have a textual and structural description of what participants experienced, and how this was experienced in terms of

their situations and context (Creswell & Poth, 2018). Therefore, the research question is given below.

1.7 Research Question

- What are the enablers and challenges that mothers with CWD experience in accessing primary healthcare in Lwandle?

The objectives are the following:

- To identify the enablers that mothers of CWD experience in accessing primary healthcare in Lwandle
- To identify the challenges that mothers of CWD experience in accessing primary healthcare in Lwandle

1.8 Main Aim

The main aim of this study is to explore the enablers and challenges that mothers of CWD experience when accessing primary healthcare in Lwandle.

1.9 Conclusion

This chapter introduced the background and aims of this study, which is about learning more about the day-to-day experiences of mothers of children with disabilities regarding access to primary healthcare for their children in Lwandle. The study problem, rationale, context, and significance were also portrayed in this chapter. The study outline is presented in the next section.

1.10 Study Outline

This study is divided into six chapters. Chapter 1 introduces the study background introducing the concepts related to the experiences of mothers of CWD, when accessing healthcare for their children. Chapter 1 also introduces the problem statement, the motivation, and the significance of this study. Chapter 2 reviews the literature, the theoretical framework, and the experiences of mothers of CWD.

Chapter 3 explains the methodology of this research which describes the research design, the sampling process, data gathering and data analysis processes, and the observance of

ethical conduct. Chapter 4 presents the results of this research using excerpts from the data and the themes that arose from the coding process. Chapter 5 discusses the study findings considering the literature and is informed by the theoretical grounding of the study. Chapter 6 shows the conclusions, limitations of this study and recommendations and suggestions for research in the future.

Chapter 2 below discusses the literature review, highlighting the search strategy and the breach that this study seeks to fill.

Chapter 2: Literature Review

2.1 Introduction

The search for literature was done on e-databases for articles on Google Scholar, PubMed, and Ebsco Host. The search terms used for the literature search included “access to healthcare for mothers of CWD”, however this brought up articles related to access to healthcare for mothers. My focus is on mothers accessing healthcare for their CWD, so the search terms were further adjusted to reflect healthcare access for CWD, and the challenges and enablers that affect healthcare access for CWD. I will begin by firstly discussing the impact of caring on mothers of CWD, and then access to PHC and cultural influences will be highlighted. This review will conclude by pinpointing the gap that this study seeks to address related to the experience of mothers of CWD.

2.2 Impact of caring on mothers of CWD

Women all-around have the duty of nurturing their children with disabilities and this affects their experiences and development (Mc Aulliffe et al., 2018). The primary caregivers are usually the mothers and due to this time-consuming need, frequently cannot be employed. Breakdown of the family is very common and furthermore isolation from friends and family has been identified in literature. Accordingly, evidence portrays that these caregivers often experience more stress, anxiety and depression compared to mothers of generally developing children (Masefield et al., 2022).

Research conducted in Australia revealed the importance of mothers of children with autism spectrum disorder (ASD) to the family, but the challenges they experience often influence their health and security (Mc Aulliffe et al., 2018). Mothers whose children have ASD, or other neurodevelopmental disabilities often face stress, psychiatric problems, and disease. These mothers mostly care for their children with disabilities than the fathers (Mc Aulliffe et al., 2018). A study from Palestine shows that mothers of CWD are exhausted and have decreased living standards (Zahaika et al., 2021). Mental health problems were common for mothers of CWD, and although they were aware that they needed professional assistance, there were several main challenges that prevented mothers from accessing healthcare.

Relatedly, mothers of children with Cerebral Palsy, for example, have lower quality of life compared to mothers of children without disabilities, and the outcomes are unfavourable for the mother whose child is immobile (Glinac et al., 2017). Societal stigma and a lack of community support exacerbate mental issues of mothers that further compromises the care provided for their CWD (Hussain et al., 2021). Furthermore, another study indicated that mothers of children with developmental disabilities do experience adverse health challenges (Lee et al., 2018). The authors also indicate that the cost of caring for their CWD, is not only physical, but psychosocial too. Many mothers found it necessary to reduce their time being employed in order to acquire and maintain the treatment programmes of their children, and this transcended their social class. The impact of reduced work affected families in different ways. Married mothers and mothers with high economic status were more concerned by the potential negative results of losing the income of one partner. However, single and lower socioeconomic status mothers experienced persistent insecurity with regard to income or employment (Brewer, 2018).

In Africa, as stated by the United Nations Children's Fund (UNICEF), the majority of CWD do not attend school. This increases the burden on their caregivers as most CWD are dependent on assistance from their caregivers. In Low- and Middle-Income Countries (LMICs) caregivers are responsible for the provision of the bulk of care (Fentanew et al., 2021).

In South Africa, a study conducted in Khayelitsha with mothers of CWD, reveal a reality of isolation and discrimination, which impacts on their ability to provide for themselves (Van der Mark et al., 2018). Other factors that further marginalize these mothers include poverty, caregiving, disability, and gender. Mothers of CWD experience violence and abuse, choosing rather to stay indoors with their children, which may disrupt access to other available support and assistance (Van der Mark.,2019). All these factors therefore impact on access to healthcare.

2.3 Access to Primary Health Care

Forty-years ago, the Alma-Ata Declaration was the first international declaration that emphasised the importance of primary healthcare (PHC). The World Health Organization explains PHC as an approach to address mental, physical, and social health and wellbeing of

a person, providing healthcare throughout the life of a person. The importance of bringing healthcare closer to families and their communities is one of the reasons why the Primary Healthcare approach is so important (De Maeseneer et al.,2020).

Grounded within the human rights framework, both PHC above and the Health Access Livelihood Framework (ACCESS), acknowledge a powerful interaction between the user and the service and aim to create better access to healthcare. According to the ACCESS framework, healthcare access is composed of five dimensions: availability, accessibility, affordability, adequacy and acceptability. Availability refers to the healthcare service addressing the needs of the client. Affordability refers to the costs of the service and the ability of the client to pay for the service. Accessibility refers to the location of the services and whether these services are located in line with the users. Acceptability refers to the characteristics of the service provider and whether they match the characteristics of the users, implying a dynamic interaction between the two -providers and users. Adequacy refers to whether the user's needs are met by the service provider. Using the five components of ACCESS to understand the experiences of people who are vulnerable, can advocate in improving the healthcare provided to improve health outcomes (Visagie et al., 2015).

However, although a right, (UNCRPD, 2006), access to healthcare for CWD especially in developing countries is limited (Asa et al., 2021). There are many factors that influence access to healthcare, which includes living conditions of people, availability of healthcare, culture, personal and community factors (Mji et al., 2017).

2.3.1 Challenges to access healthcare

Research In Zambia documents that most of the Learners with Hearing Impairments (LWHI) could not access adequate healthcare services due to inadequate communication, incorrect diagnosis, poor privacy and confidentiality, and discrimination. Other challenges that obstruct access to healthcare for these learners are lack of proper health education, lack of Institutional support staff and negative attitudes (Schichlindi et al., 2022).

Most of CWD in low- and middle-income countries are cared for at home because healthcare for CWD is limited. This increases the physical and mental burden of the family

caregivers. This also affects the family's time allocation and financial resources (Kamiya, 2021).

CWD and their families face a range of challenges when trying to access healthcare services (Nuri et al., 2020). Research emanating from Bangladesh recorded limited resources (Nuri et al., 2020), slow diagnostic process and referral pathways to a specialist (Neves et al., 2019) as some of the challenges they are confronted with. Another study from Bangladesh pinpoints the lack of ophthalmology services for CWD, where the incidence of blindness is high (Muhit et al., 2022). In Sub-Saharan Africa there is a large number of CWD who have limited access to the provision of healthcare services and rehabilitation. Poor access to healthcare is also due to a lack of trained medical staff and a shortage of therapists at health facility level (Adugna et al., 2020). Early diagnosis and referrals for specialised healthcare are often not done adequately (Khan et al., 2020) or timeously and poor education and poverty further exacerbate the situation (Adugna et al., 2020).

While the above can equally be true within the African context, experiences of mothers of CWD in Zambia reveal that in addition access to healthcare is hindered by geographic challenges and the unavailability of healthcare services (Simpamba et al., 2016). The acceptability of the service is influenced by the insufficient advice given, culture of the community, lack of proper information, and health worker attitudes (Simpamba et al., 2016). Relatedly, research in Ghana pinpoints that access to healthcare for CWD is challenged by poverty, lack of finances, and the poor operational management of health centres (Kwabena, 2021). In South African rural areas, affordability is a challenge due to transport costs and distances (Burger et al., 2018). Recent research in Khayelitsha indicated that access to healthcare for CWD is further challenged by transportation by the minibus taxis in the community. Access to healthcare for CWD is challenged even when the service is available (Makabile & Swartz., 2021).

2.3.2 Enablers to access healthcare

On the other hand, development of policies, public disability awareness and sensitivity training, support from parents and improved physical access are some enablers in healthcare access for CWD (Adugna et al., 2020). Although the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities advocate for the

rights of children with disabilities, limited resources in LMICs have challenged the implementation of policies that reflected these conventions into action (Kamiya , 2021).

However, a study in Uganda describes one example of a positive outcome. Mothers have become self-reliant and provided localized medication and physiotherapy to their CWD due to the high cost of transport and unavailability of health services (Ebrahim et al., 2014). The challenges faced by these mothers have inadvertently become enablers of agency to access alternative opportunities for their CWD. This outcome has also been recorded in South Africa by mothers of CWD who have produced their own assistive devices for their children (Van der Mark et al., 2018). Mothers of CWD are consequently developing skills to become activists and fight for the interests of their children (Ebrahim et al., 2014).

2.3 Cultural Influences

For many individuals, cultural, religious, and social elements are vital enablers in accessing healthcare services. An example can be seen in the management of child and adolescent psychiatry, where cultural and social elements are vital enablers of accessible healthcare services (Henry et al., 2016). Bilingualism and the loss of cultural markers due to immigration often results in these patients not receiving adequate healthcare (Henry et al., 2016). In Indonesia, research identified that culture and religion influenced the opinions of people on disability, and the resultant stigma was a challenge to healthcare. Furthermore, this research highlighted that mothers of children with mental disabilities were often blamed by the families because of the disabilities of their children (Sibel et al., 2012).

Culture influences the way family assist mothers with CWD (Tsai et al., 2018) who are viewed as ill-fated, because they brought bad luck to their children. Cultural faith further influence the assistance provided by the people, and it is within these intersecting experiences of oppression and extreme conditions that mothers of CWD exist and care for their children (Van der Mark et al., 2018). However, cultural and religious leaders are respected within their communities and can be enabled through ongoing education to provide more support to parents of CWD (Kiling et al., 2019). The highlighting of positive experiences and outcomes for CWD and their families, and sensitivity to differences in culture (Tsai et al., 2018) when supporting families will contribute to an enabling environment to encourage access to PHC.

Spirituality provides people with balance, hope and consolation in challenging times. Mothers of CWD highlight this role of spirituality in providing them with hope, solace, and confidence through the challenges (Yilmaz et al., 2019). In the African context, it was identified that spirituality is crucial to improve Family Quality Of Life (FQOL), and that FQOL further improves the wellbeing of CWD (Jansen Van Vuuren et al., 2021). Spirituality provides purpose and contributes to resilient wellbeing in the face of life's challenges (Ohajunwa et al., 2018).

Despite these challenges narrated above, mothers of CWD often struggle to access healthcare for their children. Exploring how they could be further supported from their own narratives is important. While the experiences of mothers of CWD from many regions of the world have been researched as presented here, this is not the same within the African continent, and even less so within peri-urban African communities. Therefore, this study is located within this space, and seeks to contribute to the knowledge related to how mothers of CWD within the peri-urban context of Lwandle access healthcare for their children.

2.4 Conclusion

Mothers of CWD are mostly the primary caregivers of their CWD. Disability, gender, care, and poverty are all inter-related issues that mothers of CWD experience. Although PHC aims to bring healthcare access closer to families and communities, access for mothers of CWD has remained a challenge. Research on the experience of mothers of CWD accessing primary healthcare within the African and South African context is needed to inform targeted healthcare services. This study aims to address this gap in research by exploring the enablers and challenges that mothers experience in accessing primary healthcare for their CWD in Lwandle.

Chapter 3: Methodology

3.1 Introduction

In this chapter, the research methodology is discussed. The study design, sampling, selection and the recruitment of the participants, data gathering, and data analysis procedures are described. Precautions implemented to enhance rigour and ethical considerations steering this research is also discussed. The research aims and objectives, and methodological framework will firstly be presented.

3.2 Aim

The aim of this study is to explore the enablers and challenges that mothers of CWD experience in accessing primary healthcare in Lwandle.

The objectives are the following:

- To identify the enablers that mothers of CWD experience in accessing primary healthcare in Lwandle
- To identify the challenges that mothers of CWD experience in accessing primary healthcare in Lwandle

3.3 Methodological Framework

The qualitative design was chosen for this study, it is aligned to the transcendental phenomenological paradigm. This is because the researcher wanted to explore the understanding and lived experience of a phenomenon, the phenomenon being access to primary healthcare services in Lwandle. This study is about the experiences and lived and structural context of the participants. Therefore, the qualitative methodology has assisted the researcher to elicit a narrative from participants to support a textual and structural description of what participants experienced, and how it was experienced (Creswell & Poth, 2018). Qualitative methodology was chosen as it was the best methodology to answer the research question (Willis et al., 2016).

The qualitative approach is dependent on qualitative information which include experiences, words, and observations that are not quantified (O'Leary 2017). Qualitative research is used to understand a specific phenomenon (Colorafi & Evans , 2016) in a natural

setting. The researcher set out to explore the experiences of mothers of children with disabilities (CWD) in a natural environment, without any jurisdiction on events taking place. This research therefore provides the study with the subjective truth and experiences of these mothers in Lwandle of accessing healthcare with their CWD. The semi-structured interviews were conducted face-to-face in the homes of the participants. This was the preferred mode of data gathering for most participants.

3.4 Research Setting

Lwandle is a township in Strand, Western Cape, where different types of houses exist, including government-funded RDP houses, and also shack dwellings. The Ikwezi Community Day Centre (CDC) is the nearest health facility. There are a number of churches, crèches, schools and informal businesses in this township as well as one police station. Lwandle was identified at the beginning of the twenty-first century by the museum as a structure of significance. The presence of the well-known Lwandle Migrant Museum here highlight the experiences of the past migrant labour system and hostel life (Murray et al., 2013).

3.5 Population and recruitment of participants

The study population consists of mothers of children with disabilities who access healthcare services by Masincedane Community Services in Lwandle. The participants were recruited with the assistance of community health workers. Consent forms were downloaded from the University of Stellenbosch Research Ethics website in English, isiXhosa, and Afrikaans. These were then further edited to suit the study focus (See appendix B). However, there were no Afrikaans-speaking participants, thus only the English and isiXhosa consent forms were used.

3.5.1 Inclusion and Exclusion Criteria

The focus of this study was based on biological mothers of children with disabilities. The researcher has not focussed on whether the mothers have a disability or not, so long as they can and are willing to participate , all biological mothers were invited.

Inclusion Criteria:

1. Biological mothers of children with disabilities (CWD) who access healthcare services from Masincedane Community Service in Lwandle
2. Biological mothers of CWD who can be interviewed, having no condition preventing this (mothers without flu/Covid and without chronic conditions that may prevent them from participating during this period)
3. Biological mothers of CWD under the age of 18-years

Exclusion Criteria:

1. Biological mothers of CWD that do not access health services from Masincedane Community Services in Lwandle
2. Biological mothers of CWD that are in no condition to be interviewed (mothers who may be ill with flu/Covid during this interview period or have a chronic condition that may prevent them from participating during this period)
3. Biological mothers of CWD over the age of 18-years

3.5.2 Sampling

Total population sampling, which involves studying the whole population of interest, was done (Etikan et al., 2016) and is often used where the total number of cases explored is relatively small. The community health workers of the NPO routinely visit mothers of children with disabilities in Lwandle to provide support. All mothers of CWD who attend the clinic were informed and invited to participate in the study. Six mothers indicated interest and were subsequently interviewed.

3.6 Data gathering tool

An interview guide consisting of semi-structured questions was used to guide the interviews. This interview guide consisting of six questions (Addendum B) was translated into isiXhosa with the assistance of the audiologist, a colleague of the researcher.

3.6.1 Data Gathering Strategy

Data gathering for this study was conducted through in-depth face-to-face interviews with mothers of CWD which were audio recorded. Open-ended questions and prompts was used

to gain in-depth narratives in order to understand the enablers and challenges that mothers experienced in accessing primary healthcare for their CWD. The community health workers assisted by relaying the information about the research to the potential participants. The researcher bought airtime for the community healthcare workers to be able to call the researcher if a mother indicated interest in this research. Then the researcher used the community health worker's phone to talk to the mother, and also to get the mother's contact details in order to plan further. In this way, the researcher avoided getting any personal details of participants through a third party, in respect of the participant privacy in terms of the POPI ACT. The researcher then further contacted the mothers who were interested, explaining more about the study, answering any questions they may have had, and setting a date for the interview. On the day of the interview all explanations were again given by the researcher, and after signing the consent form, the interview commenced.

3.6.2 Pilot Study

The pilot interview was the only interview conducted at the NPO office, because this was the choice of the participant. The interview guide was piloted by conducting an initial interview with one participant, to see what issues should be addressed. Three questions were adjusted because they were too vague and seemed to confuse the participant, before conducting the remaining interviews.

3.6.3 Data Gathering Procedures

After gaining consent, the researcher accompanied the healthcare worker to the participants' homes to conduct the interviews. The participants were contacted in order to schedule the interviews in advance at a time and place of their choice with the assistance of the community health worker. Studies have shown that ethnic minorities/populations often choose to be interviewed at home, in spaces where their voices/experiences can be validated by family members and their community (Ohajunwa, 2019; Mji, 2012)

The participants had the choice to be interviewed in isiXhosa or English. The community health worker assisted the researcher and conducted four interviews in isiXhosa. Two

interviews were conducted in English by the researcher. All the isiXhosa interviews were translated into English by the community health worker during the interviews.

The mothers were asked to relay information on the nature of the disability of the child during the interview, and the interviews began with open-ended questions about them and their children, e.g.- “Tell me about yourself and your child”. This helped them relax and open up more. Printed consent forms and all journal reflections after each interview were stored in a locked cabinet in the office of the research supervisor. Audio-recordings of the interviews were done and were transcribed verbatim. After the isiXhosa audiorecordings were transcribed, these transcriptions were translated into English. Data was backed up on Stellenbosch University’s One Drive account which is a secure space for data storage. Data was also stored by the researcher’s supervisor. The supervisor of the researcher stored all printed documents in a locked folder in the office . Data was anonymized, as each participant was given an identifier. The electronic data was only accessible to the researcher and the supervisor.

3.7 Data Analysis

Thematic analysis was done. Software programs such as Microsoft Word and Excel was used by the researcher to assemble the data. In qualitative research, thematic analysis can be used for identifying, analysing, documenting, and deciphering the findings (Braun & Clarke, 2006)

3.7.1 Thematic Analysis

Thematic analysis was used to identify emerging themes and patterns from the data set, deciphering the basic information and speculations from the data to respond to the research question (Maguire & Delahunt, 2017 ; Creswell, 2012).

The researcher was directed by Braun and Clarke’s (2006:87) recommendations in conducting thematic analysis as shown below.

3.7.1.1 Codification of Data

The six-phase, step-by-step guide was followed in thematic analysis to ensure trustworthy data (Nowell, 2017).

Phase 1- The researcher firstly familiarized herself with the details of the data, by-data immersion

Phase 2- During this phase the researcher began to do the initial coding. Specific statements from the data set were analysed and categorized with the relevant aligned quotes and were colour-coded for reference. In vivo coding , where emphasis is placed on the actual words spoken by the participants, was used to code the data. In vivo coding is known for the value and usefulness in describing the voices of participants and for its dependence on the participants themselves for providing meaning to the data (Manning, 2017).

3.7.1.2 Codes into subthemes

Phase 3

The researcher used an Excel spreadsheet categorizing recurrent codes from the transcripts into sub-themes under appropriate columns. After further assessing the sub-themes, and patterns that emerged, prominent themes were identified. Themes are patterns that pinpoint and describe significant information about the study focus, in a bid to respond to the research question (Nowell, 2017). The researcher identified and recategorized all outliers in the data into relevant themes and generated new themes as needed, which were included in the report (O’Leary, 2017). To ensure rich data , the researcher included direct quotes from the participants in the findings to provide evidence from the data.

Phase 4- All emerging themes were reviewed again, identifying all outliers and recategorizing data.

Phase 5- During this phase all themes were defined and agreed upon and peer/supervisor debriefing continued.

Phase 6- The study outcomes were written up in a relevant manner at this phase. Member checking was done by visiting each participant to share the data and check for accuracy. The data had to resonate with their experiences. The write-up included in-depth descriptions of the findings, as well as the motivation for the choice of methods and analyses utilized, as well as theories used to respond to the research question (Nowell, 2017; Maguire & Delahunt, 2017).

3.8 Rigour

In qualitative research, credible research indicators does include trustworthiness, confirmability, dependability, and transferability (O'Leary, 2017).

3.8.1 Trustworthiness

To ensure excellent research, the researcher had to self-reflect and manage subjectivities and biases by admitting their presence and influences (O'Leary, 2017). Self-reflection is an important component that shows trustworthiness in research (Berger , 2015).To show credibility, the researcher gave supporting evidence consisting of quotes from the study participants to show that the findings correctly represented what was researched. In qualitative research trustworthiness is a crucial indicator of the quality of research findings which provides the study description in detail (Meena et al.,2020). Regular debriefings were held with the supervisor of the researcher to manage the subjectivities and iases of the researcher.

3.8.2 Dependability

Dependability is another indicator to show rigour and credibility in this research and was achieved by applying data gathering procedures consistently. Dependability was accomplished by regular supervisor and peer debriefings, and the research findings were sent to the supervisor and colleagues , experts in this area , for verification (Scharp & Sanders, 2018). A detailed description of the research design was provided to ensure dependability so that this study could be carried out in a different context by another researcher. The audit trail illustrates a record of the research , and the procedures that were carried out (Johnson, Adkins, & Chauvvin, 2020; Ataro, 2020).

3.8.3 Confirmability

To ensure confirmability it is necessary to provide an in-depth clarification to connect the data to the findings (Scharp & Sanders, 2018). The researcher clarified the methodologies and methods that were used in the research. Confirmability requires that the researcher clarifies to the reader that the findings portray the information provided by the participants, and therefore not from the explanations or bias of the researcher (Johnson et al ., 2020)

With this endeavour, evidence was thus provided to other readers of the approaches and procedures which were undertaken in the research. The data gathering and the data analysis processes were orderly and well planned. The methodology was well documented to portray the relationship between the findings and data set (O'Leary 2017).

3.8.4 Transferability

Transferability refers to the degree to which the research findings can be applied to other contexts. In such an instance the researcher should provide dense information such that the reader can decide whether the findings apply to other contexts (Johnson et al., 2020). The study findings may apply to participants in similar contexts. The purpose of the research was to obtain in-depth knowledge of the experiences of mothers of CWD accessing primary healthcare and not to try and generalise the link between the findings and the original data.

3.9 Ethical Considerations

This study was guided by the Declaration of Helsinki Ethical Principles. The researcher was granted approval to conduct the research from the Health Research Ethics Committee (HREC) of Stellenbosch University (SU). The researcher also gained permission from Masincedane Community Service. (Please see Appendices A and E). The precautions that were carried out by the researcher in compliance with the ethics principles of research is discussed below.

3.9.1 Preserving Confidentiality

The researcher used pseudonyms as documented for the protection of the identity of the participants (Ohajunwa, 2019). The researcher locked hard copies of reflections and consent forms in a filing cabinet, and saved audio recordings, transcriptions and information on her personal computer which was password protected. All the information was cloud-saved to further preserve the confidentiality of the participants. Data will be safely kept for five years after completion of the study as specified by Stellenbosch University, and then destroyed.

3.9.2 Beneficence and non-maleficence

In research, beneficence and non-maleficence is about promoting what is best for the participants and minimizing harm (Department of Health, 2015; O'Leary, 2017). This means that the benefits should outweigh the risks to the participants. To maintain this principle,

the researcher ensured that no insensitive questions were asked, to avoid causing psychological harm, (O'Leary, 2017) and to minimise stress for the participants.

3.9.3 Distributive justice (or equality)

The principle of distributive justice stipulates a fair and equitable distribution of the benefits of the research to all involved in it (Department of Health, 2015). Furthermore the researcher should be fair in the recruitment of participants. The data transcripts and recordings will not be shared with anyone outside of the researcher, translator, and supervisor. The outcomes of the research study/findings will be shared with the study participants and their families, and the Department of Health and the NPO, to hopefully improve access for mothers of CWD in Lwandle.

3.9.4 Respect for persons (dignity and autonomy)

The principle of respect for persons (dignity and autonomy) includes the components of respect and independence for participants (Department of Health, 2015). It is documented that participants should decide on whether or not to participate in a study, aligning with the right to autonomy. The researcher on the day of the interview once again explained the purpose of the study, which provided an opportunity for the participants to raise any questions about the study. The researcher reminded the participants that they had a right to withdraw from the study at any time, without any repercussions (Khan, 2014).

3.10 Conclusion

In this chapter, the researcher discussed the methodology employed in gathering data for this study. The researcher utilized the qualitative approach, aligned to the transcendental phenomenological paradigm. In-depth conversations were held with the participants to gain an understanding of the enablers and challenges that they experienced when accessing healthcare with their CWD.

Ethical issues concerning the confidentiality and respect for the dignity of the participants and autonomy was discussed. The findings of this study are presented in the next chapter.

Chapter 4 : Research Findings

4.1 Introduction

In the previous chapter, the study methodology and the rigorous processes followed to gather and analyse data were presented. In this chapter the findings of the study, which is based on an analysis of study data, are presented. This is also in agreement with the qualitative enquiry as the inclusion of participant quotes supports rigour and allows room for some of their subjective experiences to be shared in their own voices. In this chapter, the participant demographics and the six themes that emanated from the data analysis will be presented.

4.2 Socio-demographics of Study Participants

Six mothers of children with disabilities were interviewed. Four mothers were isiXhosa speaking mothers. All the mothers were living with their children, mostly relying on the grant they received for their children from the government. Only one mother was employed on a part-time basis, most of the mothers were unemployed. The majority of these mothers were all single mothers, one mother was married, and one was a widow.

Table 1: Participant demographics

| Participant Names (Pseudonyms) | Participant Marital Status | Participant Employed | Language Spoken | Child's Disability | Age of Child |
|--------------------------------|----------------------------|----------------------|-----------------|-------------------------|--------------|
| Maria | Single | No | isiXhosa | Cerebral Palsy | 15 |
| Sophi | Single | No | isiXhosa | Cerebral Palsy | 14 |
| Pat | Single | No | isiXhosa | Partial Deafness | 12 |
| Ina | Married | No | English | Intellectual Disability | 7 |
| Bea | Widow | Yes | isiXhosa | Blind | 6 |
| Hayli | Single | No | English | Hydrocephaly | 5 |

The table above presents the participants demographics.

4.3 Themes emanating from this Study

The following main themes emanated from the findings of this study:

- Living in the Water
- Alone and isolated
- I am struggling
- Spirituality
- Helpful Healthcare Professionals
- Family and neighbours

Excerpts taken from the transcripts of the interviews portray the voices of the participants as they share the experiences of their challenges and enablers in accessing primary healthcare for their children with disabilities. This will be highlighted under the themes below.

4.3.1 Living in the Water

This theme speaks of the mothers' experiences when accessing care and support for their children with disabilities at home. The theme is related to the additional challenges experienced by mothers who have children with disabilities, in raising and supporting their children in the current context and conditions. The mothers are all financially constrained, reflecting their frustrations and struggles in trying to cope with life, and caring for their children. An example of these harsh conditions is the challenge to gain even the most basic amenities like adequate housing for them and their children. They are unable to even maintain their shacks which often leak when it rains. One mother captured this feeling very well by stating that she often feels like she is living in the water. Such living conditions, further impede the mothers' capacity to access healthcare, as they often focus on and worry about the wellbeing of their children in these conditions.

"And I need, uh, the house. The house, you see, because I'm staying in the water. The water is coming. The water even now it's it's wet. The water comes inside." (Ina, 17 June 2022)

"Like when it rains, I do not feel right because I get rain, I do not have someone that can help me or someone I can go to when in need of something at home. I just stay at home. Those are the things that I deal with." (Sophi, 17 June 2022)

“I persevered staying with my children. I told them and said inaudible... if I cook porridge with sugar water, you must eat as I have no choice because I am facing this situation. When my husband died, there were some clothes and household items that I had them stored in a shack that is at the back. When the storm came, the wind blew everything breaking the cupboards that were in there and everything got destroyed.” (Bea, 30 June 2022)

“Like now that it’s going to rain, I do not have a place inside or covered area like a veranda where I can hang his [CWD] clothes and so then he runs out of clothes to wear.” (Sophi, 17 June 2022).

These experiences indicate the hardship experienced by these mothers in harsh conditions that impact on their wellbeing, caring capacity of their children and access to healthcare. The next theme is presented below.

4.3.2 Alone and Isolated

This theme expresses the experiences of mothers nurturing their children with disabilities and how they feel isolated and distanced from help. *“Alone and Isolated”* is how the mothers feel about having to fight on their own every day for the survival and wellbeing of their children with disabilities,. This theme recognises the lonely journey most of the participants face with their children. An example is one mother who cried as she expressed her experiences of loneliness and suffering while caring for her child, without any support from her husband because of the child’s disability. The father is not happy with this child because of the disability, and the mother confirms this reality.

“I am happy, but my husband is not happy.” (Hayli, 13 May 2022)

Other participants have had similar experiences and expressed the following statements.

“I have not received any help from the family. I do everything myself.” (Pat, 8 July 2022)

“So, there is no one who helps me. No one like, when I do not have money to buy her nappies, that can help me. So, I end up going to loan sharks (high interest lenders) so that I can get her nappies because her nappies are expensive and they are only 40 inside. So those are the challenges I experience.” (Sophi ,17 June 2022)

“One day I will die and I need to know what will happen with my children. Because I do not have family, no mother, aunt, there is no one helping me. My problem is my problem and it ends there. Only me know what to do with it because now I live with my children. Even the family from my husband’s side do not care for me. Because only my husband loved me in his family.” (Bea, 30 June 2022)

The mothers also experience stigma and negative attitudes from the community members causing further isolation, as this mother highlighted in her narrative below.

“There are times where there are challenges when the neighbours get to quarrel then you get people insulting you about your disabled child.” (Maria, 20 June 2022)

These experiences show the reality of the loneliness and isolation mothers of CWD face in the community . This situation is already a challenge when accessing healthcare. The next theme will now be explored.

4.3.3 “I am really struggling”

This theme pinpoints the abuse of women, the health challenges and financial issues mothers of children with disabilities have to endure while nurturing their children on a day-to-day basis and fighting for their survival. An example is one mother who lost her husband a few years ago, who now experiences anxiety and stress about the future wellbeing of her children. Death-related anxiety is a struggle for her.

“I am not doing well at present. I take tablets to ease the stress level. I am struggling a lot. I am worried about my children. What if I die and what will happen to them. More especially the young one. I also said to my children that I would like to get someone who will be willing to take care of her so that when I die, she will not be a rape victim.” (Bea, 30 June 2022)

This mother struggles and has to face challenges of abuse from her husband on a daily basis, while caring for her child in difficult circumstances.

“He's working, but he likes to drink.” “You see? Me? I'm not drinking. And if he's drinking, we fight. Fight you see every time. Even now, I decided to, I said, Oh if I have a family here, I can go to stay. You see? Can leave him here because I don't like fight every day.” (Ina, 17 June 2022)

The financial struggles of this mother are portrayed below; she borrows money to make ends meet, landing her in deeper challenges because she has first to pay back, and prioritise her children's needs last.

"When I do not have money to buy what she needs during the course of the month, I then find out that there is nothing I can do except go to the loan shark and ask for the money to go buy that which she needs at that time or else when one of the children needs something for school. Then when I get paid, I need to pay back the loan shark because s/he needs the money. Then with whatever amount gets left over, go buy what I am able to get from that money" . (Sophi, 17 June 2022)

This mother also identifies her financial and health challenges living on the child support grant.

"I am a mother who is not well, I take high blood pressure, arthritis and diabetes tablets. So I do not work, I am always here at home. So X relies on the R450 child support grant. We also depend on that here at home. From that we have to eat, I buy him clothes, items for school." (Pat, 8 July 2022)

The following two mothers describe their struggle to access primary healthcare due to the high costs of transport. Although the health facility is in close proximity, their children use wheelchairs.

"When I need to go the clinic, I also struggle there. I need to save money, for instance, I cannot take her to the clinic on the wheelchair. It is far. We use Nomzamo. So I need to save money for the taxi fare." (Mari, 20 June 2022)

"My challenge is that, when I take her to the hospital or clinic, I need to drive her. I do not have transport to take her because the wheelchair that have does not fit in the taxi. I have to uber when I need to give her some rest, I then need to uber for a car that can fit in the wheelchair then going to the clinic I pay. Also when we get there, it needs to wait for us. I am also struggling because I am not working. I have no source of income except her grant and a grant that I made for having her." (Sophi, 17 June 2022)

The health challenges of these mothers accompanied by the financial constraints, transport issues and abuse are highlighted within these findings. These challenges all impact on access to PHC for their CWD. Despite these challenges, the mothers also identified enabling factors within their context that support access to healthcare for them and their children. These identified enablers are discussed below.

4.3.4 Spirituality

Mothers described how their faith made a difference in their lives in these challenging situations. In this example, spirituality for this mother was an enabler to healthcare, because she was part of a church where someone was able to give her a helpful referral.

“I got in contact with a doctor at Nomzamo through a friend I attended church with who advised that I take him to that doctor. One of the ears could not hear at all, the other could partly hear. Now he was already older about 11-12 years old and was able to tell that this side mama cannot hear and this side I can hear a little bit. So, at Nomzamo they gave me a letter to Tygerberg where we got a date booked to take him there. At Tygerberg they then did lots of tests and confirmed that one ear cannot hear and the other partly hears.” (Pat, 8 July 2022)

Two mothers were empowered by spirituality as they describe the positive effects on their lives. Spirituality is seen as an encouragement, so that they do not give up, but continue to care for their children. However, the capacity to always attend church in the case of one mother, is affected by the need to constantly tend to her child.

“Yes, I get to see and feel encouraged by prayer.” (Maria, 20 June 2022)

“I used to go with her when she was still small, put her on my back and just sit with her and just sing at church. So now that she’s grown, I do not afford to go because when I leave her on this wheelchair, I have to stay an hour and keep checking how she’s doing because there is no older person.” (Sophi 17 June 2022)

The three mothers above highlighted the importance of spirituality in their lives, and this enabled them living with so many challenges. Spirituality provides hope and consolation for mothers of CWD and is an enabler to access healthcare

4.3.5 Helpful Healthcare Professionals

This theme shows the importance of healthcare professionals in the lives of mothers with CWD. The supportive attitude of the physiotherapist at the clinic meant that mothers were able to receive help immediately when they arrived at the clinic.

“Yes, I get help immediately as I usually go to the physio. Like when I need to change the chair.” (Sophi, 17 June 2022)

“Recently I like Nomzamo clinic. I never got any problem at Nomzamo clinic. I never had any query. When I get there I get attended to. I wait like everyone does until I get called and I get satisfied. There is nothing, I can complain about.” (Bea, 30 June 2022)

The value of the community health worker in accessing healthcare for their children was highlighted in the dialogue below.

“She's a nice lady. Uh, every time if I have a problem, she helped me. She asked me, uh, X, you need something? I said yes. I need something. I have a problem. She said, okay, okay, it's fine. I'm gonna help you.” (Ina, 17 June 2022)

This theme therefore identifies the impact that healthcare professionals can and do have in the lives of mothers of CWD and enabling their access to PHC.

4.3.6 Family and Neighbours

Two participants had positive experiences of family members who played an important role in their lives by supporting them to be able to provide adequate care for their CWD. The participant below has family members who assist and support her in caring for her child with cerebral palsy. This support is an enabling factor influencing healthcare access.

“Ok my family helps at times when I need to go somewhere then someone would come and help with X. Also with feeding.” (Maria 20 June 2022)

Another example is the participant below who confirms financial assistance from her sister.

“Yes, my sister, is working by, uh, staying there by Free State. She is sending me [Money].” (Ina, 17 June 2022)

The neighbour of this participant assists and enables her with the storage of her food for her family. This is described below.

“I do not have a fridge and the microwave since January that they broke. I do not have any other way. When I buy meat, I ask the next-door neighbour to keep for us. It’s not easy. My problem is that, I do not like that people know about what happens in our home. My fridge is a cupboard it’s not a lie.” (Bea, 30 June 2022).

This theme highlights the important role family and neighbours have in enabling mothers of CWD to flourish in difficult circumstances. Family and neighbours are important enablers to mothers of CWD in the community .

4.4 Conclusion:

In this chapter, the researcher presented the participants’ experiences and narratives about the enablers and barriers to accessing primary healthcare services. The daily struggles of mothers, poor housing issues, their health challenges, financial constraints, negative behaviour from community members and domestic abuse were all identified as challenges to healthcare access for CWD. On the other hand, spirituality, caring healthcare professionals and friends and family were identified by the participants as enablers to accessing healthcare.

Chapter 5: Discussion

5.1 Introduction

The previous chapter presented the findings of the study that emanated from the analysis of the data. In this chapter key findings from the study outcomes will be discussed to highlight the experiences of mothers in gaining access to healthcare services for their CWD in Lwandle. Literature related to the focus of the study, will be adapted and used to explore and make meaning of the experiences of these mothers in accessing healthcare for their children with disabilities. The research outcomes will also be further explored whether they speak to the five criteria of the Health Access Livelihood Framework (ACCESS). The researcher will begin by highlighting the research question which is, “What are the enablers and challenges that mothers of children with disabilities (CWD) experience in accessing primary healthcare in Lwandle? ”

There are many positive and negative factors that influence the ability of mothers of CWD to access healthcare for their CWD. These factors emerged in the findings and will be further discussed under two main themes in line with the study objectives, in a bid to present a more robust understanding of the concepts of this study and to answer the research question above. These two main themes are not mutually exclusive but are also connected in a complex way to influence access to healthcare for mothers of CWD. The two main themes to be discussed in this chapter are – mental/inherent factors and physical-environmental factors.

The researcher will begin with a discussion of the mental or inherent factors that influence access for mothers of children with disabilities, thereafter, highlight how each aspect responds to the livelihood framework.

5.2 Mental and inherent factors that influence access

There are mental and inherent factors that influence access to healthcare for mothers of children with disabilities. These are factors within the individual, their mindset, and personal challenges that they have which may act as a challenge to them accessing healthcare. These factors form part of the social determinants of health. The World Health Organization highlights ten social co-determinants for health: “class, stress, early life, social exclusion,

work, unemployment, social support, addiction, food and transport” (Marmot & Wilkinson, 2009,qt by Mc Nair, 2017). These overlapping categories determine one’s health and are issues of human rights. These inherent factors are enablers of access, as some are challenges to access. To begin with, a discussion of the mental and inherent challenges that these mothers face when accessing healthcare for their children will be presented.

5.3 Mental and inherent Challenges Experienced

Most of the mothers interviewed experienced the factors listed above in their lives, often caused by the need to constantly provide for their CWD. The mothers carry a great deal of anxiety about their home and family, which subsequently impacts on their own health and wellbeing. These findings correlate with previous studies that revealed that mental health problems are common for mothers of CWD (Gilson et al., 2018). One participant in the study referred to her burden of stress, the fear and worries she carries about the future of her child when she dies one day. This is referred in literature as death anxiety (Kacan et al., 2022). Findings resonate with documented research in Pakistan which depicts that mothers of children with disabilities often experience tension and stress about the care of their children in their absence in the future (Hussain & Raihan, 2022). Parents do suffer from high levels of death anxiety, and this anxiety is related to the support they receive, death-related beliefs and the type of disability of their child (Kacan et al., 2022). Research highlights that caregivers do usually experience high levels of stress, anxiety and depression when compared to other mothers of ordinary developing children (Masefield et al., 2022). In this study the mothers’ sense of isolation and alienation are contributing factors to their challenges with mental health. One participant whose child has cerebral palsy refers to how she stays indoors to avoid dealing with the negative attitudes of her neighbours and stigmatisation of her child with a disability. Nurturing a child with cerebral palsy can affect the mental and physical health of parents (Lee et al., 2019 ; Jansen-van Vuuren et al., 2021). This kind of situation is already a challenge when accessing primary healthcare.

The discussion of the above points to the very real need to provide a dual support system of access to healthcare for mothers of children with disabilities as well as their children.

Mothers spend a significant amount of time on caregiving and enabling the participation of their children in life on a daily basis (Harris et al., 2022). Caring for a child with special needs

is more demanding for the parents (Rani et al., 2022). Caregivers often report that less time is spent on self-care, relaxation, sleep and access to healthcare for themselves (Harris et al., 2022). The mothers in this study often focus on caregiving as their priority, while often neglecting themselves. The flip side of ignoring their own need for support is that this will eventually impact on their own capacity to access healthcare for their children. Another example is the participant who described her living condition as “living in the water” and that she always needed help at home in order for her to access healthcare for her child. The demands placed on these mothers make them quite vulnerable and healthcare should be made more accessible for them (Gilson et al., 2018), and for their children with disabilities. Research shows that mothers of CWD will benefit from mental health literacy training as this will facilitate the process of them acquiring mental healthcare when they need it (Gilson et al., 2018). It is also documented that Health-Related Quality of Life (HRQOL) is lower in mothers of children with cerebral palsy. Health promotion, social support and reducing parental stress was identified as being critical for these mothers when planning psychosocial intervention for them (Lee et al., 2019). One can safely argue that any support given to mothers of children with disabilities will ultimately enhance their capacity to access healthcare for their children, especially mental healthcare support.

Furthermore, breakdown of the family is very common and isolation from friends and family is often experienced (Masefield, 2021). Family Quality of Life (FQOL) is an important result for families of children with disabilities (Jansen- van Vuuren et al., 2021). FQOL is affected by culture and circumstances. The findings of this study showed that one of the participants struggled with an aggressive husband while caring for her child in difficult conditions. In her narrative this participant emphasized the need to look for another home for her and her child where she will feel safe. These findings also emphasise what is highlighted in literature that mothers of CWD are affected by poverty, caregiving, disability, and gender (Van der Mark, 2019) and even spousal abuse. Two participants reported that they had no support from the fathers of the children because of the disability of the child. This finding is supported by literature, which reflects absenteeism of fathers in the lives of their children with disabilities, leaving the mothers to become sole carers of their CWD (Mc Aulliffe et al., 2018). This situation is a barrier to accessing healthcare, because abuse can affect the

mothers' self-confidence and agency, or even put her physically in danger. Alcohol abuse of parents can result in parents not responding adequately to the emotional and physical needs of their children (Raitasalo et al., 2019).

5.4 Mental and inherent Enablers Experienced

Despite the challenges above, participants identified spirituality as a support from which they gain resilience. Spirituality and cultural context are important for the perceptions of the mothers and their expectations concerning the disability of their children (Smith & Blamires, 2022). Spirituality provides purpose and contributes to resilient wellbeing in the face of life's challenges (Ohajunwa et al., 2018), thereby giving the mothers something to hope for, despite their current circumstances. Spirituality is positioned here as both an internal and environmental support for the mothers.

The second theme to be highlighted is the environmental and social factors that influence access to healthcare for mothers of CWD. These also create challenges to access, or support access as discussed below.

5.5 Environmental and social factors that influence access

Environmental and social factors refer to the factors that are mainly extraneous to the individual.

5.5.1 Challenges Experienced

Children with disabilities face numerous challenges in accessing healthcare because of their impairments (Asim, 2022). One of the biggest challenges is stigma and the lack of healthcare provision, especially when they live in remote areas (Whittaker & Wood., 2022). This study revealed the challenges of societal stigma on the mothers of CWD. These findings are evidenced in literature as the impact of stigma on the lives of the participants shows how inadequate community support can negatively affect the lives of mothers in caring for their CWD (Hussain et al., 2021) and impact on access to healthcare.

Furthermore, being the only caregivers of these children, many of these participants experienced challenges of unemployment and poverty. Literature on research conducted in Australia showed that the primary caregivers are usually the mothers of the children with disabilities and frequently they cannot be employed because of unavailability (Masefield et

al., 2021). Two of the participants complained of the poor housing conditions that they and their children had to endure. This challenge also emanated from a research study in Bangladesh, which revealed the poor housing conditions and extreme poverty faced by parents of children with disabilities. (Hussain & Raihan, 2022). The authors advocated for a new service delivery strategy to be implemented for caregivers of children with disabilities. This includes home care and support, respite care and financial assistance to care-givers to enhance their overall wellbeing (Hussain & Raihan, 2022).

The challenges experienced by mothers of CWD are far reaching. Research from Indonesia show that access to healthcare is a challenge in most developing countries (Asa et al., 2021). Although this is a fact, some developing countries have been able to make healthcare accessible to their population with limited resources. A study carried out in Pakistan stressed this point, that rehabilitation services are often costly and inaccessible for children with disabilities (Asim, 2022). On the other hand, the same study showed that despite these challenges and barriers, somehow healthcare services were made accessible for all the participants who came from homes with limited resources. Therefore, it is possible for healthcare to be accessible to everyone, even within resource constrained environments.

Another challenge within lower socioeconomic contexts, is early detection of disabilities. An example is the challenge with early detection of hearing impairments as reflected by the outcomes of a study in South Africa (Khoza-Shangase & Kanji, 2021). It was highlighted that referrals for specialised care were not often done adequately (Khan et al., 2020). One of the participants, whose child was partially deaf, complained that at first her child was not diagnosed properly when she reported the hearing problem. It was only after 11 years that a proper diagnosis was made, and a referral made for specialist care. These results resonate with other findings from low- and middle-income countries in sub-Saharan Africa that suggest that there is a challenge with early detection of hearing impairments and a delayed referral path to specialist services (Adugna et al., 2020). This is a real barrier, as mothers wait for a long time to get adequate intervention for their children, and which has further health implications for their children.

Transport is a challenge for many mothers of children with disabilities to access PHC because of the high costs and lack of accommodation of taxi drivers. In the Khayelitsha

community in Cape Town, research showed that minibus taxis, which are the primary mode of transportation within these communities, create challenges through their inadequate accommodation of children with disabilities when they require transportation (Makabile & Swartz., 2021). This includes wheelchair users. Caregivers highlighted the everyday struggles such as transport issues, and crowded, hostile environments which they identified to be challenges for healthcare access (Makabile & Swartz., 2021).

5.5.2 Enablers Experienced

The findings of this study show that healthcare professionals are enablers to mothers of children with disabilities in accessing PHC. A lack of knowledge by healthcare professionals, of the health needs of children with disabilities and their parents are challenges to the healthcare of children with disabilities (Paget et al., 2016). However in this study the positive effects of the speedy assistance of healthcare professionals at the two PHC facilities and hospital in accessing healthcare services is narrated. The positive influence of a community health worker in the life of one participant was also highlighted. This reinforces what literature says regarding the role of community health workers as influential in communities and an important part of the frontline work force (Kane et al., 2021; Gadsden et al., 2022) and further highlights the importance of community mobilization and inter-professional collaboration in improving the health outcomes for children with disabilities (Hussain & Raihan, 2022).

The importance of family and neighbours in the lives of mothers of CWD in enabling them to care for their children cannot be overstated. The assistance of family members can result in the increased psychological wellbeing of mothers of CWD (Hizbullah & Mulyanti, 2022). It was also found that culture affects the way in which the community treats mothers of CWD and this lack of support can result in these mothers facing hardship. However, in this study one participant highlights the support of her neighbour in her life who secured food for her family. Therefore, family and neighbours are important enablers to mothers of CWD in the community.

Below, further exploration of the alignment of the study outcomes with the ACCESS framework is used to determine how accessible healthcare is for the study participants, according to the five criteria below.

5.6 Health Access Livelihood Framework (ACCESS)

The Health Access Livelihood Framework (ACCESS) as discussed above, focuses on the powerful interaction between the user and the service and asserts that healthcare access for people is composed of five dimensions: availability, accessibility, affordability, adequacy and acceptability (Visagie et al., 2015). The outcomes discussed above will be further explored using the five highlighted criteria:

5.6.1 Availability

Availability refers to whether the existing healthcare provided, and if the goods provided meet the needs of the clients (Visagie et al., 2015). The findings reveal that that healthcare was always available to the participants and their CWD when they needed it, and the healthcare provided met the needs of their children. It was also highlighted that their children received prompt medical attention in emergency situations. Most participants did not have any complaints about the services received and did not wait long to receive the medical care that was needed. As mentioned in research from Malaysia, it is important that the expectations of mothers of CWD are known by healthcare professionals and that a multidisciplinary team executes targeted health services (Sukeri et al., 2017). No participants in this study were denied services for their children with disabilities, even during the pandemic.

5.6.2 Accessibility

Accessibility refers to whether the area of the supply is in alignment with the area of the clients (Visagie et al., 2015). Findings of the study, however, show that two participants struggled to access healthcare due to the high cost of transportation. However, the majority of participants could access healthcare on foot with their CWD. Two participants walked with the children on their backs, one participant walked with her child in the wheelchair, and one mother walked with her child to the health facility. This took place within a few minutes of walking as the health facilities were in close proximity to these participants. Previous research from Limpopo in South Africa demonstrated that children with disabilities (especially in rural areas) lack essential services and support and face an inaccessible and hostile environment (Makwela & Smit, 2022). However, most of the participants in their

narratives expressed that the healthcare was accessible to them and their children in Lwandle.

5.6.3 Affordability

Affordability refers to the price of the services rendered and whether this fits the income of the clients and their ability to pay (Visagie et al., 2015). Findings reveal that all the participants received free medical care for their CWD.

5.6.4 Adequacy

Adequacy refers to whether the administration of healthcare meets the clients expectations (Visagie et al., 2015). The findings show that healthcare provided to CWD was adequate. Nursing staff and doctors at the health facilities through their caring behaviour assisted mothers to be helped speedily.

5.6.5 Acceptability

Acceptability refers to the characteristics of providers and whether these match with the characteristics of the clients (Visagie et al., 2015). Findings show that the healthcare was acceptable to all. Participants highlighted that the doctors knew their children by name, and that they received prompt assistance. The effective communication and facilitating attitudes of the healthcare professionals made them feel special. One participant emphasized how a physiotherapist always enabled her to access healthcare when she arrived at the clinic. This study also shows the important role medical staff have on improving the health services provided for mothers and their children. The positive influence on the care provided by the doctors at the hospital was also highlighted in the experiences of the participants.

5.7 Conclusion

Key findings from the study outcomes were discussed in this chapter to highlight the experiences of mothers in gaining access to healthcare services for their CWD in Lwandle.

The findings highlight the positive and negative factors that influence the capability of mothers of CWD to access healthcare for their CWD. These factors emerged in the findings and were discussed under two main themes in line with the study objectives and to answer the research question above. These two main themes were – mental and inherent factors ,and physical and environmental factors. The discussion was further explored using the lens

of the Health Access Livelihood Framework (ACCESS) as highlighted earlier in the chapter, to better understand the challenges and enablers of access to primary healthcare for mothers of children with disabilities.

In the next chapter the conclusion, study limitations and recommendations will be discussed.

Chapter 6: Conclusion and Recommendations

This chapter presents the critical outcomes of this study, recommendations, researcher reflections of this study, limitations , conclusions and recommendations for future research.

6.1 Introduction

The main research question guiding this study is: “What are the enablers and challenges that mothers of children with disability experience in accessing primary healthcare in Lwandle?”. The participants from Lwandle shared their experiences of accessing primary healthcare. From these conversations the enablers and challenges that impact on access to healthcare were characterised. Key issues raised were the health challenges of the mothers and the impact of accessing healthcare for their children because of this, as well as the lack of support mothers experienced in caring for their children in the community.

6.2 Critical outcomes

In seeking to answer this question above, certain outcomes emerged that were relevant to the discourse of access to healthcare for mothers of children with disabilities. The findings of this study identified two critical outcomes which should be considered regarding access to healthcare for children with disabilities and their mothers.

6.2.1 Critical outcome One: Dual approach- Mothers also need support

One critical outcome of this study is that mothers also need support. The very responsibility of being the sole provider and care giver of the CWD on many occasions, reduces the quality of life of mothers of CWD. As indicated by the study participants, they often deal with various challenges brought on by their position in society and culturally as the mothers of CWD, and all the negativity that comes with that lens. When the child is brought to the clinic, healthcare professionals must use that opportunity to also engage with the mother to find out what support could be given to her to support her own wellbeing, both mentally and physically. This is because the quality of life of the CWD is only at the level of the capacity of the caregiver. Therefore, there is a need for a dual approach, which focuses not only on the child, but also to support the mother simultaneously to be in wellbeing and have the capacity to provide care.

6.2.2 Critical outcome two- Creating a contextually relevant, multidimensional support system

Participants from Lwandle shared their experiences of accessing primary healthcare with their children with disabilities. Enablers and challenges that they experienced which impacted on their children's healthcare access were highlighted. Key issues raised in this study emphasised the need for a multi-dimensional support system for these mothers, addressing the prevailing negative attitudes in the community, and the establishment of sustainable partnerships to ensure inclusion in community life. The access to Health Access and Livelihood Framework criteria could guide the process of community intervention in terms of education and awareness creation about disability. Community health workers are a very important aspect in building this community awareness and support, often utilizing their conversational skills and proximity to communities to impact people and start more positive conversations on how the community views disability and mothers of CWD. The local church or mosque, parent support groups in the community, and the local schools, could all facilitate access under different criteria of the framework. Therefore, the framework could contribute to identifying and plotting the kind of support that speaks to the many different challenges mothers of CWD face on a regular basis to access healthcare for their children on a personal, familial, communal, social and environmental platform.

6.3 Study Recommendations

Based on the study outcomes, the following recommendations are given:

6.3.1 Department of Health

Healthcare professionals should be informed of the mental health challenges faced by mothers of CWD. These mothers should be referred to social workers and mental health practitioners as part of their supportive care program. Support groups should also be established by healthcare professionals for mothers of children with disabilities, as they often live in isolation, and they will benefit from the support and guidance from sharing their stories with others.

The Department of Health should urgently provide financial assistance to mothers or caregivers of children with disabilities to alleviate the financial distress they constantly face, as most of them are unemployed due to having to care for their children. Transport must be provided for all children with disabilities and their caregivers to access healthcare at

hospitals and primary healthcare facilities. This is important as there are transport challenges with minibus taxis in the community, so transport subsidized by government is recommended to ensure optimal access to healthcare of mothers and children with disabilities. The Department of Health must also address the issue of a shortage of nappies at health facilities as a priority and urgency for children with disabilities who need them. Nappies are essential items, and it is important that the health facilities have enough stock to ensure optimal care for these children as they cannot attend the facilities without one.

6.3.2 Masincedane Community Service (NPO)

It is essential that the community health workers are supported regularly visit these mothers at their homes to provide them with the guidance and support that is needed, and this will also address the isolation issues that many of these mothers experience.

6.3.3 Community Leaders

Disability advocacy should be done in the community to address the stigma and negative behaviour of people towards people with disabilities. This advocacy can be done at schools to change the behaviour of the youth towards children and people with disabilities. The attitudinal challenges experienced by the mothers in this study reflect this need for advocacy and awareness at community level. Intersectoral collaboration is of utmost importance with The Department of Health, Masincedane Community Service, other community organizations (including religious groups) and disability groups to address the issue of stigma and negativity towards children with disabilities. Consultation must take place with the media to assist with disability advocacy in the community so that people in the community become more aware of the importance of assisting and supporting people with disabilities to enable them to flourish.

6.4 Researcher reflections of the study

Learning from the experiences of the participants in this study has changed the researcher's role as a healthcare professional by becoming more aware now of the realities that mothers of CWD face daily. There is an urgent need for healthcare professionals to improve the care and support provided to these mothers. Mothers of CWD face many challenges right from their homes, before they can even arrive at the facility. When a mother does not come for check-ups, one could assume that the mother is not diligent, but now it can be seen what

they face, because the researcher was physically there with them. It is a lesson that will remain with the researcher and influence how access to care is provided for both the mothers and their children. Further reflections of each participant and how the researcher undertook an advocacy in the school for a mother of a CWD because of the stigmatization in school as an outcome of this study is presented within these reflections (Please see appendix F.).

6.5 Limitations of this Study

This research is limited to a small geographical area of Lwandle. Therefore, the findings may not be transferable to other populations from different contexts. Another limitation is that this research is only open to participants who receive services from Masincedane Community Service. Other potential participants in the area that do not receive services by this NPO are thus excluded. Due to this being a master's mini thesis, the scope of the study and time constraints meant that only a small sample of participants could take part within this study.

6.6 Conclusions

Mental and inherent factors influence access to healthcare for mothers of children with disabilities. Most of the mothers interviewed experienced stress, social isolation, unemployment and a lack of social support. The mothers carry a great deal of anxiety about their homes and family, which subsequently impacts on their own health and wellbeing. There is anxiety and stress about the future wellbeing of the child after the death of the mother. This stress, sense of isolation and alienation of these mothers of children with disabilities are contributing factors to their challenges with mental health. Mothers stay indoors to avoid dealing with the negative attitudes of neighbours and stigma. This kind of situation is already a challenge to accessing healthcare.

Physical and environmental factors also impact on access to healthcare for mothers with children with disabilities. Poor housing and the resultant issues are struggles for some mothers who have to care for their children in dismal conditions. Furthermore, stigma and negative attitudes from community members isolate mothers of children with disabilities, and this is a barrier to accessing primary healthcare for their children. Transport to clinics

and hospital is costly for mothers with their children with disabilities. Transport with taxis is problematic in the community as mothers cannot travel with their children and their assistive devices in this mode of transport. Private transport that is then used causes financial distress for mothers.

Caring health staff at the primary healthcare facilities in Lwandle and Nomzamo and at the hospital were highlighted as enablers to healthcare for these mothers and their children. Staff assisted mothers promptly in emergency situations which facilitated access.

6.7 Recommendations for further research

Future researchers could possibly explore the experiences of fathers of children with disabilities so that their voices could also be heard in this context. Going forward it is important to understand the experiences of both parents so that interventions can be planned to support parents of children with disabilities and improve the care of children with disabilities, reduce the effect of stigma on their lives, and to improve their access to healthcare. Positive health outcomes and wellbeing will therefore be ensured for CWD and their families.

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Appendix A



Project ID :24200

HREC Reference No: S21/11/247

Approval Notice New Application

Project Title: Exploration of the enablers and challenges that mothers of children with disabilities experience in accessing primary healthcare in Lwandle

Dear Mrs MA Torres

The **New Application** received on 31/03/2022 was reviewed and **approved** by members of **Health Research Ethics Committee** via **expedited** review procedures on 28/04/2022.

Please note the following information about your approved research protocol:

Approval Date: 28 April 2022 Expiry Date: 27 April 2023

Please remember to use your Project ID 24200 and Ethics Reference Number S21/11/247 on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: [Links Application Form Direct Link](#) and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>.

Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/Index/24200>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Melody Shana

Coordinator: Health Research Ethics Committee 1

*National Health Research Ethics Council (NHREC) Registration Number: REC-130408-012
(HREC1)-REC-230208-010 (HREC2)*

Appendix B

Interview Guide

1. Please tell me about yourself and your child/children with the disability.
(Probe: Can you please tell me more about your child's disability. When was the onset of the disability? How does this affect your child/children?)
2. What do you do at home before you can go to the clinic with your child?
(Probe: What preparations must you make before the time? What challenges do you face and how do you overcome the challenges? Like someone to help you with your other children? Someone to go with you to the clinic? Arrange transportation ahead of time?)
3. Tell me all about travelling to the clinic with your child
(Probe: Are you able to access transport easily on the day? Are the transport people helpful and understanding to you? Do they assist you and your child in anyway? Do they drop you at the clinic or close to the clinic? What barriers exist at this stage for you?)
4. Please tell me more about the costs of travelling to the clinic with your child
(Probe: Do you take more than one transport? How many? How much does it cost you to get to the clinic and back? Is this the same price that everyone pays for travel? How do you overcome the barriers you face?)
5. What are your experiences at the clinic with your child?
(Probe: How does the staff at the clinic treat you when you there with your child? Are they helpful and kind? Do they listen to you and assist your child as needed? Do you spend a lot of time waiting or do they attend to you on time? Can you describe how your experiences at the clinic makes you? Have you experienced anything that supports access for you and your child?)
6. What helps you the most to be able receive healthcare at the clinic? And what makes it really challenging to access healthcare at the clinic?
7. Is there anything more you would like to discuss with me at this time?

Thank you very much for your participation, I appreciate your time and responses.

Appendix C

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

| | |
|--|-------------------------------------|
| TITLE OF RESEARCH PROJECT: | |
| A qualitative exploration of the enablers and challenges experienced by mothers of children with disabilities in accessing Primary Healthcare in Lwandle | |
| DETAILS OF PRINCIPAL INVESTIGATOR (PI): | |
| Mrs Marcia Torres | Ethics reference number: S21/11/247 |
| 12 Park Lane, Central Park Somerset West 7130 | PI Contact number: 0721024830 |

I would like to invite you to take part in a research study. This study is for a degree. Please take some time to read the information presented here, which will explain the details of this study. Please ask the researcher of any questions about any part of this study that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary**, and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits entitled to you as a student at this institution. You are also free to withdraw from the study at any point, even if you do agree to take part initially

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University**. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002),

and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

- My intention in this study is to seek information concerning the experiences of mothers with children with disabilities in accessing healthcare in Lwandile.
- This information will give the management of Masincedane Community Service and the Health Department much needed information to improve programs and support to mothers of children with disabilities
- We will use face-to-face interviews guided by an interview schedule with about seven semi-structured questions to gather information. This will only be a guideline to help us focus on the purpose of this study. This means we will be able to explore other interesting ideas to do with access that may come up in our dialogue. The interview will last for 30 to 60 minutes allowing some flexibility. Because this is a face-to-face interview, you will decide on the day and time that is most convenient to you. I will encourage you to choose a place where you are assured of privacy to conduct the interviews. I wish to request for permission to make some recordings using my cellular phone if you do not mind. I may also request for the services of a translator. This means, just like my supervisor, they will have access to the information you will share but will maintain confidentiality. The questions will be asked in either isiXhosa, English or Afrikaans and will be translated back into English. I am assisted by a translator and community health workers. Please feel free to use the language you are most comfortable with and to seek clarification where you do not understand. I expect to be done with these interviews by end of July 2022.

Why do we invite you to participate?

- Like I indicated earlier on, you are part of our program at Masincedane, receiving support from our community health workers. It is important to us to know how best to improve our services to you, and how to best assist you in accessing healthcare for your child

What will your responsibilities be?

- Your responsibility in this study will be to share your experiences in visiting the health facility with your child.
- We will be guided by the interview questions contained in this, but this should not limit you from exploring other topics

Will you benefit from taking part in this research?

- The benefits of participating in this study may be immediate. We will assist you with any issues of access you may have now that is related to how we may support you to better access healthcare for you and your child. I will also share the findings of this study with you.

Are there any risks involved in your taking part in this research?

- Although I do not anticipate any risks that may result from undertaking this study, I do not want to rule out the possibility that some of the questions I may ask may make you feel uncomfortable. Please do not hesitate to let me know so that we avoid or reduce instances of emotional trauma. If you feel distressed, we can stop the interview and reschedule to resume some other time when you feel ready to continue. I will also Mental Nurse Practitioner at Nomzamo Community Day Centre for assistance.

If you do not agree to take part, what alternatives do you have?

- Not taking part in this study will not have any negative/adverse effect on you in any way. The investigator will use information from the contributions of other participants.

Who will have access to your medical records?

- The information collected from this study will be treated as confidential and protected. It will only be used for academic purposes and will only be available to my supervisors and translator. It may be used for publication but rest assured that your identity will remain anonymous. I will use pseudo-names to shield your identity and all data-gathering equipment will be stored securely. All documents will be stored at Stellenbosch University by my supervisor under lock and key, and data will be backed

up on Stellenbosch University's One Drive account which is a secure space for data storage. Will you be paid to take part in this study and are there any costs involved?

➤ Subject to the researcher receiving funding for this research, you will be paid R100 for participating in this study

➤ You can phone Ikwezi Community Day Centre 021-8457556 if you have any further queries or encounter any problems.

➤ You can phone the Health Research Ethics Committee at +27 21 938 9677/9819 if there still is something that I may not have explained to you, or if you have a complaint.

➤ You will receive a copy of this signed information and consent form for you to keep safe. After you have read and understood this form you can sign, and I will give you a copy. Ensure to preserve privacy and confidentiality in the process.

Declaration by participant

By signing below, I agree to take part in a research study entitled: A qualitative exploration of the enablers and challenges that mothers of children with disabilities experience in accessing Primary Healthcare in Lwandle

I declare that:

· I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.

· I have had a chance to ask questions and I am satisfied that all my questions have been answered.

· I understand that taking part in this study is **voluntary**, and I have not been pressurized to take part.

· I may choose to leave the study at any time and nothing bad will come of it – I will not be penalized or prejudiced in any way.

· I may be asked to leave the study before it has finished if the researcher feels it is in my best interests, or if I do not follow the study plan that we have agreed on.

Signed at (*place*) on (*date*) 2022.

.....

Signature of participant Signature of witness

Declaration by investigator

Ideclare that:

· I explained the information in this document in a simple and clear manner to

.....

· I encouraged him/her to ask questions and took enough time to answer them.

· I am satisfied that he/she completely understands all aspects of the research, as discussed above.

·

Signed at (*place*) on (*date*) 2022.

.....

Signature of investigator Signature of witness

Appendix D



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

Translators/Transcribers

As a translator and transcriber working for the research project at Lwandle, Strand during May and August 2022 dates, you will have access to confidential information and data from interviews with study participants. These participants have consented to participate in the study with the understanding that their identities and personal information, as well as their interview responses, will be kept confidential. Once you have assisted with the translations and transcriptions of each interview, the interview transcripts will be anonymised so that participants cannot be identified from their transcripts.

By signing this confidentiality agreement, you agree to treat all information and data that you have access to through this project is confidential. You agree not to share any of the material with which you will be working with anyone else, whether verbally, physically or electronically. You agree not to discuss individual participants or their interview responses with anyone else. You agree to protect the confidentiality of both the data and the study participants. Where relevant, you agree to delete all audio files and transcripts from your personal computer once you have completed this work, unless otherwise agreed with University of Stellenbosch project staff.

Name: _____

ID Number: _____

Signature: _____

Date: _____

Appendix E

Tel: 021 854 6311
Fax: 021 854 6303
Email: dd-mas@xsinet.co.za



Market Square
Corner of Wesley & Kort St
STRAND
7140

PO Box 1165, Strand, 7139 Website www.masincedane.com
NPO 004 454 PBO 930001127

12 Park Lane
Central Park
Somerset West
7130

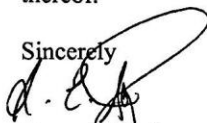
Dear Marcia Torres

Re: Exploring access to health care of mothers of children with disabilities

The management of Masincedane is aware of your proposed research project. We understand the involvement of our audiologist and community health workers in assisting you to complete your research project which includes approaching possible participants for consent, and interviewing these participants.

As the Health manager of Masincedane I have read through your research proposal and support the involvement of our organization in this project and look forward to the success thereof.

Sincerely



Roger Allingham

6 October 2021



HWSETA

HWSETA ACCREDITED SERVICE PROVIDER HW591PA0904192



Appendix F: Reflections of the researcher after each interview

Interview with Pat

I could see the despair, pain and suffering of the mother. It was as if there was no hope in this home. When the participant started talking, I realized that she was heavy laden and burdened dealing with the disability of her child. The child is partially deaf and uses hearing aids occasionally. Due to the stigma the son does not use his hearing aids daily as he should at school, as he is constantly mocked and laughed at by his peers at school and this saddens him and his mother. This situation at school further negatively affected in academic performance at school which is another concern for the mother. X celebrates his birthday the next day, but the mother is devastated as she has nothing to give him.

This mother and child need urgent support and assistance. It is us as healthcare professionals that can turn this situation around by our interventions at the household level. Constant support to the mother and child by the community health workers who know the area is needed. Counselling of the social worker will strengthen the mother also further. Staff from Masincedane Community Service will conduct disability advocacy at the school to address the stigma issue.

Interview with Bea

What moved me the most at the beginning was that this mother waited for us outside in the road. It was clear that she was so excited to talk to us about her experiences with her child who is blind.

This mother needed to share her voice with others, she was so full of sorrow, pain and anguish. When the interview started, she started to cry as she was now able to share her story. She did not want to stop talking even when I said we can stop and she can take a short while to relax before we continue, but she never wanted to stop. She just wanted to talk and talk. I got the impression she sat with all these experiences for a long time with no one to share it with. The mother loves her children very much and she lives only for her children. Caring for her child with this disability is very stressful for her through all of this. She has lost all her family and friends.

Interview with Maria

Again, we saw the poor conditions this mother lives in with her child, and the effects of the stigma and negative behaviour of the neighbours on her as a mother. This created much chaos in her life, as she is not free to spend a lot of time outside her home as she constantly faces rude comments and ridicule from neighbours because her child has a disability. Here I saw the devastating effect of a community on the lifestyle on the mother with her child just because the child has a disability. This creates much sadness and anxiety for the mother and who must live her life in this community.

Going forward there is much work to do in the community to educate the people on disability and how they should support people with disabilities. This is a necessity to enable people with disabilities to flourish.

Interview with Sophi

What moved me the most was seeing the bond between the child and mother during this interview. It was clear this mother was doing her best for this child with cerebral palsy in the most challenging conditions. I see resilience again as the mother keeps going and can still smile and laugh, living in poverty with minimal resources.

This mother was open to having us come into her space to learn more about her experiences caring for her child. I saw that she was so willing to share her life with us, this moved me so much. She was completely open and kept nothing back. She was struggling to access healthcare because of the costs of private transport, but she was such a fighter. It was clear that nothing got her down. The affection and love her child had for her showed us that she cared well for her child through all these diverse conditions, this was a positive.

Interview with Ina

The participant really cared for her child with intellectual disability with so much love and devotion. I saw that she was very proud of her child also. The picture was clear that she was struggling so much to make a living and care for her child in difficult and stressful conditions, but she was happy that we visited her as she needed so much help with her current situation.

She lives in poverty in a small shack and conditions are difficult with leaking into the shack after all the rain. Her smile continues through all these difficulties despite the alcohol abuse of her husband that she faces on a frequent basis. This abuse from her husband is her main challenge in life as she cares for her child with the disability. This participant wants to move to another place, but she has no-where to go as her family is in Eastern Cape.

This is a mother who needs much support in addressing the domestic violence she faces. Her husband also needs assistance and counselling. What I realized in this interview is the impact of the community health worker on her life. This is a strong enabler to this mother to access healthcare for her child in challenging conditions.

Interview with Hayli

It was clear that this participant loved her child so much, and they had a close and special bond. However, this participant suffers so much because of the rejection of her husband because of the disability of the child. Her husband wanted her to give up the child, but she refused to do this. Her child was her whole world. Spirituality was an important part of her life and a strength to her because she was enabled to live and care for her child through all these sufferings, as she believed that God gave her the child as a gift.