

The Mixed Experiences of Pregnant Women with Physical Disabilities in Accessing and Utilising Antenatal Care Services in Rural South-Western Uganda

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PLAGIARISM DECLARATION

I, **Ponsiano Kabakyenga Nuwagaba**, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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DEDICATION

To the memory of my beloved Dad,

Kabakyenga Basil,

who went to be with the Lord on 30 March 1998.

Dad, *okangira ngu nsome ebitabo byangye, ndugye omu mizaano.*

Your wise counsel was not in vain, and your legacy remains...

and to the Nuwagabas,

my wife, **Julie** and our children, **Jed, Jemie** and **Jemuel,**

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The Almighty God is great.

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ACRONYMS/ABBREVIATIONS

ANC:	Antenatal care
AIDS:	Acquired Immune Deficiency Syndrome
CBO:	Community Based Organisation
CBR:	Community Based Rehabilitation
CDC:	Centers for Disease Control and Prevention
CDO:	Community Development Officer
CDS:	Critical Disability Studies
CDT:	Critical Disability Theory
CPD:	Continuous Professional Development
DHRS:	Department of Health and Rehabilitation Sciences
DPOs:	Disabled People's Organisations
FGD:	Focus Group Discussion
FHS:	Faculty of Health Sciences
HIV:	Human Immunodeficiency Virus
HREC:	Human Research Ethics Committee
HSD:	Health Sub-District
HSDP:	Health Sector Development Plan
HSSP:	Health Sector Strategic Plan
ICF:	International Classification of Functioning, Disability and Health
ICM:	International Confederation of Midwives
IRB:	Institutional Review Board
MGLSD:	Ministry of Gender, Labour and Social Development
MoH:	Ministry of Health
NDP:	National Development Plan
NGO:	Non-Governmental Organisation

OPD:	Out-Patient Department
PDC:	Parish Development Committee
PDM:	Parish Development Model
PHC:	Primary Health Care
REC:	Research Ethics Committee
RMC:	Respectful Maternity Care
SDGs:	Sustainable Development Goals
TBA:	Traditional Birth Attendant
UBOS:	Uganda Bureau of Statistics
UCT:	University of Cape Town
UCU:	Uganda Christian University
UNAPD:	Uganda National Action on Physical Disability
UNCEDAW:	United Nations Convention on the Elimination of All Forms of Discrimination Against Women
UNCRPD:	United Nations Convention on the Rights of Persons with Disabilities
UNCST:	Uganda National Council of Science and Technology
UNICEF:	United Nations International Children’s Education Fund
UNMHCP:	Uganda National Minimum Health Care Package
VHT:	Village Health Team
WHO:	World Health Organization

DEFINITIONS OF KEY CONCEPTS

For the purposes of parallel understanding with the reader, I define the key concepts used in this thesis.

Access and utilisation

“The opportunity to identify antenatal care needs, to seek antenatal care services”, and identify and reach an appropriate health facility for the services (Levesque et al., 2013, p. 8).

Utilisation

“The opportunity to obtain or use antenatal care services, and to actually have the need for services fulfilled” (Levesque et al., 2013, p. 8).

Activity limitations

“Difficulties an individual may have in executing activities” (WHO, 2001, p. 10).

Antenatal care

“The care provided by skilled health care professionals to pregnant women and adolescent girls in order to ensure the best health conditions for both mother and baby during pregnancy through risk identification; prevention and management of pregnancy-related or concurrent diseases; and health education and health promotion” (WHO, 2016, p. 1).

Body functions

“The physiological functions of body systems (including psychological functions)” (WHO, 2001, p. 10).

Body structures

“Anatomical parts of the body such as limbs and their components” (WHO, 2001, p. 10).

Disability

An umbrella term covering impairments, activity limitations, and participation restrictions. It denotes the negative aspects of the interaction between an individual (with impairment) and the individual’s contextual factors (environmental and personal factors) (WHO, 2001, 2013).

Environmental factors

“The physical, social, and attitudinal environment in which people live and conduct their lives” (WHO, 2001, p. 10). These are either barriers to or facilitators of the person’s functioning.

Functioning

An umbrella term covering body functions, body structures, activities and participation. It denotes the positive aspects of the interaction between an individual with impairment and that individual’s contextual factors (environmental and personal factors). Functioning and

disability are results of the interaction between the health conditions of the person and their environment (WHO, 2001, 2013).

Health worker

A professional medical staff working at the health facility.

Impairment

“Problem in body function and structure such as significant deviation or loss” (WHO, 2001, p. 10).

Midwife

“A person who has successfully completed a midwifery education programme that is based on the ICM Essential Competencies for Basic Midwifery Practice and the framework of the ICM Global Standards for Midwifery Education and is recognized in the country where it is located; who has acquired the requisite qualifications to be registered and/or legally licensed to practice midwifery and use the title ‘midwife’; and who demonstrates competency in the practice of midwifery” (ICM, 2017, para. 1).

Midwifery

A profession of midwives as well as an approach to care for women and their newborn infants (ICM, 2017).

Participation restrictions

“Problems an individual may experience in involvement in life situations” (WHO, 2001, p. 10).

Participation

“Involvement in a life situation” (WHO, 2001, p. 10).

Persons with disabilities:

“People who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006, p. 3).

Personal factors

Particular background of an individual’s life and living; they comprise features of the individual that are not part of the disability (WHO, 2001).

Woman with physical disability

A female person with a limitation on her physical functioning, mobility, dexterity or stamina. In this study, I preferred to use person-first language, hence the term ‘*women with physical disabilities*’ and not ‘*physically disabled women*’. The ‘*women with physical disabilities*’ nomenclature is consistent with the United Nations Convention on the Right of Persons with Disabilities (UNCRPD) (United Nations, 2006).

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ABSTRACT

Title: *The Mixed Experiences of Pregnant Women with Physical Disabilities in Accessing and Utilising Antenatal Care Services in Rural South-Western Uganda*

Background: In low- and middle-income countries, several environmental barriers impede accessibility to antenatal care (ANC) services for women with disabilities, yet ANC is a critical entry point for pregnant women to receive quality maternity care services. These barriers are more pronounced in rural areas than urban areas in Uganda. Although the World Health Organisation recommends that ANC services should be designed and continually improved based on locally generated data to address access barriers, the experiences of rural pregnant women with physical disabilities are largely undocumented.

Aim: This study aimed to investigate the experiences of pregnant women with physical disabilities in accessing and utilising ANC services and suggest strategies for improving the services in rural south-western Uganda.

Objectives: The study sought to:

- describe the accessibility of ANC services
- explain the utilisation of ANC services
- explore the relationship between women with physical disabilities and health care providers
- explore how women with physical disabilities and midwives understand disability and the provision of ANC services in rural south-western Uganda

Methods: An interpretive qualitative study using a multiple case study design was conducted. Twelve women with physical disabilities and six midwives from three health facilities in Sheema district in south-western Uganda, East Africa, were selected as study participants. Women were sampled using snowball sampling. Midwives and health facilities (health centre III, health centre IV and general hospital) were sampled using purposive sampling.

Data was gathered through in-depth face-to-face interviews with the women and midwives, a focus group discussion with the women, and direct observation of the physical environment at the three health facilities, from November 2020 to January 2021. Data was transcribed, translated, and thematically analysed with support of NVivo software. Ethical approval was obtained from University of Cape Town and Uganda National Council of Science and Technology, including a Risk Management Plan for preventing the transmission of Covid-19.

Findings: Four themes were generated:

1. 'Optimising wellbeing' was shaped by exercising agency, accessing family and community support, and aligning policy and practice.

2. 'Undermining wellbeing' involved ignorance and mental ill-health (including emotional and spiritual oppression), sociocultural prohibitions, and inaccessible transport and mobility systems.
3. 'Unresponsive ANC policy to women's specific needs' included the integrated nature of ANC services, unresponsive ANC policy, and unaccommodating health facility designs.
4. 'Improving quality of ANC services' related to women's mixed experiences, preparing midwives and other health workers through education, training, and mentoring, and enabling disability inclusion for fit-for-purpose ANC services.

Conclusion: Despite a few enablers optimising their wellbeing, rural pregnant women with physical disabilities experience many barriers that negatively impact on their pregnancy experiences and pregnancy health care. Women's spirituality is integral to their wellbeing. Justice, equity, and respect for their human dignity need to be underscored in ANC policy, health system and infrastructure planning, and midwifery education, training, and practice. The establishment of accessible quality ANC services within under-served areas benefits all women. The spirit of Ubuntu, which may facilitate women's participation and functioning at the family, community, and health facility levels, cannot be overemphasised.

Going forward: An integrated framework for disability inclusive family- and community-focused ANC services for rural communities is proposed. This framework needs to be tested to determine its efficacy in other rural African settings. A further study to explore the effectiveness of maternity waiting homes from the perspective of women with physical disabilities and the community in the context of rural Ugandan setting is suggested.

Key words: *Pregnancy experiences, physical disability, health care, access, utilisation, enabling environment, ubuntu, rural*

CHAPTER 1:

INTRODUCTION AND BACKGROUND INFORMATION

1.1 Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) defines persons with disabilities as those who have “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006, p. 3) and recognises that “disability is an evolving concept” (United Nations, 2006, p. 1). The International Classification of Functioning, Disability and Health (ICF) by the (World Health Organization [WHO] 2001) defines disability as “an umbrella term covering impairments, activity limitations, and participation restrictions” (p. 3). It denotes the negative aspects of the interaction between an individual (with impairment) and the individual’s contextual factors (environmental and personal factors).

The World Report on Disability by the WHO and World Bank (2011) indicates that 16% of the world’s women have impairments. Globally, disabilities are more common among women than men, and in rural areas compared to urban areas (Mitra & Yap, 2021). In Uganda, about 4 million people (14% of the population) aged 5 years and above have disabilities, with a higher prevalence among women (15%) compared to men (10%). The disability prevalence rate is higher among those living in the rural areas (15%) compared to those in the urban areas (12%) (Uganda Bureau of Statistics, 2016).

The Disability and Development Report of 2018 (United Nations, 2019) maintains that persons with disabilities continue to report poorer health than people without disabilities. The report shows that poor health among persons with disabilities is linked to underlying health conditions or environmental barriers such as lack of social support or access to health services. The same report further points out that persons with disabilities (80%) in countries with low levels of Growth Domestic Product (GDP) per capita report poorer health than those (20%) in countries with higher level of GDP per capita. In studies conducted in low- and middle-income countries such as Ethiopia and Angola, rural women made fewer ANC visits

to the health facilities than women in urban areas (Shibre et al., 2020; Yehualashet et al., 2022).

Central to improving the health of persons with disabilities is the concept of ‘accessibility’. Denying persons with disabilities their right to access health care services greatly contributes to determining their situation of generalised poverty and social exclusion (Monedero et al., 2014). The concept of access and utilisation is crucial in exploring the quality of ANC services. In health care, Levesque et al. (2013) define access and utilisation as “the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use healthcare services and to actually have the need for services fulfilled” (p. 8). However, little is known about how women with disabilities access and utilise ANC services, particularly in rural settings.

In this chapter, I will provide the background to the study. It briefly establishes the situation for women with disabilities in their access to and utilisation of ANC services. I then present the global and national policy context of Uganda, the specific study location, and Uganda’s health care system, including distribution of health facilities. This chapter also presents the problem statement, critical research questions, aim, objectives, and significance of the study. I follow this with the description of my positionality and motivation to undertake this research. Lastly, I present the structure of the thesis and conclusion of this chapter.

1.2 Background to the study

WHO (2016) defines ANC as “the care provided by skilled health-care professionals to pregnant women and adolescent girls in order to ensure the best health conditions for both mother and baby during pregnancy” (p. 1). ANC is an entry point for pregnant women to receive maternity care services (Akhtar et al., 2018). It is known that “what women want and expect from ANC is to have a positive pregnancy experience” (WHO, 2016, pp. 1-2). Quality ANC services are critical for improved pregnancy experiences and outcomes for women. WHO (2016) and Miller et al. (2016) in the Lancet Maternal Health Series recommend that during pregnancy, interventions in health promotion, disease prevention, and early detection and treatment for complications and diseases should be provided in a coordinated and

integrated plan. This plan should be led by midwives¹, who are the most appropriate care providers to attend to pregnant women (International Confederation of Midwives (ICM), 2021), including those with physical disabilities.

In 2016, the WHO produced consolidated guidelines for routine ANC, thereby updating the Focused ANC (FANC) model of 2002 that was hitherto used for delivering evidence-based interventions. The FANC did not provide guidance on context-specific interventions (WHO, 2016). In the 2016 WHO ANC model, it was noted that continuity of care, integrated service delivery, availability of supplies and commodities, and empowered health-care providers are essential requirements for the effective implementation of ANC. The overarching aim of this model is to:

...provide pregnant women with respectful, individualized, person-centred care at every contact, with implementation of effective clinical practices (interventions and tests), and provision of relevant and timely information, and psychosocial and emotional support, by practitioners with good clinical and interpersonal skills within a well-functioning health system. (WHO, 2016, pp. 105-106)

Unlike the goal oriented four-visit FANC model, the 2016 WHO ANC model recommends a minimum of eight contacts² with interventions adaptable to each individual woman and the local context on each contact. The 2016 model emphasises context-specific and flexible interventions in the delivery of ANC services (WHO, 2016). While the WHO ANC model (WHO, 2016) is individualised and person-centred, it does not clearly address body impairment and its influence on accessing and utilising ANC services, which will be explored and highlighted in this research. The table below shows the comparison of schedules for two the ANC models.

¹ The ICM defines a midwife as “a person who has successfully completed a midwifery education programme that is based on the ICM Essential Competencies for Basic Midwifery Practice and the framework of the ICM Global Standards for Midwifery Education and is recognized in the country where it is located; who has acquired the requisite qualifications to be registered and/or legally licensed to practice midwifery and use the title ‘midwife’; and who demonstrates competency in the practice of midwifery.” (ICM, 2017)

² Within the 2016 WHO ANC model, the word ‘contact’ was used instead of ‘visit’, as it implies an active interaction and connection between a pregnant woman and a health-care provider that is not implicit with the word ‘visit’. In this thesis, the two words were used interchangeably by the participants and will be presented as given by the source. (WHO, 2016)

Table 1.1: Comparison of the FANC and 2016 WHO ANC models (WHO, 2016)

WHO FANC Model	2016 WHO ANC Model
<i>First trimester</i>	
Visit 1: 8–12 weeks	Contact 1: up to 12 weeks
<i>Second trimester</i>	
Visit 2: 24–26 weeks	Contact 2: 20 weeks
	Contact 3: 26 weeks
<i>Third trimester</i>	
Visit 3: 32 weeks	Contact 4: 30 weeks
Visit 4: 36–38 weeks	Contact 5: 34 weeks
	Contact 6: 36 weeks
	Contact 7: 38 weeks
	Contact 8: 40 weeks
Return for delivery at 41 weeks if not yet given birth.	

To date, far too little attention has been paid to the role of family and community in supporting pregnant women with disability to access and utilise ANC services. In a study about the maternal experiences of mothers with multiple disadvantages in England, McLeish and Redshaw (2019) highlight the significance of supporting such women to navigate the complex maternity care system. Their study and that of Mgata and Maluka (2019), in Dar es Salaam, Tanzania, emphasise that support from family members is important for early and regular ANC attendance. The former study was in a high-income country and the latter was among non-disabled pregnant women in an urban setting.

Persons with disabilities encounter a range of barriers when they attempt to access health care services and they have poor health outcomes (Kuper & Heydt, 2019). The Global Report on Disability states that 51-53% of persons with disabilities are unable to afford health care compared to 32-33% of non-disabled people (WHO & World Bank, 2011). They are more than twice as likely to report finding health care providers' skills inadequate to meet their needs, four times more likely to report being treated badly, and nearly three times more likely to report being denied care compared to their non-disabled counterparts (WHO & World Bank, 2011). Women with disabilities are likely to be in a more precarious position than men with disabilities (United Nations, 2019), and it has also been established that women with disabilities have more emotional, psychological and social needs than other women (WHO,

2016). However, in a phenomenological study on pregnant women with disabilities from Ireland (Walsh-Gallagher et al., 2012) and in the book “A Health Handbook for Women with Disabilities” by Maxwell et al. (2007) on the pregnancy experiences of women with disabilities from 40 diverse countries, including Uganda, it is argued that women with disabilities have been routinely denied maternity care services, often being ill-treated for getting pregnant, and are viewed as liabilities by health care professionals.

Inadequate access to and utilisation of quality reproductive health care services continues to contribute to maternal morbidity and mortality in low- and middle-income countries. In 2017, the global maternal mortality ratio was estimated to be at 211/100,000 live births with a total of 295,000 maternal deaths (WHO, 2019). Of these deaths, 99% occur in low-resource settings and most can be prevented through well-known strategies (Bueno de Mesquita & Kismödi, 2012; Miller et al., 2016; WHO, 2016). Miller et al. (2016), in the Lancet Maternal Health Series, assert that “preventable maternal morbidity and mortality is associated with the absence of timely access to quality care, defined as too little, too late (TLTL) – i.e., inadequate access to services, resources, or evidence-based care – and too much, too soon (TMTS) – i.e., over-medicalisation of normal antenatal, intrapartum, and postnatal care” (p. 2177).

In Uganda, the maternal mortality ratio has remained high at 336/100,000 live births (Uganda Bureau of Statistics, 2017b). ANC from a trained professional is important to monitor pregnancy and reduce morbidity and mortality risks for the mother and child during the pregnancy, delivery, and postnatal periods (WHO, 2016). In their integrated review summary on the experiences of women with physical disabilities accessing ANC services in low- and middle-income countries, Kazembe et al. (2022) found that women with physical disabilities experience obstacles to accessing and utilising ANC services. Inaccessibility to quality ANC services for rural pregnant women with physical disabilities in South Africa was identified as a significant barrier to their health care (Mgwili & Watermeyer, 2006).

As has been reported in a study conducted in India by Murthy et al. (2014), of concern is that women with disabilities have adverse pregnancy outcomes compared to those without a disability. While a few studies have reviewed the health care experiences of women with disabilities in general in low- and middle-income countries (Devkota et al., 2017, 2018; Mitra, Akobirshoev, et al., 2017; Morrison et al., 2014), in their review summary, Kazembe

et al. (2022) indicate that there is minimal understanding of the experiences of women with physical disabilities accessing ANC services in these under-served populations. Literature shows no studies conducted to understand the experiences of pregnant women with physical disabilities in accessing and utilising ANC services in rural Uganda, even though the WHO recommends that ANC services be “designed and continually improved based on locally generated data” to overcome supply and utilisation barriers (WHO, 2016, p. 20). This study explores pregnant women with physical disabilities' experiences in accessing and utilising these services in a rural Ugandan setting. The next section presents a brief overview of the global and Ugandan policy context regarding access to and utilisation of health care services by persons with disabilities in general and women with physical disabilities in particular.

1.3 Policy context of the study

The policy context of this study relates to the international and local policy landscape. Respectful Maternity Care (RMC) and the reproductive health rights of persons with disabilities are discussed, highlighting the need for the equalisation of opportunities for pregnant women with disabilities in accessing and utilising ANC services.

1.3.1 Global policy context

An important aspect of improving health systems and quality ANC is respectful maternity care (RMC). The concept of RMC has been widely researched and is recognised in the women's health global agenda as an important indicator for maternal and newborn health care quality (Chinkam et al., 2023; Miller et al., 2016; Molina et al., 2016; Shakibazadeh et al., 2018). In the Lancet Maternal Health Series, Miller et al. (2016) articulate that respectful care should be delivered with the consideration of women's fundamental rights and their individual cultural, personal, and medical needs. Renfrew et al. (2014), in the Midwifery Series, underscore the values and approaches to midwifery care, as articulated by women and midwives. Such values and approaches should be “in the context of respectful care that is tailored to the need and works to strengthen women's capabilities, and is integrated across facility and family settings” (Renfrew et al., 2014, p. 1141). A study in Ghana confirmed that knowledge of RMC improves maternity care practices, particularly how midwives relate to and communicate with women (Dzomeku et al., 2021). Adequate communication and information sharing between midwives and women, and women's informed consent during the ANC process, should be underscored (Chinkam et al., 2023) to promote respectful care.

In the *‘WHO recommendations on Intrapartum Care for a Positive Childbirth Experience’*, WHO (2018) defines RMC as “care organised for and provided to all women in a manner that maintains their dignity, privacy and confidentiality, ensures freedom from harm and mistreatment and enables informed choice and continuous support during labour and childbirth” (p. 19). However, it strikes me that in the *‘WHO Recommendations on ANC for a Positive Pregnancy Experience’* (WHO, 2016), the need for respectful care during ANC is overlooked. More attention has been given to intrapartum care than ANC, which is an equally important aspect of safe motherhood. Moreover, many women who experience mistreatment and abuse during ANC may not return for the subsequent health care services (Miller et al., 2016). While it is important to improve women’s experiences of labour and childbirth, there is a need to pay attention to disrespectful and undignified ANC encountered by pregnant women with physical disabilities in under-resourced settings. Such disrespectful and undignified care may have an impact on the women’s engagement (or not) in the health services for their intrapartum and/or postpartum care.

In a qualitative evidence synthesis by Shakibazadeh et al. (2018), twelve domains of RMC were identified. These domains are highlighted in Figure 1.1 below.



Figure 1.1: Domains of Respectful Maternity Care

These domains in Figure 1.1 above are applicable to all women, although the vulnerability of pregnant women with physical disabilities may call for more emphasis of some domains (eg., domains number 5 and 6) among these women than their non-disabled counterparts in accessing and utilising ANC services. RMC requires competent, motivated and adequately prepared health workers (through education, training and mentoring) to use an inclusive approach to ANC.

The UNCRPD guarantees persons with disabilities the fundamental human rights to physical, social, and psychological health (United Nations, 2006). Article 25 of the UNCRPD guarantees persons with disabilities the right to access “the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including those in the area of sexual and reproductive health” (United Nations, 2006, p. 16). Article 9 stipulates that persons with disabilities should live independently and participate fully in all aspects of life and have access, on an equal basis with others, to facilities and services (including ANC services) provided to the public, including rural areas (United Nations, 2006). In Article 6, women with disabilities are recognised as a subject of multiple discriminations and are guaranteed full and equal enjoyment of all human rights (United Nations, 2006). Women with physical disabilities have an inalienable right to access quality ANC services but their access to these services is still a challenge due to numerous contextual barriers, including attitudinal barriers and stigma arising from health care providers (United Nations, 2019).

At the heart of the Sustainable Development Goals (SDGs) is a commitment to ensure that ‘no one is left behind’ and that no goal is considered met unless met for all (United Nations Women, 2017). Specifically, SDG 3 calls for ensuring healthy lives and promoting wellbeing for all, thus implicitly establishing the goal for persons with disabilities (United Nations, 2019). Among the targets for SDG 3 is to “reduce the global maternal mortality ratio to less than 70 per 100 000 live births”, “ensure universal access to sexual and reproductive health care services”, and “ensure universal health care coverage” by 2030, for targets 3.1, 3.7 and 3.8 respectively (United Nations, 2015, p. 20). In addition, SDG 5 emphasises the achievement of gender equality and empowerment of all women, with targets to “end all forms of discrimination”, “eliminate all forms of violence” against women and “ensure universal access to sexual and reproductive health and reproductive rights”, by 2030, under targets 5.1, 5.2 and 5.6 respectively (United Nations, 2015, p. 22).

The above SDGs work in tandem with the United Nations Convention on the Elimination of All Forms of Discrimination against Women (UN CEDAW) (Articles 12 and 14) that calls for the elimination of discrimination against all women, including those in rural areas, with emphasis on their participation in community development activities and ensuring their access to appropriate and adequate health care services in connection with pregnancy (United Nations Women, 1979). In the same vein, the Beijing Declaration and Platform for Action of 1995, as a global “agenda for women’s empowerment”, emphasises that “women’s rights are human rights” (United Nations, 1995, p. 9). This Declaration reaffirms the fundamental human right for women with disabilities to access and utilise ANC services. Despite the global agenda and commitment to leave no one behind, the progress and welfare of women with disabilities is often at the top of the list for not being met (United Nations, 2019; United Nations Women, 2017).

The Primary Health Care (PHC) approach as adopted by the WHO in the Alma Ata Declaration is a conceptual basis for effective health care delivery that underscores the principles of universal accessibility, community participation and active involvement, inter-sectoral collaboration, health promotion, and use of appropriate technology. In the declaration, the member states decried the “gross inequality” in health status across and within countries as “politically, socially, and economically unacceptable” (WHO, 1978, p. 1). The Common African Position (CAP) of the African Union prioritises the improvement of maternal and child health with special focus on vulnerable groups including women with physical disabilities (Ministry of Health, 2015). The plight of women with physical disabilities in their access to and utilisation of ANC services may not be clearly understood unless their lived experiences are investigated and documented.

1.3.2 National policy framework in Uganda

The 1995 Constitution of the Republic of Uganda, Article 35 (Government of Uganda, 1995) and the progressive rights-based legislation emphasise respect for and the protection of the rights of persons with disabilities. The Persons with Disabilities Act 2006 (Government of Uganda, 2006) explicitly recognises the fundamental human right of women with disabilities to access reproductive health care services, including ANC services. Uganda enacted the National Council for Disability Act 2003 (Government of Uganda, 2003) and ratified the

UNCRPD in September 2008 (Lang & Murangira, 2009). It established a National Policy on Disability in 2006 (Ministry of Gender, Labour and Social Development, 2006) and the Equal Opportunities Commission Act in 2007 (Government of Uganda, 2007).

The fifth pillar of Uganda's Parish Development Model (PDM) emphasises mindset change and the cross-cutting issues of gender, environment, and disability, as recommended in the Third National Development Plan (NDPIII) 2020/2021-2025/2026, for the realisation of improved access to public services, including ANC services (Government of Uganda, 2020). As a way of deepening the decentralisation process, the Government of Uganda has adopted the PDM as a development approach, using a parish as the lowest reference unit for delivery of interventions for inclusive, sustainable, balanced and equitable socioeconomic transformation (Ministry of Local Government, 2022). A parish (managed by the Parish Chief) is the lowest administrative local government unit for planning, budgeting and delivery of socio-economic services in Uganda (Government of Uganda, 2020).

In order to enhance inclusive growth and development, one of the strategies in the second Uganda National Development Plan that targets persons with disabilities is geared towards the equalisation of opportunities, rehabilitation, and inclusion of persons with disabilities in their communities. The current government strategy towards interventions of persons with disabilities is through the Community Based Rehabilitation (CBR) programme (Uganda Bureau of Statistics, 2016). The programme focuses on raising awareness, capacity building, livelihoods, and influencing policy change for persons with disabilities (Oyaro, 2014).

Uganda's Health Sector Development Plan (HSDP) 2015/2016-2019/2020 and the Health Sector Strategic Plan (HSSP) 2020/2021-2024/2025 are aligned to support the health sector to implement the various global commitments (Ministry of Health, 2015, 2020). The Uganda National Health Policy II³ (2010) seeks to attain a good standard of health for all people in order to promote healthy and productive lives (Ministry of Health, 2015). This policy is guided by the principles of Primary Health Care (PHC) and aims at universal access to the Uganda National Minimum Health Care Package (UNMHCP), which includes ANC services

³ Uganda's National Health Policy is guided by the principles of Primary Health Care (PHC) and aims at universal access to the Uganda National Minimum Health Care Package (UNMHCP) which includes ANC services (Ministry of Health, 2015).

(Ministry of Health, 2015). The following section briefly describes the health care system and distribution of health facilities in Uganda.

1.4 The health care system and distribution of health facilities in Uganda

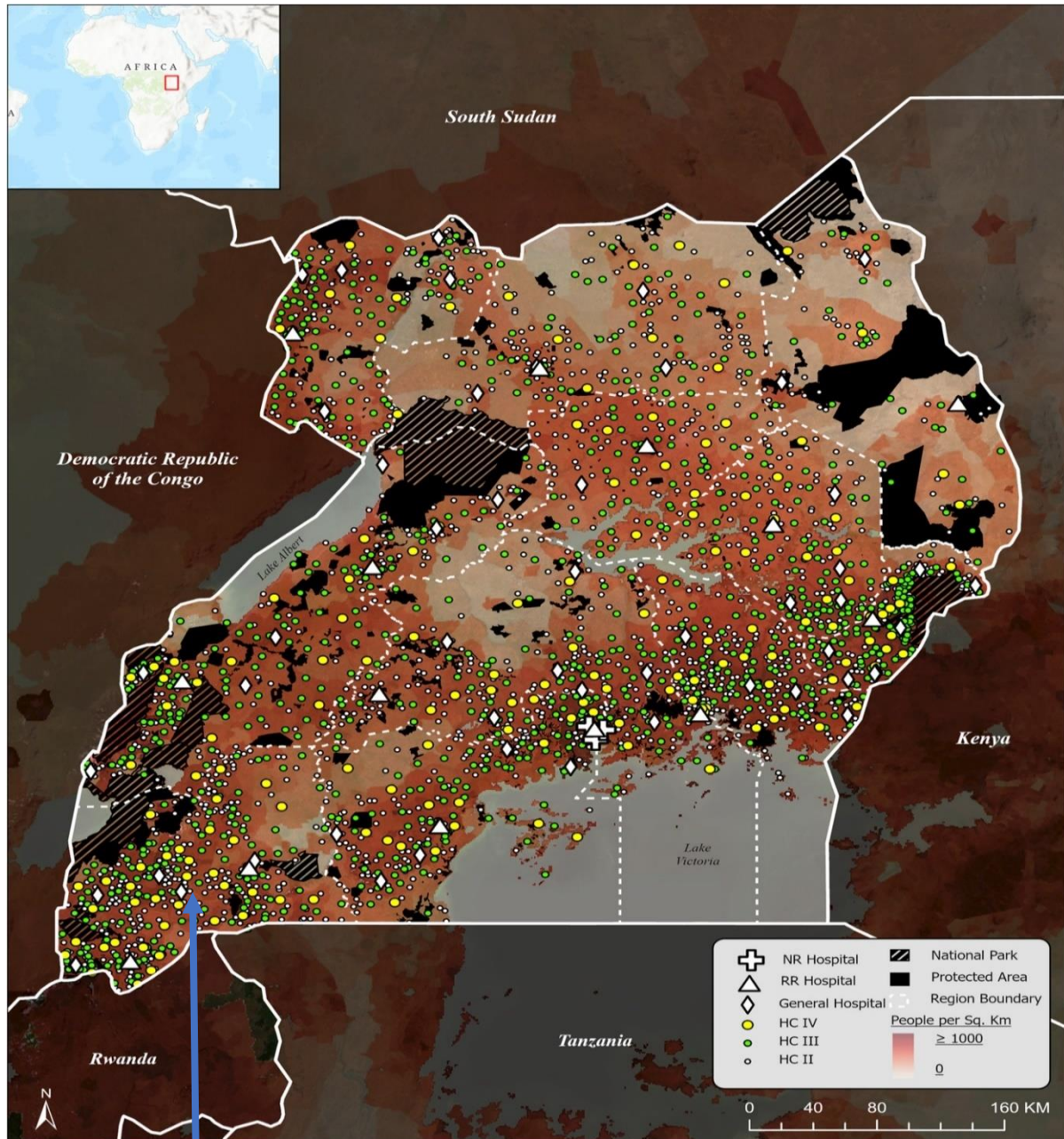
In Uganda, the health care system is comprised of institutions, structures and actors that offer facility-based and non-facility community-based health promotion, disease prevention and curative services that are Public, Private-Not-For-Profit (PNFP) and Private-For-Profit (PFP) including the Traditional and Complimentary Medicine Practitioners (TCMPs). The health care services are decentralised and the districts play an important role in the delivery and management of health care services (Ministry of Health, 2015). The health care system is organised into levels depending on the health service standards set for each tier.

At the district level, the general hospital is the highest referral health facility. In addition to the services offered at the lower-level health units, the general hospital offers obstetric and gynaecological, surgical, ultra-sound, x-ray, and advanced laboratory services. A senior medical officer heads the service. The health centre IV is the referral unit at the county (health sub-district) level. It offers maternity, emergency surgery, blood transfusion, and laboratory services and is managed by a medical officer. A health centre III covers a sub-county and offers maternity, laboratory, in-patient, and out-patient curative services. A clinical officer manages it. The health centre II provides out-patient and outreach care services at parish level and is managed by a comprehensive enrolled nurse or midwife. It links with the community through the Village Health Team⁴ (VHT) (Ministry of Health, 2010b). Currently, the government is in the process of phasing out health centre IIs and most of them have been upgraded to health centre IIIs.

Sheema district local government had one general public referral hospital, one health centre IV, three health centre IIIs, and 15 health centre IIs (Dembe, 2020). The district referral hospital, which also serves the neighbouring districts, is located in Sheema South county. In Uganda, 8873 (19.4%) households are five (5) kilometres or more away from the nearest public health facility (Uganda Bureau of Statistics, 2017a). In Chapter Five (section 5.2), a

⁴ The Village Health Team (VHT) acts as a link between the community and the health facilities, and provides community-based disease prevention and health promotion services (Ministry of Health, 2010b).

more detailed descriptive account of the context for women with physical disabilities who participated in the study is provided. The map shown in Figure 1.2 below shows the distribution of health facilities in Uganda with specific focus on Sheema district in rural south-western Uganda.



Location of Sheema district (study area)

Figure 1.2: A map of Uganda showing the distribution of health facilities in relation to population density (Dowhaniuk, 2021)

The next map in Figure 1.3 shows the percentage distribution of households which are located 5 km or more from the nearest public health facility in Sheema district.

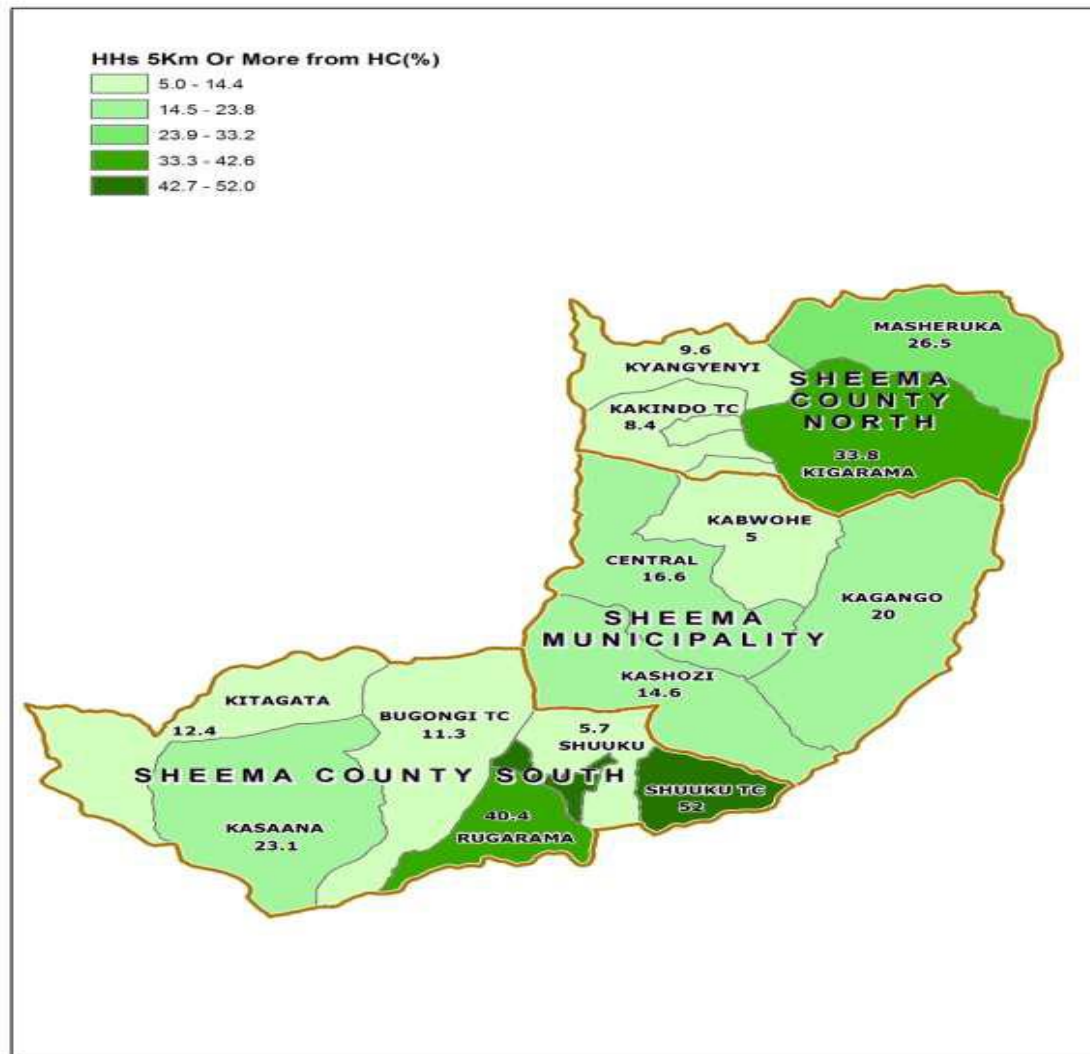


Figure 1.3: Map of Sheema district showing the percentage distribution of households which are located 5 km or more from the nearest public health facility (Uganda Bureau of Statistics, 2017a)

1.5 Study location

The study was carried out in Sheema district (part of greater Bushenyi) in Ankole sub-region south-western part of Uganda, in East Africa. The district has a total population of 207,343 where 108,118 (52.1%) are females and 99,225 (47.9%) are males (Uganda Bureau of Statistics, 2017a, p. 21). It has a total area of approximately 698 square kilometres (Sheema District Local Government, 2020).

In 2010, greater Bushenyi district was divided into five districts, namely Bushenyi, Mitooma, Buhweju, Rubirizi and Sheema (Sheema District Local Government, 2020). I chose Sheema

district because it is where the greater Bushenyi referral hospital (Kitagata hospital) is located. In south-western Uganda, the nine districts implementing the CBR programme combined have 118,813 people with physical disabilities, with greater Bushenyi having the highest at 36,858 (31%) people with physical disabilities (Uganda Bureau of Statistics, 2016). The prevalence of physical disability in the area enabled me to find a significant number of women with physical disabilities who provided valuable data for the study. Although the region borders the Democratic Republic of Congo (in the west) and Rwanda (in the south), countries that have each had a significant period of political instability in the past, it is not clear whether disability prevalence in this region is attributed to past wars in these countries.

Sheema district is bordered by Bushenyi district in the west, Mitooma district in the south-west, Ntungamo district in the south, Mbarara district in the east, and Buhweju district in the north. Sheema district local government is made up of Sheema South county and Sheema North county. Each of these counties is made up of sub-counties. Although some sub-counties are peri-urban in name, they are rural in reality. Access to social services and amenities such as health, education, water, electricity, and road infrastructure are of rural nature and challenging for persons with disabilities, particularly pregnant women with physical disabilities. The predominant tribe in Sheema, and Ankole sub-region generally, is Banyankore-Bakiga. Their main socio-economic activity is subsistence farming. The map (Figure 1.4) below shows the sub-regions of Uganda with Sheema district's location (study area) within Ankole sub-region in south-western Uganda.

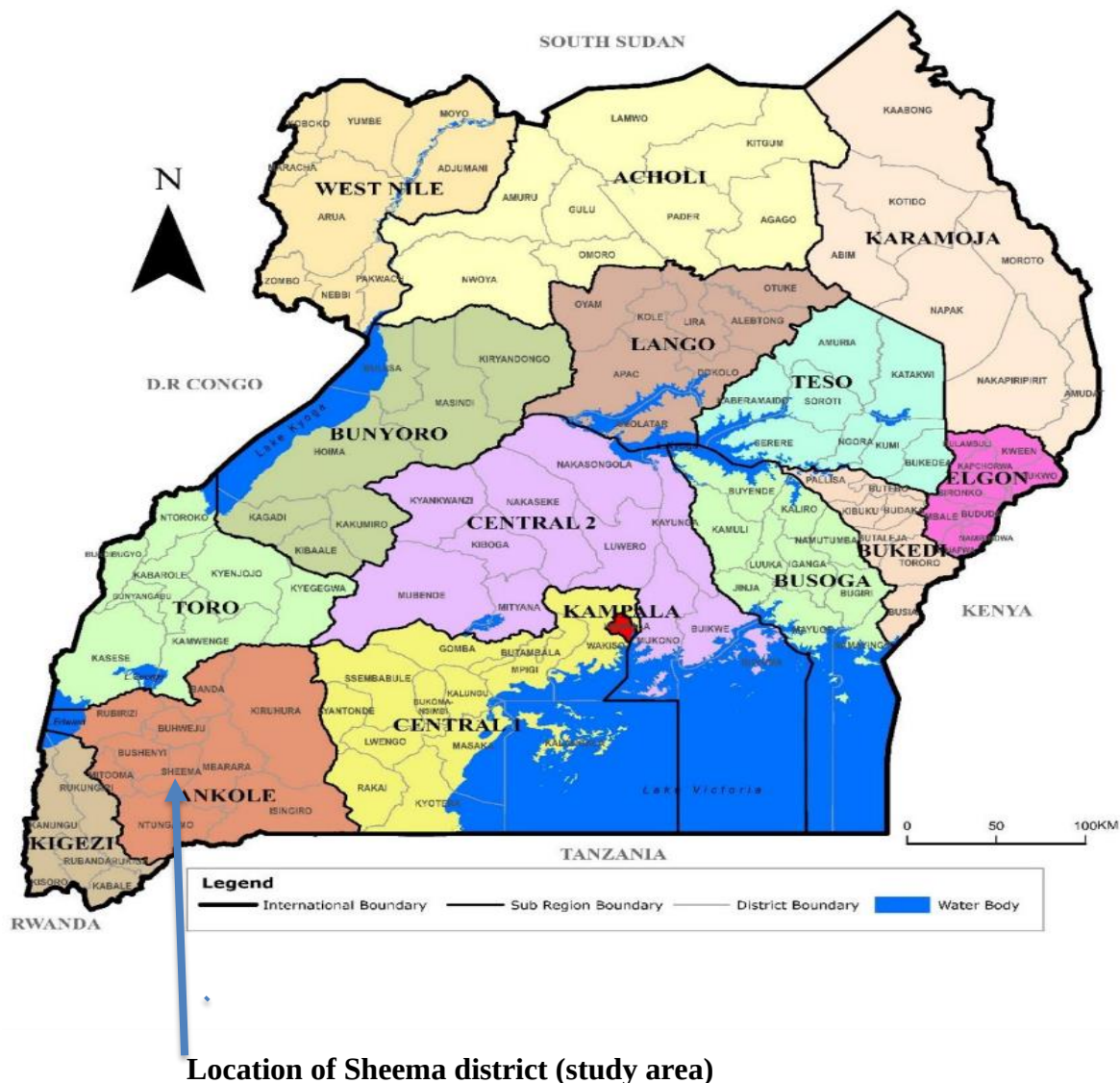


Figure 1.4: A map showing the study location (Sheema district) in Ankole sub-region, south-western Uganda (Uganda Bureau of Statistics, 2016)

1.6 Problem statement

In low- and middle-income countries (including Uganda), several environmental factors such as nature of transportation, cost of services, health care provider attitudes, and limited independence of women to make decisions for themselves on matters that directly affect their health impede accessibility to their health care, as evidenced in different studies conducted in Senegal (Burke et al., 2017), five Sub-Saharan African countries (Ghana, Kenya, Nigeria, Uganda and Zambia) (Tawiah, 2011) and Uganda (Ahumuza et al., 2014). This situation is

more pronounced in rural areas than urban areas in Sub-Saharan Africa, including in Uganda (Alem et al., 2022; Atuyambe et al., 2005).

Access to quality⁵ ANC services by women with physical disabilities is critical in improving their pregnancy experiences and pregnancy outcomes. The experiences of rural pregnant women with physical disabilities who use these services are largely un-documented. There is an urgent need to identify the barriers and facilitators they experience in accessing and utilising ANC services in their communities, in rural south-western Uganda.

1.7 Study rationale

Social identity defines citizens' voices and their ability to exercise agency and demand for their right to access services (Tanzarn, 2013). The subject of women and disability has received considerable critical attention and has been developed as a field of study in the last few years (Monedero et al., 2014). Women with physical disabilities are stigmatised and have socially excluded identities. They are often denied a voice and their rights, including the right to access antenatal care (ANC) services. They experience socially constructed perceptual biases from health service providers (Tanzarn, 2013) and society considers them to be carriers of significant faults and biases (Monedero et al., 2014). This marginalisation causes unnecessary suffering to women with physical disabilities.

In their report titled *'The Missing Billion: access to health services for 1 billion people'*, Kuper and Heydt (2019) posit that change in (and/or development of) health interventions for persons with disabilities should be informed by their lived experiences to be contextually relevant. In this study, I argue that transcending the accessibility and utilisation barriers to ANC services for women with physical disabilities, as socially excluded identities, requires involving them, listening to their voices, and fully understanding their lived experiences. Meaningfully engaging them eliminates the risk of distortion of their social realities (Seruwagi, 2012), and enhances development of unequivocal contextually relevant maternal health care interventions.

⁵ The WHO (2013) indicates that important conditions of quality are availability and accessibility, choice, the involvement of users in organising and managing services, and the presence of mechanisms of quality assurance.

Over time, I have developed an interest in the promotion of maternal health care services, especially for mothers with disabilities, who most often contend with discrimination and marginalisation at the hands of those entrusted to care for them. It is my academic training in social work, with a disability focus and professional experience in clinical medicine and public health, that prompted and largely contributed to the choice of this topic. This influenced the direction of this research.

1.8 Critical research questions

The study sought to answer the following critical research questions:

1. What are the experiences of pregnant women with physical disabilities in the access to and utilisation of ANC services in rural south-western Uganda?
2. How are access to and utilisation of ANC services by pregnant women with physical disabilities constrained and/or enabled in rural south-western Uganda?
3. Why are access to and utilisation of ANC services by women with physical disabilities in rural south-western Uganda constrained and/or enabled the way they are?

1.9 Study aim

The aim of the study was to investigate the experiences of pregnant women with physical disabilities in accessing and utilising ANC services, and to suggest strategies for improving the services in rural south-western Uganda.

1.10 Study objectives

The study aimed to address the following specific research objectives:

1. To describe the accessibility of ANC services for pregnant women with physical disabilities in rural south-western Uganda.
2. To explain the utilisation of ANC services by pregnant women with physical disabilities in rural south-western Uganda.
3. To explore the relationship between women with physical disabilities and health care providers during ANC in rural south-western Uganda.
4. To explore how women with physical disabilities and midwives understand disability and provision of ANC services in rural south-western Uganda.

1.11 My positionality in this research

In this section, I present my positionality in this research. Paradigmatically, in qualitative research, the researcher has an influence on the research process. It is important for the audience to know who carried out the research and what their background is (Stalmeijer et al., 2014). To increase the creditability of the findings and deepen our understanding of the work, it is important for the researcher to clearly describe the contextual intersecting relationships (e.g., race, socio-economic status, gender, cultural background) between the participants and themselves (Berger, 2013; Dodgson, 2019).

While the subjectivity of researchers can be valuable in qualitative research, commitment to on-going critical reflexivity regarding one's positionality is required (Mohler & Rudman, 2022). Reflexivity means "turning of the researcher lens back onto oneself to recognise and take responsibility for one's own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation" (Berger, 2013, p. 220). Reflexivity in research constitutes part of the research findings when the researcher acknowledges the epistemological, personal, and methodological insights in the research process (Palaganas et al., 2017). The researcher's position as an insider or outsider is significant when considering the similarities and differences between the researcher and participants (Berger, 2013; Dodgson, 2019; Teh & Lek, 2018). In this study, my positionality was fluid, alternating between being an insider and an outsider.

As a PhD candidate undertaking this research, my position is of a non-disabled African male academic with a health and social work background, who conducted research among women with physical disabilities in a rural south-western part of Uganda, my home country. I was raised in the area where the study was conducted. I grew up in the village where we had to work hard in the gardens, look after the few cattle that our father had, and move long distances to access basic social services such as health and education. My mother tongue is Runyankore-Rukiga, which is the language predominantly spoken by the research participants. I am the first born in a family of five boys, and am married with three children, two boys and one girl.

Currently, I am a city dweller with my family in Kampala. Since 2008, I have been residing in the city in pursuit of my tertiary education and work. I occasionally go to the village (Kitagata) for social and cultural functions such as wedding and burial ceremonies, Christmas and Easter holidays, and sometimes to visit relatives and friends. My home village is in Kitagata sub-county in Sheema district. I am a Munyankore by tribe, which is the predominant tribe in the study area. I am from a relatively well-known family within the sub-county but not as well known within the district. I completed my primary education at Kitagata Central School, while commuting from Muhito Village, about 5 kms away.

I hold a diploma in Clinical Medicine and Community Health. I did my internship at Kitagata Hospital during my training as a medical clinician⁶. That is when most of my community members, including my former primary school teachers, found out that I was training to become a clinician. Most people I met on the way to work would stop to thank me for joining a noble profession. I was well received by the hospital management and the health staff, being a “son of the soil” (as someone born from the same area). I remember the out-patient department (OPD) supervisor introducing me to OPD health staff saying, “this is one of your own, son of the soil; please help him”. It was a good feeling and I felt at home. Indeed, I was given an opportunity to learn and practice what I had learnt. Later, I worked as a manager for a Non-For-Profit health centre III in the neighbouring district (Bushenyi district) for about 3 years. Later, I did an undergraduate bachelor’s training in Social Work and Community Development with a disability focus, and postgraduate training in Public Health with a specific focus on reproductive health.

I am a registered member of Allied Health Professionals, Ministry of Health, Uganda. For over 10 years, I have worked in various health facilities in Uganda participating in the planning and implementing of Primary Health Care activities, including ANC. I remember with discomfort, during my clinical practice and even during my diploma training as a medical student, I observed mothers with physical disabilities experiencing the unfair and challenging physical and social environments at the health facilities. This situation may have been compounded by the long distances and the nature of transportation, topography (hilly

⁶ The major role of a medical clinician (also known as a medical clinical officer) in a health facility is to diagnose and treat patients, give them medical advice regarding their health, and refer complicated cases for further management, as well as promote proper public health practices in the community through health education.

area with valleys and streams), and distribution of health facilities in rural south-western Uganda.

This position as a community member makes me an insider as a researcher, an experience which helped to facilitate my entry to the study area. It also helped me to gain the participants' trust and easily build rapport with them. Sharing the same socio-cultural beliefs and values with the participants helped me to develop deeper cultural intuition and appropriately respond to cultural sensitivities on the study subject. This familiarity also helped me to identify what might not be being communicated by the participants or might be culturally hidden, and probe further to search for more hints. However, I did not take things for granted. I ensured that certain aspects of participants' beliefs, opinions, and experiences were not overlooked. For some scholars, insider position is associated with researcher legitimacy (Gair, 2012; Mohler & Rudman, 2022).

As a male researcher without disability, I was an outsider in this research. This limitation required me to create more time for women with physical disabilities to provide them with enough information about the study topic so as to gain their trust and informed consent. As a male, I may not fully comprehend certain issues about pregnancy. I agree with Berger (2013) that, in this position, the women with physical disabilities take the expert position about the research topic. I would only use my position as a male researcher to pose questions from a different point of view that would lead to new information about the study topic (Berger, 2013). As the husband of a woman who carried three pregnancies to term in an urban setting, I have witnessed the indifference of health care providers towards pregnant women, more so in public than in private hospitals, and the unfavourable transport conditions to the hospital in taxis or on boda bodas⁷. This experience triggered my inquiry into understanding the nuances of the pregnancy experiences of women with physical disabilities regarding access to and utilisation of ANC services in rural Uganda. I believe researching from an outsider position (a male researcher without disability) strengthened the validity of the study findings.

⁷ *Boda boda* is a common term used in Uganda and East Africa at large to refer to a bicycle or motorcycle used in public transport to carry passengers and/or goods from one destination to another. The boda boda parks, also known as boda boda stages, are predominantly located in towns/trading centres. In this thesis, the term boda boda(s) is used to refer to passenger motorcycle(s).

Currently, I am an academic staff member at Kyambogo University, Faculty of Special Needs and Rehabilitation, Department of Community and Disability Studies, which offers postgraduate and undergraduate academic programmes in CBR, a postgraduate programme in Disability Studies and Inclusive Development, and an undergraduate programme in Community Development and Social Justice (formerly Social Work and Community Development). These programmes emphasise the rehabilitation and equalisation of opportunities, social justice, and the empowerment of persons with disabilities and other special needs.

At Kyambogo University, I was also the secretary of the University Disability Policy Implementation Committee (from 2016 to 2019). The core mandate of the committee is to oversee and ensure disability inclusion, reasonable accommodation, and equalisation of opportunities for persons with disabilities and other special needs in the university. Outside Kyambogo University, I am a national master trainer for Sexual and Reproductive Health and Rights under the Strengthening Education and Training Project run by the School of Public Health at Makerere University, Uganda and the Institute of Social Studies at Erasmus University, Netherlands. This training targets practitioners from different fields of service such as community development officers, social workers, health workers, probation officers, police officers, teachers, lawyers, and officers from civil society organisations. In this forum, sexual and reproductive health and rights issues are discussed through a gender lens.

1.12 Structure of the thesis

In this section, I describe how the thesis is structured. This thesis is divided into eight chapters. The first three chapters provide the introduction and background information to the study, the literature reviewed, and the theoretical frameworks. Chapter Four describes the methodology employed for this study, which is an interpretive qualitative approach using a multiple case study design.

Chapters Five, Six and Seven are the interpretation and discussion of the study findings. The main issues addressed are the findings from the analysis of the data collected from the field and the discussions as per the study objectives and the literature reviewed. The findings chapters highlight the influences (the barriers and enablers) in accessing ANC services, the unresponsive ANC policy to the specific needs of rural pregnant women with physical

disabilities, and what is needed to improve the quality of ANC services. These chapters are presented as findings and discussion – parts I, II and III respectively.

Chapter Eight is the final chapter. It presents the synthesis and conclusion of the study and the way forward. It includes the study's knowledge contributions to scholarship from the Global South standpoint and recommendations for future research, policy and practice, curricula for midwives and other health professionals, and concluding reflections.

1.13 Conclusion

This chapter has covered the introduction and background to the study, briefly describing the situation of persons with disabilities in general and women with physical disabilities in particular, regarding their right to access health care services (inclusive of ANC services). The study set out to investigate the experiences of pregnant women with physical disabilities in accessing and utilising ANC services in rural south-western Uganda. The central question in this thesis asks: why are access to and utilisation of ANC services by women with physical disabilities in rural south-western Uganda constrained and/or enabled the way they are? The significance of this study has been presented, showing the justification and the identified need for this study, which is that there was a dearth of literature which represents the lived experiences of pregnant women with physical disabilities in accessing and utilising ANC services in a rural Ugandan setting. My positionality and motivation to conduct this research has been highlighted. My academic training, experience, and interest in promoting maternal health care interventions for mothers with disabilities prompted this research. The chapter concludes with the structure of the thesis.

Having presented Chapter One, I now move on to present Chapter Two, which focuses on the literature review. In this chapter, I present the reviewed literature relevant to the study topic and the gaps therein. The chapter evokes different debates on vulnerability and the oppression of women with disabilities in general and those with physical disabilities in particular, and their experiences in accessing and utilising ANC services. It further highlights the strategies for health services and systems improvement for Respectful Maternity Care (RMC).

CHAPTER 2:

LITERATURE REVIEW

2.1 Introduction

This chapter presents a review of both international and local (Ugandan) literature to provide context and a better understanding of the situation of women with physical disabilities in accessing and utilising ANC services in rural areas. The chapter begins with the search strategy I used. It further provides an overview of ANC services to establish the nature of services offered during ANC. Following this, the sexuality, vulnerability, and the experiences of pregnant women with physical disabilities are discussed to highlight facilitators and/or barriers to their accessing and utilising ANC services. Relational experiences between women and health workers, and women's and health workers' understanding of disability are discussed. Literature on strategies for improving access to and the utilisation of ANC services, as well as those for health services improvement, respectful maternity care (RMC), and preparing health workers, is presented. By reviewing and critiquing the existing literature on the study phenomenon, this study highlights the perspective of rural African women with physical disabilities in accessing and utilising ANC services, whose voices are not heard in the current literature on disability and the vulnerability of women.

2.2 Search strategy

In searching for literature to review, a search strategy was used with emphasis on low- and middle-income countries as these relate more to the setting of this study. However, in order to have a global perspective, studies on midwifery, maternity care, or ANC for women with disabilities from high-income countries were also included.

2.2.1 Databases and other sources

The databases searched included PubMed, Scopus, Web of Science, and EBSCO. In addition, good quality independent articles which were relevant to this study topic were identified, hand sourced through Google Scholar and included for review. Systematic reviews done through Cochrane and the Lancet were considered to be of good quality and comprehensive. They were considered to be the highest level of evidence in ANC practice as they rigorously synthesise the available evidence (Lunyera & Diamantidis, 2019). Reviews that reported on

the experiences of pregnant women with physical disabilities in accessing and utilising ANC services were included.

2.2.2 Population

The population/participants were pregnant women with physical disabilities.

2.2.3 Inclusion and exclusion criteria for literature

- Inclusion criteria: Studies presenting evidence on the experiences of pregnant women with physical disabilities accessing and utilising maternity care or ANC services in rural settings in low- and middle-income countries.
- Exclusion criteria: Studies that did not investigate ANC, those that did not highlight the vulnerability and/or experiences of rural pregnant women with physical disabilities, and those that focused on intrapartum and postpartum care. Studies or abstracts that were not published in English were also excluded.

2.2.4 Search terms and search operators

The concepts and MeSH terms used during the literature search included:

- Pregnant Women [MeSH]: Pregnant woman OR pregnant women OR pregnancy OR expectant mother;
- Disabled Persons [MeSH]: Disability OR physical disability OR disabled OR impairment OR mobility impairment OR mobility difficulties OR handicap OR special needs;
- Health Services Accessibility [MeSH]: Access OR accessibility OR Health Services Accessibility OR utilisation OR utilization OR use;
- Prenatal Care [MeSH]: Antenatal care OR prenatal care OR pregnancy care OR maternity care;
- Rural Health Services [MeSH]: Rural healthcare OR rural health-care OR rural health care OR Rural Health Services

2.2.5 Language, types of study, and time period

A review of the identified scholarly articles (in English) was done to evaluate their objectives, methodology, and conclusions in relation to the focus of this study.

Systematic reviews, scoping reviews, retrospective cohort studies, randomised controlled trials, multicentre studies, cross-sectional studies, comparative studies, observational studies, case studies, and other studies presenting evidence on the experiences of rural pregnant women with physical disabilities in accessing and utilising ANC services in low- and middle-income countries were included.

Peer-reviewed articles published from 2012 onwards were included in the search. Restricting the literature search to the most recent studies assured that the data was not likely subject to historical bias (Kazembe et al., 2022). Where necessary, seminal works, monographs, and reports in the field of Midwifery and Nursing practice, as well as promising references falling outside of the specified time period, were followed up on and included.

Figure 2.1 below shows the search results using the above search terms and operators, and indicates the number of articles (09) finally included after applying the inclusion and exclusion criteria. The figure also indicates the number of articles (59) that were independently followed up on and hand sourced, reviewed, and included using similar inclusion and exclusion criteria. The number of articles (68) in the figure (2.1) relates only to this chapter.

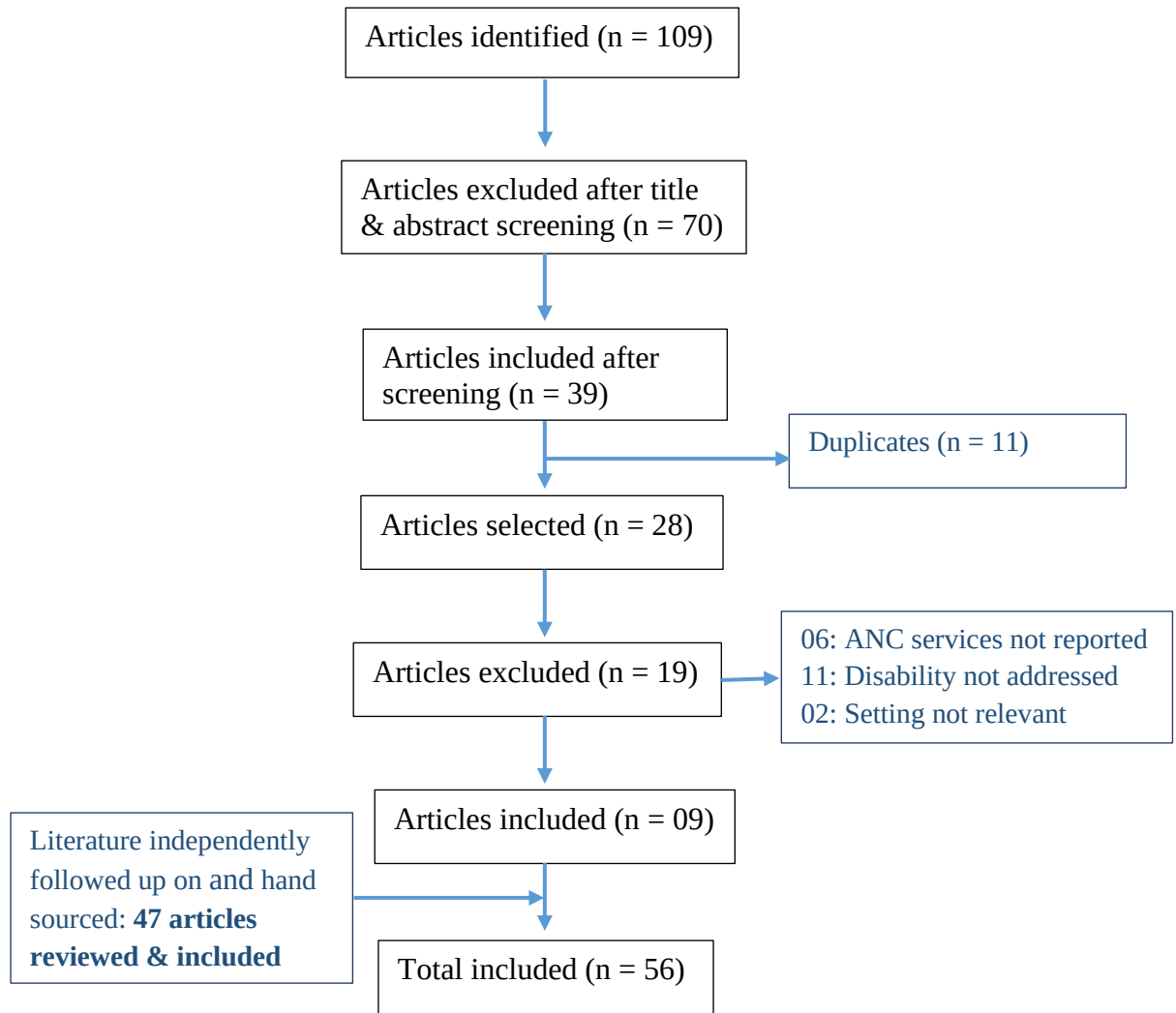


Figure 2.1: Literature review results

2.3 Review of literature

“You cannot build your own project without building on the work of others”
(Aveyard et al., 2021, p. 5).

A review of the literature was done to unpack what has already been done to identify knowledge gaps and the concepts used in disability studies and maternity care that shaped the focus and boundaries of this study. It helped me to explore findings, views, and opinions from other relevant studies and the variables regarding the experiences of pregnant women with physical disabilities in accessing and utilising ANC services. The review of literature included 56 articles identified and reviewed initially during the research proposal development and the additional literature sourced following the development of themes to see if it confirmed or contradicted the findings.

2.3.1 Sexuality and vulnerability of women with physical disabilities

Liddiard (2017) asserts that persons with disabilities, including women with physical disabilities, are routinely assumed to be asexual with no capability or capacity to embody and experience sexuality, to love and be loved, and to build and manage their own families.

However, the author does not show how rurality interacts with disability to shape the sexuality and pregnancy experiences of women with disabilities. Women with disabilities have limited access to full participation as citizens, access which does not take into account their sexuality (Peta, 2018; Peta & McKenzie, 2019). They often face rejection, stigma, and discrimination from their significant others and health workers (Peta & McKenzie, 2019).

Van der Heijden et al. (2019) maintain that disability stigma in South Africa may hamper the attainment of normative womanhood and sexual relationships for women with disabilities.

Addlakha et al. (2017) suggest that context interacts with the disability-sexuality nexus to alter the individual's experience and way of becoming.

In many African countries, including Uganda, there is little or no empirical research on the sexuality of women with physical disabilities (Carew et al., 2017; Hunt et al., 2017; Peta & Ned, 2019). Their sexuality has been constructed based on hearsay and second-hand narratives in studies which draw from the perspectives of their significant others (Peta & McKenzie, 2019). It is critical to challenge such dominant power and practices (Peta & McKenzie, 2019) by listening to women with physical disabilities themselves. In Zimbabwe, women with disabilities have challenged the social construction that they do not require space in the childbearing arena because they are disabled (Peta, 2017).

While sexuality is a broad concept encompassing sexual activity and how individuals may experience pregnancy, people making assumptions about women with physical disabilities expressing their sexuality could lead to misrepresenting their sexual and reproductive health reality, including their pregnancy experiences and access to and utilisation ANC. This current study seeks to understand the experiences of pregnant women with physical disabilities in rural Uganda with a view to influencing and creating an enabling environment for them in accessing and utilising ANC services. Women sharing their lived pregnancy experiences and views on the barriers and/or facilitators to accessing and utilising ANC services may facilitate their feeling empowered to affirm their sexuality (Peta & Ned, 2019).

In the Ugandan context, such as in many other African contexts, poverty, cultural norms, and the societal belief that women with physical disabilities are asexual beings (Hunt et al., 2017; Peta & McKenzie, 2019; Peta & Ned, 2019) put these women in a vulnerable and precarious position. They may encounter sexual coercion and rape, which may impact on their pregnancy experience and access to ANC services. They are prone to multiple sexual relationships as they struggle to build stable and reciprocal intimate partnerships (Peta & McKenzie, 2019). They are perceived as gaining diminished benefits from accessing sexual and reproductive health care services, including ANC services, and their reproduction is deemed less desirable and less possible than reproduction among their non-disabled counterparts (Hunt et al., 2017).

As their pregnancies progress, women may experience changes in mobility and altered body balance due to significant changes in their centre of gravity and altered pressure in different parts of their body. They may also experience fatigue or reduced energy related to physiological changes as a result of increased basal metabolic rate (BMR) and lung volume (Taousani et al., 2017). Although the authors show impact of pregnancy on the women's physical and physiological functioning, they do not report on how pregnancy interacts with physical disability to impact on her access to and utilisation of ANC services.

Sheldon (2014) argues that the gendered nature of disability is not given a high priority yet, while Moodley and Graham (2015) note that this intersectionality points to gender gaps in outcomes for persons with disabilities. Women with disabilities are recognised as particularly disadvantaged, face exclusion and abuse, and have simultaneous vulnerability due to their gender and disability conditions. This situation may be worse among rural women with physical disabilities who are prone to poverty and its consequences of isolation, powerlessness, physical weakness, lack of income, and vulnerability. At the same time, pregnant women with physical disabilities need ANC services and other reproductive health services (Mgwili & Watermeyer, 2006). Therefore, increasing access for these women to skilled maternity care by improving the availability and quality of maternity care for them, particularly at primary care health facilities, and promoting its use before, during, and after delivery is critical in reducing maternal mortality (WHO & World Bank, 2011).

2.3.2 Women's experiences in accessing and utilising antenatal care services

Study findings from high-income countries show that women with physical disabilities have unmet needs and experience barriers in pregnancy that are uncommon in women without disabilities. Mitra, Smith, et al. (2017), in their study exploring barriers to providing maternity care to women with physical disabilities from health care providers' perspective in the United States of America (USA), reveal barriers at the practitioner, clinical practice, system levels. Their study highlights barriers related to unwillingness to provide care, inadequate education and training of health workers, appointment scheduling constraints, insurance reimbursement policies. Their study further indicates lack of scientific clinical data and practice guides in maternity care services for women with physical disabilities. However, their study only focuses on supply barriers to maternity care, in a high-income country, unlike this study which addresses both barriers and facilitators from the users' perspective.

Women with physical disabilities have described inaccessible health care facilities and equipment, such as examination tables and weighing scales, as barriers in their access to and utilisation of ANC services (Mitra et al., 2016). Whereas their study was an interpretive qualitative study, the women were from a high-income country (USA) whose pregnancy experiences may not be similar to those of women from a low-income country like Uganda. Moreover, the authors employed telephone interviews in gathering data from the women, missing the observation of social cues like the women's body language during the interview. Social cues can provide extra information about the participants feelings which can be added to the participants' verbal answers to a question (Opdenakker, 2006).

In another study that used telephone interviews to gather data, in a high-income country, other challenges identified by women with physical disabilities include clinicians' lack of knowledge about the pregnancy-related needs of women with physical disabilities and clinicians' failure to consider the women's knowledge, experience, and expertise about their own disabilities (Smeltzer et al., 2016). Morris et al. (2017) emphasise that accessible equipment alone may not be sufficient to reduce disparities in the care experience. They contend that provider and organisation level factors must be considered in efforts to provide equitable care to pregnant mothers with physical disabilities.

Studies in many low- and middle-income countries indicate that women encounter challenges in accessing maternity care services in public (government-owned) health facilities (Afulani et al., 2019; Kyaddondo et al., 2017). Similarly, in South Africa – a middle-income country – pregnant women with physical disabilities have described barriers to accessing and utilising ANC services related to health facility equipment and furniture (Mgwili & Watermeyer, 2006). Health workers may not consider the impact of physical impairment when they provide these health care services (United Nations, 2019). In another study conducted in rural Nepal focusing on intrapartum care, Devkota et al. (2018) found that none of the health facilities accommodated the needs of women with disabilities with accessible buildings.

In the same study above, Devkota et al. (2018) found that the cost of services and delayed and inadequate drug and medical supplies are common problems for women both with and without disabilities in utilising maternal health care services. However, women with physical disabilities tend to be poor, have more health care costs, and are more likely to experience catastrophic health expenditure than their non-disabled counterparts (The Lancet, 2019). This is perhaps associated with the intersectionality between their physical disability, poverty, and gender that contributes to poor pregnancy outcomes (Moodley & Graham, 2015).

In Uganda, a study conducted in Kampala by Ahumuza et al. (2014) found that persons with disabilities encounter a multitude of challenges in accessing sexual and reproductive health services (SRH), including ANC services. Their study revealed that women with disabilities face challenges of negative attitudes of health workers, unfriendly physical structures, distant health facilities, high cost of services, and the perception from non-disabled people that persons with disabilities should be asexual. In Eastern Uganda, Apolot et al. (2019) found that women with physical disabilities have needs associated with families' and partners' acceptance and support. Their study further shows that these women have needs related to personal protective wear, basic needs, and birth preparedness items.

In a systematic review and meta-analysis of physical access to skilled care for childbirth in Sub-Saharan Africa, Wong et al. (2017) found that, in rural Uganda, physical access to health facilities impedes the utilisation of ANC services. The authors argue that utilisation is conditioned on access. Concerning the accessibility of health facilities, Apolot et al. (2019) note that women with physical disabilities encounter unsuitable transport, difficulty in finding

transport, and high costs of transport. Their study was a general one, focusing on maternal and newborn health needs without emphasis on the antenatal needs of these women.

In a study by Kyaddondo et al. (2017) on the expectations and needs of Ugandan women for the improved quality of childbirth care in health facilities, women reported that money is a necessity and that maternity care is poor for someone who is poor. Their study further revealed that women paid health workers for clinical supplies or to guarantee that they would be attended to by a skilled staff. These study results suggest that both women with and those without disabilities encounter similar challenges. There is a need to improve the relational experiences between women and health workers, and the health workers' understanding of provision of ANC services and disability to improve women's pregnancy experiences.

2.3.3 Relational experiences between women and health workers

In her seminal work exploring novice to expert practice among nurses, Benner (1982) posits that being able to form an engaged moral relationship is a characteristic of a more proficient/expert practitioner in health care practice. She argues that in an engaged moral relationship, nurses (and/or health professionals) also play a coaching function by offering avenues to understand the culturally avoided or uncharted, and can open ways of being and ways of coping for the pregnant women and their families through their attitude, demonstrations, and reactions. Benner et al. (1996) suggest that proficient and expert practice is characterised by an engaged practical reasoning with “increased intuitive links between the salient issues in the situations and ways of responding to them” (p. 142). Reading women's emotional states is an important aspect of midwives' ethical and clinical judgment, and requires perceptiveness and a commitment to checking their assumptions and interpretations in order to learn directly from women and their families (Benner, 2000).

In a qualitative study carried out in a rural community in South Africa, Mgwili and Watermeyer (2006) used a critical psychoanalytic framework to analyse the intra-psychic underpinnings responsible for the unconscious motives behind observed responses among health workers in ANC clinics. Fear, pity, and blame expressed by midwives at the sight of women's impaired bodies during ANC may serve to position women with physical disabilities “outside the realm of ‘normal’ entitlement to care” (Mgwili & Watermeyer, 2006, p. 270). They suggest that the outward expressions of health workers while attending to

women with physical disabilities are related to the health workers' projected personal feelings evoked by disability. The emotional difficulties, anxieties, and awkwardness experienced by midwives attending pregnant women with physical disabilities imply that midwives wish that these women's presence be eradicated from the ANC clinic (Mgwili & Watermeyer, 2006).

In a study by Chinkam et al. (2023) in the USA, women reported mixed experiences of both "not feeling well cared for" (p. 128) and "feeling well supported" (p. 129). Another study in rural Nepal by Devkota et al. (2017) found that women with disabilities had mixed experiences of health workers, with most women indicating that health workers had negative attitudes and inadequate knowledge, skills, and preparation for caring for women with disabilities, and a few others reporting that they experienced kind, respectful, and caring health workers. Similar studies in other low- and middle-income countries, such as India, Tanzania, and Ethiopia (Austad et al., 2017; Kruk et al., 2018; Wassihun & Zeleke, 2018), have found that women in rural settings experience disrespectful and abusive maternity care, particularly intrapartum care.

Fuzy et al. (2020) found that humiliation, victimisation, and rudeness are associated with women's negative experiences during maternal health care in public hospitals in South Africa, in their study targeting a different vulnerable group of women (middle adolescents aged 14-16 years) and their birth experiences. The vulnerabilities of pregnant middle adolescents and women with physical disabilities are similar, in terms of the way people and midwives make judgments about the women who were left to be seen last, were humiliated and criticised for getting pregnant. Such humiliating experiences may lead some women to not seek ANC services, which in turn leads to obstetric complications developing or being missed (Mgwili & Watermeyer, 2006). The humiliation of pregnant women with physical disabilities implies that they are "being told that they have no place – a place in the reproductive health system, a place in the realm of sex and sexual reproduction, or a place in the world" (Mgwili & Watermeyer, 2006, p. 271).

Similar studies in the USA, a high-income country, showed that ANC providers, including clinician obstetricians, knew little or nothing about the impact of the physical disability on the women's pregnancy and their pregnancy care needs (Lipson & Rogers, 2000; Mitra, Akobirshoev, et al., 2017; Smeltzer et al., 2016; Smeltzer et al., 2018). However, these studies were conducted in high-income countries and focused on health facility-related

barriers to maternity care – i.e., third delay, according to Thaddeus and Maine (1994). The studies do not expose the family/ community barriers and/ or facilitators in accessing and utilising ANC services by pregnant women with physical disabilities, which is partly the purpose of this study.

2.3.4 Health services and systems improvement

The WHO (2021) position paper on ‘Building health systems resilience for universal health coverage and health security during the Covid-19 pandemic and beyond’ recommends the integration of the promotion of universal health coverage and ensuring health security. The position paper emphasises the essential public health functions⁸, also recently described as ‘common goods for health’ (WHO, 2020b). The WHO (2021) position paper underscores Primary Health Care as a precursor for achieving universal health coverage. It stresses that people should be able to use essential health care services, including ANC services, when they need them without suffering financial hardship, and recommends the implementation of an accessible and “safe health facilities program at all levels of the health system” (WHO, 2021, p. 14). However, the ‘*Essential Maternal and Newborn Clinical Care guidelines for Uganda*’ (Ministry of Health, 2022) do not prescribe ANC practice guidelines for pregnant women with disabilities. To this end, there is a need to develop maternity care (including ANC) practice guidelines for women with physical disabilities (Mitra, Smith, et al., 2017) as the available guidelines are silent on women with disabilities.

Morris et al. (2017) suggest that to reduce disparities in the health care experience, contextual factors must be considered in the efforts to provide equitable care to pregnant women with physical disabilities. Nwosu and Ataguba (2019) and Ousman et al. (2019), in their studies conducted on socioeconomic inequalities in maternal health service utilisation in general in Nigeria and the social determinants of ANC use in Ethiopia respectively, suggest that policy makers, health managers, and care providers should consider a social determinants of health approach to address the socioeconomic inequalities in ANC utilisation. A systematic review of the Cochrane database by Mbuagbaw et al. (2015) assessed the effect of health system and community interventions on improving the coverage of ANC and other intrapartum health

⁸ Essential public health functions are the minimum requirements for WHO Member States to assure public health. These focus on health promotion, prevention, determinants, and security. They aim to improve, promote, protect, and restore the health of all people. (WHO, 2021)

outcomes, and concluded that combined and integrated interventions improve ANC coverage and consequently reduce intrapartum death. A study on the perceptions and experiences of access to public health care by persons with disabilities and older people in Uganda by Mulumba et al. (2014) shows that a comprehensive systems approach is needed in the Ugandan development context for quality health care services. Although, their study does not prescribe the approach for addressing the specific needs of rural pregnant women with physical disabilities.

2.3.5 Preparing health workers: education, training, and mentoring

It can be argued that the education and training of health workers about disability is crucial in preparing them to respond to the needs and concerns of pregnant women with physical disabilities, thereby enhancing respectful ANC. ‘The State of the World’s Midwifery 2021’ report by United Nations Population Fund (2021) emphasises that investing in high-quality education and training of midwives is crucial in creating an enabling environment for the ‘left behind’ groups to access care from a qualified health workforce for improved pregnancy experiences and outcomes, and that those furthest back must be actively attended to. The report further shows that “fully educated, licensed and integrated midwives supported by interdisciplinary teams and an enabling environment can deliver about 90% of essential [sexual, reproductive, maternal, newborn and adolescent health] SRMNAH interventions across the life cycle, yet they account for less than 10% of the global SRMNAH workforce” (p. vii). Moreover, the education of midwives needs to be contextually relevant to realise the intended outcomes in pregnancy care, particularly for women with physical disabilities.

A study in the USA by Robey et al. (2013) suggests the implementation of cultural competency-based education and training, where health care students’ educational and training experiences can be structured to reflect the sociocultural complexity of the ‘culture of disability’. The authors further recommend that desired competences related to culture can be defined based on the health care professional’s approach to patients with disabilities. Exposure to persons with disabilities in their homes allows the health care student (including the midwife student) to make connections between the nuances of daily life of someone with a disability and that person’s health care (pregnancy care) needs (Robey et al., 2013). In a systematic review of barriers to and facilitators of high-quality midwifery services in India, McFadden et al. (2020) indicated that hands-on experience during the training, monitoring,

and supervision of midwives is a facilitator for high-quality maternity care. While this kind of approach to training midwives could be applicable to improving maternity care of all women, exposing midwives to care for rural pregnant women with disabilities could go a long way in improving the midwives' understanding of the specific needs and concerns of this underserved population.

Disability awareness needs to be underscored as a core aspect of health professionals' training to increase awareness on the antenatal needs of women with physical disabilities (Mitra, Akobirshoev, et al., 2017; Mitra, Smith, et al., 2017; The Lancet, 2019). Mitra, Smith, et al. (2017), in their study exploring the barriers to providing maternity care to women with physical disabilities from health care providers' perspective in the USA, highlighted the need for training on the maternity care needs of these women. Although their study was conducted in high-income country (USA), this strategy could be applicable to the training of midwives and other health workers in low- and middle-income countries, including Uganda. In a study by Devkota et al. (2018) conducted in rural Nepal, improved health care provider knowledge and awareness of the human rights approach to disability and health are suggested. Devkota et al. (2017) suggest that more organised, effective training of health workers in the mainstream education system is needed to improve health workers' attitudes towards disability. Similarly, Wagner et al. (2018), in their study carried out in rural India, suggest that with proper training, community health workers can improve the health care, including ANC, of vulnerable populations in rural areas in low- and middle-income countries.

In his article on 'educating for Ubuntu', Letseka (2013) suggests that contextually relevant education has the "potential to contribute towards the ideal of creating citizens that are inclined to treating other with fairness, dignity and justice at all times" (p. 343). In that regard, it is possible that the spirit of Ubuntu, if underscored in the education and training of midwives – as key ANC providers – may enhance their moral and professional relationship with and respect for pregnant women with physical disabilities during ANC services. Ubuntu is an African philosophy that espouses African values and ethics, which need to be promoted in education and training in formerly colonised African communities (Ned, 2022) to improve the experiences of pregnant women with physical disabilities in accessing and utilising ANC services.

A study by Kemp et al. (2018) on improving student midwives' practice learning in Uganda and a review by Telfer et al. (2021) of midwifery education, also in Uganda, revealed that midwives' basic competences at all levels do not meet the ICM global standards which are required to be in midwifery education curricula. These studies identified a need for radical innovative and structural changes in midwifery and nursing education and training in Uganda, aligned to the Midwifery Model of Care (Telfer et al., 2021). Mentoring those already in practice is another strategy that needs to be implemented with midwifery twinning programmes supported through ICM and the Royal College of Midwives, programmes which have proved effective in building the capacity of midwives mentors (Kemp et al., 2018). Building the capacity of midwives is important for them to understand how to address the needs and concerns of pregnant women with physical disabilities.

2.4 Conclusion

The literature reveals that pregnant women with disabilities encounter more barriers than facilitators in accessing and utilising ANC services. The barriers are both structural and epistemic in nature. The experiences of pregnant women with physical disabilities are shaped by a multiplicity of intersecting factors. Below (Figure 2.2) is an intersectionality diagram illustrating the multiplicity of these intersections. The diagram was derived from synthesis of the reviewed literature on the women's vulnerability resulting from their different aspects of life (i.e., physical, political, economic, social, cultural and spiritual aspects) that impact on their pregnancy experiences.

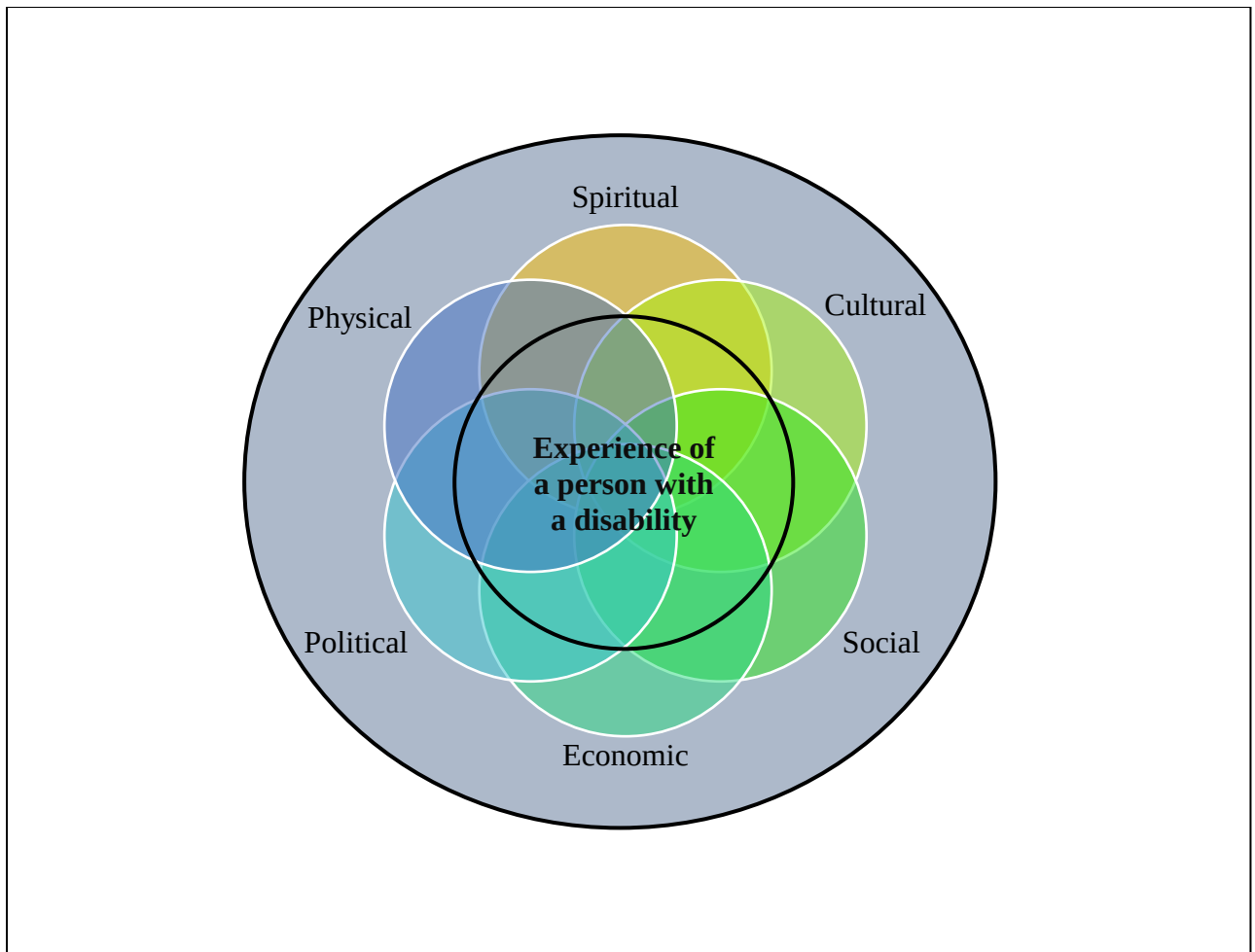


Figure 2.2: Intersectionality diagram illustrating the multiplicity of overlapping intersections in the experience of a person with a disability

Reviewed literature points to the need for holistic improvement of the health services with RMC at the centre. To this end, the education, training, and mentoring of health workers appears to be a critical strategy for improving their understanding of disability and attitudes towards pregnant women with disabilities. Adequate preparation of midwives as key ANC providers is critical in ensuring respectful care, which is an indicator for inclusive quality ANC services.

Paying attention to the vulnerability of rural pregnant women with physical disabilities by improving their wellbeing may facilitate their access to and utilisation of ANC services. Hence, there is a need to understand their lived experiences to provide contextually relevant ANC interventions, which is the purpose of this study.

Rural pregnant women with physical disabilities' and health workers' understanding of disability and provision of ANC services need to be accounted for in improving the quality of these services. However, most of the available literature is based on studies from the Global North (Devkota et al., 2017, 2018; Mitra, Akobirshoev, et al., 2017; Morrison et al., 2014). There is a dearth in the current literature about the lived experiences of pregnant women with physical disabilities in accessing and utilising ANC services in rural settings in low- and middle-income countries (Kazembe et al., 2022). Most studies in the Global South have focused either on maternity care services or ANC services for women with disabilities and/or other vulnerable groups in general. This current study contributes to bridging this gap by fronting the voices of this under-represented group of women in rural Uganda.

CHAPTER 3:

THEORETICAL FRAMEWORK

3.1 Introduction

This chapter presents the theoretical frameworks underpinning this study. It begins with a discussion on the Three Delays Model (Thaddeus & Maine, 1994), which is the main framework, highlighting its strengths and shortcomings in barrier assessment. The chapter then presents the Social Model of Disability, followed by Intersectionality and Critical Disability Theory, and how women's intersecting identities interact to create oppression and discrimination or privilege for them. Ubuntu philosophy is also discussed. In this study, Ubuntu philosophy was used to understand how families, communities, and health workers respect women's dignity and rights. The biopsychosocial framework of disability, also known as the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) is discussed. Lastly, the value of combining these frameworks in this study and the conclusion of the chapter are presented.

3.2 The Three Delays Model

Because delay is a pertinent contributor to maternal morbidity and mortality, Thaddeus and Maine (1994) conceptualised three phases of delay as part of a prevention of maternal mortality programme, particularly for low- and middle-income countries. In their article '*Too far to walk: maternal mortality in context*', the authors examined the factors relating to: 1. Delay in deciding to seek care on the part of the individual, the family or both, 2. Delay in identifying and reaching an adequate health facility, and 3. Delay in receiving adequate and appropriate care at the health facility – hence, The Three Delays Model. Figure 3.1 below shows the factors affecting the access to and utilisation of ANC services at each phase of delay.

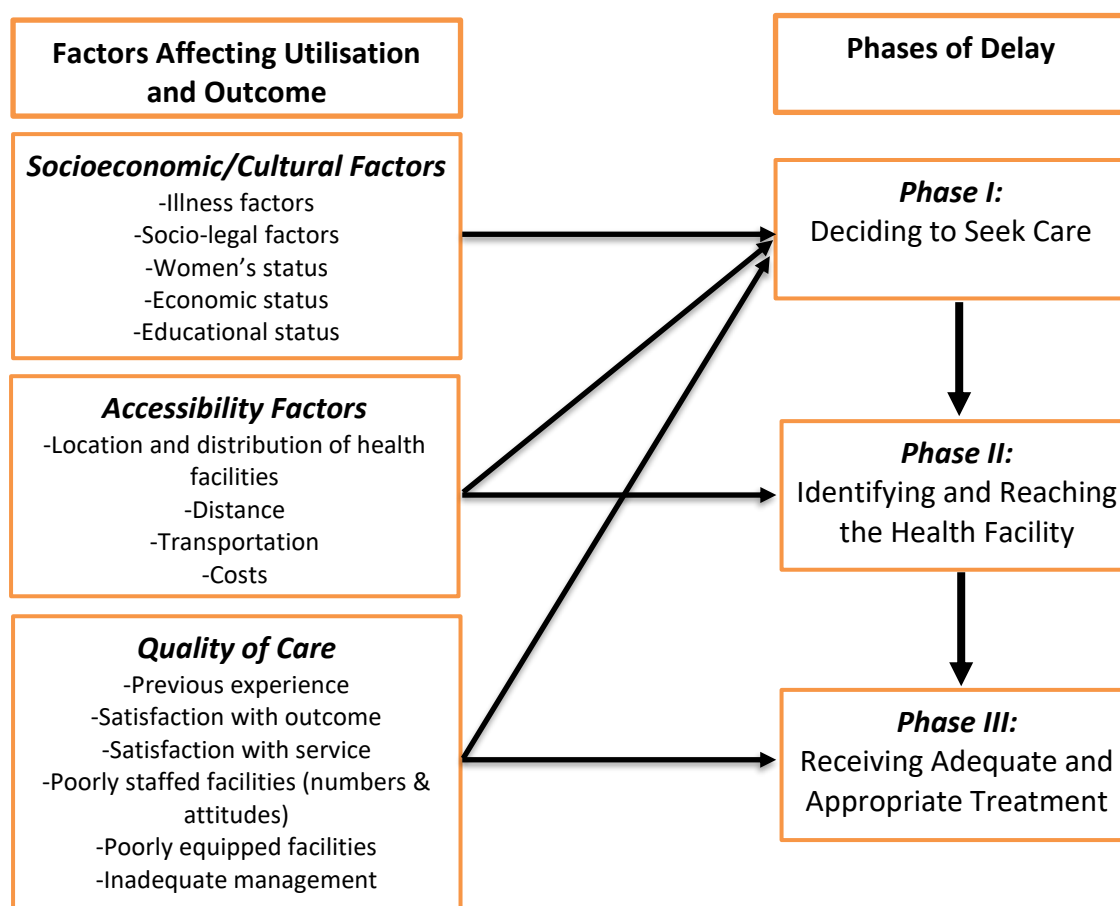


Figure 3.1: The Three Delays Model showing the factors affecting access to and utilisation of ANC services (Thaddeus & Maine, 1994)

Thaddeus and Maine (1994) postulate that the first delay is shaped by actors involved in decision-making (individual, spouse, relative, family), women's status, illness factors, distance to the health facility, financial and opportunity costs, previous experience with the health care system, and perceived quality of care. The second delay is related to the physical accessibility of health facilities, shaped by the distribution of health facilities, travel time, the availability and cost of transportation, and the condition of the roads. They describe the third delay as being associated with the adequacy of the referral system, shortages of drugs, supplies, equipment, and a trained health workforce, and the competence of the available health workforce.

Thaddeus and Maine (1994) assert that while maternal death may be a result of all three phases, any one phase on its own may also lead to death. Here, they note that 'phase' signifies the chronological order from the onset of obstetric complications to the treatment. Although there is a complex interplay between the phases, they argue that each type of delay

is not inextricably related to another. Thaddeus and Maine (1994) assumed that maternal deaths in rural under-served populations are comparable to urban well-resourced settings because a woman in a city such as New York may die due to poverty and its attendant impact on the woman's decision to seek care. However, this assumption may not hold true for pregnant women with physical disabilities, given the resultant oppression and vulnerability arising from their intersecting identities.

In their study which examined the impact of delays on maternal and neonatal outcomes in Ugandan public health facilities, Ackers et al. (2016) emphasise that 'the three delays' are important in understanding maternal and neonatal outcomes in poor-resourced settings. The Three Delays model exposes the contribution of social factors to shaping individual agency and care-seeking behaviour, and the need for holistic multi-disciplinary approaches focused on systems change as much as clinical input (Ackers et al., 2016). This model provides an evidence-based framework for policy makers to address the pragmatic challenges experienced by women with obstetric complications (Thomas, 2013).

Although this model was designed to capture the environmental factors that contribute to maternal death, it has been adopted more widely to examine the multiple sources and sites that affect a woman being able to receive the necessary health care in under-served populations. The model helps to expose the factors shaping a woman's agency in seeking ANC services. It also helps to understand the gaps in the accessibility of health facilities and quality of ANC services.

Iyer et al. (2013) used verbal autopsies of maternal deaths as an approach to decipher the missed opportunities for death prevention, and they highlighted the weakness of the implied linearity in the Three Delays Model that is silent on the power relationships between women and their families, communities, and health workers. They argue that the sequential nature of the Three Delays may pose a problem during data analysis as the delays may be intertwined in time, making it impossible to connect particular actions to specific delays. The emphasis on power dynamics points to the multiple and often conflicting narratives challenging the biomedical causes of maternal mortality and morbidity (Ackers et al., 2016). Ultimately, the wellbeing of women with physical disabilities stems from their social status in the family and community, and the most effective interventions lie in women's empowerment (Ackers et al., 2016).

While the Three Delays Model may have attractive features that are simple, comprehensive, and easy to apply, the same features may be the source of critical shortcomings in analysing why and how maternal mortality and morbidity actually occur, masking the health system barriers, especially within institutions (Iyer et al., 2013). The simple conversion of the health system and infrastructural and social factors into a uniform and easily understood metric (time) is problematic (Iyer et al., 2013). The authors contend that both the actual timeliness and appropriateness of actions matter and cannot be collapsed together. For example, they note that a correct action taken too late is a real delay. However, when an incorrect action is taken at the correct time that a problem needs to be addressed, it is only the consequence of this that is a delay. The problem here is that the action was incorrect, not the timing (Iyer et al., 2013).

Iyer et al. (2013) further contend that “by labelling all inappropriate actions as delayed actions, the model can divert attention away from the many circumstances in which the underlying cause is not time per se, but the correctness or validity of the action itself” (p. 393). They think that the reliance on one-sided narratives about the causes of maternal mortality and morbidity and the lack of unequivocal strategies to deal with power dynamics among different stakeholders can make autopsies vulnerable to inaccuracies and bias. However, they note that the model remains a powerful framework, most widely used to identify the underlying factors of the underutilisation of maternity care services and causes of maternal death, particularly in under-served populations.

3.3 Social Model of Disability

The proponents of the Social Model of Disability suggest that disability is a complex form of social oppression expressed in the form of stigma and discrimination (Barnes, 2012), which are psychologically and socially constructed within relationships (Coleman-Brown, 2013) as well as the physical environments limiting accessibility. The construction of disability is a political battle relating to the exclusion and inclusion of persons with disabilities (Barnes, 2012; Oliver, 1996, 2013). Society prioritises constructions of the body rather than the economic and social relations (Barnes, 2012). Davis (2013) suggests that the ‘problem’ is not the person with a disability, but the way normalcy is constructed to create the ‘problem’ of the disabled person. Persons with disabilities are discriminated against and isolated by society

and are viewed as a group that poses a direct challenge to commonly held social values and as different beings who are unfortunate, useless, oppressed, and sick (Barnes, 2012). Unlike the medical model of disability which focuses on the functional limitations of individuals with impairments and medicalisation to restore functioning, the Social Model provides insights into the problems caused by disabling environments, barriers, and cultures in order to generate policies and practices to facilitate their eradication (Barnes, 2012). Some critics have argued that it is unrealistic to emphasise barrier removal. “Most criticisms of the Social Model Of Disability appear to be centred on social constructionist interpretation of disablement which argues for inclusion of embodied experiences in disability accounts” (Owens, 2015, p. 389). The Social Model presumes that all persons with disabilities experience oppression, and ignores the lived experiences and the social relational nature of impairment and illness (Owens, 2015). Barnes (2012) contends that access to a range of social and material resources influences the way people deal with their impairments. Disability is not only a medical issue but also a human rights concern (Barnes, 2012) that calls for enabling the health and wellbeing of persons with disabilities while respecting their dignity and rights (WHO, 2016).

3.4 Intersectionality and Critical Disability Theory

*“Disability justice requires us to understand intersectionality,
and intersectionality requires that we learn how to
hold and value difference and contradictions”
(Mingus, 2018, para. 32).*

Intersectionality, as coined by Crenshaw (1989), is about how certain aspects of a person’s life combine to create oppression or wellbeing. It is “a heuristic term that focuses on the vexed dynamics of difference and the solidarities of sameness in the context of antidiscrimination and social movement politics” (Cho et al., 2013, p. 787). Intersectionality seeks to illuminate various factors that impact on human lives and tries to identify how different systemic conditions, varying in context, work together to reproduce conditions of inequality (Goethals et al., 2015). At the Global Disability Summit held in February 2022, it was noted that the understanding of how multiple identities intersect and create compounded experiences of discrimination and marginalisation may differ in different countries, cultures, and contexts (International Disability Alliance, 2022).

Disability acts intersectionally and therefore requires an interdisciplinary and transdisciplinary approach to researching the intersecting factors affecting the lives of persons with disabilities in the material world dominated with modernist discourses and actualities (Flynn, 2021; Goodley et al., 2019). Critical Disability Theory (CDT) is transdisciplinary and uses intersectional approaches in understanding the lived experiences of persons with disabilities (Flynn, 2021). It provides a framework for understanding the relationship between impairment, disability, and society (Hosking, 2008).

Criticality has significantly been adopted as an effective feature of Critical Disability Studies (CDS) (Flynn, 2021). CDS is “a location populated by people who advocate building upon the foundational perspectives of Disability Studies while integrating new and transformative agendas associated with postcolonial, queer and feminist theories” (Goodley, 2016, pp. 190-191). CDS presents a shift from the orthodox to the contemporary, evolving, and expansive approaches, recognising the intersecting identities of persons with disabilities, including race, ethnicity, gender, sex/sexuality, age, class, and nation (Goodley et al., 2019).

However, as a way of critiquing intersectionality in CDS, Goodley et al. (2019) indicate that there are concerns about inclusivity in an interdisciplinary field of inquiry and the dilemma of remaining true to the balancing act of consecutively theorising ability/ableism and disability/disablism without watering down the politics of disability, which is the basis for Disability Studies. They argue that for a reflexive and politicised CDS, interdisciplinary analyses are preferred. Therefore, for Disability Studies to thrive, critical self-reflexivity and self-critique are of great significance (Flynn, 2021).

In contributing to the Global South Disability Studies discourse, more responsive and transformative conceptual frameworks that identify oppressive tendencies and politicised responses are suggested (Goodley et al., 2019; Ned, 2022; Shakespeare, 2013) based on the local experiences of persons with disabilities, contesting the colonial hegemony (Chataika, 2018; Grech & Soldatic, 2016). In their study on disability policy and practice in Malawi, Wånggren et al. (2022) emphasise the need to address specific local contexts, debunking disability framings that do not necessarily fit the social, economic, cultural, and political contexts within which disability resides. They argue that such framings ignore the cultural and structural differences in the determinants of health, disability, and inequality.

“Hegemonic framings of disability individualise, pathologise, medicalise, psychologise, essentialise and depoliticise the phenomenon of disability” (Goodley et al., 2019, p. 973).

3.5 Ubuntu Philosophy

African ethics and values are espoused in the Ubuntu philosophy, “I am because we are, since we are, therefore I am” (Mbiti, 1969, p. 215), and Ubuntu ethics, which are “consensual and spiritual” (Mangena, 2016, p. 68). From the Global South stand point, Ohajunwa et al. (2021) articulate that “within African indigenous communities, understanding of spirituality frames conceptualisations and experiences of wellbeing” (p. 6). Ned (2022) posits that African societies are deeply rooted in spirituality and further suggests that in Africa, “Ubuntu encompassed a way of knowing with ethics (spirituality), before coloniality imposed a way of knowing [with a different set of ethics] and degraded Africa’s forms of spirituality” (p. 193). Although Ubuntu is an African humanist and ethical (spiritual) world view where disability is seen as part of humanity (Berghs, 2017), the non-acceptance and maltreatment of persons with disabilities in some African communities cannot be overlooked (Sefotho, 2021).

The concept of Ubuntu emphasises communal responsibility, where individuals carry responsibility for each other’s growth and development (Ned, 2022; Ramugondo, 2018). Lorenzo (2003) asserts that we need to invoke the Ubuntu philosophy and its spirit and values of interdependence and caring for one another to promote disability inclusion. Lorenzo further posits that Ubuntu’s approach to disability would foster inclusion and address the root causes of oppression and discrimination experienced by women with disabilities.

Berghs (2017) asserts that “in an Ubuntu Model of disability, impairment becomes cognitive, sensory, mental, physical (inclusive of biological) and spiritual diversity that can have a multitude of shared meanings that society, as human collective, constantly (re) make together” (p. 2). The notion of spiritual wellbeing is at the centre of the African Renaissance project, with the social and economic development of African women, including those with disabilities, at the forefront (Lorenzo, 2003; Sesanti, 2016). Spirituality and religion are significantly different from each other, even when they are sometimes used interchangeably. “Religion centres on organisation and structure that governs beliefs and behaviours” (Ned, 2022, p. 490) while spirituality is concerned with ultimate worth, meaning, and purpose in life (Cook, 2017). The negative skewed thinking about African spirituality and the resultant spiritual oppression imposed on indigenous African communities are partly blamed on

western-educated African scholars who confuse religion with spirituality and misinterpret African traditions as religious (Ned, 2022; Ojok & Musenze, 2019).

The field of Disability Studies is generally dominated by Global North thinking rather than ideas and experiences from the Global South, with the questions of knowledge and participation having been extensively addressed in the former, especially in high-income countries (Bezzina, 2018; Dirth & Adams, 2019; Ned, 2022). There is a need to apply the political and epistemological African Renaissance lens to understand and rebel against imperialist and neo-colonialist hegemony in formerly colonised African societies (Ned, 2022; Sesanti, 2016).

The concept of African Renaissance, as theorised by Diop (1996) and Mbeki (1999), is a reawakening call to Africa to recognise and rebel against colonial ways of thinking and knowing in their quest for political, social, economic, cultural, and spiritual transformation. Through the African Renaissance lens, African social ethical discourses are identified as a premise for social justice, rebelling against imperialism, colonialism, disablement, and oppression (Berghs, 2017; Ned, 2022) arising from a multitude of intersecting factors. In other words, Ubuntu could be the ‘holy grail’ for the African Renaissance where pregnant women with physical disabilities enjoy their universal citizenship rights.

However, a feminist critique of Ubuntu by Simba (2021) shows that Ubuntu philosophy can pose a challenge in dislodging patriarchal tendencies when Ubuntu is prescribed narrowly. The narrow application of Ubuntu may reproduce disability and gender norms that undermine women’s wellbeing rather than challenging them.

3.6 The Biopsychosocial Framework of Disability (the ICF)

The biopsychosocial framework⁹ of disability, also known as the International Classification of Functioning, Disability and Health (ICF), recognises the multifaceted experiences of persons with disabilities and provides a unified and standard language for describing the

⁹ The biopsychosocial framework of disability is also referred to as the International Classification of Functioning, Disability and Health (ICF) model. In this study, I will use the term ICF model to refer to the biopsychosocial framework of disability. (Barnes & Mercer, 2010)

intersecting factors impacting the wellbeing of these people (WHO, 2001). Table 3.1 below summarises the components, domains, constructs, and aspects of the ICF.

Table 3.1: Overview of the ICF (WHO, 2001)

	Part 1: Functioning and Disability		Part 2: Contextual Factors	
Components	Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Domains	Body functions and Structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological) Change in body structures (anatomical)	Capacity Executing tasks in a standard environment Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities Participation	Facilitators	not applicable
	Functioning			
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers / hindrances	not applicable
	Disability			

The advocates of the ICF view disability as a person-environment mismatch, situational or contextual, and relative (Barnes & Mercer, 2010). This model stresses disability as the outcome of a complex relationship between an individual's health condition and personal factors, and the external factors that represent the circumstances in which the individual lives (Schneidert et al., 2003; Üstün et al., 2003; WHO, 2001). It recognises that a person's functioning can be affected at the level of the body, the individual, and society (WHO, 2001). It "integrates the major models of disability – the medical model and the social model – as a 'bio-psycho-social' synthesis" (WHO, 2001, 2013, p. 6) and supports the implementation of stated international human rights mandates as well as national legislation (WHO, 2001, p. 6).

The ICF is a critical model in “identifying where the principal ‘problem’ of disability lies” (WHO, 2001, p. 251), and is hence important in the development of targeted and evidence-driven interventions. Barnes and Mercer (2010) argue that closer analysis of the interaction between impairment and the precise influence of the physical environment and attitudinal and social factors is important in theorising and researching about disability. The ICF was used to identify and describe the functioning problems of pregnant women with physical disabilities, thus supporting the identification of interventions needed (WHO, 2013).

Dantas et al. (2020) articulate that the inclusion of the ICF in health policy planning and implementation is beneficial to the health care users, including pregnant women with physical disabilities. The ICF provides information on health promotion and participation improvement (WHO, 2001), and is useful for the documentation, planning, monitoring, and evaluation of health care services and systems (WHO, 2001; Dantas et al., 2020). Figure 3.2 below shows how physical disability interacts with the components of the ICF.

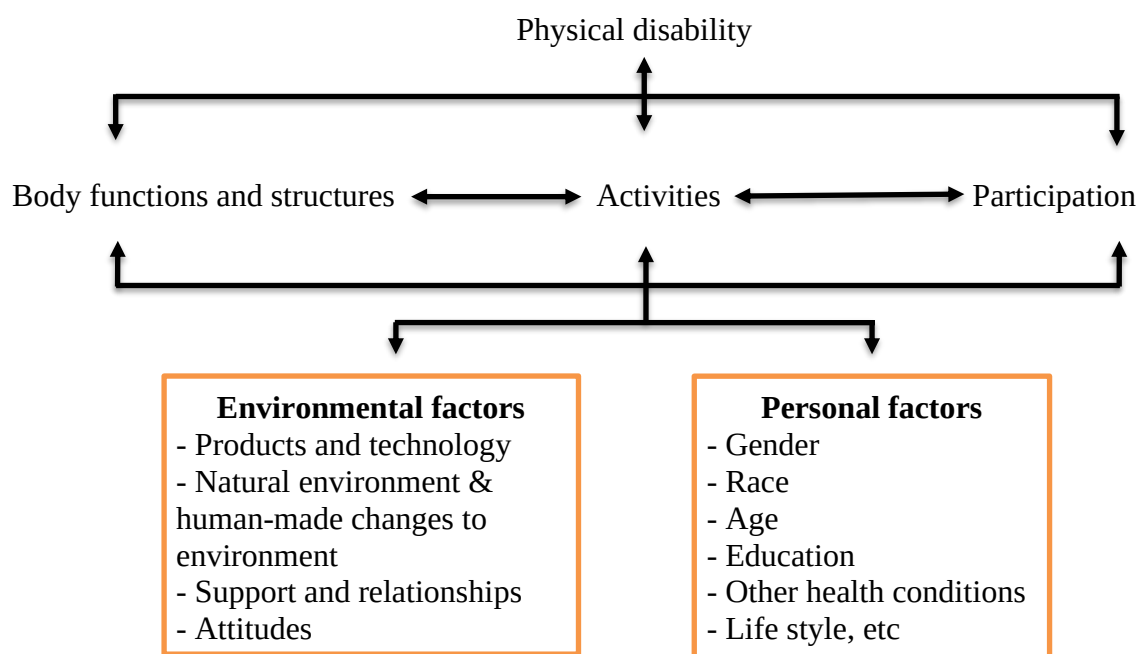


Figure 3.2: Interactions between the components of ICF (WHO, 2001)

The ICF reveals that a person’s functioning is influenced by the interaction between his/her impairment and the contextual factors. Sykes et al. (2021) assert that information on functioning is not only relevant across health systems but all areas where change in functioning is important, including social welfare. According to Cozzi et al. (2021),

functioning takes into account a combination of two aspects – physical (body functions and structures, with their impairments) and contextual (environmental and personal factors – recognised as facilitators or barriers) – that can limit activity and restrict participation in social life (Cozzi et al., 2021).

In barrier assessment, according to Cozzi et al. (2021), the two most distinctive components of the ICF classification are: 1. activities and participation, and 2. the environmental factors. The terms ‘activities’ and ‘participation’ are associated with the individual and social perspectives respectively (Cozzi et al., 2021). Equally, to understand the impact of a physical disability on an individual’s functioning, disability, and health, the evaluation of his/her participation in community activities should be considered (Ackermans et al., 2022). Chen et al. (2020) assert that community participation is both a crucial mediator and moderator for the relationship between functional disability and life satisfaction. A study in 34 European countries recommended that barrier assessment should be underpinned by both the social context and the human rights approach to participation (Waddington & Priestley, 2021), including the right to “full and effective participation in society on an equal basis with others”, as enjoined in Article 1 of the UNCRPD (United Nations, 2006, p. 3).

However, in their commentary, Mitra and Shakespeare (2019) express the need for a deeper and updated understanding of disability in the ICF framework, in which they contend that the emphasis on activities and participation is limited. Cozzi et al. (2021) echo similar concerns to Mitra and Shakespeare in that the practical use of some of the ICF classifications appears to be conceptually unclear or ontologically incoherent and some interest areas seem to be inadequately covered. For example, participation in a life situation is conceptualised as a social activity for an individual yet it may instead be considered a personal activity for someone.

Furthermore, Cozzi et al. (2021) note that the ICF does not differentiate between activities and participation, and therefore the ‘Activities and Participation’ component could be used to signify either activities or participation, or both. This implies that there was no consensus on how to objectively classify actions into two separate concepts (Cozzi et al., 2021). It is possible that a combination of frameworks recognising Global South thinking and ideas could

significantly contribute to the optimised wellbeing of women with physical disabilities in accessing and utilising ANC services.

3.7 The value of combining the above frameworks

Table 3.2 illustrates the combination of the frameworks used in this study to investigate the factors influencing the access to and utilisation of ANC services for pregnant women with physical disabilities.

Table 3.2: Combination of frameworks for assessing factors influencing access to and utilisation of ANC services for pregnant women with physical disabilities

Frameworks	Three Delays Model	Social Model of Disability	CDT	Ubuntu Philosophy	ICF
Factors	Delay 1: Deciding to seek care (Sociocultural)	Socio-economic	Intersectionality	Communal responsibility	Support & relationships
	Delay 2: Identifying & reaching the health facility (Access)	Physical	Power relationships	Humanness & interdependence	Products & technology, Natural & man-made changes (Physical)
	Delay 3: Receiving adequate & appropriate care (Quality of care)	Attitudinal	Political	Spirituality & religion	Attitudinal

It is important to note that the frameworks explained above have significant commonalities, but also distinctive contributions regarding the environmental factors influencing the access to and utilisation of ANC services by pregnant women with physical disabilities. For example, unlike the ICF and the Social Model of Disability, the Three Delays Model does not specify women with physical disabilities' participation in the access to and utilisation of ANC services. Likewise, it does not highlight any exceptional pregnancy circumstance. It does not conceptualise the interaction between the woman's impairment and participation restriction that impacts on her participation related to contextual factors, which the Social Model does.

Unlike the Three Delays Model, the other frameworks presented in Table 3.2 above do not recognise the delay factor and the three phases that may be useful in examining and

understanding access to and the utilisation of maternity care services. For example, the other frameworks do not show the adequate and appropriate care needed and/or received (quality of care), which is indicated in the Three Delays Model. Therefore, I used the ICF and the Social Model of Disability to understand how physical disability and the contextual influences which operate as facilitators or barriers (Badley, 2008) restrict or facilitate a pregnant woman's participation at each phase of delay in her access to and utilisation of ANC services. The ICF was applied as a classification framework for analysis of the environmental factors influencing the access to and utilisation of ANC services for pregnant women with physical disabilities.

CDT was used to explore the power relationships between women with physical disabilities and health workers as they are not clearly addressed by the Three Delays Model and the Social Model of Disability. It was also used to identify other axes of power (e.g., patriarchy and religion). The Ubuntu philosophy was used to understand African ethics, its ways of living and knowing, and how it can be used to promote respect, dignity, and the rights of women with physical disabilities in accessing and utilising ANC services.

Cochrane et al. (2007) suggest that barrier assessment methodologies should be aligned with the goal of the study, the target group, and the context. Combining the above frameworks in this study strengthens the design of the barrier assessment (Cochrane et al., 2007), as they complemented each other in exploring the intersecting factors and how these interact to disadvantage or advantage pregnant women with physical disabilities in accessing and utilising ANC services. Likewise, this study uses these frameworks together to identify and suggest strategies for improving pregnancy services for pregnant women with physical disabilities.

It has been demonstrated that women with physical disabilities experience intersecting barriers associated with their gender, impairment, poverty, rurality, and social support to the realisation of their sexual and reproductive health and rights (SRHR) (Gartrell et al., 2017). There is therefore a need for the formulation of SRHR policies and programmes that include the specific needs of women with physical disabilities (Gartrell et al., 2017). In their systematic review, Baker et al. (2015) agree that tailored intervention strategies to address the determinants of practice (personal and environmental) are more likely to improve health

professional performance. However, the quality of evaluations in systematic reviews is limited, which highlights the need for a conceptual framework of the complex health care processes and factors that facilitate and challenge professional performance (Grimshaw et al., 2003). The use of these frameworks fits the methodological and analytical focus of this study explained in the methodology chapter (Chapter Four).

3.8 Conclusion

In this chapter, I have discussed the Three Delays Model, which is the main theoretical framework underpinning this study, highlighting its strengths and limitations. The Social Model of Disability and the Critical Disability Theory are also discussed. These frameworks uncover the environmental and personal factors influencing rural pregnant women with physical disabilities in accessing and utilising ANC services and how these factors intersect to disadvantage these women. The ICF, which was applied as a classification framework for analysis of the environmental factors influencing access to and utilisation of ANC services for pregnant women with physical disabilities at each phase of the delay, has been presented.

I have also discussed Ubuntu as an African philosophy, and intersectionality and the role of criticality in Critical Disability Studies as reflexive, more responsive and transformative approaches to improving the pregnancy experiences of women with disabilities. African Renaissance is evoked, employing the Ubuntu philosophy to develop a nuanced understanding of the oppression suffered by pregnant women with physical disabilities and how our African way of knowing and being can act as a premise for improving their experiences in accessing and utilising ANC services (see Chapter Eight).

CHAPTER 4:

METHODOLOGY

4.1 Introduction

This chapter presents the methodological approach of this study, including philosophical assumptions. The research design is explained. A description of the study population, the sample size, the sampling strategies, and the inclusion and exclusion criteria are presented. The recruitment process and data gathering methods, data management and analysis, rigour, trustworthiness, and the ethical considerations are described.

4.2 Research philosophy

Qualitative researchers embrace the idea of multiple realities and conduct research with the intent of reporting these realities by relying, as much as possible, on the participants' views of the situation to understand their historical and cultural settings (Creswell & Poth, 2018). To understand women's ability or disability in accessing and utilising ANC services, it was crucial to appreciate their lived experiences of the services provided.

Throughout the research process, there are philosophical assumptions that underlie every decision (Coates, 2020). These beliefs and assumptions are part of my positionality, as explained in Chapter One (section 1.11).

This study is situated within the social constructivism philosophical paradigm. Social constructivism is a worldview that deals with understanding individuals' subjective meanings that are negotiated socially and historically to make sense of these meanings about the world (Creswell, 2014; Creswell & Poth, 2018). The paradigm is used to understand the complexities and multiplicity of a phenomenon where creative novel ideas and interventions are sought (Adom et al., 2016). It was used to underpin this study to understand how women with physical disabilities make sense of how they access and utilise ANC services in rural south-western Uganda.

The ontological and epistemological underpinnings of this study fit into the African Renaissance school of thought. Ontology is concerned with existing truth or reality and how the researcher defines the truth or reality, while epistemology is concerned with the process

by which the researcher comes to know the truth and reality (Kamal, 2019). The ontological underpinning of this study required a combination of theoretical frameworks (see Chapter Three), which influenced the study design, the methods used in data gathering, and the data analysis to achieve the objectives set out in Chapter One.

4.3 Study design

This study employed an interpretive qualitative approach using a descriptive multiple case study design. A qualitative approach is used for “exploring and understanding the meaning individuals or groups ascribed to a social or human problem” (Creswell, 2014). This approach helped me to answer the research questions and discover the experiences of women with physical disabilities regarding accessing and utilising ANC services.

Creswell and Poth (2018) define a case study design as a methodology within “qualitative research approach in which the investigator explores multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information and reports a case description and case themes” (p. 97). Case studies are useful in assessing access to health services to develop interventions (Baxter & Jack, 2008). Importantly, throughout the data gathering and analysis processes in this study, systematic procedures were followed and the existing evidence or biased views regarding the study phenomenon did not influence the direction of the findings and conclusions (Yin, 2009).

Yin (2003) and Yin (2014) suggest that a case study design should be considered when the focus of the study is to answer “how” and “why” research questions, and to explore the contextual conditions relevant to the phenomenon under study. The case study design helped me to analyse the process of accessing and utilising ANC services by pregnant women with physical disabilities in rural south-western Uganda and to identify the factors (barriers and/or facilitators) influencing this.

In this study, the unit for analysis (the case) is the process of accessing and utilising ANC services by women with physical disabilities in the selected public health facilities. The unit of analysis consisted of multiple cases within a multisite study (i.e., health centre (HC) III, HC IV and the general hospital). To have a holistic view of the case, I included women with physical disabilities within the scope of this study as ANC service users, and health workers

as ANC service providers, particularly midwives. Here, the focus is on the phenomenon under study for each individual case selected to build an in-depth and contextual understanding of the study topic (Creswell et al., 2007).

A multiple case study allowed for analysis within each setting and across settings (Baxter & Jack, 2008), including contextual conditions, to understand the study topic. It enabled me to analyse the experiences of pregnant women with physical disabilities accessing and utilising ANC services both at each of the individual selected health facilities and across all the health facilities. Although the scope had initially included women who do not access ANC services, they were not identified during the sampling and recruitment process. Efforts were made to look for these women as per the inclusion criteria indicated in sub-section 4.5.1 below, however, all the women identified had received ANC services. A plausible reason for this could be the sustained community sensitisation on ANC benefits and the ANC outreaches conducted by health workers within the district.

4.4 Population of interest

The primary population of interest included women with physical disabilities within the scope of this study. In this study, the scope included the following units of analysis:

- All women with physical disabilities who access and utilise ANC services
- Women with physical disabilities who access ANC services from HC III
- Women with physical disabilities who access ANC services from HC IV
- Women with physical disabilities who access ANC services from the district general hospital.

The secondary population of interest included midwives/nurses in the selected health facilities (HC III, HC IV, and the district general hospital) responsible for provision of ANC services.

4.5 Inclusion criteria

This section describes the inclusion criteria for women with physical disabilities who were information-rich about the experience of accessing and utilising ANC services. Midwives/nurses who were information-rich about the services offered were recruited.

4.5.1 Inclusion criteria for women with physical disabilities

- Aged between 18 and 45 years
- Currently pregnant or have been pregnant in the last 3 years
- Had or had not attended ANC
- Had a physical disability affecting one or more limbs (upper or lower), pelvis, and/or vertebrae:
 - Mobility, stability and/or dexterity difficulties due to amputation, polio, cerebral palsy, spinal cord injury and/or accident, or other health condition affecting their mobility
 - Variance in the nature of the physical disability, the distance to the health facility in relation to their residence, education level, age, and duration since their last pregnancy was considered (see Chapter Five, Table 5.1)

4.5.2 Inclusion criteria for health workers

The study included:

- Midwives, comprehensive nurses, or double trained nurses¹⁰ who were working in an ANC clinic:
 - With knowledge about the study topic and three or more years of experience working with women with physical disabilities. As a national standard in Uganda, midwives/ nurses are required to have a minimum of two years of work experience to advance and transition from certificate level to diploma level. In addition, since the population of women with physical disabilities is quite small, there is less opportunity for one to become familiar and well informed about pregnant women with physical disabilities and their needs. One would need a longer period to have adequate exposure. I, therefore, extended the two years by fifty percent (50%) to make it three years, which I used as a basis for the inclusion of midwives/ nurses.

¹⁰ Health professionals who have dual qualification in nursing and midwifery.

4.6 Exclusion criteria

This section describes the exclusion criteria for women with physical disabilities and health workers.

4.6.1 *Exclusion criteria for women with physical disabilities*

Women with physical disabilities that did not affect their mobility, stability, or dexterity, and those that were not willing to participate in the study, were excluded.

4.6.2 *Exclusion criteria for health workers*

The study excluded health workers who:

- Worked in other sections of the health facility than the ANC clinic
- Have less than three years working experience in ANC
- Were clinical officers and/or medical officers (not regular in ANC clinic)

4.7 Sampling strategies and sample size

This section describes how midwives, health facilities, and women with physical disabilities were sampled with their corresponding sample sizes. Purposive and snow-ball sampling techniques were used.

4.7.1 *Purposive sampling*

Purposive sampling is a non-probability sampling technique in which subjects selected for the sample are chosen according to the judgment of the researcher (Black, 2010). The intention is to identify and select information-rich cases related to the phenomenon of interest to answer the questions under study (Patton, 2002). Purposive sampling was used to identify the women with disabilities who attended specific health facilities and health workers at these facilities who were able to provide rich information about the phenomenon under study. Six midwives working in ANC clinics in the selected health facilities were identified. Midwives were selected because they interface with pregnant mothers with physical disabilities on a regular basis. The higher the level of a health facility, the more midwives it has, which meant that the most midwives (three) were from a hospital, two were from a health centre IV, and only one

was from a health centre III. This strategy was used to achieve equitable inclusion of the midwives/ nurses and balance across the whole sample.

The purposive sampling technique was used to select three health facilities (hospital, health centre IV, and health centre III). This technique helped to identify health facilities which have different physical environments, are at different levels in the health care delivery system, and have different ANC packages, in order to gain a holistic and in-depth understanding of the study topic. Permission was sought from the managers of the selected health facilities to access these facilities (see Appendix VIX).

The study was conducted in Sheema district, in Sheema South county, where the selected facilities were located. The district general hospital, located in Sheema South county, was selected (see Figure 1.2 in Chapter One). To gain a holistic picture of ANC services provision within Sheema district, the lower-level health facilities that offer ANC services were identified. A health centre IV and health centre III within the sub-counties neighbouring the district hospital were selected to make a total of three health facilities.

4.7.2 Snowball sampling

Katz (2006) described snowball sampling as a special non-probability technique for selecting participants who then help to identify subsequent participants from among their acquaintances. Its cultural competence and the inherent trust among potential participants increases the likelihood that the identified person will agree to talk with the researcher (Sadler et al., 2010). This technique is often used in hidden populations which are difficult for researchers to access. It was used to identify women with physical disabilities because there is no reliable record of these women, and it would have been difficult to find or locate them in rural communities. Twelve women with physical disabilities were identified.

4.8 Recruitment process

Here, the recruitment process for women with physical disabilities and health workers is described.

4.8.1 Recruitment of women with physical disabilities

Women with physical disabilities were identified with the help of the Community Development Officers (CDOs) and Village Health Teams (VHTs) in their respective sub-counties and villages, respectively. CDOs and VHT leaders were contacted to help identify women with physical disabilities who, in turn, helped to identify other women with physical disabilities in the communities until the consecutive consenting sample size (Setia, 2016) was realised.

CDOs helped in identifying these women because they are the change agents who interface with communities at the grassroots level. They are responsible for disseminating information on available services (including health services) and organising communities to engage in all the social development sector programmes for improving their welfare and empowerment¹¹ (Ministry of Gender, Labour and Social Development, 2008). The VHTs work with the communities in disease prevention and health promotion activities, including activities on maternal and child health promotion (e.g., see Report on National Service Delivery Survey, Uganda Bureau of Statistics, 2021).

I requested the CDOs to pass on the information (see Appendix II) about this research project to the women with physical disabilities. However, to minimise the spread of Covid-19, there was a restriction on community engagements and only a few people were allowed to gather at a time. The information on the research project was circulated by CDOs during the registration of persons with disabilities for the ‘*emyooga*’ programme (a government development programme for poverty alleviation among vulnerable groups in the communities). Women who were interested were identified and approached individually to discuss the research information sheet and their motivation to participate. Informed consent was obtained and arrangements for the date and venue for the initial semi-structured, in-depth face-to-face interview and the focus group discussion were made. Once I gained initial access to willing participants, I employed snowball sampling to further recruit potential participants until the sample size was reached. The details of the 12 women who participated in the study are presented in Chapter Five, section 5.2.

¹¹ CDOs also provide direct services to specific vulnerable and marginalised groups (including women with disabilities) in the community.

4.8.2 Recruitment of health workers

Midwives working in ANC clinics were identified with the permission and help of their respective managers in the selected health facilities. They were identified from the health workers deployment list, with their names juxtaposed with the number of years of relevant experience in ANC practice. Those with the longest experience in ANC practice, particularly in attending to pregnant women with physical disabilities, were selected. I approached them individually to explain the purpose of the study, their role in the study, and the benefits and risks involved. Those willing to participate were recruited and an arrangement for the date and venue for the interview was made.

All the midwives approached were willing to participate, especially after I had introduced myself and explained the purpose of my study. One midwife had accepted to participate after I had explained everything about the study, but because she was tired after her work, we planned for her to sign the consent form on the day of the interview. However, she later told me that she had an urgent issue to attend to at her home, which was in another district in greater Bushenyi. Unfortunately, she was unable to return to participate in the study as she stayed at home for her annual leave. I discussed with her and the manager of the ANC clinic about the possibility of identifying another midwife. In consultation with the manager, I identified another midwife with experience in attending to pregnant women with physical disabilities who was willing to participate. I approached her and took her through the information sheet, and she accepted to join the study. I had a smooth interaction with the health workers, and they were willing to help with all the needed information regarding the study.

4.9 Data gathering methods

Data was gathered using semi-structured, in-depth face-to-face interviews, a focus group discussion (FGD) with the women, and an audit of the health facilities' physical infrastructure and equipment methods. Data was gathered over a period of three months (i.e., November 2020 to January 2021).

4.9.1 Semi-structured, in-depth face-to-face interviews

Semi-structured, in-depth face-to-face interviews were used to understand the lived experiences and multiple perspectives of the participants regarding the study topic. This method is flexible, understandable, and capable of revealing important and often hidden facets of human behaviour. It has been proven to be valuable, especially if the researcher wants to understand how interviewees perceive the subject under study (Qu & Dumay, 2011).

Face-to-face interviews take advantage of social cues, such as the voice, intonation, and body language of the interviewee, which can give the interviewer a lot of extra information that can be added to the verbal answers of the interviewee to a question (Opdenakker, 2006). This method helped me to interface with women with physical disabilities and the health workers, using semi-structured interview guides (see Appendices III and IV respectively) to get answers to the research questions. The interface provided an opportunity for me to benefit from the diverse ways women with physical disabilities and health workers perceive things and express their views about the research subject.

The development of the interview guides was guided by the study objectives and the theoretical frameworks underpinning this study. The Three Delays framework was the dominant framework used to structure the questions and inform the data. The interview guides involved prepared questions and the ICF was used to identify themes relating to the activities and participation of pregnant women with physical disabilities at each phase of delay (according to the Three Delays framework). The interview questions and probes covered content on pregnant women with physical disabilities' activities and their participation at home/ family level, on the way to the health facilities and at the health facilities. The questions were organised in a consistent and systematic manner and interposed with probes designed to elicit more responses regarding the environmental factors facilitating or hindering the access to and utilisation of ANC services (see Appendices III and IV).

The interviews were recorded using a digital audio-recorder. Each interview took about one hour and was conducted in the language the participant was comfortable with, either the local language (Runyankore-Rukiga) or English. I had one in-depth face-to-face interview with each participant.

Appropriate spaces for interviews were identified together with the participants to ensure their safety, comfort, and privacy. This was at their home, health facility, or in their gardens. The picture below (Figure 4.1 A and B) shows the researcher and some of the millet gardens as venues where interviews with women with physical disabilities were conducted.

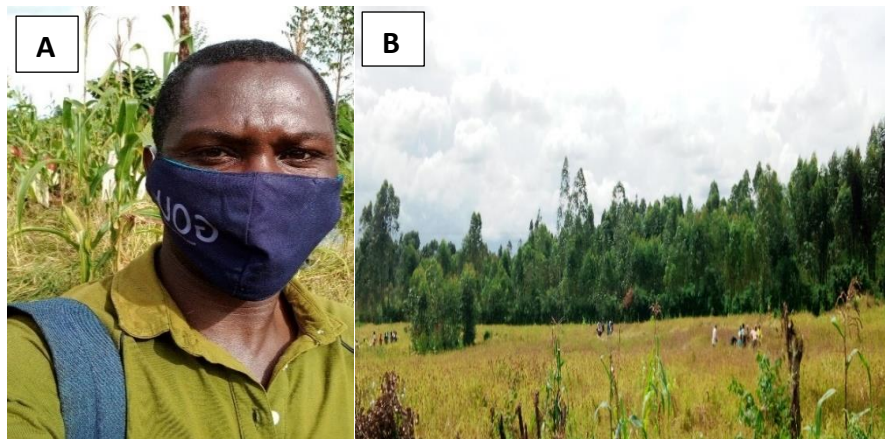


Figure 4.1: Researcher in the field at the gardens of some women where the interviews were held (under trees)

The interviews with health workers were conducted after the audit of the physical environment inside and outside each of the health facilities. Knowledge about the health facilities was used to probe for further information during the interviews. A preliminary analysis of the findings from the audit of the health facilities' physical infrastructure and equipment and the interviews with the health workers guided the probing during the interviews and FGD with the women with physical disabilities.

To avoid frequent interactions and to minimise the risk of Covid-19 transmission, there was no second follow-up face-to-face interview with the women with physical disabilities. Instead, the follow-up for member checking and filling in any realised gaps in the data was done during the FGD.

4.9.2 Focus group discussion (FGD)

A focus group is a group discussion on a particular topic organised for research purposes. The discussion is moderated by the researcher to generate rich information on collective views, and participants' experiences, opinions, feelings, attitudes, and beliefs on the study topic (Gill et al., 2008; Stalmeijer et al., 2014). A FGD was used in this study to challenge gender and

disability norms, meanings, and processes relating to the study topic. It also helped to clarify and qualify or challenge the data gathered through the interviews and audit of the health facilities' physical infrastructure and equipment (Baxter & Jack, 2008). One FGD was conducted among eight women with physical disabilities (of the 12 women who were interviewed initially) on 10 January 2021. Participants from the sub-counties neighbouring the district general hospital who were willing to participate were brought together for the FGD. An appropriate place for the discussion was identified and privacy was ensured. The development of the FGD guide (see Appendix V) was guided by the study objectives and the conceptual frameworks. The group discussion questions were informed by the preliminary findings from the face-to-face interviews and audit of the health facilities' physical infrastructure and equipment. The discussion was recorded using a digital audio-recorder and the recordings were transcribed by the researcher.

FGD size, managing group dynamics, and Covid-19 transmission: Gill et al. (2008) note that whereas a large group can be chaotic and hard to manage, having small groups may risk limited discussion occurring during the FGD. They suggest that it is better to slightly over-recruit for a focus group and potentially manage a slightly larger group, than under-recruit and risk having to cancel the session or having an unsatisfactory discussion. They also advise that each group will probably have two non-attenders. In this study, I was working with a vulnerable group where some of the participants:

- Had expressed their concern honestly about the risk of exposure to Covid-19 for themselves and/or their babies, and they could not leave their babies behind since they were breastfeeding.
- Were uncomfortable with the distance they would have to travel to the FGD venue, especially using a motorcycle ('*boda boda* '), which is the major means of transport. They feared that the transport situation would be worse if it rained on the day of the FGD.
- Were reserved and not forthcoming with regard to sharing their experiences compared to others.
- Had a busy schedule because January was a harvest season for millet in the villages, and they would be busy in their gardens – hence, a likelihood of more non-attenders.

Consequently, I conducted one FGD with eight participants instead of the originally planned two FGDs with six women each. Reducing the frequency of gatherings by having one FGD helped in minimising the risk of transmission of Covid-19 (for myself and the participants). The Covid-19 precautions were carefully adhered to. Importantly, the FGD involved participants who were interested in the topic and were comfortable and forthcoming in sharing and discussing their experiences. The four women who did not return for the FGD made a choice of not returning. As qualitative study, the focus group was not going to be a representative sample.

Choosing the FGD venue and managing resistance to travelling: I planned to have the FGD in a central place with a neutral setting. The distance between the two furthest sub-counties is about 35km, and therefore the longest distance which any of the women needed to travel was about 17km. I avoided the health facilities or sub-county headquarters because the participants may have had negative or positive associations with these places. A group meeting at the sub-county headquarters could have been associated with government funding which could have raised unnecessary expectations among the women. Health facilities were not convenient either, as the women may have thought that their views could impact on their future treatment at that health facility. Renting out a hall in a trading centre was another option but given the political and Covid-19 situations at the time, it was not favourable. A participant's home would have been a good option as the surroundings would have been familiar. However, having an FGD at a person's home would put their family at risk of Covid-19 if there was any participant who was asymptomatic.

Therefore, the FGD was held in a classroom at a primary school. The primary school venue was the most convenient for the participants and was presumed to be free of Covid-19 because the pupils were away (at home) and the classroom had been unoccupied for the last 10 months, since the closure of schools in March 2020 by the Government of Uganda due to the pandemic. The schools were expected to re-open in March 2021 and the FGD was carried out on 10 January 2021. The VHT leader where the primary school is located was helpful in providing me with the contact details of the head teacher. I contacted the head teacher, explained the nature and purpose of my research, and sought and obtained permission to use one of the school classrooms. Before and during the group discussion, I cleaned and disinfected frequently touched surfaces such as the doorknobs/handles and table and chair surfaces.

Participants were reminded to avoid handshakes or hugging throughout the interview process. I provided a handwashing container with soap and water near the classroom entrance, and all the participants washed their hands before entering and after the group discussion as they left for their homes. A bottle of hand sanitiser was placed in the centre of the group for participants to use as needed.

All participants arrived wearing their face masks and continued to wear them throughout the discussions. They were encouraged to ensure that their masks were worn correctly to prevent person-to-person transmission of Covid-19. A physical distance of at least one metre was maintained between each of the participants during the group discussion. The participants were arranged to sit in a rhombus form (see Figure 4.3 below), with two participants on each side. They sat close to the window to allow for good access to fresh air. All the classroom windows and door were kept open for good air ventilation.

Travel to the site: I travelled to the FGD venue by car (self-drive). Prior to leaving for the venue, I adequately sanitised/disinfected my hands, the phones/recorders, the notebooks, the pens, the papers, and my bag. All eight women who participated in the FGD and the scribe (notetaker) travelled to the venue by *boda boda*. The participants were encouraged to identify their own '*boda boda*' riders from their own villages to bring them and their helpers to the venue and take them back home after the group discussion. They were also encouraged to use the same riders who usually took them to the health facilities for ANC, immunisation or any other health care service or to any other place such as markets. This advice was given because these riders would have been aware of the support these women needed during travel. In addition, the participants were encouraged to ensure that they and their *boda boda* riders wear their face masks at all times during travel.

None of the participants had a helper. They did not need them at the venue as they were able to carry out most of the activities by themselves and were transported on '*boda bodas*' from their homes to the venue and back.

Strategies to get everyone to participate and ensure their voices were heard: I used different strategies for managing group dynamics during the group discussion to optimise group participation and interaction (see Appendix VI). These strategies enabled participants to share and compare their experiences and evaluate and generate ideas regarding the phenomenon under study. The pictures below show the researcher and notetaker making reflexive notes and summaries immediately after the FGD (Figure 4.2) and the participants' seating arrangement during the FGD (Figure 4.3).



Figure 4.2: Researcher and notetaker making reflexive notes and summaries after the FGD

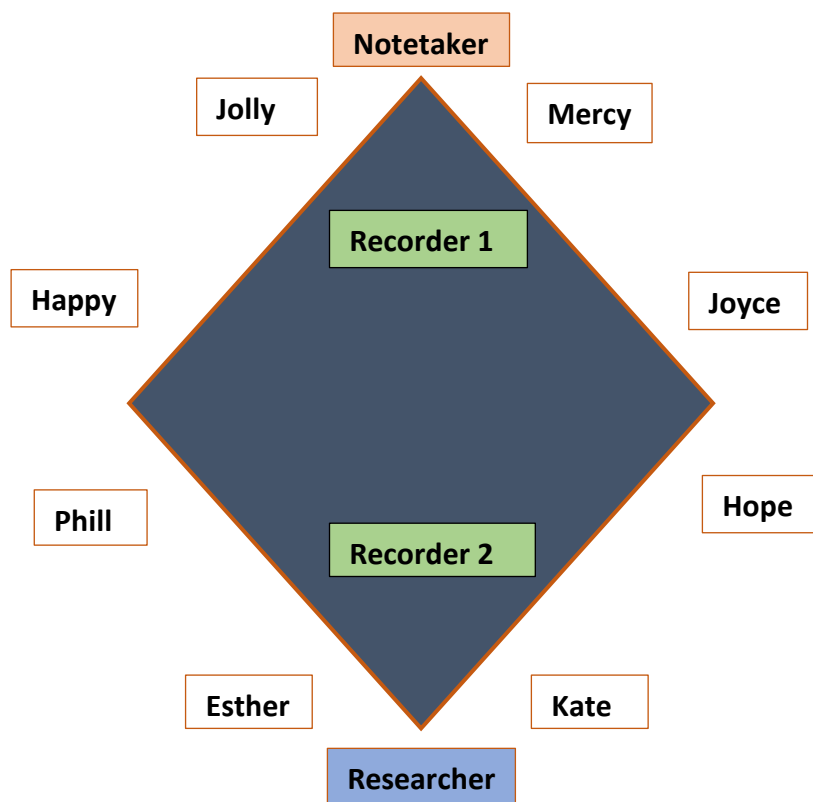


Figure 4.3: Participants¹² seating arrangement during the FGD carried out on 10 January 2021

¹² The participants' names indicated in the sitting arrangement above are pseudonyms and not the real names of the women in the FGD.

4.9.3 Audit of the health facilities' infrastructure and equipment

This is a method of gathering data by noting physical characteristics in their natural setting. It does not rely on people's willingness or ability to provide information (Centers for Disease Control and Prevention (CDC), 2008). The ICF was used to inform the observation of health facilities. A physical infrastructure and equipment audit was employed using an audit check list (see Appendix VII) to obtain data on the physical environment in each of the selected health facilities, and I requested permission from the health facility managers to carry out the audit. The women with physical disabilities were not required to be present during the audit. The development of the audit checklist about the physical environment was guided by the Accessibility Standards developed by the Uganda National Action on Physical Disability and Ministry of Gender, Labour and Social Development (2010). After the audit of the health facilities was completed, the face-to-face interviews with the health workers followed by those with the women with physical disabilities were conducted. The knowledge I gained during the audit about the health facilities guided the probing during the interviews and FGD.

4.10 Piloting the interview and focus group discussion guides

Prior to data gathering, I visited the study area to seek administrative permission to access the study area and participants, and to pilot the interview/FGD guide. I used the interview guide for practice because I was going to develop the FGD guide questions based on the preliminary findings from the interviews. I practiced leading a conversation for both the interviews and the FGD with two women with physical disabilities who were not my participants. I interviewed each woman individually and then both together as a group. These women were from the study area but outside the scope of this study. Both had given birth but more than three years prior and were not pregnant at the time of the interview. Their experiences helped to improve the interview questions. Data from the pilot interviews was not included for analysis and does not form part of this study. It was only used to improve my data gathering tools and skills.

In addition to improving my probing skills, the emphasis was on the use of Runyankore-Rukiga vocabulary in relation to my study. During and after the conversations, the following issues were noted:

- I needed to conduct the interview/FGD like a conversation and allow it to flow naturally.

- I needed to display both verbal and non-verbal cues to help or encourage the participants to open up.
- There was need to build rapport and constantly check the power gradient between myself and the participants for a smooth conversation.
- I needed to continually reflect on my professional and cultural values and show respect to the participants.
- Some words such as ‘care’ and ‘support’ were used interchangeably and needed to be explained and contextualised during the interviews.

4.11 Critical self-reflection on relationship with the participants

During data gathering, most of the participants were forthcoming and were easy to relate to. In introducing myself, I noticed that mentioning that I come from Kitagata (in Sheema), work in a Disability Studies department, and that my research is purely for academic purposes, helped in setting the scene. It also helped to clear any doubts and suspicions, given the mood in the prevailing political campaigns¹³ and the Covid-19 pandemic crisis at the time of my fieldwork. I reflected on how my relationship with the participants could influence the process and the outcome of my study. I reflected on my beliefs and attitudes regarding how pregnant women behave when interacting with health professionals and how health workers behave when discussing patients/clients with fellow health professionals, so as to bring out participants’ voices and ensure that they are heard. I continually reflected on what I know professionally and what was observed during the data gathering, and ensured balanced power relations throughout the data gathering process and its analysis. Ample time and comfortable spaces were provided to the participants to freely express themselves.

However, one woman (Joy) was a bit hesitant to answer the interview questions fully and freely. The interview venue was at her home. I built rapport very well and she told me everything I needed to know about herself and ANC generally, then she kept silent on most of the questions as the interview proceeded. From her facial expression, she seemed to have lost interest in the interview; however, I could not establish the cause of this lack of interest. I intentionally developed a friendly relational atmosphere to ensure a balanced power gradient.

¹³ Data gathering occurred during a time when there were campaigns for political positions (i.e., presidential, parliamentary, and local positions) in the country. It is possible that community members, including the study participants, could have easily thought that I was soliciting votes for a particular political contestant instead of doing research. Usually, electorates associate the soliciting of votes with receiving money and other handouts from the contestants.

I inquired from her whether we should stop the interview and maybe continue with it later/another day and she neither refused nor agreed. I suggested moving to another interview venue – from her sitting room to the compound – but she was unresponsive. I wondered if her hesitancy was due to mistrust of my outsider positionality as a male researcher without disability investigating women with disability issues, even though, in my view, I had considered this right from the start of the interview.

It is also possible that the physical distancing and face masking (to minimise the transmission of Covid-19) during the interview could have contributed to her hesitancy in opening up to a person whose facial identity was partially masked (also see Chapter Eight, section 8.5.2). We ended the discussion and I thanked her for her time and the information she had shared. She happily bid me farewell and thanked me for coming. Joy's interview was the shortest and lasted 28 minutes. The longest interview was with a midwife (manager of an ANC clinic), which lasted 1 hour and 18 minutes. The rest of the interviews were in the range of 45-60 minutes.

4.12 Data management

Data management is a significant aspect in the research process. In this section, the documentation, curation, backup storage strategies, and relevant institutional policies are presented.

I gathered qualitative data related to the experiences of pregnant women with physical disabilities. The data was transcribed in Microsoft Word. The computer-aided qualitative data analysis software NVivo was used to create a database, and to organise, manage, and store the collected data.

4.12.1 Backup and storage

I backed up my data on an external hard drive and Google drive on my University of Cape Town (@myuct) email account. I will make a final backup when submitting my final thesis after examination and destroy the earlier versions. All the data has been kept on my computer (laptop) and no one else can access it because it is protected with a password which is only known to me.

4.12.2 Relevant institutional/study policies

The following UCT policies apply to this study and influenced my data management activities: UCT Research Data Management Policy, March 2018 (UCT, 2018b); UCT Intellectual Property Policy, July 2011 (UCT, 2011); and UCT Open Access Policy, September 2020 (UCT, 2020b). The next section presents the process of data analysis, explaining the approach and steps taken to make sense of the gathered data.

4.13 Data analysis

The data gathered was analysed using inductive reflexive thematic analysis (Braun & Clarke, 2019). Reflexive thematic analysis involves “procedures [which] reflect the values of a qualitative paradigm, centring researcher subjectivity, organic and recursive coding processes, and the importance of deep reflection on, and engagement with, data” (Braun & Clarke, 2019, p. 593). The authors assert that this approach to thematic analysis is good for reflexivity, theoretical engagement, and creative scholarship. It involves generating codes and categories, summarised in the form of subthemes and themes identified by the researcher as important in a data set and then organised in a meaningful and useful manner. It can be used to analyse the access to and utilisation of services (Nuwagaba & Rule, 2015). Because the interview and FGD questions were open-ended, thematic analysis helped me to have an in-depth understanding of the views and opinions from women and midwives based on the probing during the conversations. It was also useful in comparing the data from the women, the midwives, and the audit of the health facilities’ infrastructure and equipment to understand the case that was being studied.

Thematic analysis enabled me to epistemologically focus the research whenever the focus would shift to different aspects of the data (Braun & Clarke, 2006). Although the question of epistemology is usually determined during the conceptualisation of the research project (Braun & Clarke, 2006), it also was apparent during the data analysis. Research epistemology – in the context of Ubuntu – was significant in the data analysis as it guided what I said about the data and how I theorised meaning (Braun & Clarke, 2006). The six phases of data analysis by Braun and Clarke (2006) were followed. The analysis process involved transcribing the interviews and FGD and organising the data, including the notes from the field, into emerging issues (codes/units of meaning) using an inductive approach (see Appendix I). The six phases included familiarising myself with the data, generating initial

codes, generating subthemes and themes, reviewing the subthemes and themes, defining and naming the themes, and producing the report (Braun & Clarke, 2006).

As I transcribed the interviews and translated the transcripts for the women with physical disabilities which were in Runyankore-Rukiga, iteratively, I read both versions (English and Runyankore-Rukiga) while listening to the audios in order to ensure the accuracy of the transcriptions. I also re-read my reflexive notes and contact summary notes to have an understanding of each data set in its entirety. This helped me to familiarise myself with the data. I read each transcript line by line to look for ideas or units of meaning from each small segment of data. Then I would highlight a segment of text from the data transcript and assign it a code with a label (theme) that reflects or summarises the idea in the text. As I further coded other transcripts, the repeating ideas that emerged would be added to the relevant codes previously created. Similar codes were eventually grouped together, naming the group by the commonality between the codes. Some groups of codes were combined into higher level themes/ideas while others were broken down and reconfigured as a deeper interpretation of the data developed.

Relevant units of meaning were grouped into appropriate categories. Memos were written and attached to explain unexpected findings. The themes were generated from the data collected while reflecting on the study objectives, the conceptual frameworks, and literature reviewed. As a researcher, I was actively positioned and involved in the research process (Braun & Clarke, 2006).

The themes were generated based on the patterns of shared meaning, underpinned by a central meaning-based concept (Braun & Clarke, 2019). The process involved “immersion in the data, reading, reflecting, questioning, imagining, wondering, writing, retreating, returning” (Braun & Clarke, 2021a, p. 332) until the final report was produced. Braun et al. (2022) emphasise critical questioning, which is vital for both quality and ethicality, in reflexive thematic analysis and qualitative research in general. In the analysis, both ‘empathetic’ and ‘suspicious’ interpretations were provided to clarify the meaning that is implicit and hidden in the data, respectively (Willig, 2017). Given my cultural orientation and sufficient background knowledge in the subject matter of the face-to-face interviews and FGD, I was the data coder (Campbell et al., 2013). Codes and themes generated were shared with my supervisors to ensure the dependability and confirmability of the findings. Braun and

Clarke (2019) suggest that “if more than one researcher is involved in the analytic process, the coding approach is collaborative and reflexive, designed to develop a richer more nuanced reading of the data rather than seeking a consensus on meaning” (p. 394). However, Wiltshire and Ronkainen (2021) caution about tensions that may arise in reflective thematic analysis, in which case they propose a realist approach to thematic analysis in making sense of qualitative data through experiential, inferential, and dispositional themes for richness, nuance, and consensus.

Individual case analysis and cross-case analysis (experiences of women with physical disabilities in accessing and utilising ANC services in the catchment area of the selected health facilities) were done to find out what is common across the cases and unique to each case (Stake, 2006). This analysis helped to illuminate how the context influences each woman’s individual experiences. The analysis included common themes as well as outliers, which were interrogated. The themes that were generated from the analysis are presented in the findings (Chapters Five, Six and Seven). Recommendations for improving access to and the utilisation of ANC services by women with physical disabilities emerged from the data and are presented in Chapter Eight.

4.13.1 Transcription and translation of interviews and focus group discussion

During data gathering, I ensured that I transcribed the interviews as soon as I got an opportunity because accessing electricity in the village was a challenge. After data gathering, the audios for both midwives and women were transcribed using Microsoft Word. I used virtual DJ (disc jockey) computer software to play and listen to the audios. which made it easy for me to play the audios back and forth and in slow motion to listen to and easily capture the words spoken by the participants. Immediate transcription helped me to keep track of the nuances of the conversations with the participants which would have otherwise faded with time (Cataldo & Ranson, 2015).

After transcription, the interviews with the women and the FGD were translated from the local language (Runyankore-Rukiga) into English. To ensure that I captured the true meaning of the words as spoken by the participants, I constantly consulted and cross-checked with my colleagues in my faculty at Kyambogo University who are Banyankore and well versed in the language to seek their understanding of some vernacular words within the context of my

research, especially where a word could have had more than one meaning. This is because some Runyankore-Rukiga words carry more than one meaning depending on the context. In a conversation, the true meaning of the spoken word is understood by the recipient depending on the context in which it was spoken (who has spoken the word, when it was spoken, from where it was spoken, how it was spoken, and why it was spoken or the intent of the spoken word).

Some English words also carry more than one Runyankore-Rukiga meaning depending on the context. Later, I sampled three translated transcripts and gave them to an independent person (who is a Munyankore by tribe and a third-year student of literature at Kyambogo University, and whose local language is Runyankore-Rukiga) for back translation to check and ensure that words and/or their meanings were not lost as per the original transcripts. The transcripts were given to the independent person after anonymising the participants' identities. Other transcripts with similar words were revised based on the back translated transcripts.

However, because some English words carry more than one Runyankore-Rukiga meaning, some words were translated out of context by the independent translator. Words that did not reflect the professional medical terms and reproductive and disability perspectives of women were not used. For example, the words 'disability' and 'impairment' were inaccurately translated to mean the same thing. In such cases, my original words as per the vernacular transcripts were maintained because I believe that I understood the study phenomenon and context better than the independent translator.

Throughout the whole process of transcription and translation, I ensured that the participants' words and/or sentences were not captured out of context of the study. After this process was complete, the transcripts were also shared with my supervisors. Their questions regarding the meaning of certain words led me to return to the audios, re-listen, and confirm participants' words to ensure that the written words reflected what participants had meant in their stories.

4.13.2 After listening to the recordings and reading the transcripts

Some of the things that I would have done differently: After listening to the recordings and reading the transcripts, I felt I should have talked less and allowed space for the participants to talk more during the interview. I have a feeling that my occasional

interruptions, as a way of encouraging the participants to continue talking, could have interfered with their thinking and flow of ideas. I also felt I should have considered asking for consent to make video recordings instead of audio recordings alone, especially during the FGD. This would have enabled me to record and maintain a photographic collection of the whole process without relying on my memory and field notes, and would have been very helpful in the review and analysis of the non-verbal cues during the interviews.

Quality of information obtained: Notwithstanding the “Covid-19 fear” among the health workers and the people in the community and the political situation that could have caused anxiety among participants at the time of data gathering, I felt the quality of the data collected sufficed for analysis and writing my thesis. Thankfully, I completed fieldwork with no single Covid-19 case registered in the study area. Moreover, none of my participants was actively involved in the political campaigns and the presidential elections took place shortly after data gathering was completed.

4.14 Ensuring rigour and trustworthiness

Throughout the research process, I maintained rigour and trustworthiness to ensure the good quality of the findings in this thesis. The principles of credibility, dependability, confirmability, and transferability were underscored to ensure research rigour and trustworthiness.

4.14.1 Credibility

Credibility is the extent to which the study’s findings are trustworthy and believable to others (Stalmeijer et al., 2014). During data gathering, I stayed and lived in the community for about eight weeks. Consequently, I was able to build good relationships with the study participants, community workers, health managers, and district administrative authorities, which was very significant to the research process as “building of trust is critical to indigenous community engagement” (Ohajunwa et al., 2021, p. 2).

Triangulation was employed to collect data from multiple sources (see section 4.9 above). Participants with rich information about the study topic were purposively selected. ‘Member checking’ was employed (Baxter & Jack, 2008; Jelsma & Clow, 2005; Naidu & Prose, 2018), where interpretations of the data were shared with the participants to give them an

opportunity to clarify the interpretation and contribute new or additional perspectives on the issue under study. Member checking was done during and after the primary data analysis for the participants to confirm my interpretation of the preliminary study results. Member checking was also employed during the FGD to ensure data accuracy and validity.

Participants did not make any significant changes to the preliminary results. Negative case analysis was used to challenge and question the emerging dominant patterns observed in the study (Barusch et al., 2011). In qualitative research, the transcription, translation, and back translation process is very rigorous, which helped me to ensure the credibility of the gathered data.

4.14.2 Dependability

Dependability is the extent to which the findings are consistent in relation to the contexts in which they were generated (Stalmeijer et al., 2014). Data gathering was done until no new dimensions or themes were emerging from the study. To ensure dependability, careful and reflexive consideration of when to stop data gathering was made until information power was realised (Braun & Clarke, 2021b). Information power signifies that “the more information the sample holds, relevant for the actual study, the lower number of participants is needed” (Malterud et al., 2016, p. 1759). Throughout the study process, I kept referring back to the study objectives and the theoretical frameworks to ensure that the data gathering and analysis remained within the scope of the study, and to ensure meaningful and in-depth data gathering.

4.14.3 Confirmability

To ensure confirmability, I consciously searched for data and literature that might contradict the findings (Stalmeijer et al., 2014). The issues pertaining to positionality (see Chapter One, section 1.11) and reflexivity in qualitative research were taken into consideration. I reflected back and forth on the research process and challenged my own perceptions and influence on it, in order to ensure the trustworthiness, authenticity, and good quality of the final account. Field notes and notes pertaining to personal perceptions, experiences, and decisions during the research process were recorded in a reflexive journal (e.g., see section 4.11 above and Appendix XV). These notes were regularly shared and discussed with my research supervisors and through peer debriefing with my fellow PhD students in our monthly PhD dialogues to add to the reflexive account (Marshall et al., 2010). Journaling helped to keep an

audit trail of how certain decisions and conclusions were made during the research process (Barusch et al., 2011).

4.14.4 Transferability

The transferability of a study is determined by the extent to which its findings can be compared to similar contexts (Stalmeijer et al., 2014). To ensure transferability, thick descriptions of the study context have been provided. The details about the study location (see Chapter One, sections 1.4 and 1.5) and the profiles of the study participants (see Chapter Five, section 5.2) have been provided to show the scope of this study, to ensure the reader's understanding, and to ensure that the findings can be compared to similar contexts. I ensured the gathering of detailed information from the multiple cases with different perspectives on the study topic.

4.15 Ethical considerations

In this section, issues of ethical research practice are described. The process of gaining ethical approval and Covid-19 and its effects on this study, including how these effects were addressed, are described. It was my duty to promote and safeguard the health, wellbeing, and rights of the participants by abiding by the ethical principles and standards for research as provided in the Declaration of Helsinki (World Medical Association, 2013). The ethical principles relating to qualitative research as suggested by (Jelsma & Clow, 2005) were also followed. I ensured that the principles of autonomy, beneficence, non-maleficence, and justice for research involving human subjects were adhered to. I describe each of these below.

4.15.1 Ethical approval

Ethical approval to conduct this research was sought and obtained. The research protocol was approved by:

- University of Cape Town (UCT) Faculty of Health Sciences (FHS) Human Research Ethics Committee (HREC) (HREC REF: 644/2019) on 6 December 2019 (see Appendix XVII) and subsequent yearly renewal for approval (see Appendices XVIII, XIX and XX)
- Sheema District Administrative Authority on 18 March 2020 (see Appendices VIII, IX and XXII)

- Uganda Christian University Research Ethics Committee (UCU-REC: 026) on 19 March 2020 (see Appendix XXIII)
- Uganda National Council for Science and Technology (UNCST) (Ref: SS 5262) on 30 April 2020 (see Appendix XXVI).

The guidelines for conducting research involving humans as research participants provided by UCT (UCT, 2018a) and UNCST (UNCST, 2014) were adhered to.

4.15.2 Autonomy

Participants' right to not participate or to withdraw from the study at any stage without giving reasons was explicitly communicated to them throughout the study. All the women with physical difficulties within the given scope of this study were able to make their own informed decisions. In consultation with the ANC clinic managers, midwives were identified from the health workers deployment list. To ensure that there was no coercion, and no pressure based on performance review or promotion in the future, I approached those identified individually to determine their knowledge and experience in attending to pregnant women with physical disabilities and to seek their consent to participate in the study. I explained to them that they were selected based on their experience in ANC practice, that it was voluntary to participate in this study, and that their decision (to participate or not) would be respected.

4.15.3 Covid-19 pandemic and ethical implications

On 17 March 2020, the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee (HREC) issued a notice on recommendations for research studies and research sites involving humans to minimise the risk of transmission of Covid-19 (see Appendix XXI). This required all non-therapeutic research involving human participants to be stopped. This directly affected my study.

While I was awaiting Uganda National Council for Science and Technology (UNCST) approval to commence data gathering, a strict lockdown was imposed in Uganda on 18 March 2020 and the first case of Covid-19 was registered on 21 March 2020. The lockdown affected the movement and gathering of people and significantly reduced public services. This was followed by UNCST encouraging researchers to suspend recruitment of new study

participants, on 27 March 2020 (see Appendix XXIV). This suspension was lifted on 4 June 2020 (see Appendix XXV). UNCST approval for this study was granted on 24 July 2020 subject to my submission of a Covid-19 transmission Risk Management Plan (RMP). The horizontal timeline below (Table 4.1) shows the multiplicity of approvals that were required, and the various restrictions imposed and lifted at different times from December 2019 to October 2020.

Table 4.1: Timelines for research approvals/restrictions

<i>Approvals/restrictions at different times</i>										
SA/ UCT approvals/ restrictions	UCT approval	X								
	Research restrictions imposed in South Africa		X							
	UCT approval to reopen the study									X
<i>Timelines</i>		06 Dec 2019	17 Mar 2020	18 Mar 2020	19 Mar 2020	27 Mar 2020	4 June 2020	24 July 2020	21 Sept 2020	28 Oct 2020
Sheema/ UCU/ UNCST approvals/ restrictions	Sheema approval			X						
	UCU approval				X					
	Research restrictions imposed in Uganda					X				
	Research restrictions lifted						X			
	UNCST Approval							X		
	RMP approval								X	

The Covid-19 restrictions and suspensions had profound implications for the planned research, requiring a delay in commencing fieldwork and data collection so that neither the participants, the researcher, nor their families would be exposed to harm or increased risk of transmission. In conjunction with my supervisors, I considered the ethical implications and practical challenges of engaging with my planned fieldwork (see Appendix XVI). I developed a RMP for the prevention of transmission of Covid-19, which was approved by the Uganda Christian University Research Ethics Committee (UCU REC) on 21 September 2020 (see Appendix XXVII). This became part of my detailed motivation to the UCT HREC for lifting the suspension on this research so that I could commence data gathering. This approval was granted on 28 October 2020 (see Appendix XXVIII). I then had to prepare myself to protect my study participants by entering self-quarantine at home for two weeks before travelling 400km alone in a private vehicle to reduce the possibility of being exposed to the

virus. Thus, I was only able to commence my data gathering in mid-November 2020, instead of the anticipated March 2020.

At the start of my fieldwork, I travelled from Kampala city (where I reside) to the field (in Sheema district) on 16 November 2020 and returned to Kampala on 12 January 2021. The fieldwork took place during a single (intensive) two-month visit to the field when all data gathering was done. This was a departure from the original plan (in order to reduce the potential transmission of Covid-19 with repeated visits from Kampala to Sheema district) where I would have visited for two periods. In between visits, I would have been able to start the transcribing and translation. I learnt that during a pandemic such as Covid-19, the smallest move or tweaked idea could go a long way in ensuring the principles of non-maleficence and beneficence in the research process. During the period of data gathering, I submitted a total of four reports every two weeks to UCT HREC¹⁴.

4.15.4 Informed consent

The research information sheets (see Appendices X, XI and XII) were developed in clear and straightforward non-technical language with detailed descriptions of participants' role, study benefits, and potential risks of being involved. I speak the same local language as the participants and ensured that the information sheet was explained in the local language for the participants who did not know English. I contacted and approached those willing in order to discuss the research information sheet and their motivation to participate. All participants were approached with respect and honour. Their consent to participate in the study was solicited and no woman with physical disability or health worker was coerced, induced, or deceived to participate in the study.

All participants were informed about their rights. Participants were informed of their right to ask the researcher questions about anything they did not understand or if they needed more information. Each participant was given an opportunity to talk about the study with their midwife, nurse or doctor, trusted friends, husband/partner, or any family member of their choice, if they wished. The contact number of the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee Chairperson (+27 (0) 21 406 6496) was

¹⁴ The bi-weekly reporting post-recruitment related to monitoring the Covid-19 transmission and the assessment of any change in the risk for fieldwork.

provided in case participants had any questions regarding their rights and welfare as research subjects in the study. If a participant still agreed to take part in the study, informed consent was obtained. Arrangements were made with the participant for the face-to-face interview and FGD date and location. Only participants who were capable and willing to provide informed consent (see Appendices XIII and XIV) were selected.

Written consent from the women with physical disabilities was sought and obtained. Moreover, in case it was needed, I was prepared to receive and accept verbal consent¹⁵ from those uncomfortable with signing the consent forms (Nuwagaba & Rule, 2015), which was approved by HREC. In such cases, an audio digital recording of their verbal consent and interviews would have been sought and obtained. I would have then made a statement and signed and dated it as paper trail for any future audit of this study. However, a case such as this did not arise as all participants consented by appending their signatures or thumb prints.

4.15.5 Confidentiality and privacy

Confidentiality was ensured throughout the study, including confidentiality about the mothers' disabilities and other health information. Participants' privacy was ensured by replacing their names with pseudonyms and the link to the pseudonyms was kept secure. The use of pseudonyms ensured the anonymity of the women's identity, and participants were given an opportunity to choose their own pseudonyms. Some women who were not sure of which pseudonym to use were guided with options until an appropriate pseudonym was identified and selected. Safe and comfortable spaces – at the participants' homes, in their gardens, or at a health facility – for the interviews and FGD were identified together with the participants to ensure their privacy. They were informed that taking part in the FGD may involve some loss of privacy¹⁶. All the participants' information was securely kept in a safe place. As part of the information given to them before agreeing to participate, participants were asked not to disclose what was discussed in the FGD. The scribe who took notes during the FGD signed a confidentiality agreement not to disclose participants' private information.

¹⁵ Insisting that participants should sign may seem paternalistic, infringing on their autonomy (Lahman et al., 2015). In a Ugandan context, in some cases, the requirement of signatures may denote suspicion and a lack of trust because a person is usually requested to sign if it is thought that he or she is untrustworthy and may deny what has been agreed (Nuwagaba & Rule, 2015).

¹⁶ I am a Medical Clinical practitioner and therefore employed my knowledge, skills, and expertise to observe and maintain the confidentiality, privacy, and dignity of the participants.

No one could access the information kept in my computer because it is protected with a password which is only known to me.

4.15.6 Beneficence

The term beneficence goes beyond protecting participants from harm and respecting their decisions to making efforts to secure their wellbeing, including the researcher's acts of kindness and charity (United States National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). For example, after an interview, I offered to help and transport a sack of millet in my car for one of the women with physical disabilities, from the garden where the interview was conducted to her home.

Another example was during my interaction with Joyce (pseudonym), when she expressed that she needed to use family planning methods but was worried about the possible side effects. I liaised with one of the midwives at one of the ANC clinics, and I encouraged Joyce and referred her to the health facility for family planning counselling services, where she was helped.

Research must also be evaluated on the basis of its relevance to the profession and its potential impact on social justice (Barusch et al., 2011). Importantly, participants' views and experiences were paramount in formulating strategies for improving the access to and utilisation of ANC services. The findings of this study helped in formulating a framework and recommendations for the health managers, policy makers, midwives and other health workers, and community workers to advocate for and design disability inclusive ANC services. Using this framework will contribute to improving pregnancy experiences for women with physical disabilities in Uganda.

4.15.7 Non-maleficence

Efforts were made to ensure that all participants did not suffer any harm. The risks and burdens to the participants were continuously monitored, assessed, and documented. This study focuses on women with physical disabilities who have been defined as a vulnerable group. Therefore, careful consideration was made to ensure their welfare and safety. This research touches on disability and reproductive health, which are personal issues. This could have caused distress to the women with physical disabilities or their significant others. I

employed my medical ethics as a Medical Clinician and I utilised the experience and expertise of my research supervisors in Nursing and Midwifery and in Disabilities Studies to ensure that no participant suffered any harm. I ensured that all the women with physical disabilities were protected from any harm and none of them suffered any harm arising from this research process.

No cases of rape, sexual abuse, or non-consensual sex were reported during the interviews. If such an incident had been reported, and the participant had been willing to lay charges, she would have been supported to disclose it to a trusted friend/family member if she could or to a social worker so that she could be supported through this process. If a woman with physical disability in the study had experienced rape, sexual abuse, or non-consensual sex, she would have been provided with psychosocial support. I was cognisant of the possible vulnerability experienced by the women with physical disabilities in opening up about their disability and sharing their experiences on their reproductive health to contribute to this research.

4.15.8 Reimbursement

I covered the transport costs for the women with physical disabilities to and from the venue where the FGD was held, and refreshments were provided during the FGD.

4.15.9 Justice

Justice was upheld through the fair selection of participants based on their experience of the issue under study, and their ability and willingness to participate. Power gradients between me and the participants were flattened by intentionally developing a friendly relational atmosphere to allow them to freely exercise choice regarding their continued involvement in the study (Jelsma & Clow, 2005). I took time to build rapport with the participants through open and sincere communication, and by using the language (English or Runyankore-Rukiga) spoken and understood by the participants. I am an academic and declared no conflict of interest in this research.

This study followed the WHO key universal ethical standards that were published to guide researchers in conducting research during the Covid-19 pandemic (WHO, 2020a). Among the stipulated standards is reasonable risk-benefit-ratio. I continuously assessed the Covid-19 situation in Uganda and ensured that I did not put participants and myself at risk. The study

also followed the UCT FHS HREC recommendations on minimising the risk of transmission of Covid-19 at research sites and in the context of research studies involving human participants (UCT, 2020a), and the guidelines for registration and clearance, including the resumption of research activities during the Covid-19 pandemic in Uganda (UNCST, 2020b, 2020a).

4.16 Conclusion

In this chapter, I have explained the methodological approach I employed in this study. My research philosophy as a social constructivist and the theoretical frameworks underpinning this study guided the choice of the study approach. A multiple case study design was used within an interpretive qualitative approach to understand the lived experiences of pregnant women with physical disabilities in accessing and utilising ANC services. The identification of participants, study population, sampling strategy and sample size, recruitment process, data gathering methods, and data analysis have been described, highlighting my personal critical reflections. While there are other health workers involved in ANC services for pregnant women with physical disabilities, midwives as the key ANC providers (ICM, 2021) were chosen.

Throughout the research process, I was mindful of the ethical considerations and their implications for this study. Ethical approval to conduct this study was sought and obtained, and the principles of credibility, dependability, confirmability, and transferability were underscored to ensure research rigour and trustworthiness. I have described how I was cognisant of the participants' right to autonomy, informed consent, confidentiality, privacy, beneficence, non-maleficence, and justice. The ethical dilemmas I encountered were effectively addressed, presenting learning opportunities for me at every encounter, which I discuss in Chapter Eight, section 8.6.1. In the next chapters, I present and discuss the study findings to extrapolate pregnant women with physical disabilities' experiences in accessing and utilising ANC services.

CHAPTER 5:

INFLUENCES ON ACCESSING ANTENATAL CARE

SERVICES:

FINDINGS AND DISCUSSION PART 1

5.1 Introduction

The aim of this study was to investigate the experiences of pregnant women with physical disabilities in accessing and utilising ANC services in rural south-western Uganda. In this chapter, participants' profiles are presented to provide the contextual background for the analyses that follow in this chapter and the next chapters of this thesis. This chapter also presents the findings and discussion regarding the first objective of this study:

- to describe the accessibility of ANC services for pregnant women with physical disabilities in rural south-western Uganda.

Data gleaned from the women and midwives were analysed to illuminate the enablers and barriers to accessing ANC services for pregnant women with physical disabilities. The findings are in the context of women's decision to seek ANC services and then identifying and reaching an appropriate health facility. Influences emerged as the overarching theme, which is divided into two themes. The first theme, 'optimising wellbeing', focuses on enablers in accessing ANC services, and the second theme, 'undermining wellbeing', is centred on barriers.

Under each category, women's voices are presented first and then midwives', to contextualise women's perspectives. Any convergence or divergence in their opinions and perceptions will be further analysed in the discussion section that follows.

5.2 Summary of participant profiles and influences on accessing ANC services

Tables 5.1 and 5.2 summarise the profiles of the women with physical disabilities and the midwives who participated in the study, and Figure 5.1 presents the influences for the women in accessing ANC services.

Table 5.1: Demographic characteristics of women with physical disabilities

Woman	Age (years)	Nature of physical impairment	Level of education	Marital status	Gravida¹⁷ & Para¹⁸	No. of children	Occupation	Religion
Eva	36	Stiff right hip joint	Primary 5	Married	Para 2	Two	Tailor & peasant farmer	Muslim
Esther	28	Weak hip joint	Primary 7	Single	Para 1	One	Tailor	Catholic
Mary	27	Stiff left hip joint	Senior 4	Married	Gravida 3, Para 2	Two	Peasant farmer	Catholic
Joy	21	Swollen right leg	Primary 6	Married	Gravida 2, Para 1	None	Peasant farmer	Catholic
Jolly	34	Right hemi-paralysis	Primary 7	Single	Para 2	Three	Tailor & peasant farmer	Protestant
Joyce	40	Weak hip joint	Primary 1	Married	Para 6	Six	Peasant farmer	Protestant
Happy	18	Right knee joint bent inwards	Primary 6	Married	Para 1	One	Peasant farmer	Protestant
Grace	26	Stiff left knee joint	Primary 7	Married	Para 3	Three	Peasant farmer	Pentecostal
Mercy	30	Left knee & ankle joint bent outwards	Primary 2	Married	Para 2	Two	Peasant farmer	Pentecostal
Philly	35	Right hemi-paralysis	Senior 4	Separated	Para 4	Four	None	Pentecostal
Kate	34	Right lower limb shorter than left	Primary 7	Married	Para 3	Three	Weaving & peasant farmer	Catholic
Hope	28	Weak hip & Knee joints	Primary 7	Married	Para 3	Three	Hairdresser & peasant farmer	Protestant

Although I had planned to include women with physical disabilities who were pregnant or had ever been pregnant and had attended ANC as well as those who had not, I did not find anyone who had not attended ANC. All the women that were identified had attended ANC despite the obstacles presented in this chapter and the subsequent chapters. The nearest health facility and/or the place where women had received their ANC during their previous or current pregnancy was also considered.

¹⁷ Gravida is derived from the term gravidity which means the number of times she has been pregnant, regardless of the pregnancy outcome. In the case of a multiple gestation, it is counted as 1 pregnancy.

¹⁸ Para is from the term parity which indicates the number of times a woman has given birth to a fetus of a viable gestational age (24 weeks), including livebirths and stillbirths. A multiple pregnancy carried to a viable gestation is counted as 1 birth (Colin, 2019).

Table 5.2: Demographic characteristics of midwives

Midwife	Age (years)	Level of education	No. of years in practice	Marital status	No. of children	Religion	Tribe
Midwife 1	28	Certificate	Six	Married	One	Catholic	Munyankore
Midwife 2	31	Diploma	Eight	Divorced	Two	Protestant	Munyankore
Midwife 3	34	Diploma	Twelve	Married	Two	Catholic	Munyankore
Midwife 4	33	Diploma	Four	Married	Two	Protestant	Munyankore
Midwife 5	50	Diploma	Twenty-one	Married	Three	Catholic	Munyankore
Midwife 6	40	Bachelor's Degree	Twenty	Married	Four	Muslim	Munyankore

Figure 5.1 below illustrates the categories, subthemes, and themes regarding the influences on accessing ANC services for pregnant women with physical disabilities.

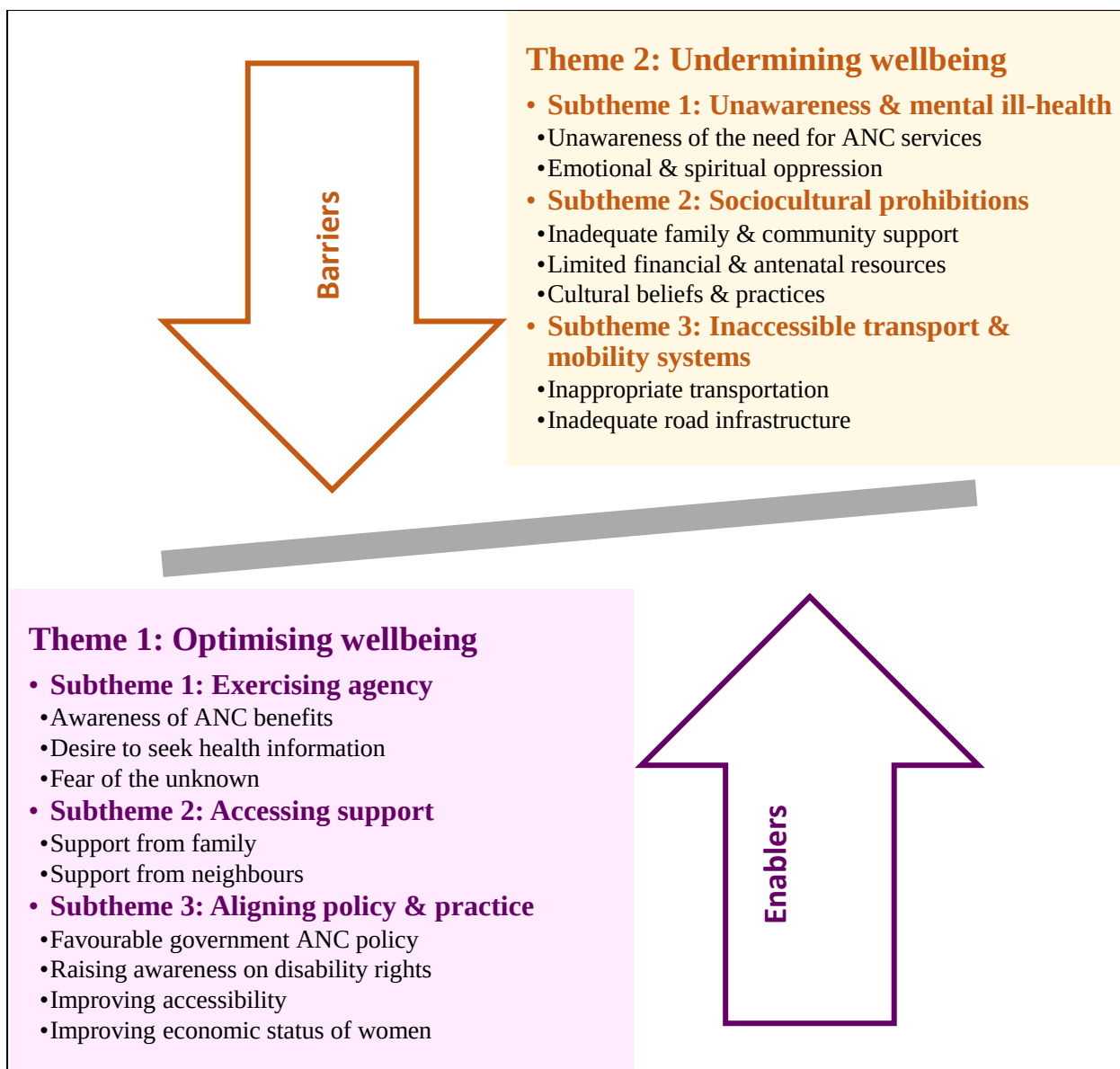
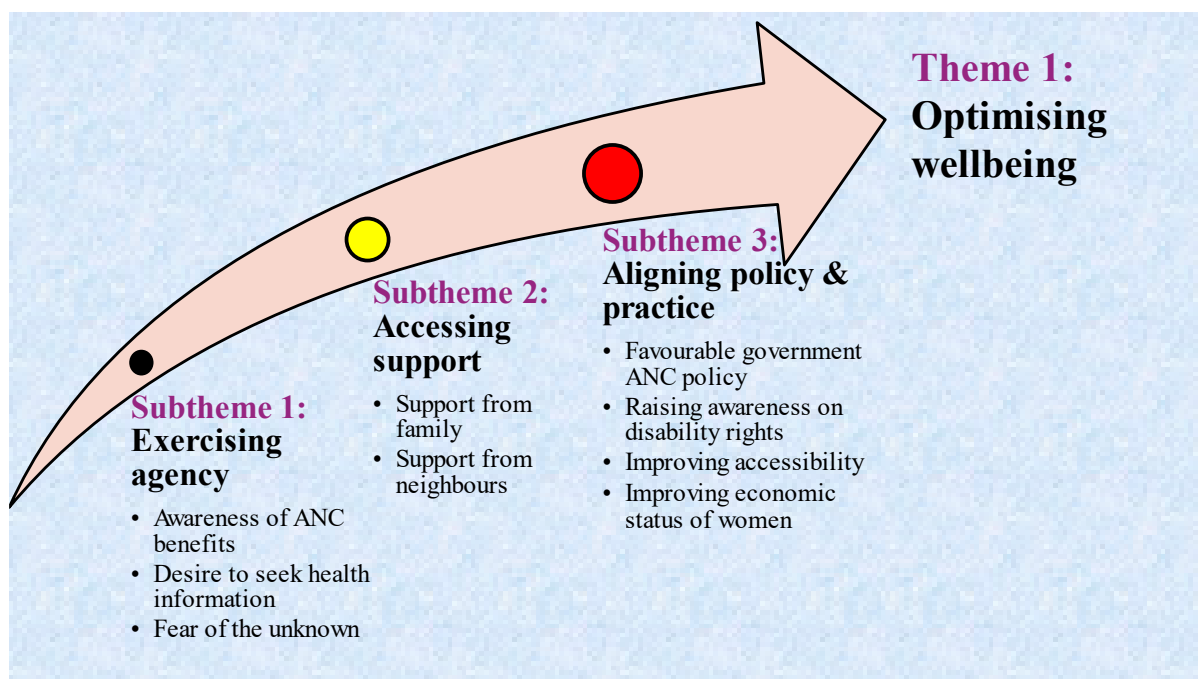


Figure 5.1: Influences on accessing ANC services for women with physical disabilities

While each theme has three subthemes, the imbalance in the figure above implies that participants highlighted more barriers than enablers, as will be seen in their descriptive accounts below.

5.3 Theme 1: Optimising wellbeing – Enablers in accessing ANC services

This theme highlights the enablers in accessing ANC services, which are illustrated in Figure 5.2 below.



5.3.1.1 Figure 5.2: Optimising wellbeing – Enablers in accessing ANC services for women with physical disabilities

5.3.1 Subtheme 1: Exercising agency

A key concept that emerged from the data is ‘exercising agency’ in seeking ANC services. Exercising agency was influenced by women’s awareness of ANC benefits, desire to seek health information, and fear of the unknown. Both women and midwives described awareness of ANC benefits and fear of the unknown, while desire to seek health information was mentioned by women only.

5.3.1.1 Awareness of ANC benefits

Most women were aware of the ANC benefits and attended ANC at different health facilities. Unlike in the past, women today are exposed to ANC and were aware of its benefits.

“... [to attend ANC], she would be knowing the benefit [of ANC] from the health facility” (Philly).

They demonstrated that they would rather seek ANC services from a qualified health worker than from a traditional birth attendant (TBA) because “... they [health workers] are the ones who know about a person’s health” (Esther). Joyce commented that she completed all the

required eight ANC visits because she was aware of her physical impairment and could not afford to miss the benefits accrued from each ANC contact. She noted:

“... by the time I attended antenatal care eight times, I was aware of my situation”.

Midwives suggested that awareness of ANC services and their benefits influenced women to seek ANC services. They attributed this awareness to the sensitisation on ANC services, which they carry out in the communities.

“...we do community mobilisation and sensitisation ... we also talk to them when we go for immunisation out reaches” (Midwife 6).

They also noted that some women may be influenced by their mothers to seek ANC services but *“if the mother is not informed [about ANC and its benefits], she is not going to bring that mother here, she will remain there”* (Midwife 3).

5.3.1.2 Desire to seek health information

Women desired information about their pregnancy. They sought ANC services to find out from health workers if they had health conditions that would affect their pregnancy. Some women suggested they were influenced by the desire to seek health information on their HIV status. Some women remarked:

“... we should be examined [when pregnant] and be told the situation [health condition] in which we are” (Joyce).

“The first thing I wanted to know was whether I was HIV positive. That was the first thing in my mind” (Mary).

Women were motivated to seek ANC services because they needed to know the cause of their physical pain during pregnancy. They also had desire for information and a general understanding about conception and pregnancy. They needed to know about physical and physiological changes one would expect when pregnant.

“I wanted to know if there were some bones that got damaged! Because I started feeling pain when I became pregnant. I wanted to know; did I get somehow damaged in the inside parts?” (Hope).

“I wanted to know; a person who gets pregnant; how does she become pregnant! How does she feel! How does she carry it [the pregnancy] and finally give birth!” (Esther).

They were also eager to find out the health status of their unborn baby. Position and presentation of the unborn baby in their womb was a concern for most of them. The common motivation that emerged from the data comparison was that women sought ANC to understand how to prevent HIV from being transmitted to their unborn baby, in case they were found to be HIV positive themselves. They sought ANC to understand how their health situation, including their physical impairment, would impact on the health of their unborn baby.

“... you want to know how you are and how to give birth to a healthy baby, especially for the first born. ... for me I did not think that the baby was alive inside. I would think that what if the baby is also having a disability!” (Eva).

5.3.1.3 Fear of the unknown

Fear of the unknown emerged as a motivator for seeking ANC services. Women feared complications that would be associated with their pregnancy and childbirth. There are always uncertainties during pregnancy and childbirth, hence *“... you help yourself and you go early so that they [health workers] also get where to start from [in case of any complications]”* (Esther). There was a sense among some women that due to their physical impairment, their pelvic cavities were inadequate and they had high chances of undergoing a caesarean section, hence the need to seek ANC. Jolly indicated that she was informed by the health workers that she would not be allowed to push the baby out because of her impaired pelvis. Another woman noted:

Giving birth would been the same but the women with physical disabilities should go to the hospital for antenatal care because you may not know what kind of impairment you have! Some women who are not disabled, give birth from villages, but for you,

you may say to yourself that, 'I am disabled, who will help me if I give birth from the village!' (Hope)

They also expressed fear of public opinion. They emphasised that they fear being accused by the community of not seeking ANC in case they get complications during pregnancy or childbirth. They sought ANC services from health professionals so that if they died, people would appreciate that the death was inevitable and not as a result of their own negligence. One woman remarked:

“... if by accident you die, people will say that she has died from a health facility. ... It would be helpful for one to go to the health facility” (Joyce).

They also reported a fear of being reprimanded by health workers, including being scolded and embarrassed, especially at the time of giving birth, for not seeking ANC services, and in time. Jolly reported that they go for ANC to ensure that they “*acquire an ANC card as evidence*” for having attended ANC.

Midwives emphasised that fear of the unknown motivates women to seek ANC services. Women feared being reprimanded by health workers for not seeking or delaying seeking ANC services.

“... they come for ANC so that when they come to deliver, health workers do not scold or chase them [away]” (Midwife 3).

5.3.2 Subtheme 2: Accessing support

Accessing support from family and neighbours was highlighted as an influencer for women with physical disabilities in accessing ANC services. Family as a source of support was expressed by both women and midwives, and support from neighbours was expressed by the women only.

Figure 5.3 below summarises the sources of support for women with physical disabilities during pregnancy.

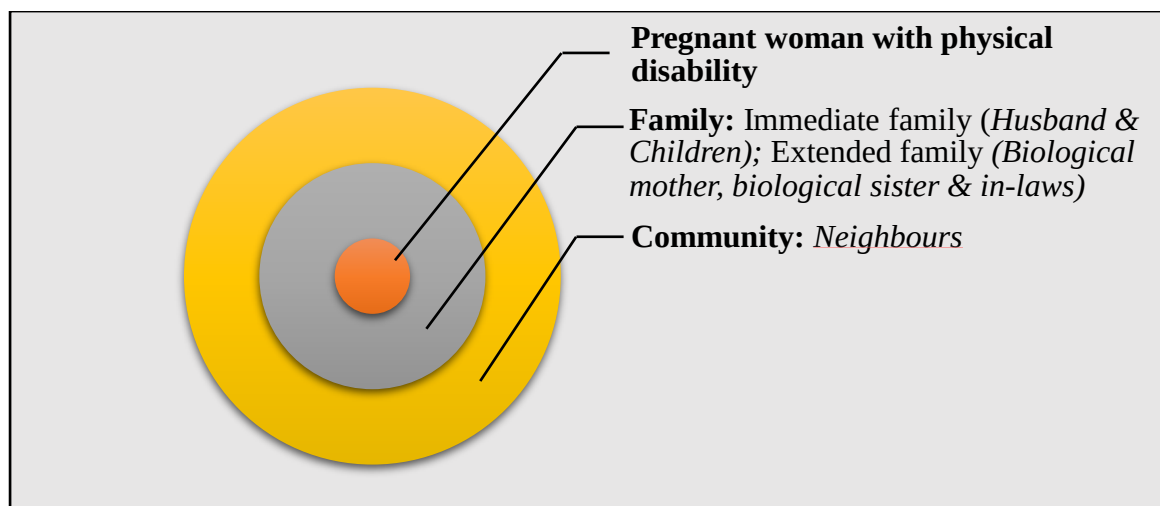


Figure 5.3: Sources of support for women with physical disabilities during pregnancy

5.3.2.1 Support from family

Some women indicated that their husbands and children supported them in accessing ANC services, especially in providing money for transport and carrying out daily activities respectively:

“It’s my husband who helped me ... and he was the one giving me transport. He would take me to the health centre, I get the antenatal care and then he would bring me back” (Hope).

“... I had my boy I was going with; he is 14 years old. The boy would support me. Even during the process of giving birth, I was with that boy” (Joyce).

Women’s biological mothers were identified as key providers of care and support. During pregnancy, especially in the late stages, women go to their biological mothers’ homes for personal assistance in carrying out daily activities as well as for material and financial support. Biological mothers were considered non-judgmental about the woman’s physical disability and her sexuality. Additionally, they go to their parents’ homes to seek care from their blood relatives, especially their sisters. One woman explained:

I left and went to the village to my mother’s place. It is like I was remaining with only one month [to give birth]. ... When I realised that I had failed [was physically weak], I called my mother. So, he [husband] said that I go home, and I come back when I finish

giving birth. I decided to go back home and said that when I finish giving birth, you will see me coming back. (Mercy)

Midwives noted that husbands play a major role in the care and support of pregnant women with physical disabilities. They provide financial support and personal assistance to their pregnant wives with disabilities, especially during travel to and from the health facility and in carrying out daily activities. Midwife 5 revealed that the type of support provided during travel depends on the mode of transport used. To put this into perspective, Midwife 6 explained:

She would come with the husband because she would not manage to lift herself from the floor to sit on those benches of ours outside and so the husband would be here to help her. ... of course, they rely on their husbands for their support, their husbands are their feet to the facilities’.

They also identified the biological mothers of pregnant women with physical disabilities and in-laws as common sources of support. Some midwives noted:

“... she had an attendant ... who was her [biological] mother” (Midwife 3).

“She was always escorted by her sister-in-law, because she said, ‘I am staying with her, and she is helping me’” (Midwife 5).

5.3.2.2 Support from neighbours

Neighbours of pregnant women with physical disabilities are influential in encouraging and supporting them to access ANC services. Neighbours and their children supported these women in carrying out domestic activities. In their accounts of events surrounding the neighbours’ support, women shared that neighbours who appreciated their disability challenges were supportive. One woman recounted:

The neighbours would help me on things to do with fetching water from the well, washing clothes and plates, mopping the house and others. For me to survive, it was

because of them. ...they would reduce on the challenges that I would have encountered. They understood my condition [physical disability] very fast. (Esther)

5.3.3 Subtheme 3: Aligning policy and practice

Under this subtheme, favourable government ANC policy, raising awareness on disability rights, and improving accessibility and economic status of women were identified as enablers in accessing ANC services. All the categories were expressed by both women and midwives.

5.3.3.1 Favourable government antenatal care policy

Women's views point to the influence of a favourable government ANC policy. Some women felt that the government has instilled a sense of responsibility for them to prevent mother-to-child transmission of HIV during pregnancy and childbirth. Seeking ANC services would go a long way in providing the required interventions, in case the mother was found to be HIV positive. They felt that not going for ANC, especially for the unborn baby's health, is against the law. They had to seek ANC services to give the health workers an opportunity to evaluate for any health risks to them or their unborn babies. Mary remarked:

“Okay, it is like a law put by the government. You must go to the health facility so that they first check you, they first see if you have HIV ...so that they protect the baby that you are having”.

Midwives reported that some women with physical disabilities were influenced by village health teams (VHTs) to seek ANC services. VHTs are usually in touch with the community and can easily identify, counsel, and refer pregnant women with physical disabilities. One midwife reported:

“TBAs have also reduced in communities. What the government did was to train most of those TBAs to be VHTs. So, they know how to refer. Most TBAs are working as VHTs, they no longer do that work [ANC] in their villages. What they do, they refer” (Midwife 4).

5.3.3.2 Raising awareness on disability rights

Women indicated that there is a need to raise awareness on the rights of women with physical

disabilities, including their sexual and reproductive health rights, the challenges they encounter as they try to participate in community development activities, and that the community's need to support them. They suggested that community members should be considerate and sympathetic to pregnant women with physical disabilities. *"Honestly, why can't they sympathise with us?"* (Jolly). Another woman noted:

...because when you educate [sensitise] the disabled people, they won't educate a person with his/her arms and two legs [non-disabled] and they listen to them. So, you [the researcher and people in authority], must educate non-disabled people on how they should treat a pregnant woman [with physical disability]. But if you don't educate them, for us we shall always be marginalised. (Esther)

However, some women observed that there is also a need to raise awareness among women with physical disabilities on creating positive interpersonal relationships with community members. They indicated that sometimes their fellow pregnant women with physical disabilities are impolite and disrespectful towards people without disabilities. They noted that there is a need for reciprocity in the relationship between pregnant women with physical disabilities and non-disabled people. One woman commented:

"For me I think what would be right is that people with disabilities should also behave well. She may be a person with a physical disability but behaving badly [disrespectful and rude to other people]. So, some don't have any manners" (Philly).

Midwives pointed out the need to empower women with physical disabilities by giving them information regarding ANC services and their right to access these services. Midwife 3 noted:

"For me I think what can be done to help them, first of all is to empower them. By empowering them, first they must get all the information on their rights".

However, Midwife 5 noted that women with physical disabilities are already empowered, and they know their rights, although she was quick to add that mobilisation and sensitisation on their rights should continue within the general public so as to enhance their access to ANC services. Family members of women with physical disabilities should be targeted for sensitisation.

“...We need to talk to those people in their homestead to take them as other human beings [equal rights holders]” (Midwife 5).

5.3.3.3 Improving accessibility

Women indicated that they use *boda bodas*¹⁹ to access ANC services because they are cheap compared to using a car, can be easily accessed from home, and make it easy for one to arrive on time for the ANC appointment. However, they revealed that there are challenges in using a *boda boda* (see section 5.3.3 below).

To manage the *boda boda* challenges, some women chose to use riders who understand physical disability challenges. Having a friend who is a *boda boda* rider was very helpful, especially when labour starts unexpectedly or when they do not have money for transport at the time of their ANC appointment. These riders would support them in climbing onto and getting off the *boda boda*. During the ride, they used the rider as support to avoid falling off the *boda boda*. Riders from their villages understood their challenges better than those from distant villages and could reduce transport charges for them. Philly recounted:

I would look for a motorcycle and it would take me, and the person taking me was only one because I don't want any other person to take me. He would take me well because I was weak. I would use only one arm; I hold him tightly so that I don't fall off. If he is a bad person, he may refuse or he may not come back the next time. Another boda boda person may say that 'okay, you are holding me, what do you want eh?' But the one that you know would be knowing your problem.

As a way of improving accessibility, some women temporarily relocated closer to the health facilities or were admitted early and stayed on the ward for monitoring by the health workers in preparation for childbirth. Likewise, when identifying health facilities, they preferred those closer to home where they could access support and care from their family members and other relatives.

¹⁹ *Boda boda* is a local name for the motorcycle taxi commonly used in towns and trading centres in the rural areas for carrying people and goods in Uganda and other parts of East Africa.

“... I decided to stay the other side. So, when the ANC appointment date would reach, I would just walk to the health facility” (Esther).

“We went early. We stayed there, time of giving birth found us there. We spent there a full month!” (Mercy).

“It becomes easy for them to come and see me and bringing me some food” (Hope).

They also revealed that the existence of more ANC outreaches would improve their access to ANC services. They reported that there is a need for ANC services to be extended to the villages where they live as they may be unable to access the health facilities.

“Those that can’t reach [the health facility], they should get a particular period and send them health workers in the village. They find them in the village, and they examine them from there” (Eva).

Women indicated that the availability of adequate money for transport improves their capacity to access transport to and from the health facility. They would be able to discuss their own terms before and during travel with the *boda boda* rider. They reported that having adequate money reduces their anxiety as they would be sure of not missing their ANC appointments. Joy pointed out that as soon as she returned from the health facility, she would inform her husband of the date for her next ANC appointment to adequately prepare money for her transport. Other women commented:

“... but if you have money, you tell him not to add another person, and you comfortably sit on your boda boda. ...in Uganda, now, everything is money” (Joyce).

“It’s about your pocket. I tell you that take me slowly, I am going to pay you; you’ve not taken me for free. Ah, if he refuses and he rides fast, you get off his motorcycle” (Hope).

They suggested the provision of free transportation for pregnant women with physical disabilities to and from the health facility during ANC as a strategy for improving their accessibility. Since the health workers knew the women’s appointment dates and where they live, it would be easier for the health facility authorities to send a vehicle to their homes to

transport them to and from the health facilities. Eva noted:

Health workers need to be aware that in a particular village, there are pregnant women When you leave the health facility, you would be knowing the time you would be going back. You would have told them where you live and then they send you the vehicle for transport.

Similarly, midwives suggested that there is a need for a special ANC outreach programme for pregnant women with physical disabilities. They indicated that such a programme could be effectively implemented in liaison with the VHTs (see also Chapter Six, 6.4.3) as they are mandated to have a record of pregnant women, including those with physical disabilities, in their catchment areas. One midwife commented:

“There can be a special programme for these people [women] that reaches out to where they are coming from, may be that can work. ...the team can go there and provide services from there” (Midwife 4).

Midwives agreed with the women’s view of providing free transportation to and from the health facilities to pregnant women with physical disabilities. They suggested that this could be done by identifying the women through VHTs and providing money or a vehicle for transport. Midwife 6 noted:

...once the VHT notifies any staff in antenatal clinic that we have a mother who needs antenatal care, the staff notifies the administration and then maybe they give you money to send to them or they give an ambulance, they can put any provision may be a motorcycle to go and bring them to the facility, they work on them and then they take them back. I wish that is done.

They reported that due to transport barriers (see section 4.3.3 of this chapter), they advise pregnant women with physical disabilities go to the health facility early and stay on the ward, especially in their late stages of pregnancy, to improve accessibility to ANC services.

“Good enough those mothers normally come early and wait from here at the hospital” (Midwife 6).

“...we always ask them to wait from the hospital. We advise her to prepare herself to come early and keep around here” (Midwife 2).

5.3.3.4 Improving economic status of women with physical disabilities

Women suggested that pooling funds together to form a group²⁰ would go a long way in improving their financial status. Improving their economic status increases their capacity to address their needs during pregnancy. Esther observed:

They should start for them a group [a savings group] as ‘abakazi abarema’ [disabled women], put for them a fund from which they can always pick [access money during pregnancy] ... now if you have a group as disabled people and we have been putting [saving] in it depending on how much the government had put in for us; there is when you can help yourself and do a small job, bring some money and you put in your group, adding on the other fund from the government.

They indicated that they needed income-generating activities. These activities reduce their dependency on others for financial support. They noted that it is better to have financial support before they get pregnant so that they can use it to generate their own income than receiving such support only once they are already pregnant. Hope observed:

“You don’t have to get a problem first to get help extended to you so that you support yourself. I was requesting that they give us aid as disabled people who can’t help ourselves because they can’t give us help every time, we get pregnant. ...If I am working, I am sure that I will get my money to give to the boda boda rider to take me to the health facility for antenatal care. That’s what would have been good.”

Midwives noted that there is a need to support women with physical disabilities to start income-generating activities. They suggested that training these women in vocational skills would enable them to support themselves. The training empowers them and reduces their dependency on others for financial support. Midwife 5 commented:

²⁰ Such a group where women pool funds together is commonly referred to as Savings and Credit Cooperative Organisation (SACCO).

If they can help them to earn some living, it would be very good because with money you are empowered.... They are good [can perform] when they are trained because the brain is working though they have a [physical] disability. The thing is, they are not unable; disability is not inability.

5.4 Theme 2: Undermining wellbeing – Barriers to accessing ANC services

Barriers to accessing ANC services led to the theme of undermining wellbeing. The subthemes of mental ill-health, socio-cultural prohibitions, and inaccessible transport and mobility systems contribute to this theme. These are presented and illustrated with their respective subthemes in Figure 5.4 below.

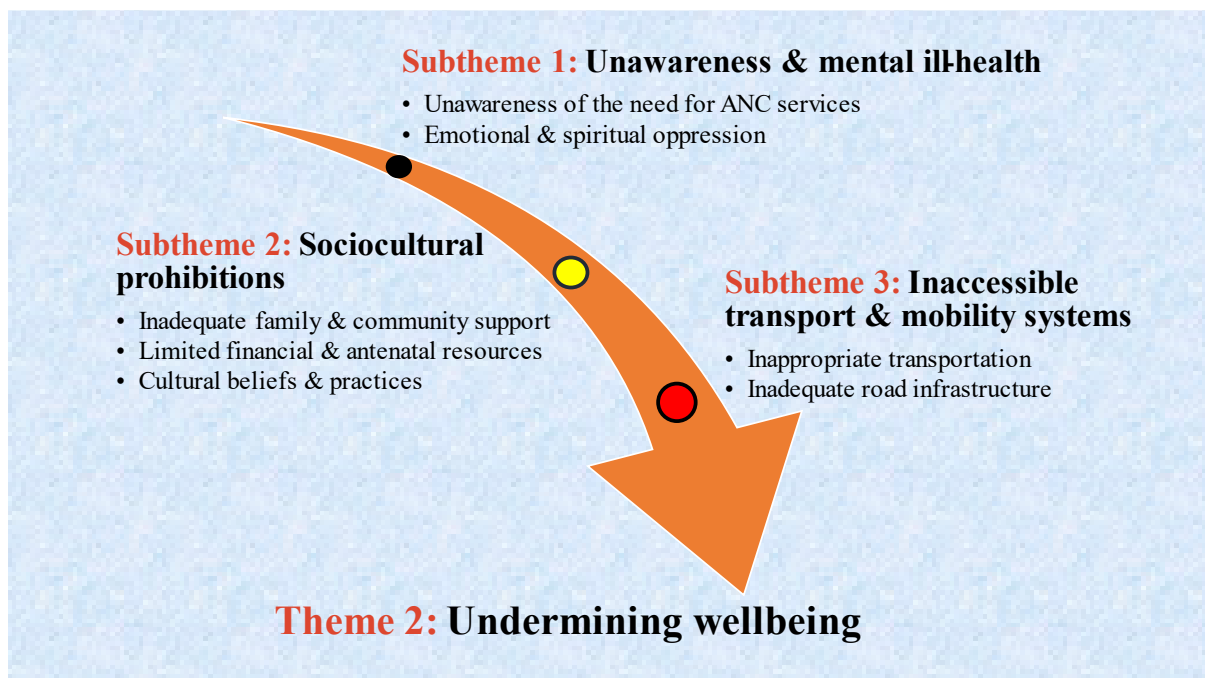


Figure 5.4: Undermining wellbeing – Barriers to accessing ANC services for women with physical disabilities

5.4.1 Subtheme 1: Unawareness and mental ill-health

The subtheme ‘Unawareness and mental ill-health’ emphasises factors that undermine women’s wellbeing, impeding their access to ANC services. Both women and midwives alluded to the categories described hereunder.

5.4.1.1 Unawareness of the need for antenatal care services

Women's unawareness of their need for ANC services was a barrier to their decision-making to seek ANC services. Some women were described as "*ababisi*" in Runyankor-Rukiga, suggesting that they were 'raw' (meaning that they were unaware of their need for ANC services). While this barrier could be applicable to all women, it may be worse among women with disabilities.

"Sometimes, there are those women I call 'ababisi' ('raw'), she doesn't know about health services. They are raw because they don't know anything about ANC from the health facility" (Hope).

Midwives indicated that some women were unaware of their need for ANC. This was partly attributed to their low level of education. This notion of 'unawareness of their need for ANC services' was emphasised by Midwife 4, who said:

"If their level of education is too low, they may not think about it as very important to seek medical services or antenatal care services compared to this person who has attained some education".

However, Midwife 1 contended that this challenge "*does not only happen to those with disabilities but also to other people*".

5.4.1.2 Emotional and spiritual oppression

Emotional and spiritual oppression was described by both women and midwives.

Emotional oppression emerged as a barrier to women's mental wellbeing. Women expressed anxiety about anticipated undesirable treatment during the ANC process at the health facility. Although this is a feeling common to all pregnant women, those with disabilities could be more vulnerable. Women needed to know how they would be treated by health workers, and where to start and end during the ANC process. They needed to be sure of the care and support they would receive while at the health facility. When Esther was pregnant, she needed to know:

“...when you go to the health facility, how do health workers treat you? ...where do you start from when you go for antenatal care and where do you end from?”

Some women revealed that they would not seek ANC services because they anticipated that they would be turned away by the health workers if not escorted by their husbands. Kate expressed this view:

“...may be like a woman fearing to go.... Now like if you tell your husband and he refuses to take you [escort you to the health facility], you also say that let me just ignore”.

They indicated that they feared testing HIV positive and having their HIV status disclosed to their husbands. They felt that this may negatively affect their relationship with their husbands and may lead to the breakdown of their marriage. This fear was common among women who may not have tested for HIV before getting pregnant or newly married women who may not have tested before marriage. Mary reported:

If you know that you are newly married, you think that now they are going to check me and tell me that I have HIV, what next? ...If it is positive, that is it [end of marriage]. So, you focus on that feeling because you don't know what the man will decide for you at that time. So, I think that is what causes many people to fear [seeking ANC services].

Women revealed that they experienced exacerbated physical pain, especially in their late stages of pregnancy and after giving birth. Such pain may prevent them from seeking ANC services because of the discomfort and travel challenges that may worsen it. The exacerbation of the pain impacts their ability to travel, especially long distances, as highlighted in subsection 4.3.3.2 below. Hope gave her account:

...because it was due to this impairment, it's why I am telling you that it [pregnancy] added into this impairment and it hurt me somehow. ... I realised a change in pain, it increased [when she got pregnant]. I didn't know that when the baby grows and increases on weight, I start paining around here [waist]. I was feeling pain around the waist because of the impairment. ... when I gave birth, I felt the pain. I was immobile, ... I was worried, thinking that I would stay down [in pain].

Midwives suggested that pregnant women with physical disabilities have exacerbated pain during pregnancy. Women may need guidance and counselling on coping with the physical impairment challenges during pregnancy, including coping with breastfeeding amidst their physical pain after giving birth. Midwife 2 commented:

“... she needs a lot of counselling compared to these ‘normal’ mothers because now she is pregnant, she has to breastfeed. She has to learn to live with her condition [physical impairment]”.

Some women expressed feelings of self-stigma. Philly observed that they feel embarrassed and ashamed of *“being seen in public”* when pregnant.

Midwives observed that pregnant women with physical disabilities are usually mocked and belittled in the community. They also observed that, while there is stigma from the community, pregnant women with physical disabilities also have self-stigma, and feel uncomfortable and embarrassed about being seen pregnant in public.

“They have [self] stigma. ...they fear to come to health units to seek services. She’s like how will people see me when I am pregnant, and I am lame? ... they don’t accept, it’s like they live in denial” (Midwife 2).

Some women expressed feelings of worthlessness and undermined sense of self-importance. They expressed regrets about living as they questioned their purpose for living. Such feelings point to **spiritual oppression**.

I would think about it [being physically disabled] that, ‘why would a woman with a physical disability be there and reach such a state [of feeling worthless]!’ I wished I had died [after being born] because we have not been useful in any way. In my state of physical disability, I would hate myself [feel disheartened]. Now I no longer think about such. I think it was the pregnancy and the pain that were making me think like that.
(Joyce)

“...you would need praying to God to help you ... because you don’t have the authority [over the outcome of pregnancy]” (Grace).

They feel disheartened, less important, and not worthy of being cared for.

They feel neglected [worthless] and ... of less importance to this world. To make matters worse, some get these pregnancies when it is not their own wish. Some are raped from the villages since they are left at home alone. Someone who can be done such; ... she feels even if I don’t attend antenatal care [not worthy of being cared for]. (Midwife 3)

5.4.2 Subtheme 2: Sociocultural prohibitions

The sociocultural factors that undermine women’s wellbeing emerged as barriers to accessing ANC services.

5.4.2.1 Inadequate family and community support

Inadequate family and community support was related to being helpless, and a change in mobility and the effects of this on work patterns, which were described by women only, and marriage challenges, which were highlighted by both women and midwives.

Being helpless in carrying out daily activities during pregnancy was expressed as a concern. Women painted a picture of sextuple (seven-fold) vulnerability arising from physical impairment, patriarchy, poverty, low education, HIV/AIDs, rurality, and their gender. The situation is compounded by not having personal disability support assistance. This vulnerability increases in the late stages of pregnancy, affecting their mobility and work pattern.

“When I am pregnant, oh! I get worse. So, I would need water and firewood to be extended to me” (Grace).

“She may have been helpless, ... unable to fetch water by herself from the well and without someone to help her do it. How to clean herself; she can’t, ... when she

reaches there [at the health facility]; they don't want to see her as a disabled person, no, they see her as a 'normal person'". (Esther)

Change in mobility had implications for women's work patterns. They needed to balance their work and rest patterns. *"I work a little and I rest a little because there are times when I feel pain"* (Hope). As the pregnancy progressed, their participation in work activities that required standing would become limited. Some women described this scenario thus:

When I am about to give birth, and I can't move, I sit; I stay in one place. Instead of going to dig, I sit because I can no longer stand. I am too heavy to do anything. You would find that I remain seated even when I am to do some work. (Mercy)

Marriage challenges, including violent and unsupportive husbands, especially if the husband was a drunkard, were identified. Some women indicated that physical violence may lead to additional impairments, and inadequate support made it difficult for them to financially sustain themselves and their families. When Jolly was craving a pineapple and told her husband, she was told to take away her *"confusion and stupidity"*. Other women explained:

"... he [the man] beats you and you sleep outside. ... I don't want to go there [into marriage] and get another impairment! You see how 'weak' my body is. It is like that of a tomato. If he impregnates you, his role is done; the rest is yours" (Esther).

"... the one I got married to is not supportive. My husband didn't help me in anything. He [the husband] is a 'waragi' [locally distilled alcohol] man [meaning he is an alcoholic]" (Joyce).

Women noted unhealthy relationships with their in-laws. There was a sense of mistrust of their in-laws. If the women were not supported by their husbands, they faced numerous challenges in carrying out daily activities. They stated that the situation may be worse for a woman who is married and living very far away from her parents' home and cannot easily access her biological mother for care and support. Some women reported:

"What can I say since I am not in their hearts! You never know [what they think of you]" (Grace).

“... if your husband doesn't help you [during pregnancy], the other family members neglect you; do you see that? So, if you are not near [your biological mother], it becomes really bad” (Hope).

Midwives reaffirmed the challenge of violence and inadequate support from women's husbands. They pointed out that some husbands hand their responsibility of care and support over to the biological mothers of these women during pregnancy. Some midwives noted:

“What I have seen is that they usually encounter gender-based violence within their families. Their husbands are not always supportive to them, especially when the man is 'okay', and the woman is not. The man looks out for other women, who are 'okay' [non-disabled] of course” (Midwife 2).

...though I have said that there are [non-disabled] mothers who come with their husbands, there is no husband who has ever come here and said that I am the one responsible for this pregnancy [for a woman with physical disability]. I have never seen any. ... they get pregnant, and you find them with [accompanied by] their [biological] mothers. They are the ones who look after them. (Midwife 5)

5.4.2.2 Limited financial and antenatal resources

Limited financial and antenatal resources were shaped by limited income and the absence of expected government support, as revealed by women, and insufficient antenatal provisions, mentioned by both women and midwives.

Women identified **limited income** as a barrier in their access to ANC services. This barrier is common to all women in rural areas, although women with disabilities are more vulnerable and their sources of income were limited. Many were involved in small enterprises such as tailoring, weaving, or hair dressing, operating part-time from their homes as they could not afford rented premises in trading centres. Limited income impacted on their capacity to meet their needs during pregnancy.

I do the salon business from home. I would have gone to town but because of limited finances, I work from home. I work less [gets less income]. ... I have no money. The most important issue is money. If you have money, you can do most of the things, you don't have to solicit for help. (Hope)

Their main economic activity was subsistence farming. Eve noted that in the village, one cannot earn much from selling harvested crops because most people plant their own food. Many reported having no gainful employment or that the jobs available to them are seasonal. Those who were formally employed, such as Philly, who was working with a security company, lost their jobs after acquiring the physical impairment. They highlighted limited participation in economic activities that require standing and using a lot of energy because of their physical impairment. “*Some jobs require standing and energy [physical strength]*” such as digging or operating a sewing machine, “*which energy we don't have*”, Esther emphasised. However, others are overprotected by their family members and “*they may stop them from going to work*”, observed Philly, even though working would help them earn money to take care of their needs. For instance, by working, they would get money to buy food and facilitate their own transport to the health facilities for ANC services.

Women reported an **absence of expected government support**. They were not financially supported by the government to start up their own income-generating activities. Philly was contemplating going to the Community Development Office to see if she was eligible for financial support under the ‘*emyooga*’ government programme to enable her to start an income-generating activity. The women felt that the Government of Uganda is not doing enough to support them financially. Some registered with the Community Development Office with the hope of receiving government support, but this was not forthcoming. Joyce remarked:

“... there is a time they [government officials] came in this village and they registered us. They had said that they were going to give us help [financial support] but up to now, I've never seen them”.

Women indicated that they had **insufficient antenatal provisions**. However, when they go for ANC, they need to be clean and presentable and travel with a drink-like porridge and

items for use in case of an emergency, such as a clean cloth and ‘maama kit’²¹. Jolly indicated that she needed a maternity dress, a cloth for laying on the examination bed, and an umbrella to protect herself from sunshine but she did not get them. They needed provisions for their unborn baby such as baby’s clothes, nappies, and soap in preparation for childbirth. They also revealed that they would get cravings for certain foods but failed to satisfy these food cravings. One woman commented:

Sometimes I would be there and think about the fact that I am going to give birth; I needed what to use to carry the baby. It is necessary that when I am pregnant before it’s time for giving birth, I be ready. ...even those [ANC provisions] may not be enough because we are not equal financially and in the way they do work [don’t have the same capacity as non-disabled women]. So, you find that I have less and the other one has much. (Hope)

Midwives noted that women’s decision to seek ANC depends on their economic status. They indicated that women are required to have some antenatal provisions. When they go for ANC, they need to be clean and presentable and well prepared for any emergency during travel to the health facility. Midwife 4 commented:

“I think the social economic status at home at family level ... also can influence her decision [to seek ANC]”.

5.4.2.3 Cultural beliefs and practices

Some cultural beliefs and practices prevented women with physical disabilities from seeking ANC services and/or seeking them timeously, although this seemed to be applicable to all women, not just those with physical disabilities. These cultural beliefs and practices included: they are not supposed to move so often during pregnancy (which was expressed by women only), they should not declare their pregnancy early on and they should trust traditional birth attendants (noted by midwives only), and they should use herbs and applications, described

²¹ To ensure a clean and safe childbirth, the Government of Uganda provides pregnant mothers with a Maama Kit that consists of basic supplies required at childbirth such as a pair of sterile gloves, cotton, gauze, cord ligature, surgical blade, tetracycline eye ointment, soap, a polythene sheet and baby wrapper (a piece of cotton cloth) and sanitary pads.

predominantly by both women, though also by midwives. Both the women and midwives spoke about the community's dehumanising attitudes.

Some women expressed a belief that a pregnant woman **should not move around the community so often** because she may come across 'something dead'. They believe that seeing 'a dead thing' may negatively affect the unborn baby. The baby may be born small, resembling that 'dead thing' that the woman had seen. Philly recalled:

... they started telling me a lot of things [because my baby was small]. When it [the baby] is born small, there is a way it looks like, like 'ekintu kyifiire' ('a dead thing'). It's not good to see a dead chameleon, a dead dog [when pregnant]; so, you shouldn't walk around so often [because you may increase your chances of seeing something dead].

Midwives described a belief about a woman **not declaring pregnancy early on**. They noted that women do not declare their pregnancy status early for fear of being bewitched by evil people in the community.

They still have their old thinking "a person is not supposed to test for pregnancy when it is not yet out to be seen, it is a shame", you know! They say that it is not good. They fear to talk about it [pregnancy] that they can bewitch you and the pregnancy comes out [spontaneous abortion] or the pregnancy disappears, things like that. ... or you stay with it without giving birth. (Midwife 6)

Trusting traditional birth attendants (TBAs) was expressed by midwives as being influential in women's decision not to seek ANC services from the health facilities.

"They may be convinced that 'if I am not able to move or have no transport and I have a senior mother [TBA] around me, I do the antenatal from there'" (Midwife 3).

Midwives do not trust TBAs because they are not formally trained and they use unscientific methods of care, which may lead to avoidable obstetric complications.

One problem I usually have with the TBAs is that they try to do things from nowhere [unscientifically]. ...they [TBAs] may tell her that ‘when you are lame, you are not supposed to go to the hospital [you will be operated] ...so, they will just tell her: ‘if you don’t go there [to health facility], we shall give you herbs and you will deliver well’.
(Midwife 2)

Women explained that **using herbs and applications** may prevent one from seeking ANC services. Grace observed:

“Once she gets pregnant, she drinks her herbs and sits [becomes reluctant] and never goes to the health facility until she gives birth. She keeps trusting her herbs”.

Women believed that such herbs facilitate the normal growth and development of the unborn baby and smooth the process of childbirth, with reduced labour pains. Some women agreed that there are negative effects involved in using traditional herbal medicines. Some herbs may have negative effects on the woman’s health or the health of her unborn baby, and sometimes may cause death.

“...she was being given herbs as she was going to give birth. The herbs became too much for the baby in the womb and the baby was already dead by the time of giving birth” (Joyce).

...when you are taking them, it becomes easy for you when you are to give birth. It can’t be the same with saying that for me let me trust [only] going to the health facility for antenatal care. ...I go back home [after attending ANC], and also use herbs. ...and when you take them, you realise they have no harm on you, but they can’t stop you from going to the health facility. (Mary)

Midwives reported that women use herbs to prevent and/or treat different health conditions during pregnancy. For instance, they take herbs to treat any increase in ‘*mushohokye*’ (vaginal discharge during pregnancy), which may be an infection that needs professional attention. They reported herb peddling on the property of a health facility – a place where a woman should be safe, or at least not be exposed to unverified ‘treatment’.

That water is coming from the baby... but its abnormal vaginal discharge which they term as 'mushohokye', So, for them they believe that there are some herbs you can take, and it stops coming. They don't know it's an infection, needs some treatment and it goes away" ... [sometimes] when someone is pregnant, the vaginal discharge increases. ... When she comes here early [and waits for childbirth at the health facility], she will interact with ... seniors [know-it-all women]. ... they will advise her, bring her drugs [herbal medicines]. (Midwife 2)

Women also take herbs for “*cleaning the unborn baby so that it is not born dirty [with vernix caseosa]*” (Midwife 6). When the baby is born with such a skin coating, “*...for them they say that “omwaana yahumba” [the baby has ‘moulds’]*” (Midwife 2).

Midwives noted that women take herbs in preparation for childbirth to reduce labour pains, to induce and quicken the labour process, and to prevent vaginal tear during childbirth. They indicated that use of herbs during pregnancy may lead to obstetric complications such as a ruptured uterus and intrauterine fetal death. One midwife narrated:

...she takes herbs when she knows that she is pregnant so that her pregnancy becomes firm and it does not ‘come out’ ...to make the child [fetus] grow ... for ‘ekintu’ [abdominal pains], ... for inducing labour and others for quickening the process and reducing the labour pains, ... for softening the hip bones. (Midwife 6)

Midwives reported that pregnant women have a bad practice of **pouring hot water on their abdomen** with a belief that this causes the fetus to turn to a normal position in the womb. This is a bad practice that may cause burns, affecting both the mother and the fetus.

“I hear that if, every morning, you wake up and put hot water on your abdomen, your baby is going to turn and be in the normal position, which it’s not right” (Midwife 2).

Community’s dehumanising attitudes, where women with physical disabilities are perceived as different beings and unfit for marriage, were reported. Women indicated that the community does not sympathise with them. There was a feeling that people’s negative attitudes towards pregnant women with physical disabilities are deeply rooted in communities and hard to reverse. Women revealed that, generally, people with physical disabilities are

maltreated, regarded with disdain, and considered a burden to the community. Esther noted sadly that some non-disabled people feel ashamed of associating with persons with disabilities. Another woman commented:

“That [negative attitude] has always existed. Even if you’re walking on knees, no one can sympathise with you. Even if you teach them [people in the community], it depends on someone’s heart. If I was born a ‘rogue’ person, can you make me straight [a good person]?” (Hope).

Midwives expressed similar views as the women, in that people’s negative attitudes are very difficult to change. They also noted that socialisation plays a big role in influencing people’s attitudes. One of them commented:

...of course, you know the way we are brought up is quite very different. The way we are brought up that’s the way we are. However much you try talking, there are some people that can never change. So, for someone’s attitude, there is nothing much [we can do], however much we try. May be that’s how they were born. (Midwife 6)

Women with physical disabilities are perceived as **different beings**. The community believes they are incomplete and abnormal, with grotesque body shapes. They are considered uneducable individuals who do not deserve any explanation on matters concerning their social economic development. One woman commented:

Many of them [community members] think that God created us when He was already tired. They think we were created last. ...really people treat them [women] badly, because when there are educational programmes for people with disabilities, sometimes, they don’t tell them because for them they [leaders] see that even if they tell such a person, they would be wasting their time. (Esther)

Midwives observed that women with physical disabilities are perceived as objects of pity, and because of their physical impairments, the community believes that their other body parts are also impaired. One midwife narrated:

...because others [non-disabled women] are looking at her, of course she is 'abnormal' [according to them]. She is not a normal human being like them. She is not walking; she is using her buttocks to walk [move], so all of them [non-disabled women] would want to look at her. They look at them and they are like 'sorry!' ... looking at them like half human beings but they are complete human beings though they do not have legs to walk. Other body parts are working. (Midwife 6)

Women with physical disabilities are also considered **unfit for marriage** and have no right to get pregnant. The community believes that women with physical disabilities do not conceive and if they do, they do not give birth or are likely to have birth complications, including death. In fact, they wondered how any right-thinking man would take a woman with physical disability for a wife. It is non-conforming for a woman with physical disability to get married and/or get pregnant.

"... when you bypass people, you hear them saying; 'she is like this [pregnant] and does not know that she is disabled! But whose wife, is she? ...why did he marry a disabled woman?'" (Mary).

...when they [people] see you get pregnant, you hear someone say that 'how can the other one [non-disabled woman] fail to conceive and you find a person with a physical disability pregnant'. They think that if she has a physical disability, the uterus also has a disability and that she can't conceive! (Grace)

Midwives noted that the community considers women with physical disabilities unfit for marriage and that they have no right to get pregnant. This negative perception is also held by the family members of pregnant women with physical disabilities and health workers. They believe that having a physical disability also impacts on the other parts of the women's body, including their reproductive organs. It is not uncommon for people to be surprised about why and how women with physical disabilities are able to fall pregnant and give birth. The perspective that women with physical disabilities are asexual was divisive, as was underscored by Midwife 1 when she argued that *"they shouldn't [or wouldn't] be getting married"* if the community's perception was that negative. Another midwife explained:

...may be the health workers may judge them. Maybe they look at them as people who shouldn't have gotten pregnant because of their physical disabilities. ...Most of those people [women with physical disabilities] are even not married. Some of them are raped. So, when they are coming to the hospital, they have a lot of expectations [reservations]. (Midwife 4)

5.4.3 Subtheme 3: Inaccessible transport and mobility systems

Inaccessible transport and mobility systems were characterised by inappropriate transportation and inadequate road infrastructure.

5.4.3.1 Inappropriate transportation

Inappropriate transportation was influenced by insufficient access to transport, voiced by women only, and high cost of transport, inappropriate transportation, and limited walking capacity, identified by women and midwives.

Women expressed a challenge of **insufficient access to transport**. They reported that *boda bodas* may not be available or they may fail to find a suitable vehicle to travel to and from the health facility. Failure to find a vehicle makes them feel dispirited and decide not to seek ANC services.

Sometimes, 'nohurira wayetamwa' ['you feel disheartened and lose interest'] like when you fail to get means to go [to the health facility]. You lose interest and say that I won't go there'' (Kate)

It is hard [to travel to the health facility] because the boda bodas from this side are few. You may call [on phone] a boda boda ridder and he says, 'I won't manage taking you'. You call another one he tells you that he is far, you call another one and he tells you that 'where I am, I won't reach you in time', you just ignore [you give up seeking ANC services]. (Esther)

High cost of transport was more challenging for women who had to travel long distances to the health facility. The cost of transport increases when the fuel prices increase. They may not have sufficient money for travel, and hence they miss their ANC appointments until they

get money for transport. Grace explained:

There are times when you may find that she doesn't have transport money and yet she can't walk up to the health facility. She decides not to go and goes there when she gets money. ... if at all the money for transporting her is available, she would go, she wouldn't be missing [her appointment].

To cope with the high cost of transport, some women chose to be carried with another passenger on the same *boda boda* to share the transport cost. Hope remarked:

He may put another pregnant woman and you become two. Now what can you do? ...they combine the two of you since you don't have a heavy pocket [enough money] to say that you will sit there alone! If you don't have money you go to the road and you wait for those [boda boda riders] returning [that would charge less].

However, some women were not comfortable sharing the *boda boda* with another passenger.

"At least if the pregnancy is still young but if it's already old, I don't accept! What if I fall down? If you fall down, you can't get up from there" (Happy).

"When I am pregnant, someone can't carry me on a boda boda with another person. I don't mind at what time I reach there [health facility]; I walk, but I can't just sit there and be squeezed" (Jolly).

Midwives identified insufficient money for transport to and from the health facilities as a barrier to accessing ANC services. Some pregnant women with physical disabilities choose to be carried with their carers on the same *boda boda* to minimise the cost of transport. They noted that without sufficient money, women are disempowered, and other people may make decisions for them on matters regarding their health.

"Now, you know in this era, money is power" (Midwife 5).

"... You might find even if she has that idea [of seeking ANC] but she has no money for transport, she ends up remaining there [at home]" (Midwife 3).

Inappropriate mode of travel emerged as a barrier for pregnant women with physical disabilities in accessing ANC services. Most women reported using *boda bodas* to and from the health facility. However, they highlighted the challenge of bad *boda boda* riding. *Boda boda* riders ride too fast either to pick up another passenger or if the woman goes into labour. This may cause or worsen the physical body pain. She may also fall off the *boda boda* during the ride and get injured. Jolly indicated that, during travel, her concern was her safety and that of her unborn twins as she thought that she would not “*reach the health facility alive!*”. Sometimes the *boda boda* riders may refuse to carry pregnant women with physical disabilities for fear of having an accident as the women may not be able to firmly hold onto the *boda boda*.

They [boda boda riders] ride badly! Sometimes he may be panicky when he has another work [passenger] and he rides you too fast hitting potholes. When you go for check-up [ANC], you find your body hurting. However, you know that it was caused by bad riding of the motorcycle rider, but you can't do anything about it. (Hope)

Women observed that there is a need to sensitise the *boda boda* riders and taxi drivers on how to handle pregnant women with physical disabilities during transportation. The *boda boda* riders and taxi drivers also inconsiderately use the roads and pregnant women with physical disabilities need to be cautious while on the road. Esther observed:

There is need to mobilise the boda boda riders or taxi drivers to educate them, to know more about what disability is and how a pregnant woman with physical disability should be handled to reach the health facility. ...If there was awareness creation, such things [bad driving/ riding] would reduce.

Midwives revealed that women with physical disabilities encounter challenges using *boda bodas* during their travel to and from the health facility.

“Even sitting on that boda boda is not easy because climbing from down up to there, you need somebody to support you” (Midwife 5).

Limited walking capacity hindered pregnant women with physical disabilities from accessing ANC services. Some women reported that they walk to and from the health facility for ANC services, albeit uncomfortably.

“... there are times when I walk, and I knock myself [toe on a stone] ...it’s because of this leg being weak. ... when you force yourself, you knock a stone, and the nails go off” (Philly).

Whereas assistive devices such as crutches and walking sticks may be important in aiding walking, Philly stressed that using them during pregnancy is as bad as walking on foot. Women with disabilities move less quickly, especially in the late stages of pregnancy, and this makes it hard for them to participate in ANC activities on the same level as their non-disabled counterparts.

A person without a disability is swift. When she decides to go to the health facility, she reaches in time, but for me, I can’t reach in time for ANC. You will not ask a person without disability whether they have transport means or not. Any time she can walk to the hospital. She cannot even miss her appointment. (Esther)

Midwives noted that limited walking capacity impacts on women’s travel to the health facility depending on the nature and severity of their physical impairment.

“She had a problem with the foot, so she was limping. The nature of the impairment and the distance where this client is going to have ANC services may influence their decisions [in seeking ANC services]” (Midwife 4).

5.4.3.2 Inadequate road infrastructure

Both women and midwives identified the poor condition of the roads and distance to the health facilities and the implications of these as hindrances to accessing ANC services.

The poor condition of the roads, including uneven surfaces and potholes, was commonly described. Esther confirmed this and noted that it is easier to have an accident on the marram²² roads than the tarmac ones. She argued that *“when the roads are good,*

²² Marram refers to dirt or gravel and uneven surfaces.

transportation becomes easy". Mary observed that the community relies on the government's goodwill to fix these roads via the local district government. Another woman commented:

There are times when you may be heavily pregnant. When you sit on the boda boda on a bumpy road, he rides it 'tu tu tu tu' [bumpy and rough]. ... remember our road has marram. So, when you reach the hospital and the nurse touches on you [to examine you], it feels hurting because you go tightening yourself like this [she demonstrates; seating still in uncomfortable position]. (Hope)

Unfavourable weather conditions worsen the already bad roads. Rain floods the roads and makes them muddy, slippery, and impassable. Esther indicated that when it rains on a day she is supposed to go for ANC, she misses her appointment and may go the following day. The women observed that *boda boda* riders prefer using short-cuts to the health facilities, and these become impassable when it rains. They highlighted that when it rains, they are charged more money for transport than their non-disabled counterparts. Grace noted that they are charged more because "*he [boda boda rider] can't ride fast like how he would be carrying other people*".

"If the weather becomes bad, you can't get a vehicle. From here [her home] going there, to the road, to get a boda boda, if it has rained, you can't get a boda boda. You won't go", (Philly).

Midwives noted that some roads are in bad condition with poor geographical terrain. "*Even the terrain may affect their movement*", observed Midwife 4. They further noted that rain makes roads impassable for pregnant women with physical disabilities. The roads become flooded and slippery, thus increasing the risk of *boda boda* accidents. The bad nature of the roads also affects the women's balance and makes it difficult for them to walk or access a vehicle for transport to or from the health facility. The situation is worse for pregnant women using wheelchairs.

"The roads are very poor. They don't favour a pregnant mother using a wheelchair. It's not simple for her to wheel that chair all the way from her home to here [health facility], because they [roads] are muddy" (Midwife 1).

“I think what would make their travel hard is rain. Assuming it is a rainy season, ... and the place is very slippery. ... and the person they have cannot walk; don’t you think that this can be so difficult for such a person?” (Midwife 3).

The distance to the health facilities and the implications thereof emerged as a barrier to accessing ANC services. Women would prefer to attend ANC and give birth at a health facility at the hospital or health centre IV level to benefit from the services available at these higher-level facilities, compared to health centre III facilities. Unfortunately, most of them lived far away from these facilities. One woman noted: *“Now for the antenatal care, my parents did not allow me to stay here [at home] because it is far from the health facility”* (Esther).

The long distance to and from the health facility negatively impacts on the pregnancy experience for a woman with physical disabilities. They reported feeling physical pain and fatigue (also seen in 4.3.1.2 above) and had more transport expenses due to distant health facilities. Some women explained:

“Walking for a long distance, I get some pain” (Mary).

“You always feel some pain around here [waist] because you travelled a long distance and more so on a boda boda” (Mercy).

Midwives explained that long distances increase the cost of transport, and this may result in some women missing their ANC appointments. One midwife commented:

Sometimes you may get a mother who has missed a visit and by the time she comes, and you try to interact with her, she tells you that the health facility is far, and you find as a health facility, we cannot do much to help her. So that one is a challenge.
(Midwife 1)

5.5 Discussion: Optimising wellbeing or undermining wellbeing

Under each theme, the subthemes will be discussed within the Three Delays (Thaddeus & Maine, 1994) and ICF (WHO, 2001) frameworks, although most of them fit more into the

former than the latter. This section focuses on how women with physical disabilities are enabled and/or constrained in accessing ANC services.

5.5.1 Optimising wellbeing: Enablers in accessing ANC services

Optimising wellbeing was shaped by exercising agency, accessing support, and aligning policy and practice. From the Three Delays Model standpoint, ‘exercising agency’ is shaped by the woman’s status, in phase I of the Three Delays which is ‘deciding to seek care’.

Ahearn (2010) defines agency as “the socio-culturally mediated capacity to act” (p. 28). In this study, agency is specifically understood as the capacity of a person/s to act independently and to make their own free choices (Wiktionary, 2022), in which the focus is pregnant women with physical disabilities. Thaddeus and Maine (1994) postulate that women’s access to health care services is influenced by their autonomy. In this study, women who were aware of the ANC benefits were more likely to exercise their agency in seeking ANC services. However, in their situation, it appears they were not able to actively engage and persuade those who had decision-making power. By contrast, as seen in subsection 5.3.1.1 above, being unaware of the need for ANC benefits may hinder a woman’s decision to seek ANC services.

Even though pregnancy and childbirth is a natural process, women sought ANC as they did not know the nature and severity of their physical impairment and how it may impact on their pregnancy and childbirth. They desired to seek health information from health professionals. Perhaps they were concerned that their physical impairment would be passed on to their unborn babies. This finding is contrary to the perception among non-disabled pregnant women that pregnancy is a normal condition or not to be considered an issue that required seeking care, as noted by Warri and George (2020) in their qualitative interview study conducted in Cameroon.

This study’s findings show that despite women’s desire to seek information during ANC regarding their health status and that of their unborn baby and the progress of their pregnancy, some of them felt that they were not in control of the ANC process. Women’s feelings of not being in control of the ANC process could be due to the complexities within the health care system (McLeish & Redshaw, 2019). They feared the health workers reprimanding them, mistreating them, and denying them other maternal health care services

(Walsh-Gallagher et al., 2012) for not seeking ANC timeously. Unfortunately, however, not being in control meant that they had to rely on the goodwill of health workers at the health facility, to guide and orient them on the ANC processes and progress of pregnancy. In addition, women indicated that they feared testing HIV positive and having their results disclosed to their male partners. This uncertainty about their relationship and social standing with their partners suggests a lack of agency for some women in seeking ANC services.

Viewing this subtheme ‘accessing support’ through the ICF lens, it is undeniable that accessing support is critical in enabling the participation of persons with disabilities in their access to ANC services. This subtheme falls under the environmental factors in part 2 of the ICF (contextual factors). Accessing support is also important to women without disabilities as an enabler in accessing ANC services, although women with physical disabilities are more disadvantaged during pregnancy. They encounter barriers including, but not limited to, inaccessible transport and mobility systems and dehumanising attitudes. Family²³ was central to supporting pregnant women with physical disabilities in their access to ANC services. Perhaps family members understand the woman’s disability challenges, and hence may know better her strengths and where she needs support.

Many women suggested that their husbands and biological mothers were critical sources of support during pregnancy. Some women relocated to their mothers’ homes in the late stages of pregnancy for support and companionship. This is similar to the findings by Fuzy et al. (2020), who explored respectful maternity care for adolescents (also a vulnerable group) and found that childbearing women needed to be near their mothers for support and companionship during childbirth. Interestingly, Mgata and Maluka (2019), in their study in Dar es Salaam, Tanzania, found that support from family members prompted early ANC attendance by non-disabled pregnant women in an urban setting.

Uniquely, this study revealed that some women relied on support from their neighbours. This is an important finding as it brings hope and points to an opportunity to cascade community care and support for women with disabilities. In another study, about maternal experiences of mothers with multiple disadvantages in England, McLeish and Redshaw (2019) reveal that

²³ In this study, family is divided into two categories: 1. Immediate family involving the woman’s partner and their children, and 2. Extended family involving the woman’s blood relatives and in-laws.

support is needed by these disadvantaged women to navigate the complex maternity care system. In this study, how to navigate the complex health care system was one of the women's concerns. McLeish and Redshaw suggest that accessing support by disadvantaged women may be a precursor to their early and regular ANC attendance, which is in tandem with the results of this study. Although theirs was conducted in a high-income country (England), it was among a diverse group of disadvantaged women with specific needs, including those with disabilities.

The subtheme 'aligning policy and practice' aligns with phase II of the Three Delays Model (identifying and reaching an appropriate health facility). Thaddeus and Maine (1994) suggest that improving women's economic status and accessibility, and the health systems and policies enhances women's access to obstetric care services. The study findings also fit the ICF (WHO, 2001) in which it is posited that aligning such economic and transportation services, systems, and policies enables people to use goods and services, and move or be moved from one place to another.

The study findings show that there was a favourable government ANC policy and that pregnant women took responsibility to seek ANC services. However, the emphasis on the prevention of mother-to-child transmission of HIV by the government suggests that women are only valuable as the carriers of a baby and not intrinsically valuable, that is, they need to be healthy only for the sake of their unborn child.

Interestingly, as a way of improving accessibility to ANC services, some women would stay and wait on the ward. Literature highlights the concept of 'maternity waiting homes' as a strategy for overcoming distance and transportation barriers to accessing skilled obstetric care and improving pregnancy outcomes (Awor et al., 2020; Bekele et al., 2019; Lori et al., 2016; Lori, Munro, et al., 2013; Sialubanje et al., 2017; WHO, 2015). Maternity waiting homes are "residential dwellings located near health facilities where women in late stages of pregnancy wait for childbirth" (Lori et al., 2016, p. 89).

While maternity waiting homes may be a good measure for improving accessibility to ANC services and timeous admission when in labour for pregnant women with physical disabilities in rural south-western Uganda, issues related to the security and care of their children and properties at home, maintenance costs for themselves and their families, and deficiencies in

quality of ANC (also see Chapters 6 and 7) in these homes remain a concern. Similar concerns have been reported in studies conducted in rural areas of Zambia, Ethiopia, and Liberia (Gurara et al., 2022; Lee et al., 2022; Lori et al., 2016; Lori, Wadsworth, et al., 2013; Scott et al., 2018) and in a systematic review involving 19 low- and middle-income countries (Penn-Kekana et al., 2017).

However, McRae et al. (2021) and Buser and Lori (2017) argue that there is no robust evidence supporting the effectiveness of maternity waiting homes. For such homes to be effective, a health systems approach, accounting for women and community perspectives (Penn-Kekana et al., 2017), is needed to allow the integration of culturally sensitive and supportive maternity services (Selbana et al., 2020).

5.5.2 Undermining wellbeing: Unawareness and mental ill-health

‘Unawareness and mental ill-health’ is framed within the ICF framework under mental functions such as consciousness/awareness, energy and drive, and emotional functions. In this study, I was particularly struck by the woman who expressed that she felt worthless and that she should have not been allowed to live. Some women indicated that they felt disheartened and less important, unworthy of being cared for. Ghaderi et al. (2018) describe the three dimensions of spiritual health as religious, individualistic, and material world-oriented. Spiritual health is determined by the connection with oneself, God (transcendent reality), others (society), and nature (Chiang et al., 2016; Ghaderi et al., 2018). From the review of the literature, it has been established that spiritual health sits at the intersection of the overlapping physical, political, social, economic, and cultural aspects of one’s life. Spiritual health affects one’s physical, mental, and social health and is recognised as a dominant aspect in human life (Ghaderi et al., 2018). Spiritual wellbeing is dynamic in nature – can be increased or decreased – based on the individual’s beliefs and opinions (Ghaderi et al., 2018).

A critical finding this study uncovers is the ‘spiritual oppression’ among women with physical disabilities during pregnancy. Spiritual oppression undermines a woman’s “inner forces and resources that allow her to develop a unique meaning of herself that is reflected through her connection with herself, others and a higher being” (Chiang et al., 2016, p. 219). Spiritual oppression points to an external influence as one of the contextual factors in the ICF

framework that restrict the participation of women with physical disabilities in accessing ANC services.

Women's spiritual oppression was compounded by the emotional oppression related to exacerbated physical pain and anticipated undesirable treatment at the health facility, undermining their wellbeing and already low self-confidence and sense of purpose, leaving them depressed and fearful (Briscoe et al., 2016; McLeish & Redshaw, 2019; Mgata & Maluka, 2019) to engage in ANC services. However, in a study conducted in Taiwan on the impact of nurses' spiritual health on their professional commitment and caring, Chiang et al. (2016) argue that "nurses' attitudes towards spiritual care may be related to their own spiritual health" (p. 218), and that this is an area that is under-researched.

In spite of having more emotional, psychological, and social needs than other women (WHO, 2016), this study's findings show that women with physical disabilities suffered spiritual oppression during pregnancy. They felt spiritually oppressed partly because of the way the community views them (see 5.3.2.3 above), namely as "unfortunate, useless, different and sick" (Barnes, 2012, p. 4). According to Barnes (2012), disability is not only a medical issue but also a human rights concern. This underscores the need for enabling the health of persons with disabilities, including spiritual health and wellbeing, while respecting their dignity and rights (WHO, 2016).

People's spirituality, as Clow (1990) suggests, may be expressed through their faith in their deity, for example the Judeo-Christian God, or in that which gives meaning to their lives, including power, social status, or material wealth. Spiritual health depicts a purposeful life, promotes human capacity, and creates a balance between physical, psychological, and social aspects of human life, including relationship with others (Ghaderi et al., 2018). People with better spiritual health are more likely to have optimised wellbeing, which then manifests in their behaviour (Ghaderi et al., 2018; Hsiao et al., 2010; Jirásek, 2015). It is possible that people with better spiritual health are more at peace with themselves, with others, and with God, and are able to express their unconditional love, compassion, and forgiveness than those who are spiritually oppressed.

Spiritual oppression may undermine women's inner forces and resources, which enable them to have a unique and meaningful life that is reflected through their connections with

themselves, others, and a higher being (Chiang et al., 2016). Women's spiritual oppression undermines their wellbeing and already low self-confidence and sense of purpose (Briscoe et al., 2016; McLeish & Redshaw, 2019; Mgata & Maluka, 2019) and hinders their access to ANC services.

In their study among the Bomvana indigenous communities in South Africa, Ohajunwa et al. (2021) assert that "health care practice must explore contextually relevant wellbeing practices that have yielded positive results and involved the narratives and understandings of the Indigenous communities which are rooted within their spirituality" (p. 6). Understanding women's spirituality and addressing their spiritual health needs optimises their wellbeing and pregnancy experiences.

5.5.3 Undermining wellbeing: Sociocultural prohibitions

Inadequate family and community support rendered some women with physical disabilities helpless and vulnerable, and this undermined their wellbeing. As discussed in 4.2.2 above, accessing support was regarded as an enabler for accessing ANC services. However, it is noteworthy that when women do not access support, they become helpless in their ability to access ANC services. Indeed, women needed support and care from their husbands and in-laws (and from the general public). This was not forthcoming for some women, leaving them helpless.

Women reported marriage challenges associated with violence, unsupportive husbands, and unhealthy relationships with their in-laws. Findings from a study done in the United States show the need for screening women with disabilities during pregnancy and childbirth for intimate partner violence and to provide appropriate interventions (Alhusen et al., 2022). In this study, findings show that some husbands abandoned their pregnant, physically-disabled wives for women without disabilities. It is possible that these husbands had not been aware of their wives' physical disabilities before marrying them. The findings are similar and complimentary to those of a study in Eastern Uganda by Apolot et al. (2019), who found that women with disabilities have needs associated with families' and partners' acceptance and support. While some women reported that their husbands were alcoholics and not supportive, what remained unclear was whether they knew that their husbands were alcoholics when they married them.

Clearly, limited financial and antenatal resources points to low economic status of women, which is located within phase I of the Three Delays Model. Women's low economic status resulting from limited income and insufficient antenatal provisions was associated with not seeking ANC services. Moreover, as expressed by women in this study, the expected government financial support to enable them to start their own income-generating activities was not forthcoming, further undermining their wellbeing.

In this study, the findings are in agreement with Thaddeus and Maine (1994) that income constraints influence the decision not to seek care. It is suggested that access to a range of material resources, including financial and antenatal resources, influences the way people deal with their impairments (Barnes, 2012), and consequently may influence their decision-making in seeking health care. Women with physical disabilities have specific personal needs during pregnancy. These needs are associated with personal protective wear, basic needs, and birth preparedness items, as discovered by Apolot et al. (2019) in their study on the maternal and newborn health needs of women with walking difficulties in Kibuku district, Eastern Uganda. Limited financial and antenatal resources among women with physical disabilities illuminates rural income poverty which constrains the access to ANC services for both disabled and non-disabled women.

From the Three Delays Model point of view, cultural beliefs and practices such as trust in TBAs, use of herbs and applications, and dehumanising attitudes fit in phase I (first delay – decision to seek care) as they influenced women's decision not to seek ANC services.

Interestingly, midwives expressed concern that such cultural beliefs and practices prevented women from attending ANC services at the health facility, a view that was not held by all women. Some women revealed that using herbs does not stop them from attending ANC. Therefore, they attended ANC and also used herbs, a practice that could put their health and that of their unborn babies at risk.

Dehumanising attitudes were held at the family, community, and health facility levels. Whereas some beliefs and practices may be common barriers to accessing ANC services for all pregnant women, women with physical disabilities seem to be more affected. For instance, from both the women's and midwives' data, it emerged that women with physical disabilities are more likely to have difficulties during childbirth compared to their non-disabled

counterparts, shaped by the belief that ‘they can’t push the baby’. This belief was held by the community, midwives, and women themselves. Women sought the services of TBAs and used herbs and applications possibly to avoid obstetric complications after they conceived.

In Australia, Barnes et al. (2019) found that women’s decision to take complementary medicine products (CMP) during pregnancy and/or breastfeeding was based on perceived benefits and safety or harm to the woman’s or the baby’s health and their trust in the source of information on CMP. In a study by Kiconco et al. (2020) in Western Uganda, 39 herbs were cited as nutri-medicinal plants used by pregnant women. They found that herbs in Lamiaceae and Asteraceae families were commonly used for the treatment of gastrointestinal disorders, for inducing labour, and for the prevention of miscarriage, among other uses. They argue that herbal medicines contain important phytochemicals *viz* saponins, alkaloids, flavonoids, reducing compounds, phenols, and steroids, which, if standardised and the correct dosages prescribed, could present therapeutic advantages to pregnant women.

Findings revealed the judgmental attitudes of health workers. Even when women sought ANC services from health professionals, they had reservations about them. This signifies that pregnant women with physical disabilities have specific needs and concerns, which are most times not attended to. These findings are consistent with those of Dean et al. (2017) in their study conducted in India, that pregnant women with disabilities encounter disparaging assumptions from both family members and professionals based on notions of their body as impaired and therefore asexual.

As expressed by both women and midwives, the community believes that women with physical disabilities are ‘different beings’ and ‘unfit for marriage’. These dehumanising attitudes hinder their access to ANC services. These findings are in line with those in studies by Mgwili and Watermeyer (2006); Hunt et al. (2017); Peta and McKenzie (2019); Peta and Ned (2019), who found that society perceives women with physical disabilities as asexual beings, and too frail or vulnerable to withstand or manage sexual contact and/or pregnancy. They are granted partial citizenship that does not take into account their sexuality (Peta, 2018; Peta & McKenzie, 2019). In addition, a study in Zimbabwe by Peta et al. (2015) shows that sociocultural constructions of disability perpetuate coercive sexual practices against women with disabilities. Their reproduction is deemed less desirable and less possible than reproduction among their non-disabled counterparts (Hunt et al., 2017). There is no doubt

that such beliefs and practices negatively impact on their pregnancy experience and access to ANC services.

5.5.4 Undermining wellbeing: Inaccessible transport and mobility systems

‘Inaccessible transport and mobility systems’ is situated within phase II of the Three Delays Model. Under this theme, inappropriate transportation and inadequate road infrastructure were identified as key barriers to accessing health facilities for ANC services. Due to inaccessible transport and mobility systems, the failure to access the health facilities made them feel dispirited and decide not to seek ANC services. Basically, one would initially have interest in seeking ANC services but would eventually lose it due to insufficient access to transport. Their interest in seeking and using ANC services is a positive opportunity that needs to be capitalised on.

Likewise, the Uganda National Service Delivery Survey Report of 2021 indicates that the choice of health facility visited by women during ANC was influenced by the mode of transport available to them, that is, walking or using a motorcycle (*boda boda*) (Uganda Bureau of Statistics, 2021), both of which are inaccessible for pregnant women with physical disabilities. The findings are in agreement with the findings by Booyens et al. (2015) in their study exploring the complexities of rural contexts in South Africa. They found that public transport systems in rural areas prevent persons with disabilities from meeting their health-related needs. Another study conducted in rural Nepal revealed that the health facilities are unevenly distributed and poorly linked with road transport facilities (Devkota et al., 2018).

Pregnant women with mobility difficulties are in a rather disadvantaged position. They have insufficient access to transport and inappropriate transportation (*boda bodas*). Similar findings by Apolot et al. (2019), in their study in Eastern Uganda, reveal that women with walking difficulties have unmet needs associated with the unsuitability of transport, difficulty in finding transport, and the high cost of transport. In another study by Ahumuza et al. (2014) in Kampala, Uganda, barriers related to transport such as inappropriate road infrastructure and long distances to health facilities were found to hinder access to sexual and reproductive health services by persons with disabilities.

In rural areas, the situation is worse, and women are less likely to initiate ANC timely, as evidenced in a multicountry analysis of demographic and health surveys by (Alem et al., 2022), perhaps due to the bad conditions of the roads in most rural areas. Particularly, pregnant women with physical disabilities are more disadvantaged because of changes in their mobility, especially in the late stages of pregnancy. Such difficulties may discourage them from seeking ANC services. Surprisingly, some women had to stay at the ward at their own cost, which had negative implications on their socio-economic wellbeing.

Interestingly, a report on the Uganda National Service Delivery Survey (Uganda Bureau of Statistics, 2021) shows that 45% of the population do not access and utilise services because government health facilities are too far away, especially in rural areas (49%). It is worth noting that non-disabled pregnant women in rural and remote areas encounter similar challenging transport and unfavourable weather conditions (Purohit, 2021) and usually relocate to relatives' homes closer to health facilities. This implies that the establishment of accessible quality ANC services in under-served areas benefits all women.

5.6 Conclusion

This chapter has shown the influences on accessing ANC services for pregnant women with physical disabilities, described as enablers or barriers. Exercising agency, accessing support, and aligning policy and practice were identified as influences on optimising women's wellbeing and enabling them to access ANC services. Families and community provided critical support in optimising their wellbeing.

However, unawareness of the need for ANC services, mental ill-health, sociocultural prohibitions, and inaccessible transport and mobility systems were influences on undermining the women's wellbeing and constraining their access to ANC services. Spiritual oppression was central in undermining their wellbeing.

CHAPTER 6:

UNRESPONSIVE ANTENATAL CARE POLICY TO THE SPECIFIC NEEDS OF RURAL PREGNANT WOMEN WITH PHYSICAL DISABILITIES:

FINDINGS AND DISCUSSION PART 2

6.1 Introduction

Having explored the accessibility for women with physical disabilities of travel from their homes to the health facilities, this chapter describes the findings for the second objective of this study:

- to explain the utilisation of ANC services by pregnant women with physical disabilities in rural south-western Uganda.

This chapter focuses on women's experiences in utilising ANC services at the health facilities. Data for this objective was obtained through in-depth face-to-face interviews, a focus group discussion, and audit of the physical environment at the health facilities (health centre (HC) III, HC IV, and general hospital). The findings will be presented and then the discussion will follow. The discussion will be juxtaposed against the existing literature to highlight the divergences and/or convergences in views and perspectives. Under each category, data from the women will be presented first followed by the midwives' voices and audit of the health facilities' physical infrastructure and equipment (only applicable to theme 3) to give context for the women's views.

From the data analysis, 'unresponsive ANC policy to the women's specific needs' emerged as the theme with three subthemes *viz* integrated nature of ANC services, unresponsive ANC policy, and unaccommodating health facility designs. These are diagrammatically illustrated in Figure 6.1 below.

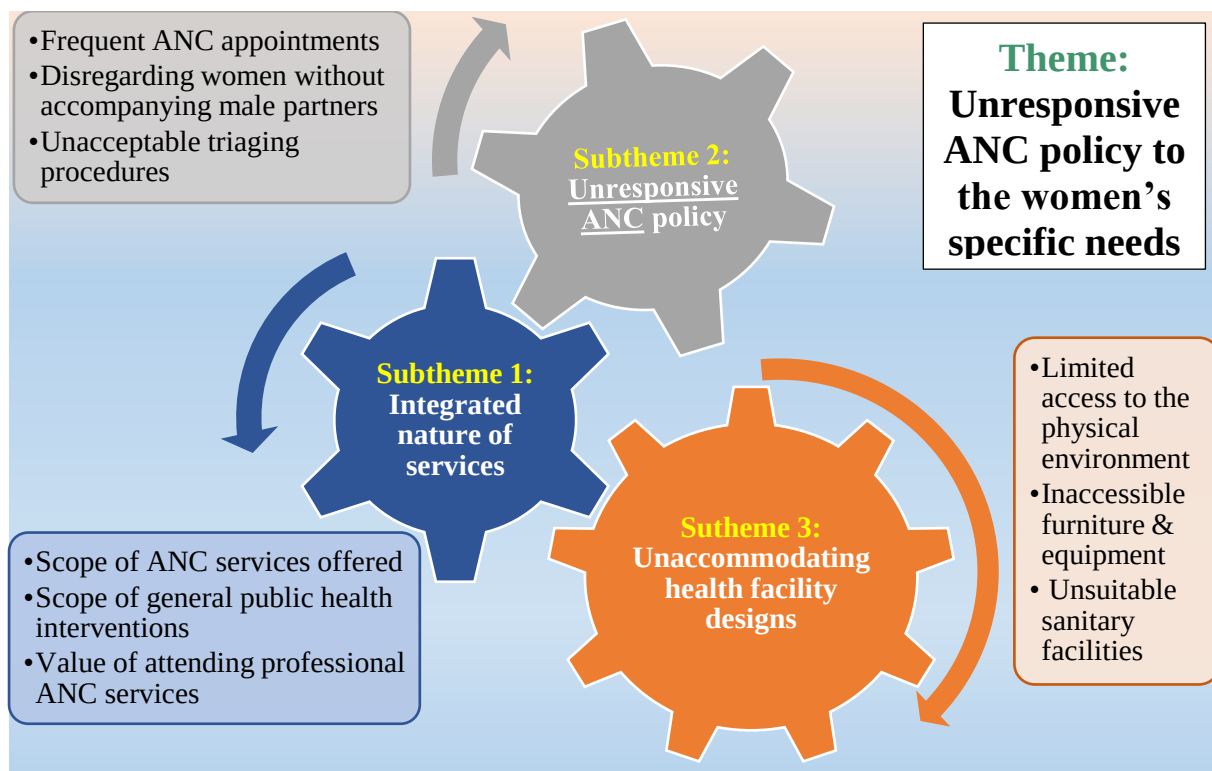


Figure 6.1: Unresponsive ANC policy to the women's specific needs

6.2 Theme: Unresponsive antenatal care policy to the women's specific needs

In this section, the gaps between policy and practices are revealed, showing the nature and scope of ANC services, the unresponsive ANC policy, and the inaccessibility of health facilities.

6.2.1 Subtheme 1: Integrated nature of antenatal care services

This subtheme explores the scope of services offered during ANC and the value of attending professional ANC services. It reveals how these services are integrated or disintegrated.

6.2.1.1 Scope of antenatal care services offered

Both women and midwives described the scope of ANC services offered. The services included: individual physical and laboratory (lab) assessment, routine antenatal drugs and supplies, birth preparedness planning, referral and ambulance services, and ultrasound scan services. Services were free of charge except the ultrasound scan and ambulance services.

Women indicated that **individual physical and lab assessments** were done. However, it was noted that midwives sent women to the lab first before doing a physical examination. They were sent to the lab for different tests, including those for HIV, syphilis, and malaria, especially on their first ANC visit.

“When you reach there, they also tell you to go to the lab. After you have finished [doing lab tests], that is when they start to examine you [physically]” (Mary).

Midwives reported that the women’s general physical examination, including abdominal palpation, is done to assess the wellbeing of the mother and her unborn baby. They confirmed that laboratory tests were done prior to the individual physical assessment. They would send women to the lab before the physical examination to avoid the queue at the lab that gets longer later as more patients come in. Paradoxically, such an initiative may create unnecessary delays for the woman if it was later established that she needs a particular lab test to confirm a health condition that was only diagnosed after the physical assessment. One midwife noted:

“We do examination from head to toe and then come to the specific one, the abdominal palpation, to assess the wellbeing of the unborn baby” (Midwife 4).

There is a policy here, because of few staff, you find that in the lab there are no people [few health workers] who will cater for the lab clients there. So, for us here we arrange and make sure we first send the mothers there, they test and after they come back here. (Midwife 3)

Midwives indicated that some lab tests such as HCG to confirm her pregnancy, haemoglobin estimation, blood group and Rhesus factor, HIV, syphilis, Hepatis B, urinalysis, and malaria are mandatory for a woman attending the first ANC visit. They reported that when a woman has a disability, these tests are done from the ANC clinic without sending the woman to the lab, save for some tests that are done at the lab. Some midwives emphasised:

“... the ministry of health tells us that for every mother who comes pregnant especially for the first time, we should do an HIV test which is mandatory” (Midwife 3)

“We do so many investigations. ... we also test urine for urinalysis because there are so many things [health/disease identifiers] in urine, though she goes to the lab outside our department [the maternal and child health department]” (Midwife 6).

Women noted that they received **routine antenatal drugs and supplies** as well as medical treatment whenever they presented with medical complaints. Routine drugs included haematinics (ferrous sulphate and folic acid), Fansidar tablets (pyrimethamine + sulfadoxine) for intermittent presumptive treatment (IPT) for malaria prevention in pregnancy, and a tetanus toxoid injection for tetanus prevention. Sometimes they received medical provisions such as long-lasting insecticide-treated mosquito nets (LLIMNs) and maama kits. However, they observed that sometimes, some of these drugs and medical supplies, such as sterile gloves, were out of stock. They would be asked to buy the drugs and medical supplies that were out of stock from private pharmacies. They highlighted the need for a regular and adequate supply of essential drugs and medical supplies during ANC.

“We should always find drugs in hospitals when we go there. When you reach there, they tell you to go and buy drugs and yet you’re helpless with no money. So, things end up becoming complex for us” (Grace).

... some drugs and medical supplies are always not there. There are times when they write drugs for a woman, and they are not available, and she goes to buy them herself. There is when you find that you are told to buy gloves because the health worker will not touch you anyhow with her bare hands and you also see that, and she tells you the truth that there is nothing to use. (Esther)

Midwives echoed the challenges with the supply of routine drugs, including mebendazole for routine de-worming, tetanus toxoid and hepatitis B vaccinations, and antenatal provisions mentioned by women. Women are given “*maama kits in time*” (Midwife 1). Midwives also provided treatment for women with medical ailments. As mentioned by the women, sometimes these drugs and medical supplies were out of stock and mothers were required to buy them from private pharmacies.

“Unfortunately, we do not have things to use in the department. We don’t have gloves to use as am talking [now]” (Midwife 6).

“... you get a mother with complications like anaemia, and you do not have drugs because they are out of stock. ... they bring few drugs” (Midwife 3).

“... If this mother has any infection according to the lab results, other drugs are dispensed from the pharmacy. Sometimes, there may be some drugs that are out of stock. There, maybe they go out and buy those drugs. ...Sometimes mothers have to buy their own gloves” (Midwife 4).

Women reported having been guided and counselled on **birth preparedness planning** during ANC. They received information on how to identify danger signs during pregnancy. Labour and possible mode of childbirth were also discussed and emphasised by midwives. Jolly and Eva indicated that they asked the health workers whether they would give birth normally and were told that given the nature of their physical impairment, they would not be allowed to push the baby out. Philly was told that they would not touch her but rather refer her for a caesarean section at the time of childbirth; despite this, she ended up having a vaginal birth. The women were told to prepare for referral to a higher-level facility if they were attending ANC at a health centre with no theatre and blood transfusion services.

“Now like me, when my date for giving birth was due, the doctor told me early enough that “you are not going to push. You should go and they operate you [do caesarean section] before you get contractions” (Mercy).

Midwives reported that they carry out birth preparedness planning with pregnant women. They counsel and prepare them for a possible elective caesarean section as some may have impaired and inadequate pelvic cavities. One midwife commented:

We made a birth preparedness plan for her [woman with physical disability], because like her pelvis must be having a problem, she was delivering for the very first time... We counselled her on what might happen when she is delivering. She may not deliver normally like any other mother [without a physical disability], but any time she feels the first contraction, she comes to the hospital simply because her pelvis is not all that well. (Midwife 2)

Women reported that the **referral and ambulance services** were generally poor. On referral, they would have to incur the costs for transport as most of the time the ambulance vehicle was not functional, had no fuel, or was not on site at the time of referral. Joyce reported:

“...they [midwives] told me to look for UGX 50,000 [about 13 dollars] to put fuel in the vehicle to take me.

Midwives revealed that, in the case of a suspected complication that required confirmation with an ultrasound scan at HC III and HC IV, mothers would be referred. They suggested that pregnant women with physical disabilities are in the high risk category, hence the need for them to be identified early, prepared, and referred for higher level assessment and management. They noted that women preferred to be referred to a health facility closer to where they resided to reduce the transport costs and to access care and support from their families. Midwife 1 explained:

We have a challenge, not only with those mothers with disabilities but also other clients, ...for ANC mothers with physical disabilities, it's a challenge, here we don't do scan, we don't have it. ... we always prepare them, and they go to the facilities where there are all those services like caesarean sections and any other major operations on them. Most of them we refer because we have what they call at-risk mothers.

Women reported that **ultrasound scan services** were necessary during pregnancy but were not free of charge during ANC. The fee for ultrasound scan services would sometimes be waived on recommendation of the midwife, depending on their judgment of the woman's capacity to pay. Jolly revealed that she had to borrow the money to pay for the ultrasound scan services, and she was happy when she was told that it showed she had twins. Most women indicated that they would have loved to have an ultrasound scan done, especially during their first pregnancy, to understand the health status and viability of their unborn baby, but could not afford it due to the costs involved. One woman narrated:

...they [midwives] would say that 'the baby is small' whenever they would examine me. That, 'is there a baby in here really?' Then I would feel scared... However, I

could not afford to go [for ultrasound scan] to see what is in my womb that they were underestimating”. (Grace)

Midwives also indicated that women needed to do an obstetric ultrasound scan during pregnancy. As mentioned by the women, they indicated that, at their discretion, women who could not afford the cost of ultrasound scan services would be recommended to the administration for a fee waiver. One of the midwives explained:

“...in fact, all mothers are supposed to do ultra-sound scan before 12 weeks and after 36 weeks. So, we identify those ones who are supposed to go for scan, some say they don’t have money, some go there... Everything is free except the scan” (Midwife 5).

6.2.1.2 Scope of general public health interventions

The scope of public health interventions was described. Health education services were described by both women and midwives, and community ANC outreach was mentioned by midwives only.

Women noted that **health education services** were also offered by health workers during ANC. Topics discussed included: nutrition during pregnancy, cultural beliefs and practices during pregnancy, mother’s requirements during ANC, how to improve personal hygiene during pregnancy, and how to conduct oneself and relate well with the health care providers. One woman explained:

“There is always someone teaching you [about pregnancy and related topics] as you wait for the midwife” (Hope).

Midwives explained that during health education sessions, they discuss different health topics. They educate mothers on common infections during pregnancy and how to observe personal hygiene. They discourage harmful cultural beliefs and practices during pregnancy while encouraging positive ones. They emphasise good nutrition during pregnancy, the relevance of doing an obstetric scan early and later in pregnancy, likely complications and how to identify danger signs during and after pregnancy, saving money for emergencies

during pregnancy, and the mother's requirements during ANC. Midwives shared what is discussed during health education talks as illustrated in the quotations below.

“We talk about the danger of taking herbs during pregnancy period. We have also started this system of telling them to come with their ‘butengye’ [sheets of cloth] and some gloves at least in case you get a problem someone can help you on the way”. (Midwife 6)

“We have to teach them that if you are walking and your legs are not equal, most of the times that's how your pelvis presents, making it unable [difficult] for the fetus to descend like any other normal fetus during delivery [childbirth]”. (Midwife 1)

Midwives reported that they conduct **community ANC outreach** that are comprehensive in nature, including ANC services. They revealed that sometimes this outreach is conducted late in the evening, and this was inconvenient to women with mobility challenges who would only return home after dark. Women are encouraged to have their first ANC visit at the health facility to have a comprehensive assessment, including doing lab tests, *“then after the tests, she can continue attending her antenatal care from the outreach site”*, (Midwife 4). During the outreach, the ANC services are offered inside an ambulance. Midwife 6 explained:

There is a time we did an outreach between 6:30pm to 7:30pm. But the reason was that it rained, and the ambulance had taken a referral, so we had to wait. ...our outreach is integrated. We do antenatal, immunisation for children, immunisation for mothers for tetanus, hepatitis B, family planning...

6.2.1.3 Value of attending professional antenatal care services

The value of attending professional ANC services was explained by both women and midwives.

Women indicated that it is worth attending professional ANC services because they are of great value to their health and that of their unborn babies. By attending ANC, they got to understand and appreciate their pregnancy and general health status from the professional point of view. Attending ANC helped them to prepare for childbirth and avoid complications. If they were sick, they received treatment and care from the health care professionals. They

shared that attending ANC with the traditional birth attendants (TBAs) in the villages may be risky and result in the death of either the woman or her unborn baby. Kate noted:

“You miss [professional] treatment and care if you don’t go there [to the health facility for ANC]”.

“It was worth the energy and that money I put in”. ... when you’re attending antenatal care, for example for my case in my condition [with a physical impairment], it shows me how the baby is, inside the womb. You know whether the baby is alive or not. You also know how your health is. So, if you feel pain and you don’t go to the hospital, how do you know what is paining you? The good thing is going to the health facility and get to know what you’re [your health status]. (Hope)

Midwives indicated that a pregnant woman with physical disability is at risk and therefore *“needs all the support and encouragement from the health workers”* (Midwife 4). They emphasised that women should be encouraged and supported to attend ANC with professionals. Midwife 2 observed that, unlike TBAs, health care professionals help the women to *“prepare and avoid complications associated with obstructed labour”*.

6.2.2 Subtheme 2: Unresponsive antenatal care policy

Both women and midwives noted frequent ANC appointments, women without accompanying male partners being disregarded, and unacceptable triaging procedures.

6.2.2.1 Frequent antenatal care appointments

Women reported that there are too many ANC appointments and the interval between each appointment is too short for them to adequately prepare for the next one. They argued that it is unrealistic for them to complete all eight mandatory visits. The earlier they started ANC visits, the more ANC appointments they would get. They therefore delayed starting ANC so as to have fewer visits to the health facility and spend less money, especially on transport. They noted that the intervals between ANC appointments are short, too short to properly plan and prepare finances for the subsequent visit. They shared that they would receive a maama kit on the eighth ANC visit to encourage them to complete all the required ANC contacts. Joyce noted:

It's not that you get pregnant, and you start [ANC] ... unless the health centre is nearby in a walkable distance. ...where it's far, you need to have assessed at what appropriate time of your pregnancy you need to start the check-ups [ANC]. Because remember, you are also spending from your own pocket, and when given a month to return, you need to prepare.

Midwives emphasised that women are required to report early on in their pregnancy for the first ANC contact and are required to have a total of eight ANC contacts. Midwife 2 commented:

"...from the time she knows that she is pregnant she is supposed to attend monthly for eight times [contacts]".

6.2.2.2 Disregarding women without accompanying male partners

Women observed that the presence of their male partners at their ANC appointments meant that they were given priority and attended to first. The women felt that midwives do not give priority to women who arrive for their appointments with anyone other than their male partner, even if that person is supporting her and engaging in the pregnancy, such as another family member. Some women reported that their husbands refused to escort them to the health facility. Sometimes women had to lie about the reasons as to why they were not escorted by their husbands so as not to be chased away by the midwives. They noted that their partners were needed, especially during HIV couple's counselling and testing, one of the strategies for the elimination of mother-to-child transmission of HIV.

"It's a rule, if you go together with your husband, they work on you first" (Mercy).

"They [health workers] first test your blood [before other services are offered] and when they find that you have HIV, they tell you that 'we would like you to come with your husband'. ...they send you for the man [male partner]" (Hope).

“If you know your man [that he can’t escort you], in the health facility if they ask you for your man, you say that he is in Kampala [in the city] working - you use that, you devise means [to be attended to]”. (Mary)

Midwives indicated that they attended to women escorted by their husbands first as a way of encouraging male participation and involvement in ANC activities.

“...if someone comes with her husband, you know men are very impatient, we serve them first” (Midwife 2).

“We are advocating for male involvement, because we tell them ... when you have a husband, we work on you first... if you don’t have a husband, go outside and tell those boda boda men to come with you and we work on you... They come back and tell us, ‘Musawo, [general term referring to medical personnel] mine [husband] can’t even listen to me’”. (Midwife 6)

6.2.2.3 Unacceptable triaging procedures

Women’s voices point to unacceptable triaging procedures during ANC. They explained that health workers attended to them on a ‘first-come-first-served’ basis with no consideration for their physical disabilities.

“There is no difference that these [women] have physical disabilities and the other ones don’t have physical disabilities. So, you won’t skip the line [queue] because you have a physical disability” (Grace).

They reported that the health workers would only attend to them first if the health workers saw that they were severely disabled, yet some physical disabilities may be hidden and not seen by the health workers. Jolly reported that she had to convince them that she has a physical disability for her to be attended to first. Women with physical disabilities do not want to be regarded as normal because they have specific needs for assistance.

“They look at you [consider you] as a person who is "normal". For you even if you are in your wheelchair, pregnant with the tummy touching [extended to] your mouth, if they see that you are not in pain, it means you are ‘normal’” (Mary).

Sometimes women were asked by the health workers to pay before being attended to for ANC services which are supposedly free, even though the women do not have money. Indeed, if such services were free, then “*what was the money for?*”, Jolly wondered about being told to pay.

Contrary to the women’s views above, midwives reported that they carry out triage to identify women who need urgent attention, and this is when women with physical disabilities would be identified.

“We do triage, we assess at-risk mothers” (Midwife 4).

Midwives pointed out that in some departments, such as the laboratory and pharmacy, health workers financially exploit women. They ask women to pay them for the services which are actually free, before attending to them. This situation worries and scares the women, although they still go to the health facility. Midwife 4 remarked:

You see some health workers, they come [to their workstations] but before you give them money, they will not work on you. So, imagine she is coming to the health facility, she is even not sure whether they will touch her [attend to her] because she has no money. So, even when she is seated there [waiting], she is even scared. You say next [for the next woman to enter the examination room, and she does not enter] until she is the last.

6.2.3 Subtheme 3: Unaccommodating health facility designs

‘Unaccommodating health facility designs’ incorporates data from women and midwives and audit of the physical infrastructure and equipment at the health facilities. Limited access to the physical environment, inaccessible furniture and equipment, and suitability of the sanitary facilities emerged as the categories. All three sources of data highlighted these categories.

6.2.3.1 Limited access to the physical environment

Women encountered limited access to the physical environment, which was worse when they had no carer. They highlighted the need for disability support personnel at the health facilities for them to access different service points. Some women noted:

“... a health worker will not treat you and at the same time be your attendant when they are not related to you” (Mary).

If a woman is alone, and may be in a wheelchair, she gets challenges. She must have a person that she can go with so that in case she fails [to manoeuvre the wheelchair] somewhere, that person pushes her. If she has crutches and she reaches a slope and she fails [to move], that person supports her. (Esther)

Midwives indicated that the health facility designs are not accommodative and that there is a need for accessible buildings. They suggested that health facilities should have accessible labs and pit latrines. Midwife 3 noted:

“... like here [at the health facility] it is not easy for a person in a wheelchair to move from here to access the lab [in out-patient department]. So, these government facilities, if they are to construct them, they should make sure that every building is accessible by the disabled person”.

From the independent audit of the physical environment at the health facilities, it was noted that pregnant women with physical disabilities may encounter challenges in manoeuvring through the physical environment at the health facilities. Limited physical access at the health facility compound and within the buildings was noted as a barrier to utilisation of the ANC services. This limited physical access can sometimes pose hazards, such as tripping. One of the health facilities did not have parking space, and the two that had did not have designated parking areas for persons with disabilities. While there were pathways, some were unpaved and slippery, and in some areas, there were no clear pathways connecting buildings. Some of the available ramps were steep and had worn-out edges. Not all the walkways had handrails, especially those to the pit latrines. In some areas, women made their own footpaths through the grass.

The pictures below (Figures 6.2, 6.3 and 6.4) illustrate the limited access to the physical environment at different health facilities.

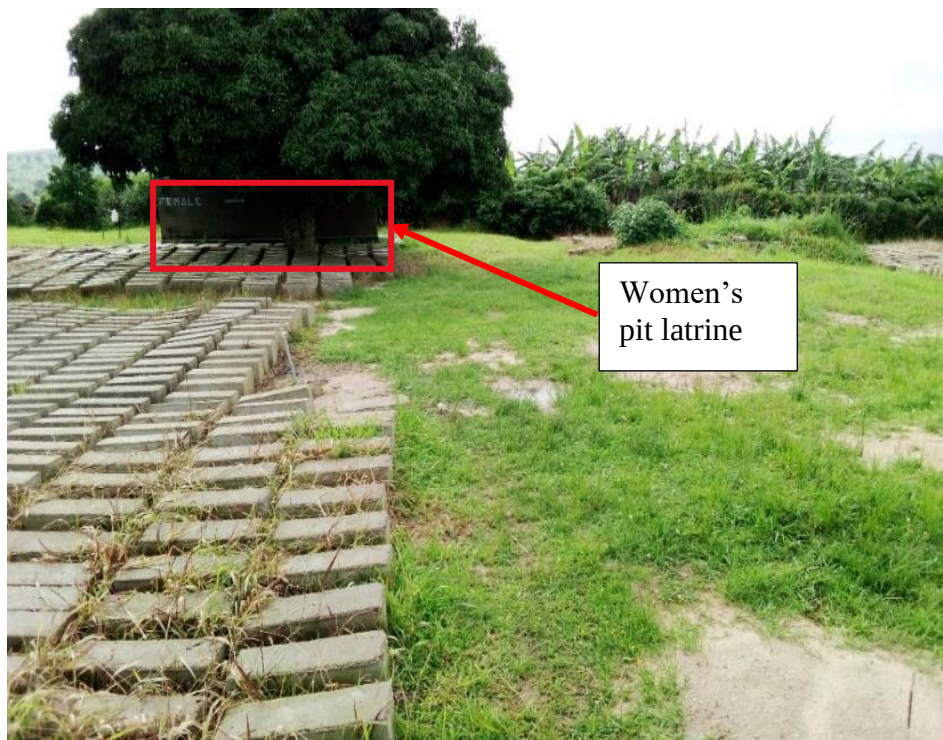


Figure 6.2: Unclear pathway to the pit latrine (behind the mango tree) and bricks laid out to dry in the compound (Source: Field photo)



Figure 6.3: Footpath to the pit latrine away from the ANC clinic (Source: Field photo)



Figure 6.4: Walkway to the ANC clinic with a steep ramp and no handrails (Source: Field photo)

An audit of the physical environments further revealed that some health facility buildings were insufficient and inappropriate for ANC services for women with physical disabilities. Some buildings had narrow entrances (about 0.8 metres wide), limiting access for a pregnant woman on crutches or in a wheelchair. At health centres III and IV, the waiting areas at the ANC clinic were incommensurate with worn-out floors.

At health centre (HC) III, the waiting area was in the corridor of a building where perinatal services, immunisation services, and the ANC clinic were housed. There was one bench along the corridor where pregnant mothers waited for ANC services (see Figure 6.5). The same corridor was used by all the staff and clients accessing and using the other services in the building. The corridor was about 1.2 metres wide and 6 metres long. The entrance to the ANC room was in the middle, along that corridor. The bench in the corridor was near the entrance to the ANC room, leaving a small space for people to walk to and from the immunisation room and labour ward, which were at the far end of the corridor. The space in the corridor was inadequate for pregnant women to be able to move and would be worse for those using wheelchairs.



Figure 6.5: Corridor used as a waiting area where women wait for ANC care at one of the observed health facilities (Source: Field photo)

6.2.3.2 Inaccessible furniture and equipment

Women pointed out that the health facility furniture was inaccessible. They indicated that there were not enough benches in the ANC clinic and lab waiting areas. They had to improvise seating, sitting uncomfortably on the floor and waiting unbearably for the ANC services.

In some places you find like three or four benches and the rest you lay your cloths down and sit on them” (Happy).

“... whether you sit down there [on the floor] or you remain standing if you can manage standing, there is no one who will squeeze herself to create space for you space just because you are disabled, no” (Mary).

They revealed that the health facility seats were also inappropriately high for pregnant women with physical disabilities. When the seats are at an appropriate height, the surfaces are hard and uncomfortable for the women. Esther remarked:

There is a person who might have legs stopping here [showing above the knee/above the knee amputation] or you might find both are very small when she is just walking with arms. For sure, don't you see that such a person, when she is going to sit in a chair [or bench], it may take her time? She lays down [a cloth] because she can't reach the chairs.

Women explained that to climb onto the couches for the physical examination, there were wooden steps or a wooden stool provided as a measure for them to reach the examination beds, which are not height adjustable. They indicated that these steps or stools were not stable and there were no supports to enable them to climb onto the examination beds. They also revealed that some health facilities did not have such interim measures and the pregnant women manoeuvred on their own to climb onto the beds. *"What do you do? You persevere!"*, Esther remarked with despondency, underscoring the precariousness of their situation in accessing and using examination beds. Women also noted that the examination beds are too narrow to accommodate a pregnant woman with physical disability and one could easily fall off.

"... the bed is like this desk [pointing to a classroom desk during the FGD], you can't fit there" (Happy).

"Whenever the health worker would tell me that 'climb here and we examine', I would think to myself that maybe they get a cloth and put me down! Remember I would just lift the leg [to walk]" (Jolly)

Contrary to the women's views, midwives noted that there were enough seats in the waiting areas at the ANC clinic, dispensary, and laboratory as women do not all come at the same time. However, they also observed that the health facility seats were inappropriately high for some pregnant women with physical disabilities.

"My dear, it is too much [challenging], ... she would not manage like to lift herself from the floor to sit on those benches of ours outside [in the waiting area]" (Midwife 6).

Midwives noted that the examination beds were not height adjustable, and hence not fit for pregnant women with physical disabilities. The women had to be supported and/or lifted onto the examination beds, sometimes with the help of the woman's attendant, if available.

"...as a person I realised that we are lacking something as a facility. We should be having an antenatal bed for the disabled women" (Midwife 3).

"... I called the husband to help me. We lifted her together, ... put her hands around us, me and the husband and lifted her to the bed" (Midwife 6).

Even the couches [examination beds] ..., there are no provisions [supports]. They are the normal ones [ordinary beds]. We have the wood-made ladders [steps made of wood used for climbing onto the examination bed]. Even these other women who are "normal" may find it hard. However, you may find a client who is so disabled, even that ladder [wooden steps] may not be enough [may not be appropriate]. The beds that we have are not height adjustable, we only adjust the back [back-rest]. (Midwife 4)

During the audit of the physical environment at the three health facilities (HC III, HC IV, and general hospital), it was noted that benches were inappropriate for pregnant women with physical disabilities (see Figure 6.6 below). At HC IV and general hospital, the benches in the waiting areas in the out-patient departments where the laboratory and dispensary were housed were made of concrete, measuring about 0.6 metres high and 0.4 metres wide (see A of Figure 6.6). In the ANC clinic waiting areas, there were wooden benches in all the three health facilities (see B of Figure 6.6) measuring 0.6 metres high and 0.4 metres wide on average.

The examination beds had no provisions to support the women to climb onto them. They were metallic and not adjustable, measuring about 1 metre high and 0.6 metres wide (see Figure 6.7 below). There were stools or wooden stairs on the floor near the beds to aid pregnant women in climbing onto the bed. Each stool measured about 0.4 metres high, 0.3 metres wide, and 0.35 metres long (see A of Figure 6.7). The stairs were made up of two steps, each step measuring about 0.3 metres high, 0.3 metres wide, and 0.4 metres long (see B of Figure 6.7).



Figure 6.6: Benches used by pregnant women in the waiting areas at some of the observed health facilities (Source: Field photos)



Figure 6.7: Non-adjustable examination bed (A) and wooden stool/steps (B) used by pregnant women during ANC (Source: Field photos)

The audit of the health facilities also revealed that some health facility equipment was inappropriately designed and unsuitable for use by pregnant women with physical disabilities. For instance, the weighing scale (about 0.5 metres by 0.3 metres in size) for measuring the pregnant mothers' weight was placed on the floor in the waiting area, with a vertically attached metallic tape measure for measuring height, only designed for mothers who can stand. The tape measure is pulled from the bottom (at the base of the weighing scale, where the woman's feet rest while standing to be measured), upwards (to their head) along the height of the woman standing close to the weighing scale (see Figure 6.8 below).



Figure 6.8: Weighing scale with an attached height measuring tape, in an ANC clinic at one of the observed health facilities (Source: Field photo)

6.2.3.3 Unsuitable sanitary facilities

Women recounted difficulties in using sanitary facilities at the health facilities. There were no supports in the latrines and squatting was hard for them. They indicated that they would struggle to use the latrines if they did not have a carer. Joyce described it as *“a tug of war”*. Even when they managed to squat, *“getting up would be difficult and can easily fall”* (Esther). The situation worsened as the pregnancy progressed.

“Now like me, I can’t sit or squat to use a pit latrine ... because squatting is hard for us. When I go to ease myself, I have to be standing” (Hope).

“... when the pregnancy is old, you can’t squat, you hurt in the thighs. You feel like you need support, but where can you touch? There is no support” (Kate).

They decried the unsafe sanitary conditions at the health facilities. They reported that the latrines were soiled and unfit for use by a pregnant woman with physical disabilities. They noted that the same latrines were used by all the women and girls at the health facility, and

that they could easily contract infections from such latrines. With a heavy heart, Philly remarked:

“They were badly off [soiled] but I went there because I had nothing to do”,

... you can't even get where to step! Sometimes you be patient [hold the urine] and wait until you go back home and use your own toilet [latrine] but you feel pain I would rather go back home, instead of getting diseases from there. (Hope)

Midwives noted that the latrines were located outside, away from the ANC clinic, and were not easily accessible to pregnant women with physical disabilities. There were no supports in the latrines. *“I don't think it [the latrine] favours them”* (Midwife 1). *“In case she wants to go for a short call, it can be tough [for her]”,* Midwife 3 remarked in a sympathetic tone. Despite this, women are sometimes sent to these facilities to collect either urine or stool samples for lab tests.

“When she is here [at ANC clinic], she uses the same latrines as the other patients. They are behind there [pointing behind the maternity ward]. Just a few meters [about 300metres] from here. They pass through grass [no clear pathway]” (Midwife 2).

Midwives agreed with women that the sanitary conditions were deplorable. The sanitary facilities were unhygienic and unsafe as they might lead to the acquisition of certain infections, such as urinary tract infections. Midwife 5 remarked:

“... because when they go there [to the pit latrines], the place is all dirty, they don't have shoes, the whole thing becomes filthy”.

An audit of the physical environment at the health facilities showed that there were no supports in the latrines used by women with physical disabilities. The latrines at all three observed health facilities had limited space inside to allow for a wheelchair to be turned around and to accommodate the pregnant woman's altered centre of gravity. Unsafe and unhygienic sanitary conditions were glaringly evident. In some latrines, the concrete floors were soiled with human excreta. At some latrines, there were no handwashing facilities. Others had foot operated tippy-taps for washing hands (erected outside the latrines) which were unsuitable for wheelchair users.

6.3 Discussion: Unresponsive antenatal care policy to the women's specific needs

It was evident that ANC policy was unresponsive to the specific needs of rural pregnant women with physical disabilities. This unresponsiveness was reflected in the fragmented nature of ANC services, the frequency of ANC appointments, disregarding women who were without an accompanying male partner, and unacceptable triaging procedures. Moreover, the health facility designs were unaccommodating to women with physical disabilities due to limited access to the physical environment, inaccessible furniture and equipment, and unsuitable sanitary facilities. From the Three Delays Model (Thaddeus & Maine, 1994) point of view, these findings are situated in phase III of the model – receiving appropriate and adequate ANC services.

6.3.1 Integrated nature of ANC services – unaffordability and unavailability

Despite the government ANC policy that emphasises universal access to ANC services which are free at the point of service, and which is enshrined in the Uganda National Minimum Health Care Package (UNMHCP) (Ministry of Health, 2015), women encountered direct and indirect costs in utilising ANC services in public health facilities. Some women were required to make informal payments pay for supposedly free services for them to be attended to, especially at the laboratory and pharmacy service points. Many indicated that they would have loved to do an ultrasound scan to understand the health status of their unborn babies but could not afford to because the service was not free and their finances were limited. This is consistent with the systematic review and meta-analysis study by Tekelab et al. (2019), which found that income improves a person's ability to afford and utilise ANC services. The 2021 report on National Services Delivery Survey in Uganda indicates that, although 86% of all women sought ANC services from government health facilities, some women (6%) paid for these services (Uganda Bureau of Statistics, 2021) even though they should have been free. Free ANC services in government health facilities in rural areas would enhance their uptake by women with physical disabilities (Ajaegbu, 2017).

In this study, the findings are consistent with the evidence that, despite inherent synergies and overlaps in actions to realise universal health coverage and health security, the current approach at both the global and national levels is disjointed (Wenham et al., 2019; WHO,

2021). For example, in this study, the evidence for this disjointedness is reflected by the irregular and inadequate supply of essential drugs and supplies, poor referral and ambulance services and the high cost of ultrasound scanning services. The actions in the implementation of ANC services were in contravention of the WHO (2021) position paper on *'building health systems resilience for universal health coverage and health security during the COVID-19 pandemic and beyond'*, which seeks to integrate the promotion of universal health coverage and ensure health security, underscoring Primary Health Care as a precursor for achieving universal health coverage. The paper stresses that people should be able to use essential health care services, including ANC services, when they need them without suffering financial hardship, and recommends the implementation of accessible and 'safe health facilities' programmes at all levels of the health system (WHO (2021)).

In their study about antenatal doppler ultrasound implementation in rural mid-western Uganda, Ali et al. (2021) argue that women need to accept and use ultrasound scans during ANC to improve their health and that of their unborn babies, although the study did not include women with physical disabilities. In the Lancet Maternal Health Series, Miller et al. (2016) argue that the over-medicalisation of pregnancy and childbirth (referred to as Too Much, Too Soon) is becoming a common practice and can include the excessive or inappropriate use of interventions with no evidence of benefits. The authors suggest that this reflects weak regulatory capacity and little adherence to evidenced-based guidelines. In this study, women with physical disabilities wanted to do an ultrasound scan due to their desire to ascertain the health status of their unborn baby, perhaps due to the fear that their unborn baby might also have an impairment (see Chapter Five, section 5.2.1.2). Such fear could be attributed to the dehumanising attitudes in the community that the women are different beings and 'unfit for marriage and childbirth' as discussed in Chapter Five, section 5.3.2.3.

Related to the unaffordability of ultrasound scan services was the unavailability of drug and medical supplies, requiring women to buy the prescribed drugs and the needed ANC medical supplies from private pharmacies. Drugs and medical supplies appeared to be inadequately budgeted for as the government supplied less compared to the population served. Similar to the findings of this study, in a study by Kyaddondo et al. (2017) on the expectations and needs of Ugandan women that need to be met in order to improve the quality of childbirth care in health facilities, the women reported that money is a necessity and that maternity care is poor for someone who is poor. The study further revealed that women paid health workers

for clinical supplies or to guarantee that they would be attended to by a skilled staff member.

In Uganda, the gap between ANC policy and its implementation emanates from “inadequate financial and human resources, capital investment and management issues” in the public sector, as highlighted in the National Health Policy II (Ministry of Health, 2010a, p. 7). The unavailability of drugs and medical supplies puts a strain on women’s already constrained finances. However, the unavailability of drugs is a health system issue in terms of budget and supply chain management. It is not specific to pregnant women with disabilities but affects all pregnant women and other users. It is the greatest concern about access to services in public health facilities in Uganda (83%), followed by long waiting times (59%), travelling long distances to health facilities (52%), limited range of services (54%), and limited staffing (53%) (Uganda Bureau of Statistics, 2021). Nonetheless, the implications of a lack of stock may affect women with physical disabilities differently to other pregnant women because of the precarious situation women with physical disabilities find themselves in.

A study in rural Nepal showed that the cost of services and delayed and inadequate drug and medical supplies are common problems for both women with and without disabilities in utilising maternal health care services (Devkota et al., 2018). It is noteworthy that an improvement in the system would benefit everyone. Likewise, the WHO ANC model shows that continuity of care, integrated service delivery, availability of supplies and commodities, and empowered health care providers are essential requirements for the effective implementation of ANC (WHO, 2016). Notably, all the issues highlighted affect all pregnant women. This points to the prevailing poverty among the general population in the country. However, women with physical disabilities are more vulnerable than their non-disabled counterparts.

The findings of this study are consistent with the evidence presented in The Lancet (2019) that the affordability of health care services by women with physical disabilities is an obstacle to their utilisation of ANC services and to the realisation of universal health coverage. Women with physical disabilities tend to be poor, have more health care costs, and are more likely to experience catastrophic health expenditure than their non-disabled counterparts (The Lancet, 2019). Moreover, this study’s findings indicate that some women with physical disabilities have low levels of awareness, perhaps due to their limited access to formal education. It is possible that these women are disproportionately less likely to have

any formal education or that they have fewer years of formal education than their non-disabled counterparts. Some researchers have concluded that the intersectionality between their physical disability, poverty, and gender contributes to poor pregnancy outcomes (Moodley & Graham, 2015), hence the need to understand their lived experiences to provide comprehensive ANC interventions.

6.3.2 Unresponsive antenatal care policy and power relations

While evidence shows that more ANC visits save lives (WHO, 2016), in this study, women pointed out that making eight ANC visits is burdensome as it constrains their “pockets” (finances), given the transport and mobility challenges they encounter trying to access and utilise ANC services. The more ANC visits they make, the more costs they incur related to transport, antenatal provisions, and preparation for the ANC visit. In addition, women indicated that the intervals between these appointments were too short for one to adequately prepare materially and financially for the subsequent ANC visit. Surprisingly, while midwives were aware that a woman’s social economic status at family level influenced the availability and sufficiency of such antenatal provisions and consequently influenced her decision to seek ANC, they did not take women’s economic status into consideration when scheduling their ANC appointments. It is important that the ANC targets are achieved through accommodative strategies, such as community ANC outreaches, without discriminating and unfairly treating the very people the policy is meant to benefit.

In addition, the study findings point to women’s vulnerability. Their vulnerability underscores the irony of women wanting to be regarded as “not abnormal”, which is then used against them when there are specific needs for assistance. Surprisingly, midwives indicated that they prioritised women with physical disabilities during triage, although most women expressed dissatisfaction in their experiences regarding the triaging procedures. Women indicated that it was ‘first come first served’, a principle that applied to all women irrespective of whether one had a disability or not. In other words, midwives were not paying attention to the specific pregnancy needs and concerns of women with physical disabilities.

The Ugandan Ministry of Health (2022), in the ‘Essential Maternal and New-born Clinical Care Guidelines for Uganda’, and WHO (2016) recommend eight ANC contacts for every woman during pregnancy and less than two kilometres as the maximum distance someone

should need to travel to access the ANC. Contrary to this WHO recommendation about distance, the “average distance to a government health facility is four kilometres” in Uganda (Uganda Bureau of Statistics, 2021, p. 89). From this study’s findings, only a part of these recommendations is being heeded in this policy, putting the burden on the users, not the government – which has an obligation to provide and equip the health facilities.

The findings concur with Wong et al. (2017) systematic review and meta-analysis of physical access to skilled care for childbirth in Sub-Saharan Africa, which found that, in rural Uganda, difficulty in physically accessing health facilities impedes the utilisation of ANC services. The authors argue that utilisation is conditioned on access. This chapter further exposes women’s vulnerability which results from their intersecting identities. Similar findings were found in a study in rural South Africa by Grut et al. (2012), in which persons with disabilities in resource-poor settings faced challenges in utilising health care services.

A gap between ‘the male involvement policy’ and its implementation was revealed. Although the idea of husbands accompanying their wives for ANC is well intentioned in the context of men as responsible partners of women, gatekeepers, and decision-makers for prompt access to ANC services (WHO, 2015), limited understanding of the policy by the midwives resulted in unintended consequences. Interestingly, women believed that their partners were needed during ANC for HIV couple’s counselling and testing, contrary to midwives’ view that they were advocating for male participation and involvement in pregnancy care. Notably, not every pregnant woman had a partner and, more so, getting pregnant does not equal partnership or marriage. This points to a mismatch between intention and outcome, perhaps due to ineffective communication or interpretation of the intention of the policy but also worryingly reveals strong overtones of patriarchy. It also gives falsehood to the fact that the midwives are advocating for male involvement. It does not speak to an engaged male partner (who will support the woman through her pregnancy and childbirth) if the women are told by the midwives to bring the *boda boda* riders or any random man to accompany them at the appointment (see section 6.1.2.2 above). There is a need for midwives to understand the sociocultural context and power dynamics underlying male involvement in ANC services for women with physical disabilities in rural south-western Uganda.

Similar to this study’s findings, a study by Gopal et al. (2020) on male involvement in reproductive, maternal, newborn, and child health in Uganda found that women appear at the

health facilities with random men, such as *boda boda* riders, just to beat the queues during ANC. This is because midwives disregard women who are without an accompanying male partner and prioritise those with a partner. This practice points to the low level of power of and disrespect for a woman without a male partner, which absolutely needs to be addressed in the ANC policy. Such unequal power and disrespect for women flouts the ethos of midwifery care that promotes equal partnership, respectful and flexible care, women's participation, and informed decision-making on matters regarding their health, as enshrined in the International Confederation of Midwives (ICM) philosophy and model of midwifery care (ICM, 2021). In addition, WHO (2015) emphasises that male involvement interventions should be “implemented in a way that respects, promotes women's choices and their autonomy in decision-making and supports women in taking care of themselves and their new-borns” (p. 17).

The findings of this study are similar to those in a study carried out in rural Tanzania in which men highlighted the social stigma associated with HIV testing and traditional gender norms and roles, as well as limited family resources, as being prohibitive to male involvement in ANC services (Boniphace et al., 2022). Mitra, Smith, et al. (2017) recognise the unresponsiveness of the ANC policy to the specific needs of the women in their study exploring barriers to providing maternity care to women with physical disabilities from health care providers' perspectives in the United States of America. They note barriers related to the practitioner, clinical practice, and system levels, including those related to appointment scheduling constraints and insurance reimbursement policies in maternity care services for women with physical disabilities. Their study highlights the need for practice guidelines, and education and training of midwives regarding the maternity care needs of women with physical disabilities. Importantly, this study brings to the fore the voices of rural women with physical disabilities utilising ANC services that are silent in the current literature on the utilisation of ANC care services, as most studies focus instead on respectful intrapartum care.

The inadequate training of midwives and absence of guidelines for implementation could be linked to the poor implementation of the male partner involvement policy in maternal health in Uganda, as suggested by Gopal et al. (2020), and in Lesotho, as identified by Vian and Bicknell (2014) in their study that investigated good governance and budget reform in Lesotho public hospitals. Although these studies did not focus on women with physical

disabilities, issues identified therein are pertinent to male involvement in ANC services for this group of women in rural south-western Uganda.

6.3.3 Unaccommodating health facility designs

The findings revealed unaccommodating health facility designs associated with limited access to the physical environment, inaccessible furniture and equipment, and unsuitable sanitary facilities. Remarkably, there were no supports for pregnant women with physical disabilities to help them in maintaining their balance when climbing onto the examination beds. Such unaccommodating designs made it difficult for them as they had to maintain good body balance when climbing onto the beds, possibly leading to accidents.

In this study, the findings are consistent with those of Apolot et al. (2019) in their study conducted in Eastern Uganda in which they reveal that women with physical disabilities have infrastructural needs while accessing and utilising maternal and newborn health care services. Their needs were related to accessible examination beds, seats, and pathways at the health facilities. Interestingly, similar studies in South Africa (Mgwili & Watermeyer, 2006), a middle-income country, and in the United States of America (Iezzoni et al., 2015; Mitra et al., 2016), a high-income country, have described inaccessible health care facilities and equipment, such as examination beds (which are not height-adjustable), chairs/benches and weighing scales, as barriers to the utilisation of ANC services by women with physical disabilities. In another study conducted in rural Nepal, Devkota et al. (2018) found that none of the health facilities accommodated the needs of women with disabilities with accessible buildings, although their study focused on intrapartum care.

The unaccommodating health facility designs contradict the accessibility standards stipulated by the Uganda National Action on Physical Disability and Ministry of Gender, Labour and Social Development (2010), the ICF (WHO, 2001) and Article 9 of the UNCRPD (United Nations, 2006), which emphasise women's full independence and participation in all aspects of life, and the access to facilities and services provided to the public, including in rural areas. It also highlights the need to consult with the community of persons with disabilities when designing facilities, as reflected in the slogan "nothing about us without us". The practice also

contravenes the Principles of Universal Design²⁴ as put forward by Story (2001), which prescribe how to promote usability and inclusivity for everyone (Sanford, 2016).

In addition, the suitability of sanitary facilities was challenged by both women and midwives. Fundamentally, one expects a health facility to not cause harm or danger to a person. One also expects a public facility to adhere to health and safety standards, including hygiene. Clean, accessible, and private sanitary facilities are essential for all pregnant women, whose bladder capacity is reduced in later pregnancy, and who are usually required to produce urine specimens to test for certain danger signs in pregnancy. Of interest is that, in Uganda, almost half (47%) of the toilet facilities were identified as inadequate, worse in rural areas (50%) than in urban areas (38%), in the 2021 National Service Delivery Survey Report (Uganda Bureau of Statistics, 2021). In addition to this, depending on the severity and nature of their physical impairment and mobility difficulties, some pregnant women may be more vulnerable and exposed to infections. Moreover, the handwashing technologies were not appropriate for them after visiting the latrines.

6.4 Conclusion

Women faced difficulties utilising ANC services related to disjointed ANC services, unresponsive ANC policy, and unaccommodating health facility designs. This chapter has exposed the mismatch between the intended practice and the outcome in the delivery of ANC services for pregnant women with physical disabilities. In addition, study findings point to unequal power relations between midwives and women as well as disrespectful ANC, which should be addressed in midwifery education, training, and practice.

²⁴ The Centre for Universal Design at North Carolina State University defined Universal Design as the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design. The seven principles of Universal Design are: 1. Equitable Use; 2. Flexibility in Use; 3. Simple and Intuitive Use; 4. Perceptible Information; 5. Tolerance for Error; 6. Low Physical Effort; 7. Size and Space for Approach and Use (Story, 2001).

CHAPTER 7:

IMPROVING QUALITY OF ANTENATAL CARE SERVICES: FINDINGS AND DISCUSSION PART 3

7.1 Introduction

In this chapter, the study findings for objectives three and four will be presented. The objectives were:

- to explore the relationship between women with physical disabilities and health care providers during ANC in rural south-western Uganda.
- to explore how women with physical disabilities and midwives understand disability and the provision of ANC services in rural south-western Uganda.

From the data analysis, the theme ‘Improving quality of ANC services’ was generated with three subthemes: 1. Women’s mixed experiences of midwives and other health workers, 2. Preparing midwives and other health workers, 3. Enabling disability inclusion. These subthemes and their categories are illustrated in Figure 7.1 below. In the presentation of the findings, under each category, women’s perspectives come first followed by those of midwives for better understanding of what women said. Then, a discussion of these findings follow. This has helped me to understand and contextualise women’s experiences of health workers and how health workers understand disability and provide ANC services to them.

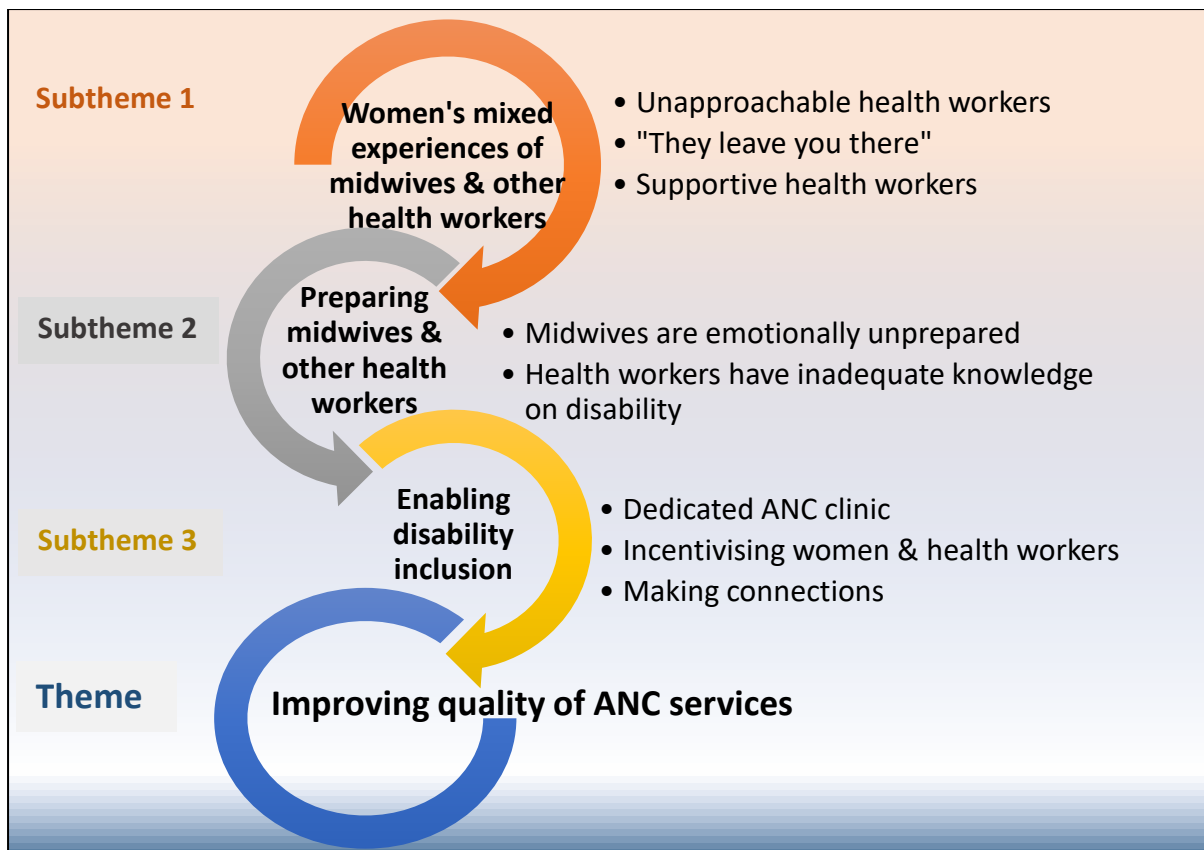


Figure 7.1: Improving quality of ANC services

7.2 Theme: Improving quality of ANC services

The theme of improving the quality of ANC services includes women’s mixed experiences of midwives and other health workers, preparing midwives and other health workers, and enabling disability inclusion in ANC services.

7.2.1 Subtheme 1: Women’s mixed experiences of midwives and other health workers

Women expressed mixed experiences of midwives and other health workers. The identified categories under this subtheme are unapproachable health workers, “they leave you there”, and supportive health workers. All these three categories (as mentioned in Figure 7.1) were described by both women and midwives.

7.2.1.1 Unapproachable health workers

There was a feeling among women that health care providers were unapproachable. They described them as merciless, humiliating, rude, intimidating, and abusive.

“... but there are those [health workers] you find unapproachable” (Jolly).

“If they [midwives] can tell you to climb [the examination bed] ... and even climbing you find them talking to you rudely that ‘what did you come to do if you knew that you can’t climb the bed?’” (Mercy).

“You suffer [when traveling to the health facility], you walk and end up being caught up by time. They don’t want to feel compassion for you and eventually they abuse you [for arriving late]” (Esther).

Joyce revealed that she witnessed a scenario where a pregnant woman with physical disability was mercilessly chased away by the midwives because she was not clean and presentable enough. She recalled:

...another woman [with physical disability] had also come for antenatal care, I was the one following her, when she reached, was checked and was found too dirty [wearing dirty under garments]. She was brought back and humiliated amidst all of us who were present there. ... "that you go back home". The woman got up and went home.

Mercy observed; *“she could have been poor and needy”*, possibly with no carer at home.

Midwives’ comments reflected the same views as the women that some health workers are unapproachable. With sadness, some midwives acknowledged that sometimes women justifiably anticipate intimidation and mistreatment from health workers. They observed that some health workers have a negative attitude, which hinders the utilisation of ANC services. Midwife 4 remarked:

When these women come to the health facility, they expect [anticipate] intimidation, some of them are scared. But I think what would make them get scared is that they are not sure of how the health workers will look at [treat] them.

Midwives suggested that some health workers may behave negatively towards women when the workers are tired due to work overload or transference of their own domestic problems while at work.

“It happens sometimes [and some midwives behave negatively towards women] when they are tired... Here we are few midwives. We carry out antenatal, family planning, and immunisation. Here you will do everything” (Midwife 3).

“...some of us carry our issues right from home. ... problems of money and also having nothing [no presentable clothing] to put on, so with such attitude we have them [unapproachable midwives] here and they behave terribly” (Midwife 6)

7.2.1.2 *“They leave you there”*

Women reported that they spend long hours waiting to be attended to. Even when they are in pain and weak, they are not given the attention they deserve. Health workers attend to them without paying due attention to their physical disability. Sometimes, they are attended to late even when they reported early at the clinic. Hope suggested that *“...people with [physical] disability should be worked on early because sitting for a long time hurts them.*

“If they are not used to issues of disability, they leave you there. You stay there and you are in pain, and they attend to the ones without a disability” (Philly).

.... really, why can't they see you as one who is disabled and attend to you very first. Why do they first put you on the chair and you first sit when you are in pain, hmm? They leave you there..., they attend to the one [without disability] who has just arrived and then for me the disabled one remains on the chair seated. You stay there and be the one to be attended to at the end. (Jolly)

Midwives indicated that women are served based on the principle of *“first come first served”*. Midwife 3 noted that it is easy to initially miss a woman's disability and only notice it during physical examination. They felt that women spend a lot of time at the laboratory when sent for tests, and therefore returning home late even though they reported early to the ANC clinic. *“The turn-round time for those investigations [is long]”,* commented Midwife 4.

7.2.1.3 Supportive health workers

Although many women reported that they experienced unapproachable health workers, some women indicated that sometimes health workers were supportive and caring. *“They gave me good care”* (Hope). They indicated that health workers were welcoming and compassionate. Women felt that they were treated well, sometimes better than their non-disabled counterparts.

“Every time I would go there, they wouldn’t treat me bad. ...whenever I would reach, they would quickly attend to me”, Esther recalled.

Esther noted that she was treated well possibly because health workers were already aware of her physical disability as she had previously been to the same health facility for the treatment of other general medical conditions. Another woman explained:

...the health workers would receive me when I reach like this, work on me and sometimes they would tell me that you go back and reach home early ...personally, I attended antenatal care up to the end without being talked to rudely. I think they feel compassion for a person with a physical disability. ...They treat you well if you find them fine [in good mood]. (Joyce)

Midwives reported that they give priority to women with disabilities during ANC and that they do not discriminate against them. They felt that they were welcoming, supportive, and encouraging to women and that women were appreciative of the care provided. Midwife 3 noted that the care and support depend on the health workers’ attitudes because they are not all the same. Some midwives reported:

“...when you see this mother, you know what she is going through. There is that feeling you get, “if I was the one”, and you feel you should assist her whenever she needs help” (Midwife 2).

Of course, for us, the health workers, we welcome them as they are. We are empowered, we know what it means. Being disabled does not mean you are not supposed to get services like others, so we have to make her priority and we work on

her. We help them in case she fails to go there [on the examination bed], you have to support her and put her on the bed, we encourage her to come back again. (Midwife 5)

7.2.2 Subtheme 2: Preparing midwives and other health workers

Two categories emerged under this theme: ‘health workers have inadequate knowledge on disability’ and ‘midwives are emotionally unprepared’. The former was described by both women and midwives and the latter was described by midwives only.

7.2.2.1 Health workers have inadequate knowledge on disability

Women revealed that some health workers have inadequate knowledge on disability. Women suggested that continuing education on contemporary disability issues be provided for midwives to improve ANC services for pregnant women with physical disabilities.

“There are some health workers who don’t understand well the issues concerning disability” (Esther).

“...if they [health workers] understood what disability is, then they would say let us first attend to the disabled one and then we handle the other one without disability [later]” (Philly).

“When you reach there, they don’t want to know [don’t appreciate] that you’re disabled, yet, you don’t have all the necessary care and support...” (Joyce)

Midwives echoed similar views as the women that some health workers do not understand disability issues well. Many indicated that they had never thought of disability inclusion in ANC services.

“Some of us have a knowledge gap” (Midwife 2).

“...honestly, I had never thought about it ...maybe because I had never taken much interest. I had never been keen” (Midwife 4).

They also felt that the issue of disability inclusion in ANC services is under researched locally. They revealed that they did not have documented data on the demographics of women with physical disabilities who attended ANC.

... we had never gotten such kind of people [researchers] coming to us [investigating disability issues]. Today it would have been best for you [the researcher] because you would be having some references [baseline data] to follow, now no one had ever come to ask us about such issues. We would work on them [pregnant women with physical disabilities] and just let them go [without recording details about their disabilities]. ...now that you have come, you have sensitised our brains. (Midwife 6)

7.2.2.2 Midwives are emotionally unprepared

Midwives indicated that they were emotionally unprepared to care for women with physical disabilities. They expressed feelings of fear and uneasiness in caring for a pregnant woman with physical disability. They highlighted that it is a painful experience, which requires one to be emotionally prepared.

“First of all, I also got scared. I thought eh! This person, will she make it? Will she deliver? How am I going to handle this person?” (Midwife 3).

...we could help her and bring her to the [examination] bed but it [the experience] is painful and it hurts, not every midwife can do it. But the attitude is the cause as to why one cannot do it and practically some of them may not have seen such cases during their practice. The first time I helped her, eh! It was hard, you know! (Midwife 6)

They noted that emotional unpreparedness is compounded by the negative attitudes of women exhibited towards health workers.

“Even the attitude of these mothers [towards health workers] is not good, ... she [midwife] also feels demotivated” (Midwife 2).

7.2.3 Subtheme 3: Enabling disability inclusion

The categories identified under this subtheme were dedicated ANC clinic, incentivising women and health workers, and making connections. The first category emerged from both women's and midwives' data, while the last two categories were from the midwives' data only.

7.2.3.1 Dedicated ANC clinic

Women suggested that health workers need to be considerate, paying attention to the women's extra health care needs during ANC. They indicated that they need to be attended to first so that they can return home early enough. There was a feeling that a physically disabled pregnant woman with other co-morbidities needs an accommodative health workforce. They suggested that the ANC services should be appropriate and adequate.

"They [health workers] should know that we have disabilities and then give us the care we deserve" (Hope).

...a person [woman with physical disability] with hypertension when you add in pregnancy, it becomes a different story. So, the care needs to be good [appropriate]. When they reach, they should get enough [adequate] care services like finding the health workers there so that when you arrive, they see you [attend to you] as a person with a disability, quicken the process for you and you look for how to go back home. Whether she gets a boda boda, walks or hires a car but night-time [darkness] should not get her outside home. (Esther)

They also suggested that a deliberate ANC programme for pregnant women with physical disabilities should be designed with a special, separate examination room. In the same way that people with diabetes mellitus or HIV/AIDS have specific clinic days and spaces, they feel that similar accessible spaces with a dedicated health workforce should be created for them.

...they should put a special room for the disabled in every hospital; so that we also get services and easily get helped whenever we visit them. Because it's always hard for us to crawl on the cement [sitting and queuing on cement benches in waiting

areas] and even when you reach there, you get chased away that you're dirty. At least if they chase you early, you go home, clean up and come back and catch up with time, because you will have wasted a full day. (Esther)

However, other women were opposed to having separate ANC spaces, indicating that such segregation may create envy and acrimony among non-disabled women. They proposed that there should be awareness creation about disability inclusion among midwives.

... I don't agree with this one on separating the rooms. We all go for antenatal care and the other ones are also pregnant. Perhaps, the midwives should be educated that women with disabilities should be worked on first. ... it's not right if they're to segregate [us]. The HIV/AIDS and diabetes patients have different drugs, but the drugs are the same for the pregnant women. (Hope)

Midwives had similar views, suggesting that women should receive services without undue delay and that a special ANC programme should be created for pregnant women with physical disabilities that specifically addresses their ANC needs. Some midwives suggested working faster when attending to women.

"May be if we could increase on the speed when we are working on those people, such that they get the first service and they go" (Midwife 5).

May be there can be a special programme [ANC programme] considering the different types of disabilities of these people. Like there are programmes for adolescents, may be there can be a special programme [also for them]. Of course, where that programme involves all that is needed ... [including] provision of some little transport depending on where you [woman] are coming from. (Midwife 4)

7.2.3.2 Incentivising women and health workers

Incentivising women and health workers was described by midwives only. They suggested the provision of incentives for all pregnant women (with and without disabilities) and health workers as a way of improving the utilisation of ANC services. They suggested providing

extra maama kits to pregnant women and recognising and appreciating health workers' positive attitude.

“Maybe they [managers] can help to appreciate people working with good attitude because they know us, they know every one of us” (Midwife 6).

May be some other people come to the hospital because there some incentives. Maybe if there can be incentives. Like recently in antenatal, because we want mothers to attend antenatal as early as four weeks, we have told them that a mother who makes eight visits will always take two maama kits. So, that is exciting mothers! Two maama kits! when other people fail to get even one! There are those who don't have what to use after giving birth. So, if you have maama kit you are a 'king' [queen]. (Midwife 4)

7.2.3.3 Making connections

Midwives suggested that it is important to make connections with community workers and other stakeholders who are in touch with women with physical disabilities in the community, unlike the midwives who remain at the health facility. They observed that making connections with different stakeholders would facilitate the early identification of pregnant women with physical disabilities and then linking them to health facilities for ANC services. They noted that making connections would also facilitate awareness raising about the challenges these women encounter in accessing and utilising ANC services. However, midwives suggested that good communication with and motivation of the community workers are critical for such connections to be effective. Some midwives explained:

“VHTs know better these people. At times you find that this person knows the whole village, knows people in his catchment area” (Midwife 6).

“If there is a woman with a physical disability in a certain village, then the VHT connects with the health facility” (Midwife 4).

Every disabled mother who gets pregnant should be known and they [the VHTs] inform us like the nearest facility. ... if there is good communication [with VHTs] we can go and find that person [woman with physical disability] from her place. If

possible, we do antenatal from there. But the whole thing gets spoilt from down there [at village level]. The VHTs are not motivated. You find he/she has no record of the people who are pregnant in his/her village and yet that is the sole purpose of why they were put there or recruited. (Midwife 3)

7.3 Discussion: Improving quality of ANC services

The theme ‘Improving quality of ANC services’ is viewed through the Three Delays Model (Thaddeus & Maine, 1994) and the findings are situated in Phase III – receiving appropriate and adequate ANC – which points to quality and disability inclusion in ANC services.

7.3.1 Women’s mixed experiences of health workers – room for improvement

Women with physical disabilities expressed mixed experiences of midwives and other health workers during ANC. Although women reported that they experienced supportive health workers, they noted that sometimes (or other) health workers were unapproachable and “they leave you there” without paying due attention to one’s physical disability, negatively affecting the quality of ANC services provided. Women indicated that the care they received was conditioned by health workers’ mood. Health workers were supportive if they were in a good mood, and unapproachable and abusive if in a bad mood. There was a similar view among midwives that some health workers were unapproachable. This suggests that there is some insight among the midwives that there is room for improvement, which is a positive opportunity for change. The study findings also indicate that both women and midwives wished for quality disability inclusive ANC services.

Similarly, in a study by Chinkam et al. (2023) in the USA, women reported mixed experiences of “not feeling well cared for” (p. 128) and “feeling well supported” (p. 129), although their study was on women with diverse ethnicity and racial backgrounds and did not focus on women with disabilities who may have different types of vulnerabilities. Another study in rural Nepal by Devkota et al. (2017) found that women with disabilities had mixed experiences of health workers, with more women indicating that health workers had a negative attitude and inadequate knowledge, skills, and preparation for caring for women with disabilities. In the same study, a few women experienced kind, respectful, and caring health workers.

Similar studies in other low- and middle-income countries, such as India, Tanzania and Ethiopia (Austad et al., 2017; Kruk et al., 2018; Wassihun & Zeleke, 2018), have found that women in rural settings experience disrespectful and abusive maternity care, particularly intrapartum care. While these studies were on all women in underserved settings, they do not highlight the experiences of women with physical disabilities in utilising ANC services, which was a focus of this study.

Fuzy et al. (2020), found that humiliation, victimisation, and rudeness are associated with negative experiences for women during maternal health care, in their study targeting a different vulnerable group of women (middle adolescents) and their birth experiences. Such experiences may influence some women not to consider seeking ANC services, which in turn impacts on their pregnancy health care (Mgwili & Watermeyer, 2006). Mgwili and Watermeyer (2006) further posit that such experiences of women with physical disabilities imply that they are “being told that they have no place – a place in the reproductive health system, a place in the realm of sex and sexual reproduction, or a place in the world” (p. 271).

Some women experienced supportive and caring health workers during their ANC encounters. This points to health workers being able to form an engaged moral relationship as a characteristic of a more proficient/expert practitioner exhibited by those health workers. Benner (1982), in her theory ‘From Novice to Expert’, recognises five performance levels for a practitioner: 1. Novice, 2. Advanced beginner, 3. Competent, 4. Proficient, and 5. Expert. Benner indicates that patients’ experiences can be used to describe or assess expert practice, in which case the intended practice of the health worker should match the outcomes. She argues that in an engaged moral relationship, nurses (and/or health professionals) also play a coaching function by offering avenues for understanding the culturally avoided or uncharted, and can open ways of being and ways of coping for the pregnant women and their families through their attitude, demonstrations, and reactions. She further argues that at the competency level, the practitioner has the “mastery and the ability to cope with and manage the many contingencies of clinical nursing”, and is able to plan and coordinate “multiple, complex, patient demands” (P. 405).

Interestingly, in this study, midwives assumed that pregnant women with physical disabilities should be given preferential treatment, yet this clearly was not an experience shared by all the women. This shows the mismatch between what was intended and the outcome, further

revealing the gap between the espoused and actioned, as discussed in Chapter Five. I contend that it is not enough for midwives to focus only on the structure and process of ANC services delivery but also on their relational demeanour, including respecting women's dignity in midwifery practice. It is necessary for them to come together, fully understand what each requires/can give, and plan together.

In his book, Damasio (1999) notes that “when we sense that a person is “tense” or “edgy”, “discouraged” or “enthusiastic”, “down” or “cheerful”, without a single word having been spoken to translate any of these possible states, we are detecting background emotions” (p. 52). Reading women's emotional states is highly relevant to midwives' ethical and clinical judgment, and requires perceptiveness and a commitment to checking assumptions and interpretations in order to learn directly from women and their families (Benner, 2000).

Good nursing [and/or health profession] practice relies on the human back-drop of embodiment and our embedded capacities to experience life-manifestations and our common human condition of finitude, dependence and interdependence. Openness and attentiveness can be cultivated through the development of perceptive skills, character and skilful ethical comportment as learned directly from those we would help; from education and other practitioners. The schooling of nurses [and/ or health professionals] should encourage and not swart the ability to see and respond to the other. (Benner, 2000, p. 14)

According to Benner et al. (1996), proficient and expert practice is characterised by an engaged practical reasoning with “increased intuitive links between the salient issues in the situations and ways of responding to them” (p. 142). It is important to recognise that humans inhabit their worlds in an involved way and therefore intuition is an important aspect of clinical judgment (Benner et al., 1996). The authors note that intuition is not a magical or mystical quality but is born of experience.

7.3.2 Preparing midwives and other health workers – a beacon of hope!

Inadequate knowledge on disability among health workers and limited local research on disability in pregnancy are critical gaps that need to be addressed. As revealed from the findings, my presence raised awareness among the midwives. Indeed, some of them gained

new insights from the interview process, especially with regard to disability in pregnancy and the need for accommodative strategies for the inclusion of women with physical disabilities in ANC. As most of them had not thought of physical disability as an issue for ANC, it is possible that some could have attended to these pregnant mothers without realising the physical and psychological pain they were inflicting on them. This study presents an opportunity as its findings will be used to further raise awareness among the midwives, women, and other health workers and stakeholders in Sheema district. Raising awareness will enable midwives to improve their documentation of and attention to disability issues.

Furthermore, the findings in this study show that midwives were emotionally unprepared, and this points to their unattuned emotional engagement in attending to pregnant women with physical disabilities. Midwives expressed a sense of impotence, as they did know what to do to address the challenges and specific needs of pregnant women with physical disabilities. Such unattuned emotional engagement may jeopardise midwives' professional relationship with women during ANC. Particularly, midwives need to be prepared regarding how to attend to women's physical impairments and their disabilities, and to record their experiences for reference by health services management and in future research. In addition, there was a recognition by the midwives that these women have specific needs, and that the health service management system was unresponsive such needs.

In a systematic review of barriers to and facilitators of high-quality midwifery services in India, McFadden et al. (2020) found that the unavailability of a competent and motivated workforce able to provide quality midwifery care and manage complications was a significant barrier to accessing and utilising quality maternity care services. However, the systematic review did not highlight the competences needed by midwives to provide disability inclusive ANC services. Being competent with attuned emotional engagement in caring is a characteristic of a proficient or expert practitioner (Benner et al., 1996). At this level of expertise, Benner et al. (1996) assert that "rather than becoming uniform or standardised, emotional engagement varies considerably depending on the need and openness of patient [or pregnant woman] and family" (p. 143). Midwives' emotional unpreparedness may be a result of limited exposure during their education, training, and practice.

In a qualitative study carried out in South Africa, Mgwili and Watermeyer (2006) articulate that fear, pity, and blame expressed by midwives at the sight of women's impaired bodies

during ANC may serve to position women with physical disabilities “outside the realm of ‘normal’ entitlement to care” (p. 270). They highlight that the needs and concerns of these women are instead positioned as ‘additional and special’, receiving more charity and altruism than ANC services as equal citizens with equal rights. In this study, midwives’ expressions such as ‘how am I going to handle this person!’, according to Mgwili and Watermeyer (2006), seem to be related to their projected personal feelings evoked by disability. The emotional difficulties, anxieties, and awkwardness experienced by midwives in interacting with women with physical disabilities implies that midwives wished that these women’s presence could be eradicated from the ANC clinic (Mgwili & Watermeyer, 2006).

Interestingly, similar studies from the USA, a high-income country, showed that ANC providers, including clinician obstetricians, knew little or nothing about the impact of the physical disability on the pregnant women’s experiences (Lipson & Rogers, 2000; Mitra, Akobirshoev, et al., 2017; Smeltzer et al., 2016; Smeltzer et al., 2018). Disability awareness needs to be underscored as a core aspect of health professionals’ training to increase their awareness about the antenatal needs of women with physical disabilities (Mitra, Akobirshoev, et al., 2017; Mitra, Smith, et al., 2017; The Lancet, 2019). Devkota et al. (2017) suggest that more organised, effective training of health workers in the mainstream education system is needed to improve health workers’ attitudes towards disability. In addition, there is a need to develop maternity care (including ANC) practice guidelines for women with physical disabilities (Mitra, Smith, et al., 2017).

7.3.3 Enabling disability inclusion – dedicated ANC clinic

A dedicated ANC clinic implies an accommodative health workforce, offering respectful and dignified ANC care to pregnant women with physical disabilities, tailored to their specific needs. It is possible that addressing the specific needs of pregnant women with physical disabilities would facilitate disability inclusion and create an enabling environment for them to utilise ANC services. Considerations could be made, given the physical limitations of pregnant women with physical disabilities. Such considerations would reflect a person-centred approach to ANC, which is consistent with the Midwifery Model of Care (ICM, 2021). For instance, in health facilities where there is more than one laboratory personnel, one of them could come to the ANC clinic and take all the required samples from women instead of every pregnant woman going to the laboratory and samples getting delayed.

Another example of what could be done is segregating ANC rooms, although there is a clear difference of opinion in this among the women. Both groups have valid points, including those in favour of having a dedicated clinic, given that women with other conditions/ circumstances also get a dedicated clinic to meet their needs, for example, a specific room with a specialist for diabetic patients or a specific dedicated clinic day for pregnant teenager girls. Likewise, pregnant women with physical disabilities need space that would physically accommodate them, in terms of bed heights, ramps, toilet/ latrine facilities among others. However, a dedicated clinic would require adequate health workforce who use an inclusive approach to ANC to avoid the unintended negative consequences of such as stigma and further pressure on overworked and stretched health workers.

In addition, the difference in opinion relates to the debates about segregation, integration and inclusion, and the notion of special versus specific needs. Accordingly, the principles of universal design emphasise “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design” (Story, 2001, p. 4.3). Plausibly, there is an issue of educating not only the health workers but the community in general, including community workers, so that women without the additional challenge of a physical disability are more aware of the extra consideration required by their disabled counterparts. In their study in rural Nepal, Devkota et al. (2018) highlight the need for orienting health workers on the human rights approach to disability and health. Although, in this study, incentivising women and health workers was identified as an enabler for disability inclusion, a systematic review of the Cochrane database by Till et al. (2015) reveals that there is limited evidence that incentives may increase the utilisation and quality of ANC services.

Wagner et al. (2018), in their study carried out in rural India, suggest that with proper training, community health workers can improve the health care, including ANC, of vulnerable populations in rural areas in low- and middle-income countries. If well-oriented and motivated, VHTs can be good ‘obstetric care navigators’ in rural south-western Uganda. Austad et al. (2017) refer to ‘obstetric care navigation’ as a strategy to “improve health outcomes for vulnerable populations and promote patient autonomy by providing linkages across a fragmented care continuum” (p. 1). Although this strategy was proposed to improve the care experiences of vulnerable women during childbirth in rural India, it can be applied in

other rural contexts in low- and middle-income countries to improve the ANC experiences of women with physical disabilities. VHTs would play the critical role of improving communication between women with physical disabilities and health workers through language and cultural interpretation and deflecting abuse and mistreatment from health facility staff (Austad et al., 2017). This awareness would increase the approachability of health workers.

7.4 Conclusion

This chapter highlights women's mixed experiences of health workers while utilising ANC services. They noted that although some health workers were unapproachable, sometimes they (or other health workers) were supportive and caring. Midwives' comments reflected similar views that health workers were unapproachable. Both women and midwives envisioned a dedicated ANC clinic with an inclusive health workforce.

Despite women's mixed experiences of health workers, the findings point to positive opportunities and hope for change towards improving the quality of ANC services. The study findings show that preparing health workers will facilitate disability inclusion in ANC services. This study presents an opportunity as its findings will be used to further raise awareness among women, midwives, and other health workers and stakeholders in Sheema district. In the next chapter, I present the synthesis of the findings and conclusion of the study.

CHAPTER 8:

SYNTHESIS AND CONCLUSION OF THE STUDY

8.1 Introduction

In this final chapter, I present a brief overview of this thesis and synthesis of the study findings and discussion (presented in Chapters Five, Six and Seven) to illuminate the convergencies and divergencies. This synthesis highlights how and why access to and utilisation of ANC services by pregnant women with physical disabilities in rural south-western Uganda are enabled and/or constrained. The strengths and limitations of the study are presented, followed by the contributions to scholarship and the recommendations of the study. The recommendations have implications for future research, policy, practice, and curricula. Lastly, concluding reflections are presented.

8.2 Overview of the thesis

In Chapter One, the research problem stated that despite the existence of several environmental factors impeding the access to and utilisation of ANC services by women in general, the specific experiences of pregnant women with physical disabilities accessing and utilising these services in rural south-western Uganda are largely un-documented. There is at present minimal understanding of their experiences in accessing and utilising these services. Consequently, it may be difficult to improve their experiences without understanding the enablers and/or barriers in the context in which the services are provided. This understanding is crucial because access to and utilisation of quality ANC services is critical in improving women's pregnancy experiences and pregnancy outcomes.

The aim of this interpretive qualitative study was to investigate the experiences of pregnant women with physical disabilities in rural south-western Uganda. A descriptive multiple case study was chosen as the study design. To achieve the study objectives, data was gathered from multiple sources, namely, interviews, a focus group discussion, an audit of the health facilities' physical infrastructure and equipment, and reflexive journaling (see Methodology chapter). Data was analysed using Braun and Clarke's (2006) thematic analysis.

Multiple data gathering methods helped to generate valuable data, which provided an opportunity to broaden the understanding of the diverse and intersecting issues impacting on women's experiences. This helped in understanding and conceptualising how and why the access to and utilisation of ANC services by pregnant women with physical disabilities in rural south-western Uganda is enabled and/or constrained in the ways it is.

The study findings and discussion (Chapters Five, Six and Seven) respond to the study objectives using the Three Delays Model (Thaddeus & Maine, 1994) – deciding to seek ANC services, identifying and reaching an appropriate health facility, and receiving appropriate and adequate ANC services – based on the themes that emerged. This final chapter argues for inclusive policies and practices and for adequate education and training of midwives and other health professionals about disability inclusion to improve pregnancy experiences and outcomes for women with physical disabilities in rural Uganda, which could be transferable to other rural communities.

8.3 Synthesis of the findings

The study findings revealed that:

- Women's vulnerability and resultant oppression are shaped by intersecting barriers related to inaccessible transport and mobility systems, inadequate family and community support, limited financial and antenatal resources, and judgmental attitudes of health workers. Their vulnerability is responsible for their limited participation and functioning²⁵ in accessing and utilising ANC services. Aligning policy and practice through awareness raising on disability rights, targeted support services, and providing financial and antenatal resources in a coherent inclusive system enhances women's agency and optimises their wellbeing.
- Women's spiritual health is integral to their wellbeing. Good spiritual health depicts a purposeful life, enhances women's capacity, and creates a balance between the physical, psychological, and social aspects of their lives.

²⁵ Functioning denotes the positive aspects of the interaction between an individual with impairment and that individual's contextual factors (environmental and personal factors) (WHO, 2001).

- Likewise, women’s spiritual oppression undermines their wellbeing, which impedes their access to and utilisation of ANC services. In contrast, their spiritual wellbeing facilitates their full participation in accessing and utilising ANC services.
- Fit-for-purpose ANC services entail disability inclusive ANC policy, to ensure accessible health facility designs. In addition, fit-for-purpose ANC services include accommodative ANC services where there is engaged moral relationship with equal power relations and better understanding of disability, which promote respectful and dignified ANC services.
- Holistic health services improvement through preparing midwives and other health workers, and adequate planning, budgeting procurement, and supply of drugs and medical supplies, are crucial.

Synthesis of the study findings highlights three factors. Figure 8.1 below illustrates the summary of the synthesised study findings, highlighting the relevant concepts discussed in this section.

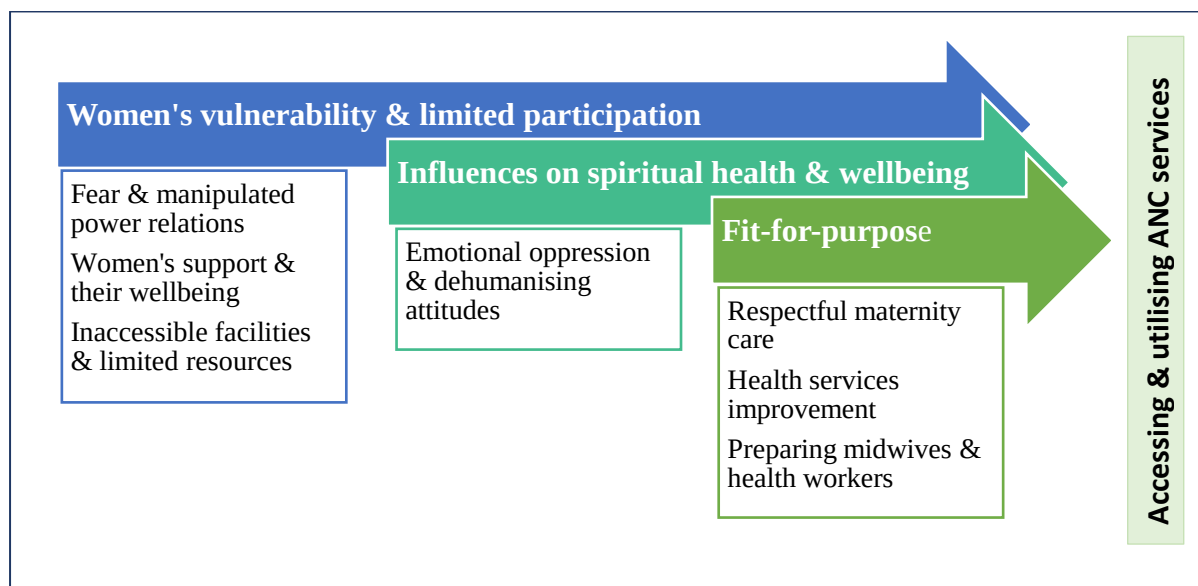


Figure 8.1: Summary of the synthesis of the findings

8.3.1 Women’s vulnerability and limited participation

The study findings highlight the notion of vulnerability and limited participation of pregnant women arising from their physical impairment and their intersecting identities, as

conceptualised in the ICF (WHO, 2001). An integrated review summarising 11 studies on the experiences of women with physical disabilities in low- and middle-income countries by Kazembe et al. (2022) confirms women's vulnerability and limited participation in accessing and utilising ANC and childbirth services.

Disability is a complex form of social oppression expressed through stigma and discrimination (Barnes, 2012). This form of social oppression impedes participation. In this study, the findings show that society prioritises constructions of the body rather than economic and social relations (Barnes, 2012). The Ubuntu philosophy was utilised to understand how families and community support pregnant women with physical disabilities. The relationship between women and health workers was situated within Intersectionality and Critical Disability Studies to understand the power held by health workers over pregnant women with physical disabilities.

The study findings indicate the complexity of accessing and utilising ANC services by pregnant women with physical disabilities and midwives' ability to provide these services to the women. The study findings indicate that while some women were able to access support from family, community and health workers and were able to exercise agency in accessing and utilising ANC services, many women experienced vulnerability and limited participation at home, during travel and at the health facilities. Women's vulnerability and limited participation was identified across the three types of delay (Thaddeus & Maine, 1994): first delay (at home), second delay (in the community – during travel to the health facility), and third delay (at the health facilities). Their vulnerability was related to fear and manipulated power relations, inadequate support and undermined wellbeing, and inaccessible facilities, and limited resources, as discussed below.

8.3.1.1 Fear and manipulated power relations

Women's decision to seek ANC services was driven by their fear of the unknown related to uncertainties in pregnancy, fear of public opinion in case a complication developed, and fear of being reprimanded by midwives at the time of giving birth if they had not sought ANC services. The study findings also suggest that women's fear of the unknown was associated with their desire to seek information regarding their health and that of their unborn baby.

Sometimes they thought that the pain due to their physical impairment may lead to complications in the womb, and that this would affect their unborn baby's health.

Surprisingly, the information women received from midwives was that their physical impairment may not allow them to push the baby out at the time of giving birth, negative information which could have fuelled their fear further. It is possible that they sought ANC services to prepare themselves in case a caesarean section was suggested by the midwives. Midwives' negative information pointed to their inadequate knowledge on disability and their emotional unpreparedness to attend to woman with physical disabilities, as seen in Chapter Six, section 6.3. Likewise, women's fear of reprimand by midwives suggests undignified and disrespectful care and manipulated power relations, with midwives imposing their professional power over women. For example, midwives demanded that women should come for their ANC appointments with their male partner, which disregards those women without partners.

Often, persons with disabilities are addressed as a homogeneous group without consideration of their agency and knowledge (Grech, 2015; Sonpal & Kumar, 2012). Stereotyping of persons with disabilities and not recognising their individual agency impacts on their participation in health care activities, including ANC care services. Such stereotyping is reflected in the organisational and structural challenges, such as inaccessible transport and mobility systems, and sociocultural prohibitions, which are hindrances to exercising agency and optimising wellbeing for persons with disabilities (Nett, 2021). Although disability is a recognised issue on the development agenda (Grech, 2015), there is "a disability and development gap" (Groce, 2018; Groce & Kett, 2013). In the Global South, persons with disabilities are yet to benefit from the socioeconomic development gains (Groce & Kett, 2013; Nett, 2021; Niewohner et al., 2020). Such a development gap undermines their wellbeing, and, in this case, their access to and utilisation of ANC services.

8.3.1.2 Women's support and their wellbeing

In this study, while accessing support optimised the wellbeing of pregnant women with physical disabilities, the inadequacy of this support undermined their wellbeing. The findings suggest that aligning policy and practice through raising awareness on disability rights and improving the economic status of women would enhance their agency. This, in turn,

optimises their wellbeing, therefore improving their access to and utilisation of ANC services. This study's findings correspond with those of Groce (2018), in her study *'Bridging the Gap: Examining disability and development in four African countries'*, including Uganda. Her study proposes targeted resources, services and support, and programmes linked to a coherent system of inclusion and support for persons with disabilities to address disabling barriers to equality. She further suggests that to close the existing development gap, policy implementation should be strengthened and harmonised, holding policy makers and donors accountable to these policies.

In addition, sociocultural beliefs and practices (see Chapter Five, sub-section 5.4.2) prevent women from accessing ANC services. Transcending beliefs and practices that prevent women from accessing ANC services requires community workers to understand and appreciate the communities' sociocultural norms and values. This approach enables the community workers to target attitude and mindset change within the families and communities of persons with disabilities (Booyens et al., 2015) in collaboration with midwives as appropriate ANC care providers (ICM, 2021). Raising awareness on disability rights at the family, community, and health facility levels remains the main intervention for attitude and mindset, with emphasis on justice, equity, and respect for the human dignity of women (ICM, 2021).

In this study, women who had inadequate family and community support reported being helpless in carrying out daily activities. The helplessness was not only experienced at home and during travel to and from the health facility, but also at the health facility. Their helplessness may be related to change in mobility and its impact on work patterns, or marriage challenges such as unsupportive husbands and unhealthy relationships with in-laws. Women's vulnerability worsens in their late stages of pregnancy, arising from intersecting barriers associated with their sextuple oppression²⁶ (Gartrell et al., 2017). These barriers impact the women's participation and wellbeing, putting them in a more precarious position.

8.3.1.3 Inaccessible facilities and limited resources

Women's vulnerability and limited participation were further expressed in their inability to access health facilities due to inaccessible transport and mobility systems related to

²⁶ In this study, sextuple oppression signifies women's vulnerability arising from seven intersecting factors: physical impairment, patriarchy, poverty, low education, HIV/AIDs, rurality, and gender.

unsuitable transportation and inadequate road infrastructure. Despite their vulnerability in accessing health facilities, women were required to attend ANC every month for a minimum of eight ANC visits. The high number and frequency of ANC appointments presented financial hardships to these women. Notably, financial hardships are generally experienced by all women. However, women with physical disabilities are disproportionately affected due to changes in their ability to be economically active, and the disproportionate cost/burden of transport associated with their physical needs which were exacerbated by pregnancy. While women were appreciative of the benefits associated with professional ANC services, to them, there were too many required visits to the health facility with too short intervals in between each visit, especially given the long distances they had to travel and the associated transport costs.

Consistent with the review summary by Kazembe et al. (2022) in low- and middle-income countries, women with physical disabilities experienced limited financial and antenatal resources, perhaps resulting from their reduced functioning. These women encounter activity restriction and limited participation in development programmes. However, midwives did not consider women's economic status when scheduling their ANC appointments. Women felt that midwives needed to be considerate of their reduced functioning capacity. It is possible that women could have sought the services of Traditional Birth Attendants (TBAs) or used herbs and applications because these are accessible and affordable.

Surprisingly, without considering women's precariousness in accessing financial and antenatal resources, midwives humiliated and sometimes chased away these women with physical disabilities because they were not presentable enough or dressed as required by the midwives. The expectations of midwives about clean clothes and provisions that the women need to bring with them exhibit a lack of tolerance and a degree of superiority and judgment, which have no place in a professional relationship. Arguably, this lack of tolerance could be an issue of reciprocal vulnerability where midwives too could be feeling vulnerable and reacting that way. It is possible that midwives' vulnerability was related to their inadequate knowledge and emotional unpreparedness, exacerbated by the negative attitudes exhibited by some women towards them, as noted in Chapter Seven, section 7.2.2.2. There is a need for mutual acceptance and respect between women and midwives during ANC.

8.3.2 Influences on spiritual health and wellbeing

In addition to women's vulnerability and limited support explained in the previous section (8.3.1), their spiritual health and wellbeing affected their access to and utilisation of ANC services. In a study explaining the concept of spiritual health from the experts' perspective in Iran, Ghaderi et al. (2018) identified two major dimensions: "religious health, which is shaped in connection with God or supreme power (a transcendent and holy existence) and existential health in human connection with himself [or herself], others and the nature, the meaningful purpose in life" (Ghaderi et al., 2018, p. 5). The authors further recognise one's connection with God as the most important part of spiritual health. They assert that a person's connection with himself or herself, others, and nature were not specific to spiritual health because these components are also present in mental and social health. People with improved spiritual wellbeing are more likely to exercise their agency, which optimises their wellbeing, and in turn is expressed in their behaviour. They are more likely to live in harmony with others, feeling worthy enough to trust and be trusted, to forgive and be forgiven, and to accept and be accepted.

It can be argued that an individual's behaviour is partly an outward expression of his/her overall spiritual health. It is noteworthy that caring for women's physical, mental, and social spiritual health needs during pregnancy is critical for their wellbeing. It could be possible that the unprofessional attitude (rudeness and bad behaviour) of women with physical disabilities exhibited towards midwives and other people is associated with their undermined spiritual wellbeing. As articulated by Pargament and Exline (2022), "spiritual struggles can be both a cause and effect of both psychological and physical health problems" (p. 80).

The findings also show that while some women rely on God's omnipotence and benevolence in overcoming their disability challenges associated with pregnancy and childbirth, others expressed feelings of worthlessness, an undermined self-image, and a lack of purpose in life. These feelings point to spiritual oppression which undermined their wellbeing. In her study on the effect of civil unrest on nursing personnel and nursing services in South Africa, Clow (1990) noted that people's spirituality may be expressed through their faith in their deity, for example, the Judeo-Christian God, or in that which gives meaning to their lives, including power, social status, or material wealth.

Spiritual health moves the thinking beyond the biophysical/political discourse on disability into other areas of achieving optimum health and wellbeing. Spiritual wellbeing depicts a purposeful life, promotes human capacity, and creates a balance between the physical, psychological, and social aspects of human life (Ghaderi et al., 2018). In other words, spiritual wellbeing influences our physical, mental, and social wellbeing and drives our sense of being worthy of living. Lorenzo and Duncan (2021), in their article on the spirituality of disability among women with disability in South Africa, found that women's spirituality was integral to their social, economic, and political experiences. Their study further revealed that spiritual wellbeing restored women's hope and renewed sense of agency and belonging.

8.3.2.1 Emotional oppression and dehumanising attitudes

The findings in the theme 'Undermined wellbeing' revealed that women's spiritual oppression was worsened by their emotional oppression, with feelings of anxiety about anticipated undesirable treatments at the health facility and fear of testing HIV positive and their HIV status being disclosed to their husbands, as well as exacerbated physical pain. Moreover, they feared their in-laws, who they did not trust and with whom they had unhealthy relationships.

In addition to emotional oppression, the community's dehumanising attitudes – regarding women with physical disabilities as different beings, with grotesque bodies and unfit for marriage – could have contributed to women's sense of worthlessness, further compounding their spiritual oppression. It was noted that midwives reaffirmed these beliefs, saying that women with physical disabilities were not in a position to give birth normally. Likewise, Mgwili and Watermeyer (2006) assert that "relentless messages regarding one's legitimacy and adequacy as a participant in the social interchange surrounding sexuality would, over time, provide increasing momentum to the capacity for self-denigration we all have" (p. 269).

From the study findings, the unresponsive ANC policy and practices of unapproachable and abusive health workers contributed to women's spiritual oppression. One could say that very little attention was paid to the dimension of spiritual health and wellbeing for these women, although this is widespread in the pregnant community. There is a need to care for women's basic needs during pregnancy as well as their emotional and spiritual wellbeing and to respect their individuality, as part of holistic and respectful maternity care (RMC) (Fuzy et al., 2020),

not only at health facilities but also at the family and community levels. Women's spiritual oppression during pregnancy is inconsistent with the International Confederation of Midwives (ICM) Philosophy of Midwifery Care which is "grounded in the understanding of social, emotional, cultural, spiritual, psychological and physical experiences of women" with "midwives as the most appropriate care providers" (ICM, 2021, p. 2). Inclusive ANC policy with clear interpretation and implementation guidelines, and well-prepared competent health workers will facilitate the optimal participation and spiritual wellbeing of pregnant women with physical disabilities.

In their study among the Bomvana Indigenous communities in South Africa, Ohajunwa et al. (2021) assert that "health care practice must explore contextually relevant wellbeing practices that have yielded positive results and involved the narratives and understandings of the Indigenous communities which are embedded within their spirituality" (p. 6). Midwifery practice should be holistic, taking cognisance of women's spirituality as integral to their wellbeing. To overlook the impact of spiritual oppression on the wellbeing of pregnant women with physical disabilities is to ignore a critical barrier to their accessing of ANC services. From the Critical Disability Studies standpoint, women's spiritual oppression points to the need for more responsive and transformative approaches (Goodley et al., 2019; Ned, 2022; Shakespeare, 2013) to enhance their wellbeing in accessing and utilising ANC services in rural Uganda.

8.3.3 Fit-for-purpose ANC services

Fit-for-purpose ANC services involve a dedicated clinic with accommodative ANC services, where an adequately prepared and skilled health workforce provides ANC services in an engaged moral relationship, respecting the dignity of women. The gaps between policies and practice point to the need for the improvement of health services for fit-for-purpose ANC services. In this sub-section, I explain the concept of RMC and the strategies for health services improvement. The need to prepare health workers through education, training, and mentoring is underscored. Aspects regarding accessible health facility designs and the availability of drugs and medical supplies are also addressed.

8.3.3.1 Respectful maternity care

Respectful maternity care (RMC) is a priority on the women's health global agenda and is an important indicator for maternal and newborn health care quality (Chinkam et al., 2023; Miller et al., 2016; Molina et al., 2016; Shakibazadeh et al., 2018). In promoting RMC, adequate communication and information sharing between midwives and women, and women's informed consent during the ANC process, are crucial (Chinkam et al., 2023).

While some midwives and other health workers were supportive and caring, portraying an engaged moral relationship and respectful care, women reported that sometimes these same health workers or other health workers were unapproachable to the extent that "they leave you there" (see Chapter Seven, sub-section 7.2.1). With this, women are saying that health workers were not paying due attention to their specific pregnancy needs and concerns. Admittedly, if the women (the cared for) do not approve of the care being provided, then midwives (the carers) are perceived to be uncaring. The findings indicate insufficient concern and mindfulness about disability inclusion on the part of the midwives. Serendipitously, my presence investigating the study phenomenon raised midwives' awareness on disability. In addition, midwives noted that they had not had researchers approaching them to investigate disability issues, which points to limited local research on disability in maternity care, particularly ANC services.

In the Lancet Global Health, a study by Afulani et al. (2019) in Kenya, Ghana and India showed that disrespectful maternity care is common in low-level health facilities in rural settings. Disrespectful or unwelcoming 'care' can demotivate women to attend ANC, especially when they are faced with the kinds of barriers reported in this study. This kind of care has implications for the clinical management later on in the pregnancy and during labour.

The findings of this study show that midwives and other health workers did not respect and/or paid little or no attention to the ethos of midwifery care. The evidence for this was that some women were asked to pay for supposedly free services for them to be attended to. Although some payments were formally required and sanctioned by the health facility (for example, payment for obstetric ultrasound scan services), other payments were encouraged by individual health workers as a form of extorting money from women. This unethical

practice appears to be a general problem for all women accessing maternity care services in public health facilities in many low- and middle-income countries, including Uganda (Afulani et al., 2019; Kyaddondo et al., 2017). Kyaddondo et al. (2017) and Afulani et al. (2019) argue that the level of respectful care should not be based on the woman's willingness and/or capacity to pay for the health care services. Women with physical disabilities may be in a more precarious position than non-disabled women when it comes to paying for ANC services due to their poverty situation and other intersecting vulnerabilities.

The Lancet (2019) editorial titled '*Prioritising disability in universal health coverage*' articulated that physical inaccessibility at health facilities may present logistical challenges to women with physical disabilities. In addition to the direct costs related to transport and ANC provisions, women also incurred direct and indirect costs related to the care and support they needed in preparation for ANC visits, on the way to and from the health facility, and at the health facility in their navigation of the complex health care system and the unaccommodating health facility designs. These findings point to the need for health services improvement for accommodative ANC services.

8.3.3.2 Health services improvement and preparing health workers

Nwosu and Ataguba (2019) and Ousman et al. (2019), in their studies regarding the socioeconomic inequalities in maternal health service utilisation in Nigeria and the social determinants of ANC use in Ethiopia respectively, suggest that policy makers, health managers, and care providers should consider a social determinants of health approach to address the socioeconomic inequalities in ANC utilisation, which may be applicable to women with physical disabilities in rural south-western Uganda. Midwives, as key ANC care providers, need to assess and duly consider the socioeconomic needs and concerns of these women during ANC. The adequate planning, budgeting, procurement, and supply of drugs and medical supplies may improve the availability of these and the accessibility of the physical environment at the health facilities, thus improving the utilisation of ANC services. A study on the perceptions and experiences of access to public health care by persons with disabilities and older people in Uganda by Mulumba et al. (2014) shows that a comprehensive systems approach is needed to achieve fit-for-purpose health facilities in the Ugandan development context. Such a comprehensive improvement in the health services

would benefit not only pregnant women with physical disabilities but all pregnant women, making it a ‘win-win’ for everyone.

In this study, the findings show that midwives were emotionally unprepared to work with and had inadequate knowledge on disability. Midwives’ emotional unpreparedness to attend to pregnant women with physical disabilities hinders their clinical judgment during ANC. Clinical judgment occurs in the context of a particular situation and when one is attuned to the situation, meaningful aspects stand out as important and the choice of response is guided by one’s interpretation of the particular situation (Benner et al., 1996). Benner et al. further note that, to some extent, emotions are socially constructed, and knowledge and emotions are mutually constitutive. They argue that the way clinicians are socialised into their professional culture may lead them to develop habitual ways of seeing and responding to patients.

In the Ugandan context, the midwives are socialised into their own home culture (which would be similar to that of the women) as well as the professional culture. However, it appears that midwives’ professional culture took precedence over their own home culture during their professional practice. It is possible that they are inclined to defend their professional culture with little or no attention to the specific needs and concerns of pregnant women with physical disabilities. Fundamentally, “both notion of the good and practical wisdom are prominent aspects of clinical judgment” of experienced, proficient or expert nurses (and/or health professionals) (Benner et al., 1996, p. 14), and are critical in an engaged moral relationship (see Chapter Seven, section 7.3.1).

In their study conducted in the USA, Robey et al. (2013) propose cultural competency-based education and training, where health care students’ educational and training experiences can be structured to reflect the sociocultural complexity of the culture of disability. They further recommend that desired competences related to culture can be defined based on the health care professional’s approach to patients with disabilities. Midwifery education and training should expose midwives to pregnant women with physical disabilities in their natural settings, including their homes (Robey et al., 2013). They argue that such exposure would enable midwives to understand women’s culture and the interaction between the nuances of women’s daily life with a disability and their pregnancy care needs.

My findings are consistent with the review summary on the experiences of pregnant women with physical disabilities accessing ANC services in low- and middle-income countries by Kazembe et al. (2022), which indicated the inadequate knowledge, attitudes, and skills regarding disability among midwives and other health workers and the need for their enhanced training. A study by Kemp et al. (2018) on improving student midwives' practice learning in Uganda and a review by Telfer et al. (2021) of midwifery education in Uganda revealed that midwives' basic competences at all levels do not match the ICM global standards for midwifery education curricula. In this study, both women and midwives acknowledged the knowledge gap and inadequate skills in attending to pregnant women with physical disabilities. Midwives indicated that they would get scared at the sight of these women during ANC. Interestingly, in a study on developing a work/study programme in East Africa, Edwards et al. (2018) found that all East African countries fall short on the midwifery training standards recommended by the ICM.

In the next section, I present the new knowledge contributions of this study to scholarship in Disability Studies and Maternal Health, particularly in maternity care for pregnant women with physical disabilities attending ANC services.

8.4 New contributions to scholarship

The new knowledge contributions from this study come from a Global South standpoint, within an African Renaissance school of thought and the Ubuntu philosophy of knowing and being. From the findings of this study and the reviewed literature presented in Chapter Two, it is clear that spiritual health is central to the wellbeing of pregnant women with physical disabilities in accessing and utilising ANC services in rural south-western Uganda. The findings show that the access to and utilisation of ANC services has been understood and defined from a Global North perspective in the current literature regarding the study phenomenon, with little or no consideration for the women's participation and their spiritual wellbeing.

8.4.1 Midwifing disability inclusive maternal health services

Globally, Disabilities Studies is concerned in various ways with the ubiquitous injustices and inequities that persons with disabilities are subjected to (Ned, 2022). In her article on '*African Renaissance as a Premise for Reimagined Disability Studies in Africa*', Ned (2022) posits

that persons with disabilities are “often positioned as the objects of research rather than equal thinkers and knowledge bearers in their own right” (p. 485). This situation is worse among women with disabilities, compounded by their epistemic oppression and vulnerability.

The concept of African Renaissance, as theorised by Diop (1996) and Mbeki (1999), is a reawakening call to Africa to recognise and rebel against colonial ways of thinking and knowing in their quest for political, social, economic, cultural, and spiritual transformation. In decolonising Disability Studies²⁷, Africa is positioned “as a cradle for humanity while providing a framework for modern Africa to re-emerge as a significant partner in the New World Order” (Marumo & Chakale, 2018, p. 184). It is critical to position the plight of African people, and particularly women (Sesanti, 2016), at the centre of the re-emergence of modern Africa to disrupt oppressive knowledge formations associated with the understanding of their ability (Dirth & Adams, 2019). To this end, Lorenzo (2003) contends that there is no African Renaissance without fostering the social and economic development of women with disabilities through the equalisation of opportunities and social integration. This study’s findings suggest that family and community support and the values of interdependence and shared/reciprocal responsibility for each other are crucial in fostering the inclusion and wellbeing of pregnant women with disabilities in accessing and utilising ANC services.

8.4.1.1 Family and Community support in the spirit of Ubuntu

In this study, women indicated that they were generally maltreated, regarded with disdain, and considered a burden to their family and community. They revealed that their husbands were often not supportive and refused to assist or accompany them for ANC services. Inadequate family and community support undermined women’s wellbeing and negatively impacted their pregnancy experiences. The non-acceptance of women with physical disabilities in some Ugandan communities notwithstanding, women emphasised that neighbours and their children were an invaluable source of support for them during pregnancy. Support from neighbours points to the communal African way of being and living embedded in rural Ugandan communities. The emphasis of communal responsibility is rooted

²⁷ In this study, decolonising Disability Studies means continually challenging the social category of disability (which holds significance for how women experience the world) as an invention of colonial capitalism. In other words, decoloniality favours analyses and practices that move away from the categories of Global North thought to engage with thinking and ideas from African communities that have been marginalised and discredited as uncivilised and barbaric (Zembylas, 2018).

in the African concept of Ubuntu, in which individuals carry responsibility for each other's growth and development (Ned, 2022; Ramugondo, 2018).

Indeed, neighbours' support of pregnant women with physical disabilities dispels the heavy skew towards negativity ascribed to disability in the Global South (Sefotho, 2021). It is possible to conclude that support from neighbours hinges on the Ubuntu philosophy, which says that "I am because we are, since we are therefore I am" (Mbiti, 1969, p. 215), and Ubuntu ethics, which are "consensual and spiritual" (Mangena, 2016, p. 68). The revelation that neighbours were critical in providing support suggests the existence of hope and points to an opportunity to cascade community care and support for pregnant women with physical disabilities in Ugandan rural communities.

Notably, Uganda's Ubuntu (known as *Obuntu* in Runyankore-Rukiga) is echoed in one of the old Runyankore-Rukiga adages: *ómuto tasheka bulema* – meaning that a young person should never laugh at a person's disability (or predicament) as he/she may not know what tomorrow holds for him/her. In other words, a person (with or without disability) needs to and should be treated as *Omuntu* (a human being). Mangena contends that Ubuntu ethics transcend horizontal relations between living beings to vertical relations that include human beings' relations with the spirit world, contrary to the western world's view of ethics that are only horizontal. The findings of this study are complementary to an assertion by Letseka (2012) that Ubuntu articulates the social interdependence entrenched in African communities.

As Lorenzo (2003) noted, we need to evoke Ubuntu, and its spirit and values of interdependence and caring for one another, to promote disability inclusion. She posits that the Ubuntu approach to disability would address the underlying causes of oppression and discrimination experienced by women with disabilities. Equally, Ubuntu is paramount in supporting pregnant women with physical disabilities to access and utilise ANC services. The connectedness and relationships within African Indigenous communities signifies the need for midwives and other health workers to build trust in the interest of the sustained wellbeing of women with disabilities (Ohajunwa et al., 2021). Midwives and other health workers need to accord empathy, respect, and dignified care to all women – with and without disabilities. This change will eliminate women with physical disabilities' fear of anticipated undesirable treatment and enhance their sense of being worthy of living.

African societies are deeply rooted in spirituality, not religion, as dominant narratives from the Global North seem to suggest (Ned, 2022). Often, when reference is made to African Indigenous communities, a single story prevails (Ned, 2022). As posited by Adichie (2009), *'the danger of a single story'* is that it creates untrue and incomplete stereotypes and consequently robs people of their dignity and distorts human relations, emphasising their differences rather than similarities. "Stories have been used to dispossess and to malign, but stories can also be used to empower and to humanise. Stories can break the dignity of a people, but stories can also repair the broken dignity" (Adichie, 2009, p. 17:24).

In this study, it can be concluded that the spiritual oppression and undermined wellbeing suffered by pregnant women with physical disabilities is partly associated with contemporary imperialism and neo-colonialism in Uganda, a former British protectorate. From the Intersectionality and Critical Disability Studies standpoint, where critical reflexivity, self-critique, and politicised and interdisciplinary analyses are preferred (Flynn, 2021; Goodley et al., 2019), the control by and power of midwives over pregnant women are challenged. It is possible that ANC knowledge is generated, passed on, and practiced based on Global North thinking and experiences, with little or no attention to Ugandan structural and sociocultural contexts, and the harsh realities encountered by pregnant women with physical disabilities in rural communities. It is interesting that in the "western" or "Global North" approach to evidence-based practice (EBP), the emphasis is on the treatment/intervention yet the totality of EBP also speaks to the acceptability and the affordability of the practice to the patient and the community. This is very relevant to the issues of creating policy where only the treatment/intervention is considered and not these other two pieces of EBP, which would result in a policy or care package that is more responsive to context.

8.4.1.2 Sociocultural beliefs and practices

In this study, midwives exhibited limited or no tolerance and a judgmental (superiority) attitude towards pregnant women with physical disabilities, which should be addressed. The midwives were part of the Banyankore tribe from Ankole, which is the same community and cultural background as the women with physical disabilities, but the midwives had been shaped differently by their professional education and socialisation. Midwives' expectations and demands that the women bring presentable clothes and provisions with them suggests the

use of perceived professional power to oppress the women. It is possible that midwives' professional education and training did not orient them in disability culture.

Kessi et al. (2021) argue that classrooms and curricula serve as significant spaces for professional and academic decolonisation. The authors further posit that decolonising African studies “entails a political and normative ethic and practice of resistance and intentional undoing – unlearning and dismantling unjust practices, assumptions, and institutions – as well as persistent positive action to create and build alternative spaces, networks, and ways of knowing” (p. 271). Similarly, the adequate education, training, and mentoring of midwives and other health workers could empower them to promote and practice disability inclusive ANC, including caring for the emotional and spiritual health needs of pregnant women with physical disabilities.

Relatedly, women encountered sociocultural prohibitions that undermined their wellbeing. Among the cultural beliefs and practices identified in this study was a belief in and use of herbs and applications. Women indicated that they used herbs and applications (African Indigenous knowledge), as well as western medical drugs when they sought ANC services. Women took both African medicines and western medicines, the latter perhaps for fear of being ridiculed and scolded, especially by midwives, if they took only herbal medicines. While some herbs and applications may be unsafe and harmful to the woman's health and her unborn baby, other herbs may be beneficial to them during pregnancy, for example, in the treatment of gastro-intestinal disorders (see e.g., Kiconco et al., 2020). There is a need for recognition of African herbal medicine in medical education and research and its role in pregnancy.

Non-recognition of ways of caring for pregnant women in rural Ugandan communities generally puts pregnant women in jeopardy. Pregnant women with physical disabilities seem particularly disadvantaged, given the inaccessible transport and mobility systems, and emotional and spiritual oppression that undermines their wellbeing. The onus is on us to salvage what remains of African Indigenous knowledge and harness that which benefits these women. A combination of both western and African Indigenous approaches to pregnancy care needs to be promoted. If the African Indigenous knowledge is not harnessed and recognised by the formal health care system, women with disabilities will continue to practice

it outside of the purview of the formal health care system, with midwives and other health workers left out (Ohajunwa et al., 2021).

Undertaking this disability research, that is, focusing on a women's under-researched area in maternity care, was timely and important in advancing African Renaissance in Disability Studies as the findings will be used to influence disability inclusive policy and practice. Women's experiences documented in this study contribute to the literature on African thought, which denounces western dominance in researching, documenting, and interpreting the world (Ned, 2022).

8.4.2 Conceptualising inclusive family- and community-focused ANC services for rural communities

Levesque et al. (2013) repurposed the Three Delays Model and conceptualised access and utilisation as “the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use healthcare services and to actually have the need for services fulfilled” (p. 8). They note that a true assessment of access requires context-specific measures to judge whether the characteristics of the services, providers, and systems meet the needs of the users. In this study, the findings show that for a rural pregnant woman with physical disability to seek and reach an appropriate health facility, use ANC services, and have her need for services fulfilled were influenced by her optimised or undermined wellbeing, unresponsive ANC policy to her specific needs, and improving the quality of ANC services.

Drawing from the Three Delays Model, the ICF, the Social Model of Disability, Intersectionality, and Ubuntu (discussed in Chapter Three), I propose an integrated framework for accessing and utilising ANC services by pregnant women with physical disabilities in rural communities. By applying the three phases in the Three Delays Model, three dimensions are proposed: **1. Wellbeing, 2. Access, 3. Fit-for-purpose**. These dimensions relate to the corresponding concepts of **1. Seek, 2. Reach** and **3. Utilise**, as repurposed by Levesque et al. (2013) within the Three Delays Model.

The proposed framework is a further development of the Three Delays Model through the recognition of **Ubuntu (Obuntu)**, **spiritual health**, and the **participation** of pregnant women with disabilities within the context of holistic health services improvement (see Figure 8.2).

In addition, this proposed framework recognises the intersectionality of the influencing factors and relationships between women and their families, communities, and health workers. This intersectionality is not addressed by the implied linearity in the Three Delays Model (Iyer et al., 2013). The figure (8.2) below shows an integrated framework for inclusive family- and community-focused ANC services for rural communities.

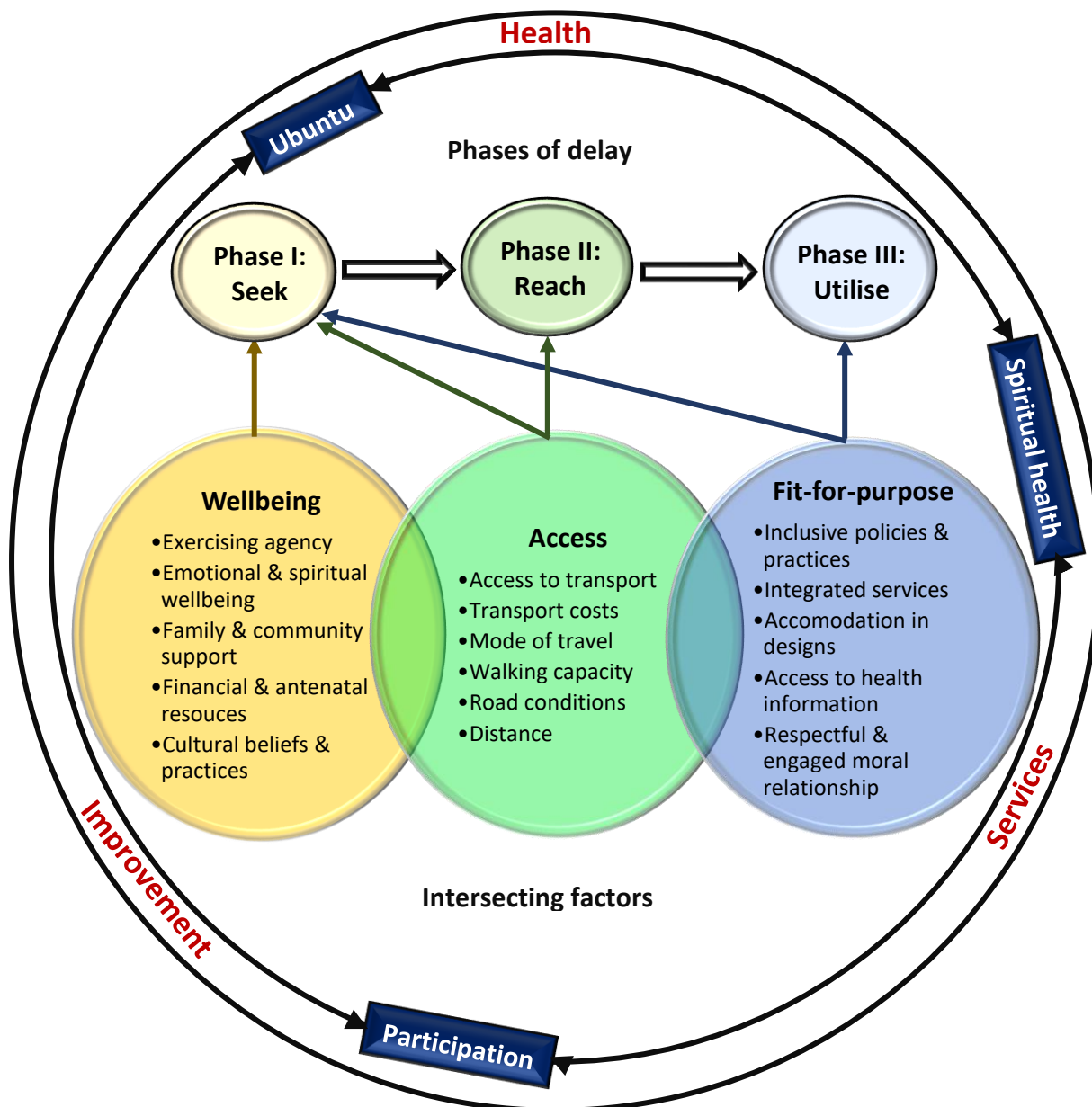


Figure 8.2: An integrated framework for inclusive family- and community-focused ANC services for rural communities

8.4.2.1 Phase I: Seek (Okusherura) – Wellbeing

As explained in Chapter Two, the first phase of delay is in deciding to seek obstetric care. From the ‘political and epistemological African Renaissance’ point of view, the seeking of ANC services by pregnant women with disabilities relates to their optimised wellbeing: politically, socially, economically, culturally, and spiritually. It is clear that the vulnerability of pregnant women with disabilities in rural south-western Uganda is associated with the structural injustices and epistemic oppression that undermine their wellbeing at the family, community, and health facility levels. This vulnerability greatly impedes their decision to seek ANC services.

Based on the findings of this study, I assert that denouncing the spiritual oppression of pregnant women with disabilities is an integral part of African Renaissance. There is a need to align policy and practice through raising awareness on these women’s disability rights and targeting support, services, and financial and antenatal resources in a coherent inclusive system for women to participate in political, social, economic, and cultural life in their indigenous communities, fully and meaningfully. Ubuntu ethics and values facilitate harmony among women with disabilities, their families, community, and health workers. Harmonious living, in turn, facilitates women’s care and support during pregnancy.

Optimising the wellbeing of women with physical disabilities requires supporting them at the family, community, and health facility levels to exercise their agency in accessing and utilising ANC services. In contrast, disenfranchising these women at any of these levels, directly or indirectly (for example, through sociocultural beliefs, practices, and prohibitions), undermines their emotional and spiritual wellbeing, and consequently hindering or delaying their access to ANC services. Limited access to ANC services negatively impacts on the utilisation of these services, as the latter is conditioned on the former. The two arrows in Figure 8.2 originating from transport (reach) and fit-for-purpose (utilise) imply that women’s experiences at these two phases impact on their wellbeing and decision to seek ANC services.

8.4.2.2 Phase II: Reach (Okwuhikayo) – Access

Identifying and reaching an appropriate health facility for pregnant women with disabilities is determined by the accessibility of transport and mobility systems. Here, appropriate transportation and adequate road infrastructure are key. Women’s accessibility to health

facilities is negatively influenced by insufficient access to transport, the high cost of transport, and inappropriate modes of travel, including limited walking capacity. The poor condition of the roads and the long distances to the health facilities are also significant barriers. The findings show that aligning policy and practice, and accessing support and financial and antenatal resources, enhance the women's wellbeing and their participation in accessing ANC services. Raising awareness on disability rights particularly among transport operators, especially *boda boda* riders, may influence women's support during travel to health facilities. When scheduling ANC appointments, midwives need to be mindful of the harsh realities encountered by pregnant women with disabilities in accessing health facilities in rural communities in low-income countries. Regular community ANC outreaches could serve to reduce on the number of physical visits to the health facility.

8.4.2.3 Phase III: Utilise (Okweyambisa) – Fit-for-purpose

Receiving and utilising appropriate and adequate ANC services requires a fit-for-purpose, dedicated ANC clinic with accommodating health facility designs and a competent inclusive health workforce. The physical environment, furniture, and equipment should be suitable for all pregnant women, including those with physical disabilities. There is a need to improve the walkways and the distance to the pit latrines/toilets, laboratory, and other facilities and service points by conveniently positioning them to reduce the long distances walked by pregnant women with physical disabilities. Moreover, these long distances required the women to navigate hazardous paths that were uneven with obstacles. The long waiting times, ineffective and unacceptable triaging procedures, and ANC appointment scheduling system also need to be addressed.

Inclusive policies and practices, women's relational experiences of health workers, and health workers' knowledge on disability rights are significant aspects of quality ANC services. In this case, ANC services need to be integrated and ANC policy implementation should reflect conformity with the actions of health workers and outcomes, in the context of material conditions in rural Ugandan communities. The adequate planning, budgeting, procurement, and supply of drugs and medical supplies, and access to health information, cannot be overemphasised in enhancing the utilisation of ANC services.

Equally, midwives and other health workers (nurses, doctors, laboratory, and pharmacy personnel) need to be prepared through adequate midwifery and other health professionals' education, training, and mentoring. For that reason, African cultural consciousness-based education, training, and mentoring, with an emphasis on Ubuntu values and ethics, is suggested. An Ubuntu approach to care needs to be incorporated into Respectful Maternity Care education and training. The health workers, specifically midwives as the most appropriate ANC providers, need to be approachable, supportive, and emotionally prepared to meaningfully engage with women with disabilities as equal partners, respecting their dignity.

Lastly, respectful and dignified ANC and engaged moral relationships would contribute to improved women's pregnancy experiences and outcomes. The concept of respectful ANC is in line with the midwifery approach to care for women and their newborns (ICM, 2017), the White Ribbon Alliance campaign for RMC (White Ribbon Alliance, 2022), which is now an official WHO policy (WHO, 2018).

8.4.2.4 Ubuntu, spiritual health, and participation

As discussed above (see 8.4.1.1), the influence of the Ubuntu philosophy in the process of accessing and utilising ANC services in African rural settings is crucial. Across all the three phases of delay, highlighted in Figure 8.2 above, Ubuntu ethics and values, spiritual health, and the participation of pregnant women with physical disabilities remain the foundation for disability inclusion in accessing and utilising ANC services. The women's spiritual health shapes their wellbeing and sense of being worthy of living. Their spiritual wellbeing promotes their participation and involvement in different spheres of life and access to financial and antenatal resources.

Using an Ubuntu lens, the family, community, health workers, and other stakeholders understand and appreciate the structural injustices and epistemic oppression encountered by these women with physical disabilities, and provide appropriate and adequate care and support to them. Such care and support will enhance their participation and functioning in accessing and utilising ANC services, consequently improving their pregnancy experiences and pregnancy outcomes.

The double arrows (Figure 8.2) connecting Ubuntu, spiritual health, and participation in a circle indicate that these three concepts are continuously interconnected. They affect and are affected by one another. They encircle the three phases of delay because they are applicable to women's pregnancy experiences at each phase. From the Global South point of view, it is possible that Ubuntu is a buttress against contemporary spiritual oppression and misunderstanding of the plight of pregnant women with disabilities in rural Uganda. Likewise, spiritual health is a foundation for their pregnancy experiences.

8.4.2.5 Health services improvement

Inclusive quality ANC services are envisioned in the context of holistic health services improvement using the determinants of health. A comprehensive approach to improving ANC services is critical for the benefit of all women, and a 'win-win' for everyone. In the above framework, health services improvement is placed in the outermost circle as it is intended to address both the demand and supply factors at each phase of delay in accessing and utilising ANC services. Nevertheless, I recognise the diversity and intersectionality of oppressing factors for pregnant women with disabilities in rural Ugandan communities. This intersectionality is represented by the intersecting circles in the framework.

Importantly, health services improvement includes structural improvement and mindset change through awareness raising on disability rights at the family, community, and health facility levels. When adopted in maternity health policy, practice, and curricula, I believe this *integrated inclusive family- and community-focused* ANC framework will be the beginning of rebelling against the Global North hegemony to create a better understanding of the authentic specific pregnancy needs and concerns of women with disabilities in rural Uganda. This framework will contribute to improving women's pregnancy experiences and outcomes.

8.5 Significance of the study

The study presented in this thesis is one of the first investigations to focus specifically on the experiences of rural pregnant women with physical disabilities accessing and utilising ANC services in rural Uganda. It aimed to explore the environmental factors that influence their experiences in accessing and utilising ANC services. The research was guided by the social perspective which recognises disability as being socially constructed. This creates an opportunity to present a nuanced perspective on the contextual social influences that act as barriers and/or facilitators for pregnant women with physical disabilities in the access to and

utilisation of ANC services. Such a perspective is often marginalised in the literature, which is dominated by the notion of disability and vulnerability in the Global North that may not be applicable in the African socio-cultural contexts. The findings will enhance our understanding of women's physical disability and their overlapping identities, and how these identities interact to influence the women's access to and utilisation of ANC services.

To situate their experiences and understand them better demands a particular theoretical position. I employed the Three Delays Model (Thaddeus & Maine, 1994) and the ICF (WHO, 2001), as well as the Social Model of Disability, Ubuntu, intersectionality and Critical Disability Theory, as illustrated in detail in Chapter Three (Theoretical Framework). These theoretical frameworks were used to understand and illuminate the contextual factors which act as barriers and/or facilitators at the family, community, and health facility levels (Three Phases of Delay). This fills a clearly identified gap in the literature which is that the existing literature on access to and utilisation of ANC services does not reflect the participation and functioning of women with physical disabilities at each phase of delay.

This research aimed to reflect this 'other' context and undocumented perspective, and as a result, data gathered from the field was inductively analysed to identify the gaps in terms of the three phases of delay, namely: phase one (at home) – delay in deciding to seek care on the part of the individual, the family or both; phase two (during travel to the health facility) – delay in identifying and reaching an adequate health facility; and phase three (at the health facility) – delay in receiving adequate and appropriate care at the health facility. By positioning this study in the African Renaissance school of thought, using Ubuntu philosophy, the study provides a better understanding of the epistemic oppression and structural injustices suffered by pregnant women with physical disabilities in rural Uganda. The study proposes an integrated framework for disability inclusive family- and community-focused ANC services for rural communities.

The study adds knowledge and provides baseline information for midwives and other health workers, community workers, Disabled People's Organisations (DPOs) and Civil Society Organisations regarding the provision of quality ANC services to pregnant women with physical disabilities. The findings will also be of interest to researchers and policy makers to design unequivocal and evidence-based policies and disability inclusive maternal health interventions. This will contribute to the improvement of the reproductive health of mothers

with disabilities. Specifically, the study proposes recommendations, and I will seek an audience with the participants, Sheema District Health Management Team, and policy makers in the Department of Community Health and the Department of Nursing and Midwifery Services in the Ministry of Health to present them. I will also seek to present these recommendations on Kyambogo University Disability Commemoration Day, which is held every year in March with various stakeholders invited, including representatives from the Ministry of Health and the Ministry of Gender, Labour and Social Development (MGLSD), members of parliament, and representatives of persons with disabilities. The recommendations will contribute to the improvement of ANC experiences and pregnancy outcomes for mothers with physical disabilities in Uganda.

Considering the above, I reiterate that my major justification and identified need for this study is that there was a dearth in literature which represents the lived experiences of pregnant women with physical disabilities in accessing and utilising ANC services in a rural Ugandan setting. Whereas this study's contributions to scholarship are presented throughout the thesis, I extensively examine this in section 8.4 above.

8.6 Strengths and limitations of the study

This section describes the strengths and limitations that were present in this study.

8.6.1 Strengths of the study

This study is a novel one and it presents findings which extend the literature on the experiences of pregnant women with physical disabilities in the fields of Disability Studies and Maternal Health, focusing on ANC services – an under-researched but important area – in a rural setting in a low-income country (see Kazembe et al., 2022). The combination of conceptual frameworks used in the assessment of barriers provided a comprehensive understanding of the intersecting factors impacting the access to and utilisation of ANC services for rural pregnant women with physical disabilities, whose voices are not heard in the current literature.

As an insider, sharing the same language and sociocultural beliefs and values with the study participants helped me to build rapport, interact, and effectively communicate with them during our conversations. While English is not my first language and posed some challenges,

the fact that I shared the same first language as the research participants, an under-represented group, is a significant strength. In addition to my clinical background, staying and living in the district and my prolonged engagement with the health workers during data gathering helped me to understand the culture in the health care practice. My positionality helped me to navigate the health care system at the health facilities and to easily collaborate with the health managers, including selecting suitable midwives to participate in the study. I was familiar with the relational dynamics in a clinical setting, which helped me to observe and maintain an equal power gradient in relating with the midwives during the interviews. For instance, I would address a midwife as '*musawo*', signifying respect and recognition of their health profession while maintaining my researcher position. Consequently, as an insider, I was able to build good relationships with the study participants, community workers, health managers, and district administrative authorities, which was very significant to the research process as "building of trust is critical to indigenous community engagement" (Ohajunwa et al., 2021, p. 2). This relationship enabled me to collect rich data.

As an outsider, being a male without disability enabled me to see things differently from women with physical disabilities. I only used my position as a male researcher to pose questions from a different point of view that would lead to new information about the study topic (Berger, 2013) and therefore a nuanced understanding of women with physical disabilities' pregnancy experiences. Critical self-reflexivity and self-critique are of great significance in Disability Studies and have been emphasised throughout the study process.

8.6.2 Limitations of the study

My outsider position as a male researcher could have limited women from opening up on sensitive issues regarding abortion, sexual abuse, and the risks involved in sexual intercourse such as sexually transmitted infections, including HIV/AIDS. However, my outsider position as a researcher enabled me to pose questions from a different point of view while women took the position of experts on the research topic. Moreover, as the husband to a woman who has carried three pregnancies to term, I have some understanding of the care and support needed for a pregnant woman. This, along with my medical and social work background with a disability focus, meant that I was mindful of the personal issues related to disability and reproductive health.

This study did not include women with other types of impairments who could be experiencing different barriers and/or facilitators from those identified in this study. While I focused on women with physical disabilities, I was cognisant of the vulnerabilities of women with other types of impairments who may also struggle in the access to and utilisation of ANC services in Uganda, but this is for another study. I would not have been able to recruit women with physical disabilities who did not engage the services and perhaps, this was a missed opportunity for understanding their reasons for not participating and engaging the services.

In addition, the study did not include the husbands and mothers of pregnant women with physical disabilities, who appear to be key sources of support for these women during pregnancy. It is possible that the husbands' and mothers' views and opinions could have provided a more comprehensive understanding of the women's experiences in accessing and utilising ANC services in rural Uganda. However, in the face of a dearth of literature in this type of setting, this study is a starting point and will inform future studies which can expand the scope to people with different disabilities and other key informants.

As a qualitative study, language and meaning-making were critical as I was part of the research instruments used for the data collection and analysis (Nasri et al., 2021). As much as I share the same language and the sociocultural milieu with the study participants, I recognise that with English not being my first language, it could have limited my usage of words in creating themes, subthemes, and categories, especially given the fact that a word can have several meanings depending on the context. In that regard, Diop (1996) posits that this requires “double efforts: to assimilate the meaning of words and then, through the second intellectual effort to capture the reality expressed by the words” (p. 36). Bearing this in mind, I put a lot of emphasis on ‘word smithing’²⁸ during the data analysis and interpretation. My supervisors, whose first language is English, were instrumental in critiquing the proposed names of categories, subthemes, and themes, which helped me to continually review, remould, and refine them to ensure that they fit within the realms of the data and context of the study. Both ‘empathetic’ and ‘suspicious’ interpretations were provided to elucidate the meaning that is implicit and hidden in the data, respectively (Willig, 2017) (see Chapter Four,

²⁸ In this study, the term ‘word smithing’ is used to mean continually ‘moulding/shaping and refining’ names for identified categories, subthemes, and themes.

section 4.14). This approach to data analysis helped to improve the trustworthiness of the findings.

Given the fact that many community activities were suspended due to the Covid-19 pandemic, CDOs were not engaging with persons with disabilities. Their absence made the identification of women with physical disabilities a bit cumbersome. In addition, December and January are festive months (Christmas, end of the year, and beginning of another year) and a harvesting season for millet; therefore, some CDOs were preparing to join their families as they were not residents in the same sub-counties where they worked, and some women with physical disabilities were involved in harvesting their millet gardens²⁹. The study was initially suspended and then later resumed for the recruitment of participants (see Appendix XXVIII) during this busy season of the year. The suspension was due to the Covid-19 pandemic, which had implications for this study (see Appendix XVI). In liaison with the CDOs, VHTs were instrumental in the identification and recruitment of women with physical disabilities. The VHTs also helped me to locate the homes and/or gardens of women, where I would meet them for recruitment discussions and our subsequent interview.

The physical distancing and face masking (to minimise the transmission of Covid-19) during the interviews could have limited women's eagerness and confidence in opening up to a person whose facial identity was partially masked. However, working together with the VHTs in the communities helped me to easily build rapport and trust with the participants. The VHTs work with these same communities in disease prevention and health promotion activities, including activities in maternal and child health promotion (Uganda Bureau of Statistics, 2021), and therefore the community members are very familiar with them.

8.7 Recommendations of the study

The study findings indicate the need for quality disability inclusive ANC services. In this section, areas for further research and recommendations to relevant stakeholders involved in improving the pregnancy experiences and outcomes of women with physical disabilities and policy makers are presented. These recommendations have the potential to influence policy,

²⁹ The study approval was suspended for seven (7) months (from 17 March 2020 to 28 October 2020) due to Covid-19 restrictions on fieldwork. However, the original plan would have had the field work completed before the festive and harvesting seasons.

practice, and curricula in institutions of higher learning, particularly midwifery training institutions, in Uganda.

8.7.1 Recommendations for future research

I have proposed an integrated framework for inclusive family- and community-focused ANC services for rural communities. This framework needs to be tested to determine its efficacy in other rural African settings, hence adding more value to the evidence base regarding African Renaissance as a premise for re-imagined Disability Studies (Ned, 2022) and inclusive ANC practices.

The findings indicate that very little attention was paid to the dimension of spiritual health and wellbeing of pregnant women with physical disabilities. A further in-depth investigation on the relationship between midwives' spiritual health and their attitudes to spiritual care for pregnant women with physical disabilities is suggested. There is also a need to understand the relationship between the spiritual health of the families and community members where women with physical disabilities live and their attitudes to these women. This focus will help to contextualise and understand the inadequate support for, poor tolerance of, and judgmental attitudes towards pregnant women with physical disabilities.

The husbands and mothers of women with physical disabilities appear to be key sources of support for pregnant women with physical disabilities. There is a need for a further study involving the husbands and mothers of these women to understand and document their experiences in supporting them. This understanding will help to identify strategies for addressing the challenges faced by families in supporting pregnant women with physical disabilities, which will further advance a disability inclusive family- and community-focused approach to pregnancy care.

Due to inaccessible transport and mobility systems, women with physical disabilities stayed on the wards or relocated closer to the health facilities during their late stages of pregnancy. This points to the need for the establishment of maternity waiting homes in rural Uganda as a measure for improving the accessibility to ANC services by these women. However, a further study to explore the effectiveness of such homes from the perspective of women with physical disabilities and the community in a rural Ugandan setting is recommended.

As trainers, midwives engage VHTs on issues of disability inclusion in ANC activities. There is a need to evaluate the training of VHTs by the midwives on disability inclusion in community ANC outreaches.

The findings of this study show that women used both herbs and applications (Indigenous knowledge) as well as western medicine during pregnancy. Studies need to be conducted to ascertain the interactions of these drugs with each other and their effects on the woman's health and that of her unborn baby. A deeper understanding of traditional herbal medicines and their role in pregnancy will provide a basis for the further advancement of African Indigenous knowledge. There is a need for a blended approach where African Indigenous knowledge and practices are recognised in ANC practice.

8.7.2 Recommendations for policy

The recommendations for policy focus on policy makers and health managers in Uganda.

8.7.2.1 Policy makers in Uganda

There is a need to align policy and practice to address the structural barriers and systemic oppression that women with physical disabilities encounter in accessing and utilising ANC services. There is a need for the government to provide free transportation to pregnant women with physical disabilities to improve their accessibility to health facilities during ANC. It can be in the form of refunds for transport money or putting in place a vehicle and/or a budget for fuel for their transport in each health sub-district. Their transportation can be arranged in collaboration with the VHTs and midwives.

In addition, setting up a mobile outreach service, which could support persons with physical disabilities in general and pregnant women with physical disabilities in particular to access care, is recommended. Such a mobile service would enhance the service for all persons with disabilities, not just pregnant women with disabilities. In the same way, this kind of accommodation for women with physical disabilities will be a win for women without physical disabilities. The pregnant women with disabilities then become the champions of access to care for a wider population – a role reversal!

There is a need to provide an explanation of ANC policies, including the partner involvement policy, to the midwives for their better understanding and optimum implementation of these policies. This will, in turn, enhance their inclusive ANC practices.

Through the Parish Development Model (PDM), the Government of Uganda should include a targeted budget line for women with disabilities. These targeted funds will enable the women to start or boost their income-generating activities. Supporting women with disabilities to engage in and/or access economic opportunities will enhance their economic status, and, in turn, optimise their wellbeing, thereby enabling their access to and utilisation of ANC services.

8.7.2.2 Health managers

Each health facility manager should ensure that there is a training programme database for the health facility that includes disability issues. This database will enable them to monitor and follow up on education, training, and sensitisation activities on disability inclusion.

Moreover, because the District Human Resource Office plans, budgets, and oversees the implementation of human resource development activities, health facilities should create their own training plans and budgets for the system-wide education, training, and sensitisation of health workers on disability. These plans and budgets should then be forwarded for incorporation into the Health Sub-District (HSD) ones, which the HSD then forwards for consolidation into the district ones to set aside the necessary funds for these activities.

The apparent knowledge deficit regarding disability among midwives and other health workers (nurses, laboratory, and pharmacy personnel) needs to be addressed. Regular Continuous Professional Development (CPD) on disability inclusion should be emphasised for all the categories of health workers involved in the provision of ANC services to pregnant women with physical disabilities. CPD is built in at the regulatory level in Uganda. I suggest that this CPD should be made mandatory for health workers as prerequisite for renewal of their annual practicing licences by the respective professional governing/licencing councils. The CPD should be co-ordinated and facilitated by the District Human Resource Office, through the District Health Office. The District Health Offices should then link with the

relevant academic units in universities and disability advocates for awareness raising on disability rights and disability inclusion in maternal health care services.

In addition, ANC practice guidelines for women with physical disabilities should be developed, in the context of rural Ugandan communities. The collective and inclusive development of these guidelines involving women with physical disabilities, midwives, and other relevant stakeholders is critical for effective implementation.

Health facility physical environments, buildings (including sanitary facilities), furniture, and equipment should be accessible by all pregnant women, including those with physical disabilities. Health managers need to ensure that they need to plan and budget for the appropriate facilities, furniture and equipment (like height adjustable beds and chairs) to accommodate persons with disabilities rather than ordering duplicates unnecessarily and incurring unnecessary costs on health infrastructure. Currently, there is a need for modification of the physical environment to allow for the reasonable accommodation of pregnant women with physical disabilities.

Health services should be improved to realise a fit-for-purpose and dedicated ANC clinic. The adequate planning, budgeting, procurement, and supply of drugs and medical supplies should be emphasised with due consideration of the material conditions of pregnant women with physical disabilities. An improvement in the system would benefit all women, making it a ‘win-win’ for everyone.

The findings show that there was little attention paid to women’s spiritual health and wellbeing. To improve women’s emotional and spiritual wellbeing, the integration of mental and spiritual health care services into ANC services, with midwives as key providers, is suggested.

8.7.3 Recommendations for practice

The recommendations for practice relate to both health facility and community services. They are intended for midwives and other health workers and community workers.

8.7.3.1 Midwives and other health workers

Midwives need to be mindful of the specific pregnancy needs and concerns of rural pregnant women with physical disabilities. Particularly, they need to reflect on their attitude towards women with physical disabilities, and to recognise the uniqueness of each pregnant woman and her intrinsic value. They should consider equal partnering with these women in an engaged moral and professional relationship – as a norm, not an option – in midwifery practice. Partnership with women is fundamental to midwifery practice, yet this partnership was seemingly not taught to or nurtured in the midwives.

There is a need to raise awareness on the disability rights of pregnant women with physical disabilities among midwives and other health professionals *viz* nurses, clinical officers, doctors, and those working in the laboratory and dispensary/pharmacy. They need to understand the hegemonic and/or unprofessional practices they could be inadvertently advancing against women with physical disabilities which hinder these women from receiving appropriate and adequate ANC services (phase III delay).

8.7.3.2 Community-based services

The Ugandan Parish Development Model (PDM) (Ministry of Local Government, 2022) offers an opportunity for community-based workers to target the societal mindset, beliefs, and practices that prevent pregnant women with physical disabilities from accessing and utilising ANC services. These community-based workers included CBR workers, CDOs, VHTs, and other community workers in collaboration with the Parish Development Committee (PDC), health workers, cultural and religious leaders, and civil society. This workforce calls for awareness raising on disability rights, including the sexual and reproductive health rights of women with physical disabilities, by these workers. Families of women with physical disabilities, *boda boda* riders, taxi drivers, and non-disabled women should be targeted for positive attitude change.

Similarly, the PDM should be used as a tool for improving the economic status of women with physical disabilities. Through the PDM, community workers should work to address the barriers impeding women with physical disabilities in accessing and utilising ANC services. Ubuntu ethics and values should be emphasised at the family, community, and health facility levels to enhance support for pregnant women with physical disabilities. This support will

enable women to exercise their agency and optimise their wellbeing in accessing and utilising ANC services.

8.7.4 Recommendations for curricula

These recommendations are particular to curricula changes in health training institutions.

8.7.4.1 Health training institutions

This study clearly reveals the need to prepare health workers, particularly midwives as the most appropriate ANC providers (ICM, 2021), to enable disability inclusion in ANC services. Midwives' competence, including their emotional intelligence, needs to be improved. Midwifery education and training should expose midwives to pregnant women with physical disabilities in their natural settings, including their homes, to understand these women's culture and the nuances of their daily life with a physical disability, as well as the interaction between pregnancy and function (Robey et al., 2013). This exposure will enhance midwives' emotional preparedness in caring for pregnant women with physical disabilities.

Midwifery education and training curricula should reflect the sociocultural complexities and the diversity of intersecting oppressing factors undermining the wellbeing of pregnant women with physical disabilities in rural Uganda. The Ubuntu philosophy needs to be underscored in the design of midwifery curricula and the delivery of its content to reflect the political, social, economic, cultural, and spiritual context in rural Ugandan communities. Such education and training will provide midwives with a nuanced understanding of the plight of pregnant women with physical disabilities in accessing and utilising ANC services in rural communities. This will enable the midwives to appreciate the pregnancy needs of these women, and treat them humanely, with respect and as equal partners. In addition, such curriculum changes will empower midwives to attend to pregnant women with physical disabilities, paying particular attention to their impairments and disabilities, and appreciating and recording important details for reference by health services management and in future research.

8.8 Concluding reflections

In this section, I reflect on the insights and skills I garnered along this PhD journey. I then provide the concluding remarks of the study.

8.8.1 *Self-reflection*

In Chapter One (section 1.6), I discussed my positionality and motivation for undertaking this study. I feel this PhD study has greatly enhanced my abilities as a researcher and my capacity for intellectual analysis. In addition, I have learnt more in the subject area of ANC services for women with physical disabilities and the diversity of disability. I recognise that only some work has been done and that there is more to do, but, most importantly, I now recognise how I can contribute to improving the pregnancy experiences and pregnancy outcomes of women with physical disabilities. It was evident that even with the socioeconomic transformation being realised in Uganda, women with physical disabilities are yet to benefit from this transformation due to the structural barriers and systemic injustices these women encounter in accessing and utilising ANC services. This study enabled me to broaden my understanding of the diverse and intersecting issues shaping their pregnancy experiences.

Along my PhD journey, I have had the opportunity to learn from my study participants, my supervisors, the literature, conference and seminar/workshop presentations from scholars in the fields of Disability Studies and Midwifery, and my fellow PhD students in various fields. I have acquired more knowledge and skills in many areas, including but not limited to critical analysis, scholarly writing, data management, and the application of and implications for research ethics during a pandemic. In addition to refining my research skills, this study enabled me to enhance my negotiation and project management skills. Part of this reflection is put into perspective as I do a personal critical reflection on the data gathering process, data transcription and translation, and the lessons learnt (see Methodology Chapter and Appendix XV).

8.8.2 *Conclusion*

In conclusion, this study aimed to explore the experiences of pregnant women with physical disabilities in accessing and utilising ANC services and to suggest strategies for improving these services in rural south-western Uganda. The critical research question was:

- why are access to and utilisation of ANC services by women with physical disabilities in rural south-western Uganda constrained and/or enabled the way they are?

I believe that the critical question central to this study has been answered. I reiterate that this is the beginning as more needs to be done. The evidence presented extends the literature on the experiences of pregnant women with physical disabilities, focusing on ANC services – an under-researched but important area – in rural settings in low-income countries (Kazembe et al., 2022). The study findings show that while access to ANC services by pregnant women with physical disabilities was enabled by optimising their wellbeing, undermining their wellbeing constrained it. This study exposes the vulnerability of pregnant women with physical disabilities in accessing and utilising ANC services shaped by a range of ubiquitous injustices and inequities at the family, community, and health facility levels. Raising awareness on disability rights at each of these three levels is critical for attitudes and mindset change, with emphasis on justice, equity, and respect for the human dignity of women (ICM, 2021), including those with disabilities.

Midwives need to meaningfully engage with women with disabilities, listening to their voices to understand their lived experiences. Similarly, the establishment of accessible quality ANC services in under-served areas benefits all women. Families and community provide critical support, and accessible transport and mobility systems create an enabling environment for women to access ANC services. Spiritual health is an important aspect in these women's lives which needs to be recognised in midwifery education, training, and practice. This study reveals the mismatch between the midwives' intentions and the outcomes in the delivery of ANC services, the manipulated power relations between midwives and women, and the existence of disrespectful ANC, which should be addressed.

Despite Uganda's steady socioeconomic progress, pregnant women with physical disabilities in rural areas are yet to benefit from the gains. The government of Uganda ratified and domesticated the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and therefore has an obligation to ensure that the rights of persons with disabilities in rural areas, including pregnant women with physical disabilities, are respected and protected. The government needs to honour its role of providing the infrastructure,

adequate planning, budgeting and funding of health care services, to enhance the ability of all people accessing the care they need.

The findings point to hope and positive opportunities for change towards the establishment of fit-for-purpose ANC clinics with accommodative quality ANC services. The spirit of Ubuntu, which may facilitate the participation and functioning of women with physical disabilities in the process of accessing and utilising ANC services, cannot be overestimated. To this end, awareness raising on disability rights for positive attitudes and mindset change, health services improvement for integrated ANC services and accessible health facility designs, and a paradigm shift in preparing midwives (as the key ANC providers) for disability inclusion through education, training, and mentoring, should be promoted.

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APPENDICES

Appendix I: Data analysis tables

Appendix I-A: Influences on accessing ANC services

Objective 1: To describe accessibility of ANC services for pregnant women with physical disabilities in rural south-western Uganda

a) Findings from women and midwives

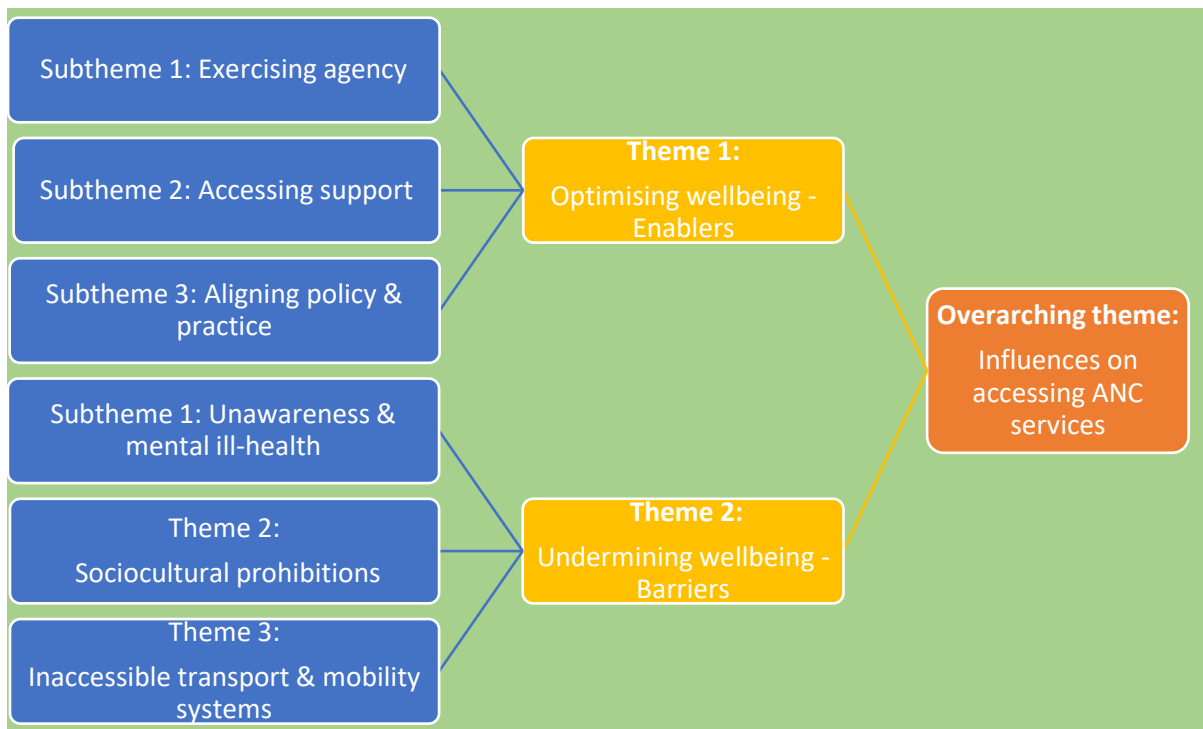


Figure A.1: Influences on accessing ANC services

b) Findings from women

Table A.1: Categories, subthemes and themes from women's data

A: Optimising wellbeing – Enablers in accessing ANC services			
Unit of meaning = Codes	Category	Subtheme	Theme
<i>She would be knowing the benefits of ANC</i>	Awareness of ANC benefits	Exercising agency	Optimising wellbeing
<i>These days women are exposed to health information</i>			
<i>Going to the hospital when it is still early before encountering problems</i>			
<i>It becomes easy for you during childbirth</i>			
<i>It gives health workers a picture of how to handle you at birthing time</i>			
<i>Traditional birth attendants (TBAs) may cause more harm than good</i>			
<i>I attended ANC to know if I am HIV positive or negative</i>	Desire to seek health information		
<i>We should be examined and told the situation in which we are</i>			
<i>I wanted to know if there were some bones that got damaged</i>			
<i>Wanted to know how a woman becomes pregnant</i>			
<i>You know how old your pregnancy is</i>			
<i>You always want to know that you have got pregnant</i>			
<i>Wanted to know how the baby was fairing in the womb</i>			
<i>Thought that they might find my baby not properly positioned or not well in some way</i>			
<i>Wanted to know how my pregnancy was or what kind of baby I had inside</i>			
<i>I wanted to know how a woman feels during pregnancy</i>	Fear of unknown		
<i>Fear that the baby inside the womb may not be presenting well</i>			
<i>Was worried about the health status of my unborn baby</i>			
<i>Fear of getting difficulties and have nowhere to start from</i>			
<i>Fear to be managed from the village and you die</i>			
<i>If the woman dies, people will say that she died from the health facility</i>			
<i>Fear of being scolded and embarrassed by health workers for not seeking ANC services, and in time at the time of giving birth</i>			
<i>Being prepared in case a caesarean section is recommended</i>			
<i>Did not want to add another challenge to my impairment</i>			
<i>Going to the health facility early before getting problems</i>			
<i>There are uncertainties in giving birth</i>			
<i>You may be lame in the pelvic bones and you don't have to give birth from the village</i>			
<i>Health workers told me that the baby could not pass through the pelvis because of my impairment</i>			
<i>Doctor said that my bones narrowed my pelvic opening and that I am not supposed to push the baby</i>			
<i>As a family they decide that she goes for ANC</i>	Support from family	Accessing support	
<i>Husband helped me in making the decision to go for ANC</i>			
<i>My husband would be aware of my return date and he gives me money for transport</i>			
<i>My husband would support me in domestic chores</i>			

Unit of meaning = Codes	Category	Subtheme	Theme
<i>I tell my husband and then he buys for me food craved for</i> <i>My husband was doing everything that I needed at home</i> <i>Children are young but you can send them</i> <i>I had my boy who was helping me, he would support me</i> <i>Her mother might have attended ANC and tells her to go</i> <i>I was told by my mother to go for ANC</i> <i>I was helped by my step-mother to seek ANC</i> <i>Mother did a big job because she supported me so much</i> <i>A parent is always pure at heart without being judgmental</i> <i>I would find when my mother has already cooked for me</i> <i>When I realized that I was physically weak, I called my mother</i> <i>It's my mother in-law who was helping me in daily activities</i> <i>If my mother-in-law is around, I tell her to give me money for transport</i> <i>My sister insisted and became hard on me to go for ANC</i> <i>My aunt and my sister remained here at home to support me</i>			
<i>I was helped by my neighbour to seek ANC</i> <i>My neighbour told me to go to the health facility for ANC</i> <i>Neighbours would help me in domestic chores</i> <i>For me to survive, it was because of my neighbours</i>	Support from neighbours		
<i>ANC is like a law put by the government</i> <i>If you don't go to for ANC, you would be 'mad'</i> <i>You have to make sure that you go to the health facility for ANC</i>	Favourable government ANC policy	Aligning policy and practice	
<i>People with disabilities should also behave well</i> <i>They should be polite when asking for favour</i> <i>Educating people on the rights of women with physical disabilities</i>	Raising awareness on disability rights		
<i>Boda boda is cheap</i> <i>Can easily be accessed from home</i> <i>Easy for one to keep time for ANC</i> <i>Using rider who understands my physical challenges</i> <i>Saving adequate money for transport</i> <i>Having a friend who is a boda boda rider</i> <i>Choosing a health facility closer to home</i> <i>Relatives coming to see me</i> <i>We went early and spent there a full month</i> <i>ANC services should be extended to the villages</i> <i>They should find them in their villages and examine them from there</i> <i>Sending them a vehicle to pick them for ANC services</i> <i>There need to sensitise the boda boda riders and taxi drivers on how to handle them during transportation</i> <i>Educating boda boda riders and taxi drivers about what disability is</i> <i>They need to reduce speed on the road</i>	Improving accessibility		
<i>Enabling them to start savings group as women with physical disabilities</i> <i>When one is in need and is a member of the savings group, you pick some money and give to her</i>	Improving economic status of women		

Unit of meaning = Codes	Category	Subtheme	Theme	
Government should support us financially				
Government should provide aid for them to start income generating activities				
You don't have to get a problem first to be supported				
I also need to put money in my pocket to buy necessities during pregnancy				
When I am working, I don't depend on others for financial support				
B: Undermining wellbeing – Barriers in accessing ANC services				
Unit of meaning = Codes	Sub-category	Category	Subtheme	Theme
Won't I give birth if I don't attend ANC?		Unawareness of the need for ANC services	Unawareness and mental ill-health	Undermining wellbeing
Forgets to know that there are challenges in future				
You may refuse to go for antenatal care and you find that the baby inside is not presenting well				
When you go to the hospital, how do they treat you	Anticipated undesirable treatment	Emotional and spiritual oppression		
When you go for antenatal where do you start from and where do you end from				
Fear of testing HIV positive				
Fear of your positive HIV status being disclosed to your husband				
Being turned away by the health workers for not being escorted by the husband				
You may find that someone got amputated due to Diabetes Mellitus	Exacerbated pain			
You may find that she is disabled and also has hypertension				
I can't shift from the ground				
When you add in pregnancy to the physical impairment, it becomes a different story				
I have something extra about my health				
I was feeling pain in the legs				
I realised a change in pain, it increased				
Paining around the waist because of the impairment				
Cannot make her own decision on mode of childbirth if she has impaired pelvis				
Feeling disheartened				
Feeling less important and not useful in the community				
Feeling embarrassed and ashamed of being seen in public when pregnant				
Feeling sad about being disabled				
Regretting why she was born				
No control and authority over the outcome of pregnancy				
You are supposed to have an attendant	Being helpless	Inadequate family and community support	Sociocultural prohibitions	
I needed to be cared for and supported during pregnancy				
A physically disabled woman with a young baby and also pregnant can't reach the health facility without support				

Unit of meaning = Codes	Sub-category	Category	Subtheme	Theme
May have soap to wash but both arms can't hold anything				
No person to help				
We are helpless				
When I am pregnant, I get worse				
If your husband doesn't help, you become helpless				
Become weak and I could no longer help myself in anything				
Care and support would be unavailable in case you get heavily pregnant				
You don't have that energy to keep on sitting and standing	Changes in mobility and its effects on work patterns			
I work a little and I rest a little				
If a woman is alone, and may be in a wheelchair, she gets challenges when pregnant				
Due to my physical impairment, I need to balance my work during pregnancy				
Instead of going to dig, I sit because I can no longer stand				
I remain seated even when I am to do some work				
The man beats you and you sleep outside	Marriage challenges			
I don't want to go into marriage and get another impairment				
My health can't manage a family				
You see how weak my body is				
The man I got married to is not supportive				
Sometimes you get a bad chance and get married to an alcoholic				
Husband gets money to drink but no money for the woman				
You can't know what the in-laws are 'inside'	Absent expected government support			
Other family members neglect you				
Government was going to give us financial support but nothing up to now				
You only hear that government sent money and was given out in secrecy				
I would have gone to town but because of limited finances, I work from home		Limited income		
You don't get enough money from crop harvest				
If I had money, I would be in a big area and I also work				
I would work for a day in a banana plantation or a garden for casual labour				
If she goes for hand crafts, from such, she may get money for transport				
When money became scarce, I came back and sat here				
There is nowhere to work from to enable me to earn something				
I think of what to do but I don't get it				

Unit of meaning = Codes	Sub-category	Category	Subtheme	Theme
Family members may also stop them from going to work	Insufficient antenatal provisions			
Only if I could get money and I start my own business				
My husband does not have a job				
You can't get all the ANC requirements				
I did not get all the things that I needed				
Even soap was not available at home				
You wouldn't get the maternity dress				
Being told by the health workers not to wear a skirt				
Needed what to use to carry the baby				
The requirements are always too many				
A merciful person giving her what to use to carry the baby				
May not have enough of those ANC requirements				
Going to the health facility with hope of getting a top up on the few you have				
No food at home				
Should be supported with what to eat and drink				
Could not satisfy her food craving				
You should not walk around so often when pregnant	Should not move so often	Cultural beliefs and practices		
People would say that I crossed over a dead thing because my baby was small				
Not good to see a 'dead thing' when pregnant				
You should not eat before going for ANC, health workers may fail to locate the fetus	Beliefs regarding food			
If you deny her what she wants to eat, she may get a miscarriage				
Taking herbs and sitting at home without going to the health facility	Use of herbs			
She keeps trusting herbs				
Herbs facilitate normal growth and development of the fetus				
When you take herbs, you don't feel much labour pain				
Being given herbs by fellow women at the health facility at the time of giving birth				
The herbs became too much and the baby died after birth				
Negative attitude has always existed	Community's Dehumanising attitude			
No one can sympathise with you				
Considered as a community burden				
They are perceived as abnormal beings	Different beings			
They are considered as half-human beings				
They are considered uneducable				
Created last when God was tired				
No right to get married	Unfit for marriage			
Considered unfit for marriage				
People think the uterus also has a disability and can't conceive				
They are likely to get birth problems if they conceive				

Unit of meaning = Codes	Sub-category	Category	Subtheme	Theme
Boda bodas may not be available	Insufficient access to transport	Inappropriate transportation	Inaccessible transport and mobility systems Inaccessible infrastructure	
May fail to get a suitable vehicle for travel				
The boda bodas are few				
You are the one who knows how you will always move to the health facility				
Boda boda transport charges being high	High cost of transport			
Having no money for transport				
Transport money not being enough				
Temporary relocation closer to the health facility				
Being carried with another passenger				
Bargaining with boda boda riders				
Getting the boda boda along the way				
Would rather walk				
Boda boda causing or worsening physical pain	Inappropriate mode of travel			
Falling off the boda boda				
The one with a physical disability will first say that ‘stop and I sit well’ on the boda boda				
A person without a disability is swift and can quickly climb on to a motorcycle				
Delaying on the way	Limited walking capacity			
You walk and get tired				
I walk and knock myself				
The leg being weak				
The leg pains and I sit for almost a week without moving				
The knee joint doesn’t fold				
Can’t walk a long distance				
Starting the journey early				
Taking rests on the way				
I am also supposed to walk and stretch my legs				
Most of the roads are bad	Poor condition of the roads	Inadequate road infrastructure		
Risky short-cuts taken Boda boda riders				
Bumpy roads with potholes				
When it rains, accessing a vehicle becomes a problem				
When it rains roads become muddy and slippery				
Home being far from the health facility	Long distance to the health facility and its implications			
Was going to health centre III because health centre IV and hospital are far				
Feeling pain and tiredness after travelling a long distance				
Increased boda boda charges due to long distance				
Missing ANC appointment				
Not reaching the health facility in time				
Seeking ANC services late in pregnancy				
Preparing a drink to travel along with				
Ensuring that money for transport is available				

c) Findings from midwives

Table A.2: Categories, subthemes and themes from midwives' data

A: Optimising wellbeing – Enablers in accessing ANC services				
Unit of meaning = codes	Category	Subtheme	Theme	
We do community mobilisation and sensitisation on ANC services	Awareness of ANC benefits	Exercising agency	Optimising wellbeing	
We also talk to them when we go for immunisation outreaches				
The understanding of the people the woman is living with enables her to seek ANC services				
I think it the family members who decide about seeking ANC				
Fear of being scolded by health workers for not seeking or delaying seeking ANC at the time of giving birth	Fear of unknown	Accessing support		
She would come with the husband to provide support	Support from the family			
They rely on their husbands for support				
She was always escorted by her sister in-law				
The mother in-law and the father in-law can tell the man to take his wife for ANC				
Village health teams (VHTs) are doing a great job in influencing them to seek ANC services	Favourable government ANC policy	Aligning policy and practice		
Traditional birth attendants (TBAs) have reduced in the communities				
Most Traditional birth attendants are working as village health teams				
Need to empower them by sensitising them on their rights	Raising awareness on disability rights			
They know their rights and they are empowered but sensitisation must continue				
Sensitising family members about sexual and reproductive health rights of women with physical disabilities				
If there can be a transport program that reaches out to where they are coming from	Improving accessibility			
Village health team (VHT) connects with the health facility team to provide outreach services				
If the mother is not able to one, we can find her at home				
Identifying mothers with physical disabilities through VHTs				
Providing money or a vehicle for transporting them to and from the health facility				
Training them in vocational skills	Improving economic status of women			
Supporting them to start income generating activities				
B: Undermining wellbeing – Barriers in accessing ANC services				
Unit of meaning = codes	Sub-category	Category	Subtheme	Theme
There is lack of awareness about ANC benefits		Unawareness of the need for ANC services	Unawareness and	Undermining wellbeing
If their level of education is too low, they may not consider ANC as important				

If her mother is not informed about ANC benefits, she will not support her to seek ANC services			mental ill-health	
Unit of meaning = codes	Sub-category	Category	Subtheme	Theme
They have more health care needs	Exacerbated pain	Emotional and spiritual oppression		
She needs a lot of counselling compared to the 'normal' mothers				
She has pregnancy and physical disability				
They are usually mocked	Feeling of worthlessness			
Feeling disheartened				
Feeling not worthy of being cared for				
They have self-stigma				
Husbands not taking responsibility for the pregnancy	No support from husbands	Inadequate family and community support	Sociocultural prohibitions	
Husbands are usually not supportive	Marriage challenges			
They usually have gender-based violence in their families				
The man looks out for other women who are able-bodied				
Social economic status at family level influences their access to ANC	Insufficient antenatal provisions	Limited financial and antenatal resources		
Not having enough personal requirements during pregnancy				
Not declaring pregnancy early for fear of being bewitched	Not declaring early pregnancy	Cultural beliefs and practices		
You may 'walk over' bad herbal medicines				
When the linea nigra goes beyond the woman's umbilicus then the fetus' umbilical cord is too long	Cutting around the mother's umbilicus			
They cut around the mother's umbilicus to shorten the fetus' cord				
They may be convinced by the traditional birth attendants (TBAs) not to seek ANC	Trusting in TBAs			
TBAs are not professionally trained				
When you pour hot water on the abdomen, the baby turns to a normal position	Use of herbs and applications			
Using herbs to treat any increase in vaginal discharge during pregnancy which they think comes from the fetus				
Women use different herbs during pregnancy				
Using herbs to clean the unborn baby so that it is not born dirty				
Using herbs to reduce labour pains, quicken the labour process and prevent vaginal tear during childbirth				
Women peddle drugs at the health facility				
Using herbs may cause complications				
There are some people who can never change their attitude			Community's dehumanising attitude	
She is not a normal human being like them	Different beings			

<i>They are Considered half human beings</i>				
Unit of meaning = codes	Sub-category	Category	Subtheme	Theme
<i>No right to get pregnant</i>	Unfit for marriage			
<i>Most of them are not married</i>				
<i>Most of them are raped</i>				
<i>People think the uterus also has a disability and can't conceive</i>				
<i>The woman with physical disability and carer using one motorcycle</i>	Insufficient money for transport	Inappropriate transportation	Inaccessible transport and mobility systems	
<i>Some of them are very poor</i>				
<i>With no money for transport, she remains at home</i>				
<i>Some walk to the health facility because they can't afford money for boda boda transport</i>				
<i>Not easy for her to climb, sit and get off the boda boda</i>	Inappropriate mode of travel			
<i>She was using her buttocks to move</i>	Limited waking capacity			
<i>Was limping</i>				
<i>She cannot walk up to the health facility</i>				
<i>The geographical terrain may affect their movement</i>	Poor conditions of the roads	Inadequate road infrastructure		
<i>Rain makes their travel worse</i>				
<i>The roads become muddy and slippery</i>				
<i>Long distance increases the cost of transport</i>	Long distance to the health facility and its implications			
<i>Missing their appointments due to long distance to the health facility</i>				
<i>Need to travel along with a drink</i>				

Appendix I-B: Utilising ANC services

Objective 2: To explain the utilisation of ANC services by pregnant women with physical disabilities in rural south-western Uganda

a) Findings from women and midwives

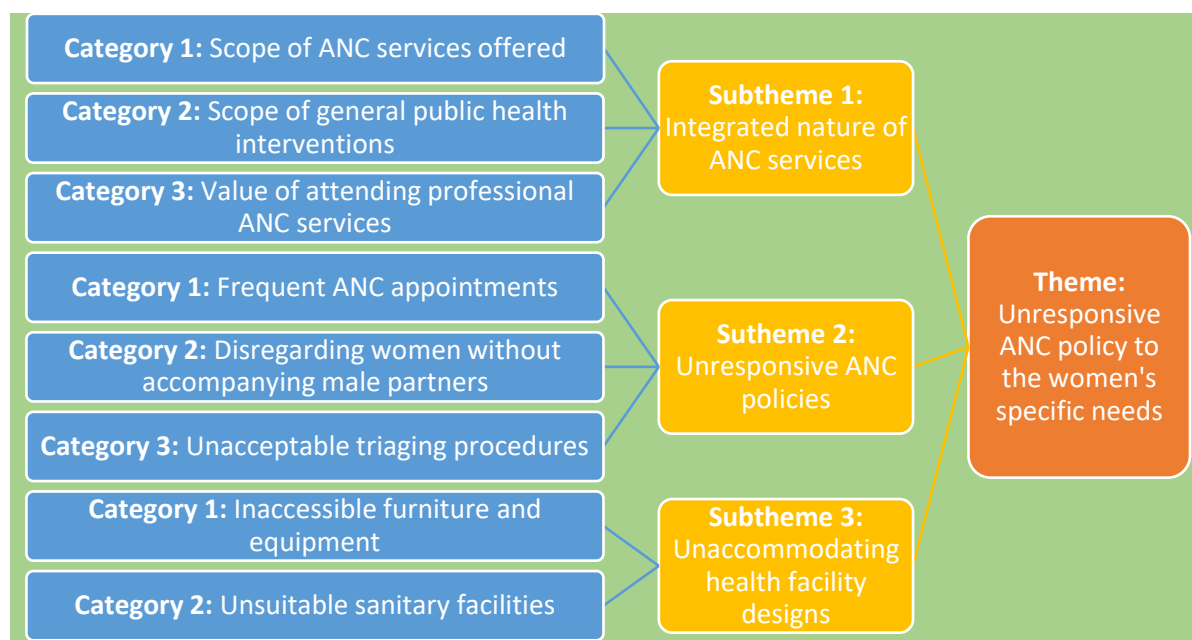


Figure B.1: Categories, subthemes and theme on 'Influences on utilisation of ANC services

b) Findings from women

Table B.1: Categories, subthemes and theme from women's data

Units of meaning = codes	Categories	Sub-themes	Theme
ANC services are free except the scan	Scope of ANC services offered	Integrated nature of services	Unresponsive ANC policy to the women's specific needs
Ultrasound scan services are paid for			
Being physically examined by health workers			
Being sent to the laboratory for tests			
Being referred for higher facility level services			
Birth preparedness planning			
Received information on labour signs			
Received information on mode of childbirth			
Was given tablets for blood and Fansidar to prevent malaria			
Given an injection on the arm to prevent tetanus			
When you are sick, they give you medicine			
Was given a mosquito net			
They give you maama kit with lots of things inside like gloves, cotton, gauze etc			
No fuel for ambulance			
There are times when they write for a woman drugs, and they are not available			
You reach and find no single glove at the health facility			
Required to pay for transport when referred			

Units of meaning = codes	Categories	Sub-themes	Theme
<i>There is always someone teaching you as you wait for the midwife</i>	Scope general public health interventions		
<i>Being educated on different health topics</i>			
<i>Knowing how her health and that of her unborn baby is</i>	Value of attending professional ANC services		
<i>It is worth the energy and money I put in</i>			
<i>It becomes easy for you during childbirth</i>			
<i>If you need an operation, they operate you</i>			
<i>Helps to prepare for childbirth and avoid complications</i>			
<i>Can't make eight visits unless the health centre is nearby in a walkable distance</i>	Frequent ANC appointments	Unresponsive ANC policy	
<i>I went there four times and on the fifth one, I gave birth</i>			
<i>You need to prepare finances for the next ANC visit in time before the next appointment</i>			
<i>Requires you to have assessed at what appropriate time you need to start the ANC</i>			
<i>It a rule, when you go with your husband, they work on you first</i>	Disregarding women without accompanying male partners		
<i>I went with him once</i>			
<i>Sometimes I would go with him, other times I would go alone</i>			
<i>He just tells you to go alone for ANC</i>			
<i>Not being accompanied by the husband</i>			
<i>When they find you with HIV, they tell you to bring your husband</i>			
<i>Was asked to pay to be attended to yet services are free</i>	Unacceptable triaging procedures		
<i>When I reach, I tell the health worker that I am physically disabled</i>			
<i>If they see that you are severely disabled, they attend to you first, but some physical disabilities are not visible</i>			
<i>Being treated the same way as 'normal people'</i>			
<i>Being served on first come first served basis</i>			
<i>Not having enough benches at the waiting area</i>	Inaccessible health facility furniture	Unaccommodating health facility designs	
<i>Inappropriately high chairs and benches</i>			
<i>Unable to sit on the bench</i>			
<i>No supports for climbing the examination bed</i>			
<i>There are wooden steps for climbing the examination bed</i>			
<i>Narrow examination beds</i>			
<i>Located outside, far away the ANC clinic</i>	Unsuitable sanitary facilities		
<i>No supports in the latrines</i>			
<i>Squatting is hard</i>			
<i>If you don't have a carer, you suffer</i>			
<i>They are used by many people, and they are not clean</i>			
<i>Sanitary conditions not good for a pregnant woman with physical disability</i>			

c) Findings from midwives

Table B.2: Categories, subthemes and theme from midwives' data

Units of meaning = codes	Categories	Sub-themes	Theme
<i>Carrying out physical examination</i> <i>Sending women to the laboratory for tests</i> <i>Ultrasound scan services being paid for</i> <i>Referring women for services like ultrasound scanning that are not available</i> <i>Birth preparedness planning</i> <i>Provision of routine drugs</i> <i>Giving them long lasting insecticide treated mosquito nets</i> <i>Giving them maama kits</i> <i>Giving them tetanus toxoid and Hepatitis B vaccinations</i> <i>There may be drugs that are out of stock and they asked to go out and buy them</i> <i>As I talk now, we don't have gloves and face masks to use and sometimes mothers have to buy their own gloves</i>	Scope ANC services offered	Integrated nature of ANC services	Unresponsive ANC policy to the women's specific needs
<i>Conducting health education</i> <i>Carrying out community outreaches</i>	Scope of general public health interventions		
<i>They are at risk mothers</i> <i>Needs all the support and encouragement from health workers</i> <i>Counselling and preparing them</i>	Value of attending professional ANC services		
<i>First attending to women being escorted by their husbands for ANC</i> <i>Others tell their husbands and they refuse</i> <i>We are advocating for male involvement in ANC</i> <i>When we get him, we have to make sure he tests for HIV and syphilis</i>	Disregarding women without accompanying male partners	Unresponsive ANC policy	Unresponsive ANC policy
<i>Doing triage to identify women to be attended to first</i> <i>Some health workers ask for money before attending to them</i> <i>Women get scared they will be asked to pay</i>	Unacceptable triaging procedures		
<i>Need for accessible and safe buildings</i> <i>Need to have antenatal beds for physically disabled women</i> <i>Need for more wheelchairs at the health facility</i>	Limited access to the physical environment	Unaccommodating health facility designs	
<i>Inappropriately high chairs and benches</i> <i>Unable to sit on the benches</i> <i>Examination beds not height adjustable</i> <i>No supports for climbing the examination bed</i> <i>There are wooden steps for climbing the bed</i>	Inaccessible health facility furniture		Unaccommodating health facility designs
<i>Located outside, away the ANC clinic</i> <i>They pass through grass when going to the latrine</i> <i>No supports in the latrines</i> <i>Latrines are dirty and unsafe</i> <i>Pregnant women may acquire infections</i>	Unsuitable sanitary facilities		

Appendix I-C: Improving ANC services

Objective 3: To examine the relationship between women with physical disabilities and health care providers during ANC in rural south-western Uganda

Objective 4: To explore how women with physical disabilities and midwives understand disability and provision of ANC services in rural south-western Uganda

a) Findings from women and midwives

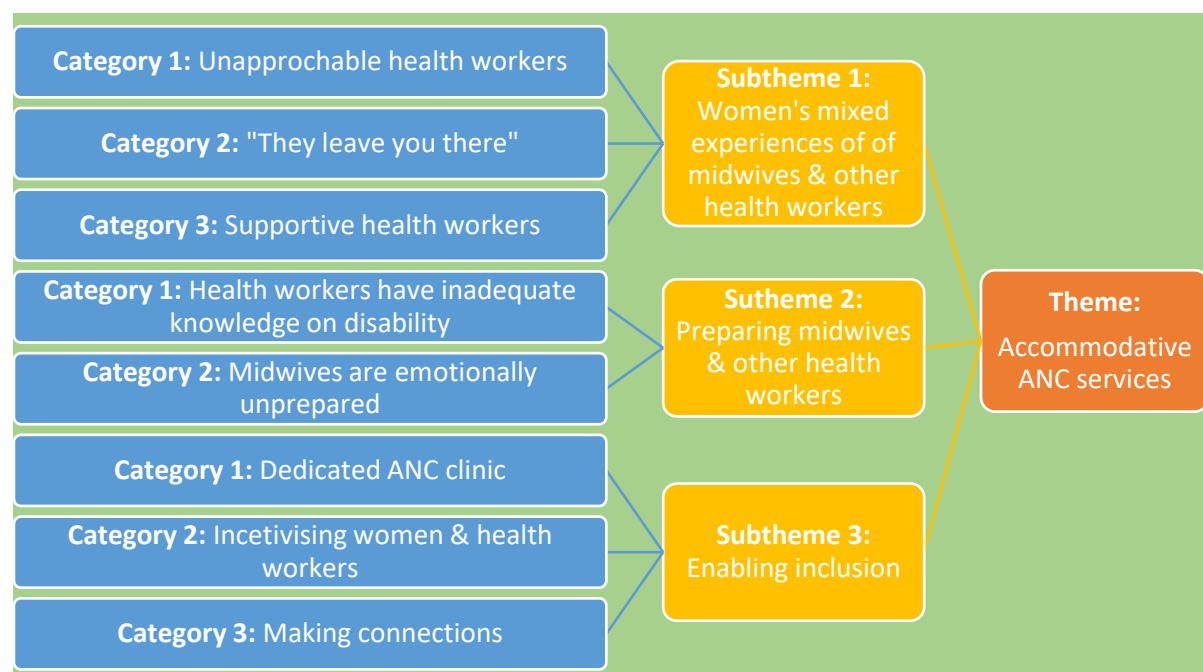


Figure C.1: Categories and subthemes on 'Accommodative ANC services'

b) Findings from women

Table C.1: Categories, subthemes and theme from women's data

Units of meaning = codes	Categories	Sub-themes	Theme
<i>If you find them angry, they treat you badly</i>	Unapproachable health workers	Women’s mixed experiences of midwives and other health workers	Accommodative ANC services
<i>Some health workers are not approachable</i>			
<i>Woman was humiliated amidst people</i>			
<i>Health worker was merciless</i>			
<i>They don’t feel compassion for you and abuse you when you reach late</i>			
<i>Health worker talking to you rudely</i>			
<i>If they see that you are not in pain, it means you are normal</i>	“They leave you there”		
<i>They attend to you but they don’t pay necessary attention to one’s disability</i>			
<i>Attending to one without disability and they leave you there</i>			
<i>You the disabled person gets attended to at the end</i>			
<i>Why can’t they see that you are disabled and attend to you very fast</i>			
<i>They treat women well, even better than those without disabilities</i>			
<i>They receive you well when you have a disability</i>			
<i>Health workers being caring and supportive</i>			
<i>Have never been talked to rudely</i>			
<i>Health workers being encouraging</i>			
<i>They would quickly attend to me</i>			
<i>They treat you well if you find them in good mood</i>			
<i>Continue educating health workers on disability</i>	Health workers have inadequate knowledge on disability	Preparing midwives and other health workers	
<i>Health workers don't understand disability issues well</i>			
<i>If they are not used to issues of disability, they leave you there</i>			
<i>Care should be good</i>	Dedicated ANC clinic	Enabling disability inclusion	
<i>They should not forget that we need something extra about our health</i>			
<i>They should quicken the process for us and we go back home</i>			
<i>Should be attended to first</i>			
<i>A woman who wants to sit on the bench should sit there and those who want to sit down should sit there</i>			
<i>Need for special ANC examination room for physically disabled pregnant women</i>			
<i>We should always find drugs when we go to the health facility for ANC</i>			
<i>They should always consider us as disabled people because we are helpless</i>			
<i>If she reaches a slope and fails, the support personnel should help her</i>			

c) Findings from midwives

Table C.2: Categories, subthemes and theme from midwives' data

Units of meaning = codes	Categories	Sub-themes	Theme
Women anticipate intimidation	Unapproachable health workers	Women’s mixed experiences of midwives and health workers	Accommodative ANC services
Even the attitude of these mothers is not good			
Health workers judge them			
Some health workers have negative attitude			
No considerations for women with disabilities in standard operating procedures			
Health workers feel demotivated			
Long waiting time at the health facility			
Use of abusive language by health workers			
We welcome them	Supportive health workers		
Supporting and encouraging her to come back again			
Being disabled does not mean you are not supposed to get services			
They have no other hope other than that hope from us			
We don’t discriminate them			
Health workers don’t understand disability issues well	Health workers have inadequate knowledge on disability	Preparing midwives and other health workers	
Never thought of disability inclusion			
Midwife got scared	Midwives are emotionally unprepared		
Helping her was a painful experience and not every midwife can do it			
Health workers feeling demotivated			
Need for ANC program for physically disabled pregnant women	Dedicated ANC clinic	Enabling disability inclusion	
Having disability support personnel			
Should be attended to first			
Need for disability sensitive health workers			
Providing incentives for physically disabled pregnant women	Incentivising women and health workers		
A mother who makes eight visits will takes two maama kits			
Management appreciating health workers with positive attitude			
I think Community Development Officers know these women better than me who stays at the health facility	Making connections		
Since health inspectors’ worker is in the community, they can help to identify these mothers			
Village health teams link women to the health facilities			
There should be contact tracing of these mothers			

Appendix II: Request letter to Community Development Officers

University of Cape Town, Faculty of Health Sciences



Date.....

The Community Development Officer

.....

Dear Sir / Madam,

**RE: REQUEST FOR IDENTIFICATION AND RECRUITMENT OF WOMEN
WITH PHYSICAL DISABILITIES FOR A PhD STUDY IN SHEEMA
DISTRICT**

I am a PhD Student at the University Cape Town, South Africa. I am conducting research on issues relating to women's physical disability and access to antenatal care services. In addition to the above, Sheema is also my home district. Particularly, I come from Kitagata sub-county. I teach at Kyambogo University, Department of Community and Disability Studies. The area of study and the research topic are both important to me. I have been permitted to conduct this study by University of Cape Town and Uganda National Council of Science and Technology.

I am kindly requesting that during your routine community mobilization and sensitization for government programs in stakeholders' meetings and community dialogues, you pass on this information about my PhD research project to women with physical disabilities and help to identify for me those who are willing to participate.

THE INFORMATION TO PASS ON:

What is the study on?

Topic: ‘Access to and utilisation of antenatal care services by women with physical disability in rural south-western Uganda’.

Who is conducting the study?

My name is Ponsiano Kabakyenga Nuwagaba, a PhD student at the University of Cape Town, South Africa. I come from Kitagata sub-county, Sheema district.

What is the purpose and benefit of the study?

I am carrying out this study to understand how pregnant women with physical disabilities access and use antenatal care services in Sheema district. The selected women with physical disabilities will share their experiences regarding access to and utilisation of antenatal care services in Sheema. I believe the information obtained will be useful to different stakeholder like the health workers, policy makers, researchers, community-based organizations and non-governmental organizations. The information will help to develop strategies for improving access and utilisation of antenatal care services by pregnant women with physical disabilities in Sheema and Uganda at large. It will serve to improve the experience of antenatal care for pregnant women with physical disabilities in Uganda.

Where will the study be conducted?

This study will be conducted in the sub-counties where the three selected health facilities are located. Your sub-county will be one of them.

Who is eligible to participate?

Women with physical disabilities, for example due to amputation, polio, cerebral palsy, spinal cord injury or accident and are pregnant or have ever been pregnant in the past three years.

What will the study involve?

Women with physical disabilities who indicate that they are willing to participate in the study will be contacted and approached by the researcher to give them more details about the study and respond to their queries. Confidentiality and privacy of all the participants’ information will be ensured. Voluntary participation of women with physical disabilities to achieve the purpose of this study will be highly appreciated.

Contact address:

Please, you or a mother with physical disability is free to contact me on my Mobile Telephone Number **0781 644616** or Email: NWGPON001@myuct.ac.za.

You can also contact the research project supervisor: Associate Prof. Sheila Clow on Tel: **+27 (0) 21 406 6449** or Email: sheila.clow@uct.ac.za.

I thank you in advance for your positive response and I look forward to hearing from you.

Yours sincerely,



Ponsiano Kabakyenga Nuwagaba

PhD Student (NWGPON001)

Appendix III: Face-to-face interview guide for women with physical disabilities

University of Cape Town, Faculty of Health Sciences



Study title: “Access to and utilisation of antenatal care services by women with physical disabilities in rural south-western Uganda”.

Introduction: My name is Ponsiano Kabakyenga Nuwagaba, PhD student at the University of Cape Town, South Africa. I work at Kyambogo University in the Department of Community and Disability Studies. I am from Kitagata. The area of study and the research topic are both important to me.

Purpose of the interview and confidentiality assurance:

I have passion for disability inclusive health care services especially in maternal health care. I am keen to hear your views and experiences on how you are able to access and use antenatal care services. Thank you for agreeing to take part in this study. This interview will take us about one hour.

I would like you to know that your privacy will be ensured throughout the research process and the information you are going to share will be kept confidential. Please, be assured that your views and experiences will not bear your name or address. Please, in case you have any question regarding this study, you are free to ask me now or any time during or after this interview.

Interview begins:

The researcher will use different interviewing techniques like repetition, interim summaries to encourage further disclosure and re-focus the interview. Good ideas will be followed-up with probes to seek elaboration or clarification.

- i. I know you are pregnant (if she is pregnant). What else can you tell me about yourself?

(General information: probe for age, level of education, occupation, level of income – command of personal or public economic resources for economic self-sufficiency, marital status, previous pregnancy history and childbirth experience, pregnancy status, impairment – for how long and extent of impairment- probe to find out severity e.g. Mild, moderate, severe or complete).

- ii. Tell me what you know about ANC (Probe to find out examples of services offered, distance and name of health facility, number of ANC visits for the current or previous pregnancy etc).
- iii. How do you access these ANC services? *(Probe what it entails for her to make a decision to seek or not to seek ANC, identify and reach the health facility, see the health worker and be attended to - systems)*

Activity limitation and participation restriction at home/family

- iv. How do you reach your decision to seek or not to seek ANC services?
 - ✓ In your present state of health and/or in your family or community (Regarding when, where, who makes decision to seek care and why. Probe to find out her agency and social cultural issues)
- v. How is this different with a pregnant woman, just like yourself but without disability?
- vi. How is your participation in decision making made worse or better, by the way your family or community is arranged? *(Probe for social cultural barriers and facilitators at family/community level - norms, beliefs, attitudes etc)*

Activity limitation on the way to health facility

- vii. Tell me about your travel to the health facility without assistance. *(Probe to find out her functioning capacity and the qualifiers such as mobility of joints, muscle power and involuntary movements)*

Participation restriction on the way to health facility

- viii. How is your travel to the health facility with assistance? (Probe to find out the distance, use of assistive devices, who assists, how they assist etc)
- ix. How is this travel to the health facility made worse or better by your actual surroundings? (probe for barriers and facilitators - weather conditions, terrain, means of transport, cost of transport, societal attitudes and cultural norms and beliefs etc)

Activity limitation at the health facility

- x. In your present state of health, how are you able to access buildings, equipment and use ANC services at the health facility without assistance? (*probe to find out her functioning capacity and the qualifiers - such as mobility of joints, muscle power, muscle tone and involuntary movements*)

Participation restriction at the health facility

- xi. Tell me your story/ experience about accessing and utilizing ANC services (*probe to find out intersectionality between her disability and environmental and personal factors at home, on the way and at health facility X*).

✓ In your present surroundings, how are you able to access buildings, equipment and use ANC services at the health facility? (Probe to find out accessibility of the ANC clinic, waiting area and the chairs, examination/consultation room, laboratory, latrines etc, availability of health workers and their attitude etc)

✓ How is this access to buildings, equipment and use of ANC services at the health facility made worse or better by your actual surroundings? (*Probe to find out attitudes of health workers, procedures, fees, laws, policies, regulations, guidelines and standards*)

- xii. In your own opinion, what do you think should be done to improve access to and utilisation of ANC services for pregnant women with physical disabilities? (*probe for strategies for better decision making to seek care, improving transport and quality of ANC services*)
- xiii. In your own view, how do you describe the relationship of health workers towards pregnant women with physical disabilities? (*probe to find out attitudes and reasons*)

Other information

- xiv. What type of care / support / information do you need / receive in pregnancy and from whom?
- xv. What care would you like to have received from the health service?
- xvi. Do you have any other information you would like to share with me about ANC or disability in general that may be useful in this study?

Please, I will inform you when I will be coming back to share with you my interpretation of what you have shared with me today. I will also come back in case I find out that I need clarification on a particular issue from you.

Thank you for sharing your perspectives with me.

Appendix IV: Face-to-face interview guide for health workers

University of Cape Town, Faculty of Health Sciences



Study title: “Access to and utilisation of antenatal care services by women with physical disabilities in south-western rural Uganda”.

Introduction: My name is Ponsiano Kabakyenga Nuwagaba, PhD student at the University of Cape Town, South Africa. I work at Kyambogo University in the Department of Community and Disability Studies. I am from Kitagata. The area of study and the research topic are both important to me.

Purpose of the interview and confidentiality assurance:

I have passion for disability inclusive health care services especially in maternal health care. I am keen to hear your views on access to and utilisation of antenatal care (ANC) services by women with physical disabilities. Thank you for accepting to take part in this study. This interview will take us about one hour.

I would like you to know that your privacy will be ensured throughout the research process and the information you are going to share will be kept confidential. Please, be assured that your views and experiences will not bear your name or address. Please, in case you have any question regarding this study, you are free to ask me now or any time during or after this interview.

Interview begins:

The researcher will use different interviewing techniques like repetition, interim oral summaries to encourage further disclosure and re-focus the interview. Good ideas will be followed-up with probes to seek elaboration or clarification.

- i. Other than being a health worker in ANC clinic, what else can you tell me about yourself? (General information: observe sex, probe for age, level of education, experience, marital status, professional trainings etc).
- ii. Tell me about the ANC services you offer here at this health facility (*services, systems and policies*).
- iii. How do you find the provision of ANC services to pregnant women with physical disabilities? (*Probe to find out reasonable accommodation for women with physical disabilities from the time they reach the health facility to when they leave, attitude*)

Activity limitation and participation restriction at home/family

- iv. From your interactions with pregnant women with physical disabilities, what do you think influences their decisions to seek or not to seek ANC? (*Regarding when, where, who makes decision to seek care and why. Probe to find out her agency and social cultural issues, role of TBAs,*)
- v. How does this compare with a pregnant woman without disability?
- vi. How is their participation in decision making made worse or better, by the way their families or communities are arranged? (*Probe for social cultural barriers and facilitators at family/community level - norms, beliefs, attitudes etc*)

Activity limitation on the way to health facility

- vii. What is your view about the travel for the pregnant women with physical disability from her home to this health facility without assistance? (*Probe to find out functioning capacity and the qualifiers such as mobility of joints, muscle power, muscle tone and involuntary movements*)

Participation restriction on the way to health facility

- viii. What is your view about the travel for the pregnant women with physical disability from her home to this health facility with assistance? (Probe for to find out the distance, use of assistive devices, who assists, how they assist etc in relation to participation)
- ix. How is this travel to the health facility made worse or better by the actual surroundings? (probe for barriers and facilitators - weather conditions, terrain, means of transport, cost of transport, societal attitudes and cultural norms and beliefs etc)

Activity limitation at the health facility

- x. How do pregnant women with physical disability go through the process of ANC without assistance? (*Probe to find out her functioning capacity and the qualifiers - such as mobility of joints, muscle power, muscle tone and involuntary movements in*

the clinic, waiting area and the chairs, examination/consultation room, laboratory, latrines etc)

Participation restriction at the health facility

- xi. Tell me about the process of ANC for a pregnant woman with a physical disability at this health facility (their access to buildings, equipment and use of ANC services)
(Probe to find out accessibility of the clinic, waiting area and the chairs, examination/consultation room, laboratory, latrines etc, availability of health workers and quality of ANC)
- ✓ How is this access to buildings, equipment and use ANC services at this health facility made worse or better by the actual surroundings? *(Probe to find out attitudes of health workers, procedures, fees, laws, policies, regulations, guidelines and standards)*
- xii. In your own opinion, what do you think should be done to improve access to and utilisation of ANC services for women with physical disabilities? *(probe for strategies for better decision making to seek care, improving transport and quality of ANC services –services, systems and policies)*
- xiii. In your own view, how do you describe the relationship of pregnant women with physical disabilities towards health workers? *(probe to find out attitudes and reasons)*

Other information

- xiv. Do you have any other information you would like to share with me about ANC or disability in general that may be useful in this study?

Please, I will inform you when I will be coming back to share with you my interpretation of what you have shared with me today. I will also come back in case I find out that I need clarification on a particular issue from you.

Thank you for sharing your perspectives with me.

Appendix V: Focus group discussion guide for women with physical disabilities

University of Cape Town, Faculty of Health Sciences



Study title: “Access to and utilisation of antenatal care services by women with physical disabilities in rural south-western Uganda”.

Purpose of the group discussion, setting the stage and confidentiality assurance

Thank you for coming and accepting to take part in this study. Now, we are going to discuss as a group. This discussion will take us about one hour to one hour and a half.

I have already met and talked to each one of you during the face-to-face interviews. Today’s discussion will be to understand better your views and personal experiences on your access to and utilisation of ANC services. The value of meeting in the group is that someone might say something that you (the participant) had forgotten, and this could let you expand your story or your story might remind someone else of something similar. In this way I hope to get a fuller understanding.

There is no right or wrong answer, please feel free to say what you want to say. Here, each person’s view or opinion will be respected. You are free to respond to each other’s contributions. Kindly, I request that we be organized and orderly, one person speaking at a time so that I am able to capture clearly everyone’s view.

I would like you to know that your privacy will be ensured throughout the research process and the information you are going to share will be kept confidential. We should all be responsible to each other not to tell anyone outside this group what any particular person shared in our discussion. We shall use only our first names during the group session, or you may choose another name just for use in this group. Please, be assured that your views and experiences will not bear your name or address.

Please, in case you have any question regarding this study, you are free to ask me now or any time during or after our discussion.

Introduction:

Researcher's self-introduction: My name, once again, is Ponsiano Kabakyenga Nuwagaba, a PhD student at the University of Cape Town, South Africa. I work at Kyambogo University in the Department of Community and Disability Studies. I am from Kitagata. The area of study and the research topic are both important to me.

Participant's self-introduction: First name only or you may choose another name just for use in this group.

Focus group discussion

Participation and functioning of pregnant women with physical disabilities at each phase of delay (**at home, on the way and at the health facility**) in the access to and utilisation of ANC services guided the formulation of discussion themes. I will give them a bit of a framework (the Three Delays Model) for conversation so they can concentrate on each phase – while still leaving the opportunity for people to come back to a previous part of the conversation

Group discussion questions and their sequencing were informed by the objectives, conceptual frameworks and the preliminary findings from interviews and physical infrastructure and equipment audit.

1. During face-to-face interviews, we discussed ANC services. Some people mentioned ... and others mentioned Do others of you feel the same or are there any other things you would like to add?" (Probe about when should a pregnant woman start ANC, how many times, what are their expectations during ANC visit, what is required to prepare for an ANC visit, etc)
2. **Decision making (at home) to seek ANC**
 - Who influenced you to seek care during your pregnancy and who helped you make this decision / get this care? (Probe about knowledge on ANC, previous ANC experience, social cultural issues e.g Traditional Birth Attendants (TBA), family support, economic status, her age, etc.).

- Do you think this may be similar or different to a pregnant woman without a physical disability?

3. On the way to the health facility

- As a pregnant woman with a physical disability, what is your view about using a motorcycle ('boda boda') as a means of transport to the health facility? (Probe about what makes it worse or better).
- In case you don't get a 'boda boda' at the time of ANC visit, what do you do? (Probe to find out other alternative transport means available)

4. At the health facility

- Please, who would like to describe for us the process of accessing and utilising ANC services at the health facilities? It could be HC II, HC IV or General Hospital. Is there anyone else who would like to add their experience? (Probe about attitude of health workers, fees, policies/regulations, the waiting area, examination bed, latrines/toilets).
 - Was your experience at the health facilities worth the resources (time/money) spent? Why?
5. What do you think needs to be done to improve access to and utilisation of ANC services by pregnant women with physical disabilities? (Probe about increasing her economic status, power to decide, assistive devices, appropriate toilet/latrine facilities, benches in the waiting area, examination beds etc)
 6. As woman with a physical disability, how do you/did you address to your needs during pregnancy?
 - a) Care/ support needed eg craving for certain foods and drinks, babies' clothes, soap, fetching water and fire wood etc.
 - b) What care would you like to have received during pregnancy?
 7. Please, is there anything anyone would like to share?

Please, I will inform you when I will be coming back to share with you my interpretation of what you have shared with me. I will also come back in case I find out that I need clarification on a particular issue from any of you individually.

Thank you for sharing your perspectives with me.

Appendix VI: Strategies for managing group dynamics during the FGD

I used different strategies to get everyone to participate in the FGD and ensure their voices were heard. The strategies used were:

- I spaced them so that they were in four smaller groups of two participants each. They started by sharing with each other (about 5 minutes) in a small group as they gained confidence to share with the whole group. I also tried to keep a mental picture of the links between different participants in the conversation.
- I had them talking in pairs initially as it gave space for the quieter or less confident participants to share but did not have to report back. Once they felt comfortable with the group, they were able to open up.
- I used the ‘thinking space’ process, where each woman would get 2-3 minutes to share without being interrupted; it allowed them to pause and think without someone else jumping in.
- To break the ice, the woman who started to speak, named the next person to go; that way they learn each other’s names (pseudonyms) as well.
- I ensured that all the members were included equally in the discussion including the shy or silent ones. Some individuals who were not be comfortable intervening on their own behalf so an offer to participate was helpful.
- I informed them that they didn’t have to be concerned being in agreement with the views of other members in the group.
- I took the non-directive moderator style so as to allow the discussion to flow naturally, without being rigid to the focus group discussion questions but only use them as a guide.
- I occasionally found out other participants’ views on a particular issue by going around the group. For instance, I would use phrases like ‘so and so has told us why she feels (mentioning participant’s feeling/ view). Does anyone have another view about this?’
- Specific attitudes were explored by finding out their intensity and the reasons behind.
- Good ideas were followed-up with probes to seek elaboration or clarification.
- Oral summaries were made to check out researcher’s perceptions and their validity was checked with the participants.

Appendix VII: Audit of the health facility physical infrastructure and equipment

University of Cape Town, Faculty of Health Sciences



Study title: “Access to and utilisation of antenatal care services by women with physical disabilities in rural south-western Uganda”.

The following aspects on the physical environment will be audited within and outside the selected health facilities with permission from the respective managers. The development of this audit tool was guided by the Accessibility Standards by (Uganda National Action on Physical Disability & Ministry of Gender Labour and Social Development, 2010). The “Trip Chain”³⁰ principle will be used to audit the physical environment and assess the process of accessing ANC services by pregnant women with physical disabilities in the selected health facilities (from arrival to departure). One inaccessible link in the trip chain renders ANC service inaccessible for a pregnant woman with a physical disability.

Physical environment at the health facility		
Domain	What to be audited	Observation
General	Generally, changes in level should be avoided.	
Floor	Floor surfaces should be hard, even and slip resistant.	
Rails	Rails should be provided on stairs and ramps. Handrails should be easy to grasp	

³⁰ A Trip Chain is the sum of all parts of movement from one place to another which must be accessible in order to ensure a barrier-free environment (Uganda National Action on Physical Disability, & Ministry of Gender Labour and Social Development, 2010).

Ramps	Ramps should have resting places and be of low slope along travel routes	
Domain	What to be audited	Observation
Pathways	Pathways should be of limited slope and include sufficient turning radius	
Doors	Doors should be light and easy to turn, and entrances should be sufficiently wide	
Parking	Parking space should be close to the main entrance	
Furniture and equipment	Furniture, counters, equipment should be placed at suitable heights reachable by persons who use wheelchairs	
Toilets/ latrines	Toilets/latrines should be easily accessed for use, handrails should be provided and inside space should be wide enough to accommodate her altered center of gravity	

Appendix VIII: Letter to Sheema district administrative authorities

University of Cape Town, Faculty of Health Sciences



17th March, 2020

To: **The Chief Administration Officer,
Sheema District**

Dear Sir

RE: PhD FIELD WORK IN SHEEMA DISTRICT

I am a PhD Student at the University Cape Town, South Africa. I am conducting research on **“access to and utilization of antenatal care services by women with physical disabilities in rural south-western Uganda”**. In addition to the above, Sheema is also my home district. Particularly, I come from KitagataSub-county. I teach at Kyambogo University, Department of Community and Disability Studies. The area of study and the research topic are both important to me. I have been permitted to conduct this study by University of Cape Town, Human Research Ethics Committee. Please, hereto attached is a copy of ethics approval letter - HREC REF: 644/2019.

The study will involve women with physical disabilities and health workers in the selected health facilities. Community Development Officers (CDOs) will help in identifying women with physical disabilities in their respective sub-counties. I believe the information obtained will be useful to different stakeholders like the health workers, policy makers, researchers, community based organizations and Non-governmental organizations. The information will help to develop strategies for improving access to and utilization of antenatal care services by pregnant women with physical disabilities. It will serve to improve the pregnancy and antenatal care experience for pregnant women with physical disabilities in Uganda.

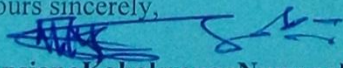
The purpose of this letter is to kindly request your office for:

1. Permission to conduct this study in your district
2. An administrative clearance letter, to be presented to the Executive Secretary, Uganda National Council for Science and Technology (UNCST) for final my clearance.

For more information, please contact me on my Mobile Telephone Number **0781 644616** or Email: NWGPON001@myuct.ac.za. You can also contact the research project supervisor: Associate Prof. Sheila Clow on Tel: **+27 (0) 21 406 6449** or Email: sheila.clow@uct.ac.za.

I thank you in advance for your kind consideration and I look forward to your positive response.

Yours sincerely,


Ponsiano Kabakyenga Nuwagaba
PhD Student



Appendix IX: Permission to access facilities and study participants

7/11/2020
received and
allowed to visit
specified facilities

He has been
active at
our Health Center

Allowed for information
to Mr. Nuwagaba
20/11/2020

THE REPUBLIC OF UGANDA
SHEEMA DISTRICT LOCAL GOVERNMENT

Office of the Chief Administrative Officer,
P.O. Box 160, Kabwohe
e-mail: dembebayeza@gmil.com

Tel: 0782-666686
Your Ref:
Our Ref: CR/D/302

March 18, 2020

Permitted to carry
out research
20 NOV 2020

HOSPITAL
KITAGATA HOSPITAL
P.O. BOX 160, KABWOHE SHEEMA

RE: ADMINISTRATIVE CLEARANCE LETTER FOR MR. NUWAGABA
KABAKYENGA PONSANO TO CONDUCT RESEARCH IN SHEEMA
DISTRICT

Mr. Nuwagaba is a student pursuing a Degree of Doctor of Philosophy (PhD) in Disability Studies at the University Cape Town, South Africa. His PhD research is on "Access to and utilization of antenatal care services by women with physical disabilities in rural south-western Uganda". His area of study is Sheema District. He has been permitted to conduct this PhD study by the University of Cape Town, Human Research Ethics Committee (HREC REF: 644/2019).

He is conducting research on an important aspect of health services provision and his findings will be helpful in improving antenatal care service delivery to this vulnerable group of mothers in Sheema District and Uganda at large. This office has granted him permission to conduct his study in Sheema District.

The purpose of this letter, therefore, is to forward him to your office for consideration of his study for research ethics approval and final clearance.

Dembe Bayeza Davis
Chief Administrative Officer
Sheema District Local Government

Copy to: The District Health Officer, Sheema District
The District Community Development Officer, Sheema District

Received and
accepted
20 NOV 2020
MEDICAL SUPERINTENDENT
KITAGATA HOSPITAL
P.O. BOX 160, KABWOHE SHEEMA

Forwarded to Shauke, Rugaramu, Kasasana and Kitagata T/C and Sub County for assistance by Community Devt Officers - CD Bugolizi T/C Inclusive

27/11/2020

Appendix X: Information sheet for women with physical disabilities (English version)

University of Cape Town, Faculty of Health Sciences



Study title: “Access to and utilisation of antenatal care services by women with physical disabilities in rural south-western Uganda”.

Investigator: My name is Ponsiano Kabakyenga Nuwagaba, a PhD student at the University of Cape Town, South Africa. I am conducting this research under the supervision of Associate Prof. Sheila Clow and Prof. Theresa Lorenzo, both from University of Cape Town, South Africa. I would like to invite you to take part in this study because I believe that you have rich information and experience on this study subject. Please, before you make your decision to take part, you need to understand why the study is being done and what it is all about.

Purpose and scope of the research: This form will tell you why I want to do this study. I am carrying out a study to find out how pregnant women with physical disabilities access and use antenatal care services. I want to know your experiences in accessing and using these services during pregnancy. I want to identify what makes your access and use of antenatal care services better or worse. This will help to develop strategies for improving access and utilisation of antenatal care services by pregnant women with physical disabilities. It will serve to improve the experience of antenatal care for women with physical disabilities. This study will be conducted in three selected health facilities within Sheema district. I am particularly interested in getting your views and experiences on this issue and I will also interview the health workers who provide these antenatal care services. I will also observe the physical environment within the health facilities to get more information on the accessibility of antenatal care services by pregnant women with physical disabilities in the selected health facilities.

Please you are free to ask me questions about anything you do not understand or if you would like more information. I will be happy to explain this to you more than once. Please take whatever time you need to talk about the study with your nurse or doctor, your trusted friends, your partner or any family member of your choice, if you so wish.

What will the study involve?: In this study, you will be asked to share your views, opinions and experiences regarding your access to and utilisation of antenatal care services with the researcher during the face-to-face interview and in a group discussion with other women with physical disabilities. I will be asking you questions to get more information about particular aspects regarding the study topic. The interview session and the group discussion will likely take an average of one hour each. Both interview and focus group discussion will be recorded with a digital audio-recorder and later transcribed so as the researcher to be able to write your views and experiences as you will exactly submit them. I will need your permission to do this recording. I will inform you as an individual and/or as a group when I will be coming back to share with you my interpretation of what you will share with me. I will also come back in case I find out that I need clarification on a particular issue from you.

What will happen to the data?: Confidentiality will be ensured throughout the study. The information you will share with me will not be shared to anyone else without your permission. To protect your privacy, I will replace your name with a pseudonym (fake name). I will only use this pseudonym on the information about you. I will do my best to keep your pseudonym private. It is however always possible that someone could find out your name but this is very unlikely to happen. I will share the information with my supervisors without revealing your identity. After the group discussions and interviews have been copied from the recorders, the memory card will be formatted, and the recordings deleted. Your individual identities will not be used in any reports or publications that may result from this study.

Voluntary nature of participation and right to withdrawal: Please, I would like you to understand that it is a personal decision if you choose to take part in the study. In other words, it is up to you whether you want to participate in the study or not. You can say “yes” and join the study; or you can say ‘No’, if you don’t want to join. If you participate in the study, you can change your mind later during data collection and decide that you don’t want to participate anymore and you do not want your information to be used in this study. Please let me know and I will destroy the data about you and it will not be used in the research

report. You will not be required to explain to anyone as to why you changed your mind. Whether you decide to join the study or not, the way you will be treated at the health facilities now and in future will be the same. Please, it is voluntary to participate in this study and your decision (to participate or not to participate) will be respected.

Potential risks associated with the research: One potential risk of participating in this study is that information about your disability and reproductive health may become known to people who should not have this information. A focus group member may share your information with her friends or relatives. I will ask group members to respect each other's information and not to share it with anyone outside the group. There is a small risk that someone who should not have your information could learn something about you. Also, considering the fact that this research touches on disability and reproductive health, which are personal issues, it could cause distress to you or other people close to you. This may be possible during the interviews as you may recall difficult moments that you and/or your family could have gone through during the current or previous pregnancy. As a professional clinician and social worker, I will work together with professional counsellors and health workers to provide psycho-social support or medical help to you in case of any harmful effect arising from this research process.

Risk to groups or other unknown risks (e.g., group discrimination, stigmatization): When I report my study results, people will know about the reproductive health issues particular to women with physical disabilities during pregnancy. However, the results are intended to provide knowledge for increasing awareness, changing negative attitudes and beliefs, and improving access to ANC services for pregnant women with physical disabilities, particularly in Uganda.

How your privacy will be protected: The interviews will be conducted in a place that you are happy with that does not compromise confidentiality. This place could be your home, your garden, at the health facility or anywhere you may choose. Your information will be kept confidential. Pseudonyms for participants will be used in the report or any other document written or published from this study. It will not be possible for anyone to identify you with the information that you will share with me. All the information will be securely kept in a safe place. No one will access the information kept in my computer because it is protected with a password which is only known to me. It is always possible that someone

may find out that you participated in this research project. However, it is very unlikely that this will happen, and I will do my very best to ensure that it will not. Taking part in the focus group may involve some loss of privacy; however, we will keep your records as confidential as possible. I will ask you and the other people in the focus group to use only first names during the group sessions. I will also ask group members to be responsible not to tell anyone outside the group what any particular person shared in the discussion. However, I cannot guarantee that everyone will keep the discussions private.

Potential benefits associated with the research: Although the study will help the researcher to fulfil the requirement for a PhD in Disability Studies at the University of Cape Town, its findings will add knowledge and provide baseline information to inform policy, practice and further research in antenatal care for pregnant women with physical disabilities, particularly in Uganda. The findings will be particularly useful to the health workers, Disabled People's Organizations, Civil Society Organizations, researchers and policymakers in the Ministry of Health. The findings will help them to plan better policies and antenatal care services for pregnant women with physical disabilities. As a researcher, I will not be able to provide you with advice or solutions to the physical or social challenges you may be facing regarding your disability or reproductive health. However, I will make necessary arrangements to connect you to the professionals that I know may be of help to you.

Participant compensation: I would like to pay you back the money you will spend on transport to participate in this study. I will cover the costs of travel to the venue where we shall meet for the focus group discussion and during our community meeting when I am presenting to you the results of this study. Local travel rates will be used to determine these costs. This will range from 20,000/= (fifteen thousand shillings) to 25,000/= (twenty thousand shillings) per meeting, depending on the distance from your home to the venue. In case, you have a disability support assistant, the same amount about will be reimbursed to him/her for his/her transport. I will provide refreshments at the venue during the focus group discussion.

Return of results: When the study is finished, I will share the study's general findings with you and your community. I think this will take about eight months after completing data collection. Sharing the results of this study will be my priority. I will organize a meeting in a convenient venue to share with you (all the participants) the results after the study. With the

help of the Community Development Officers (CDOs) within their respective sub-counties, I will present my findings in a community meeting/dialogue and health workers will be requested to attend. After the study, I will organize a meeting at each of the selected health facilities to present my findings to the health workers and you will be invited to attend. I will also provide at least one copy of the findings at each of the selected health facilities and at the District Health Office (DHO) for all the health workers and the community, for publication and dissemination of results.

Contact address of the researcher

Ponsiano Kabakyenga Nuwagaba
Department of Health and Rehabilitation Sciences
Faculty of Health Sciences, University of Cape Town, South Africa
F45 Old Main Building, Groote Schuur Hospital, Observatory, 7925
Tel: +27 (0) 835487876 (South Africa)
+256 (0) 781644616 (Uganda)
Email: NWGPON001@myuct.ac.za

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Division of Nursing & Midwifery, Department of Health and Rehabilitation Sciences
Faculty of Health Sciences, University of Cape Town, South Africa
F45 Old Main Building, Groote Schuur Hospital, Observatory, 7925
Tel: +27 (0) 21 406 6449
Email: sheila.clow@uct.ac.za

Contact address of the research project co-supervisor

Prof. Theresa Lorenzo
Division of Disability Studies, Department of Health and Rehabilitation Sciences
Faculty of Health Sciences, University of Cape Town, South Africa
F45 Old Main Building, Groote Schuur Hospital, Observatory, 7925
Tel: +27 (0) 21 406 6326
Email: theresa.lorenzo@uct.ac.za

Contact details of the Chairperson of the Faculty of Health Sciences Human Research Ethics Committee (HREC REF: 644/2019)

Name : Prof. Marc Blockman
Address : Room E52.24, Old Main Building, Groote Schuur hospital,
Observatory, Cape Town 7925
Telephone : +27 (0) 21 406 6496
Email : marc.blockman@uct.ac.za

Contact details of the Chairperson of Uganda Christian University Research Ethics Committee (UCU REC:026)

Name : Prof. Peter Waiswa
Address : Plot 67-173, Bishop Tucker Rd, P.O Box 4, Mukono – Uganda (EA)
Telephone : +256 (0) 312 350 885
Email : pswaiswa@musph.ac.ug

Appendix XI: Translated information sheet for women with physical disabilities (Local language – Runyankore-Rukiga version)

University of Cape Town, Faculty of Health Sciences



Omutwe gw’okucondooza: “Ebikwatirine n’okuhikirwa hamwe enkozesa yobuzanzabi bwabakazi baine oburema bwomubiri baba baine enda, omubyaro by’amumashuma goburengyerwa izzoba, omu Uganda”.

Ebirikukwata aha mucondoozi: Eiziina ryangye ni Ponsiano Kabakyenga Nuwagaba.

Ninshoma diguri yidara rya kashatu omu University ya Cape Town, South Africa.

Okucondooza oku nikukurirwa bakakensa abarikushomesa omu University ya Cape Town, South Africa. Amaziina gabo ni Prof. Sheila Clow na Prof. Theresa Lorenzo. Mbweni namba ninkushaba ngu obe omwe omuryabo abarikuza kuganira kandi bakanyegyesa aha ebikwatirine nomutwe gw’okucondooza ahakuba ninyesiga ngu oyine okumanya kamutano ahabikwateine nomutwe gw’okucondooza. Mbweni otakasazireho, nabaninshaba ngu oyetegyerereze ebirikukwata aha kuchondooza oku.

Omugasho gw’okucondooza oku: Ebaruha egi neyoreka ahabwakyi nincondooza aha mutwe ogu. Ningyezaho kucondooza ahabikwateine n’okuhikirwa hamwe enkozesa yobuzanzabi bwabakazi baine oburema bwomubiri baba baine enda. Ningyezaho kumanya oku orikutunga n’oku orikukozesa obuzanzabi waba oyine enda. Ningyezaho kwetegyerereze ebintu ebiri kukuyamaba ningashi ebirikukuzibira kutunga obuzanzabi obu waba oyine enda. Eki nikyiza kuyamba munonga omu kutekaho enkora yokwimutsya omutindo gw’okuha obuzanzabi abakazi abaine oburema obw’omubiri baba baine enda. Okucondooza oku nikwiza kubamu amarwariro ashatu agarabe gatworeinwe. Mbweni ninshaba ompe entekatteka yawe nebyorikumanya aha mutwe ogu. Nituzza kuba nitukozesa emiringo etari emwe omu kucondooza oku.

Nobasa kumbuza ebibuuzo byona ebyoyine aha kucondooza oku. Ningashi kuwakuba noyenda kweyongyore kumanya ebikwatirine nokucondooza oku, nobasa kweija ntyo nyongyere okukushoborora. Tikyinenshonga yona wabanoyenda kubanza wayebuuza aha mushaho waawe, munywani waawe oworikwesiga, omushaija waawe ningashi omunyabuzare waawe.

Niki ekyoyine kukora?: omu kucondooza oku, ninyiza kukushaba ongaanire, ompe ebityekyerezo byawe n'ebiyorabiremu omu kutunga hanwe nokukozesa obuzanzabi bwabakazi abaine enda. Nituza kukozesa emiringo etari emwe okumanya ebekwateine nomutwe gw'okucondooza oku. Buri muringo nigubasha kutwara obwire burikwingana nkeshaha emwe. Ahamwe nituza kuba turi babiri twenka kandi ahandi nituza kuba turi baingi. Ninyiza kuba ninkubuza ebibuuzo rero haza otyo ontangaze ahanshonga egi. Ebibuuzo ebi tibirikwiza kuba bigumire. Ninyiza kukushaba onyikyirize kwate amaraka gaitu twaba nitugaanira. Ekyi nikyiza kunyamba okuhandika ebyorabe ongambiire nk'okuwabintebeza. Bwanyima nimbasa kukushaba kunshoborera ekindabe ntakyengyiregye.

Ebirarugye omukugaanira nibiza kuzahi?: Byoona ebituragaanire nibyiza kuguma nanye. Tihaine muntu weena owundagambire ebyorabe ongambire otampaire orusha. Ninyiza kukuma byoona ebyorabe ongambiire. Ekyi nikyiza kubasika ahabwokuba ninyiza kukozesa amaziina agandi agatari gawe genyni. Abantu abarosome ripoota tibaramanye noha awagambire ebirimu. Ninyiza kugaanira nabokura okucondooza oku ahabikwateine nokugaanira kwaitu, kanka tindabamanyise owangambiire ebigambo ebyo noha.

Okuza omu kucondooza oku kandi okarugamu oyekundire: Oyine okweshariraho okuza omukuchondooza oku. Nobasa kugirangu wikiriza waba noyenda kuza omu kucondooza oku ninga oyangye waba otarikwenda. Nobuwakuba washazireho okuzamu, nobasa kugaruka oshareho bwanyima ogire ngu torikwenda kugumizamu kandi ogire ngu nebiwaba waheza kugaanira torikwenda bihandikwe omu ripoota. Nobasa kumanyisa haza ebyorabe ongambiire tindikwiza kubiteka omu ripoota. Ekyo noyija kukikora buziima otaine okweshoboraho kwoona. Okusharaho kwawe kwoona tikwine kakwate n'engeri oyorabe neherezebamu obuzanzabi omumarwariro aga ningashi agandi goona. Okusharaho kwawe kwoona ninkuha ekitinisa.

Obuzibu obwakubasa kuba buri omu kucondooza oku: Obuzibu obwakubasa kuba nibukwatagana nokuza omu kucondooza oku nokugira ngu ebiri kukwata aha burema bwawe n’ebyamagara omukuzaara kwawe nibibasa kumanywa abandi bantu. Omu muringo ogumwe ahuturize kugaanira turi baingi, omwe omubingi nabasa kutebezaho munywaniwe ninga omunyabuzarewe. Konka omugisha nimukye munonga kugira ngu nkobuzibu nkobu bwabaho. Kandi okugira ngu ebitukuza kugaaniraho nibikwata aha burema n’ebyamagara omukuzaara kwawe, ekyi nikiyibasa kukuteganisa obwongo n’entekateka yawe ningashi abantu bawe abokutuura nabo. Ekyi nikibasa kubaho omungyeri yokwijukiririra ebizibu ebiwarabiremu ningashi ebyoriyo norabamu oyine enda. Nyowe nk’omusaho atendekyirwe, ninyiza kukoragana nabashaho abandi hamwe nabatendekyirwe omu byokubudabuda okukuyamba omubuzibu nkobwe obukubasa kuretwaga okucondooza oku.

Obuzibu obwakubasa kubaho aha bantu abandi abaine oburema (ekyukureberaho, okubasosora): Ripoota erarige omu by’okucondooza neyiza kutangaza aha bekwateine n’ebyamagara gokuzaara kwabakazi abaine oburema bwomubiri baba baine enda. Konka baitu ekigyendererwa nokumanyisa abantu, tukahindura entekateka n’entwaza embi eri omu bantu hamwe nokwongyera omutindo gw’emperaza yobuzanzabi bwabakazi abaine oburema bwomubiri baba baine enda, okukira munomga omu Uganda.

Ebyokukwataho nibiza kukumwa bita?: Nobasa kweshariraho oronde omwanya ahu turagaanire. Omwanya ogwo nigubasa kuba omumaka gawe, omu musiri gwawe, ahirwariro ninga hoona ahorakunde. Ninyiza kukuma byoona ebyorabe ongambiire. Ninyiza kukozesa amaziina agandi agatari gawe genyini. Abantu abarosome ripoota tibaramanye noha owagambire ebirimu. Obyorangambire byoona ninyiza kubibiika kurungi. Nikibasika kugira ngu nihabasa kugira owakymanya ngu okaza omu kucondooza oku. Baitu tikiyangu okukymanya ngu okazamu kandi ninyiza kugyezaho kukiitangira okureba ngu tikiyabaho. Okuganira omubingi nikiyibasa obutakuma ebyokukwataho, konka ninyiza kugyezaho kubikuuma. Omukuganira turi baingi, buri muntu nayiza kuba nakozesa eiziina rimwe ryonka kandi ninyiza kusaba buri muntu atagamba ebituraabe tugaanire nabantu abandi. Baitu tinkahamisiriza ngu buri muntu nayiza kukikora.

Amagoba agari omu kucondooza oku: Okucondooza oku kurimu amagoba maingi. Ebirarugyemu nibyiza kwongyera okumanyisa ahari abo abokutukurira omu gavumenti nomubitongore ebitari bya gavumenti, nabashaho abokutuzanzaba hamwe nabandi

bacondoozi omu Uganda. Ebirarugye omu kucondooza nibyiza kuyamba omuntekateka zokutungura ebyobuzanzabi bwabakazi abaine oburema bwomubiri baba baine enda. Nimbasa obutakuyamba omuburi kyimwe ekyiri kukwata aha burema ninga omu byamagara gokuzaara kwawe. Baitu ninyiza kugyezaho okukuteraho entekateka yokureba abantu abaine obukugu, abunakubasa kuba nimanya.

Okurihirira abo abarayegaite omu kucondooza oku: Ninyiza kukugaruza esente zawe ezorabe okozise omu kwegaita omu kucondooza oku. Esente ezirakutambuze kuza aha mwanya ogu turagaaniremu, ninyiza kuzikugaruza. Ninyiza kukoze ebishare ebyaburizo, okuruga aha mitwaaro ebiri (20,000 UGX) okuhika aha mitwaaro ebiri nekichweka (25,000 UGX) Ninyiza kutekaho ebyokunywa twaba nitugaanira.

Ebirarugyemu ahamuheru twaheza: Ahamuheru naheza okucondooza, ninyiza kuhandika ripoota kandi nimwe nimwiza kugireeba okuhamya buzima yaba ebimwangabiire nibyo nahandikiyire. Ekyi nikyibasa kutwara emyezi nka munaana ahanyuma okucondooza kwaheza kuhwa. Ekyokuboreka ebirarugye omu kucondooza ninyiza kukyitwara nka kyikuru munonga. Ninyiza kutekaho entekateka yokubabugana mwena abaraabe begaisire omu kucondooza oku kubamanyisa ebirabe birugiremu. Ninyiza kutekateka omwanya omumagaborora gowaitu ahiturize okweteranira okumanyisibwa ebiraabe birugire omu kucondooza. Kandi, ninyiza kumanyisa abashaho, mbasabe okutwegaitaho. Ninyiza kutekaho entekateka yokubuganana nabashaho omu marwariro agatworinwe mbamanyisa ebirarugye omu kucondooza kandi nimwe ninyiza kubashaba okutwegaitaho. Ninyiza kutekaho ripoota omu buri rwariro eriraabe ritoorinwe hamwe nomu hofisi yomukuru webyamagara omuri Sheema district kugira ngu abashaho abandi hamwe nabantu baburiyo bakagisoma.

Endagiro y'omucondoozi

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**Endagiriro yomukuru wakakyiko kebyokucondooza aha bantu nebyamagara omu
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Appendix XII: Information sheet for health workers

University of Cape Town, Faculty of Health Sciences



Study title: “Access to and utilisation of antenatal care services by women with physical disabilities in rural south-western Uganda”.

Investigator: My name is Ponsiano Kabakyenga Nuwagaba, a PhD student at the University of Cape Town, South Africa. I am conducting this research under the supervision of Associate Prof. Sheila Clow and Prof. Theresa Lorenzo, both from University of Cape Town, South Africa. I would like to invite you to take part in this study because I believe you have rich information on this study subject. Please, before you make your decision to take part, you need to understand why the study is being done and what it is all about.

Purpose and scope of the research: This form will tell you why I want to do this study. I am carrying out a study to explore the accessibility and utilisation of antenatal care services by pregnant women with physical disabilities and find out their experiences in accessing and utilizing these services. The study seeks to explore the barriers and facilitators of access to and utilisation of antenatal care services by women with physical disabilities and will develop strategies for improving access to and utilisation of antenatal care services by pregnant women with physical disabilities. This will serve to improve the experiences of antenatal care for pregnant women with physical disabilities. This study will be conducted in three selected health facilities within Sheema district. I am particularly interested in getting your views as a health worker who interfaces with these mothers on a regular basis during antenatal care. I will also get the views and experiences of women with physical disabilities about this study topic. I will observe the physical environment within the health facilities to get more information on the accessibility of antenatal care services by pregnant women with physical disabilities in the selected health facilities.

Please you are free to ask me questions about anything you do not understand or if you would like more information. I will be happy to explain this to you more than once. Please take whatever time you need to talk about the study with your supervisor, trusted friend or colleague, if you so wish.

What will the study involve?: In this study, you will be asked to share your views, opinions and observations regarding access to and utilisation of antenatal care services by pregnant women with physical disabilities with the researcher during the face-to-face interview. I will be asking you questions to get information about particular aspects regarding the study subject. The interview session will likely take an average of one hour. The interview will be recorded with a digital audio-recorder and later transcribed so as the researcher to be able to write your views as you will exactly submit them. I will need your permission to do this recording. I will inform you when I will be coming back to share with you my interpretation of what you will share with me. I will also come back in case I find out that I need clarification on a particular issue from you.

What will happen to the data?: Confidentiality will be ensured throughout the study. The information you will share with me will not be shared to anyone else without your permission. To protect your privacy, I will replace your name with a pseudonym. I will only use this pseudonym on the information about you. I will do my best to keep your pseudonym private. It is however always possible that someone could find out your name, but this is very unlikely to happen. I will share the information with my supervisors without revealing your identity. After the interviews have been copied from the recorders, the memory card will be formatted, and the recordings deleted. Your individual identities will not be used in any reports or publications that may result from this study.

Voluntary nature of participation and right to withdrawal: Please, I would like you to understand that it is a personal decision if you choose to take part in the study. In other words, it is up to you whether you want to participate in the study. You can say “yes” and join the study; or you can say “No” if you don’t want to join. If you participate in the study, you can change your mind later during data collection and decide that you don’t want to participate anymore, and you do not want your information to be used in this study. Please let me know and I will destroy the data about you, and it will not be used in the research report. You will not be required to explain to anyone as to why you changed your mind. Whether

you decide to join the study or not, the way you will be treated as a health worker now and in future will be the same and it will not affect your work. Please, it is voluntary to participate in this study and your decision (to participate or not to participate) will be respected.

Potential risks associated with the research: One potential risk of participating in this study is that information about you may become known to people who should not have this information. There is a small risk that someone who should not have your information could learn something about you. As a researcher and clinician, I will use my professional skills to keep all your information private and confidential and will try my level best to avoid this risk.

Risk to groups or other unknown risks (e.g., group discrimination, stigmatization): It is possible that when I report my study results, they will change the way women with physical disabilities and others see health workers providing antenatal care services. I will do my best not to let this happen but cannot always prevent it.

How your privacy will be protected: The interviews will be conducted in a place that you are happy and comfortable with that does not compromise confidentiality. This place could be a free private room at the health facility or anywhere you may choose.

Your information will be kept confidential. Pseudonyms for participants will be used in the report or any other document written or published from this study. It will not be possible for anyone to identify you with the information that you will share with me. All the information will be securely kept in a safe place. No one will access the information kept in my computer because it is protected with a password which is only known to me. It is always possible that someone may find out that you participated in this research project. However, it is very unlikely that this will happen, and I will do my very best to ensure that it will not.

Potential benefits associated with the research: Although the study will help the researcher to fulfil the requirement for a PhD in Disability Studies at the University of Cape Town, its findings will add knowledge and provide baseline information to inform policy, practice and further research in antenatal care for pregnant women with disabilities, particularly in Uganda. The findings will be particularly useful to the health workers, Disabled People's Organizations, Civil Society Organizations and policymakers in the Ministry of Health to advocate for and design clear and evidence-based policies and disability inclusive health

interventions for improving the reproductive health of pregnant women with physical disabilities. As a researcher, I will not be able to provide you with advice or solutions to the challenges you may be facing regarding your work as a health worker. I will provide refreshment (soda/mineral water and a cake) during our face-to-face interview.

Return of results: When the study is finished, I will share the study's general findings with you and other study participants. I think this will take about eight months after completing data collection. Sharing the results of this study will be my priority. I will organize a meeting in a convenient venue to share with you (all the participants) the results after the study. With the help of the Community Development Officers (CDOs) within their respective sub-counties, I will present my findings in a community meeting/ dialogue and you will be invited to attend. After the study, I will organize a meeting at each of the selected health facilities to present my findings to you and other health workers and women with physical disabilities will be requested to attend. I will also provide at least one copy of the findings at each of the selected health facilities and at the District Health Office (DHO) for all the health workers and the community, for publication and dissemination.

Contact address of the researcher

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Appendix XIII: Informed consent form for participants

University of Cape Town, Faculty of Health Sciences



Study title: “Access to and utilisation of antenatal care services by women with physical disabilities in rural south-western Uganda”.

*I have read the **Information Sheet for Participants** for this study and have had the details of the study explained to me. The purpose of the study, benefits and the risks involved have been explained to me and I have understood. My questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any time.*

I also understand that my participation is voluntary and that I am free to withdraw from the study at any time, or to decline to answer any particular questions in the study without giving reasons. I understand that this will not affect me in any way.

I agree to provide information to the researcher and grant him permission to audio-record it under the conditions of confidentiality set out on the Information Sheet.

I agree to participate in this study under the conditions set out in the Information Sheet.

Please sign your name: _____

Please write today's date: _____

Name of the researcher: Ponsiano Kabakyenga Nuwagaba

Signature:

Date:

Appendix XIV: Translated informed consent form for participants (Local language – Runyankore-Rukiga version)

University of Cape Town, Faculty of Health Sciences



Omutwe gw’okucondooza: “Ebikwatirine n’okuhikirwa hamwe enkozesa yobuzanzabi bwabakazi baine oburema bwomubiri baba baine enda, omubyaro by’amumashuma goburengyerwa izzoba, omu Uganda”.

Noshoma ebirikukwata aha kucondooza oku kandi nebindi byona ebinyine kumanya aha kucondooza oku babinshoborora. Ekyigyendererwa, emigasho hamwe nobuzibu oburi omu kucondooza oku babinshoborora kandi nabikyenga. Ebibuuzo byangye ebikwatirine n’okucondooza oku babinshoborora kurungi kandi nimanya ngu ninbasha kubuuzza ebibuuzo ebindi eshaha yoona.

Nimanya ngu okwegaita omu kucondooza oku nimba nyekundire kandi nimbasha kukurigamu eshaha yoona ningashi obutagarukamu ebibuuzo ebimwe ntaine kweshobororaho kwoona. Ninanya ngu ekyi tehaine ngyero yoona eyi kirankoremu kubi.

Ninyikiriza kugambiira omu kucondoozi ebindikumanya kandi nimwikiriza kukwata eiraka ryangye okurigirira aha binashoma/ebibanshomesa ebikwatirine n’okucondooza oku nengyeri eyi barakumemu ebi ndagambe.

Ninyikiriza okwegaita omu kucondooza oku okurigirira aha binashoma/ebibanshomesa ebikwatirine n’okucondooza oku.

Ninkushaba otekeho omukono gwawe ningashi ekyinkumu: _____

Handiika ebiiro byokwezi byerizoba: _____

Eiziina ry’omucondoozi: Ponsiano Kabakyenga Nuwagaba

Omukono gwo’mucondoozi: _____

Appendix XV: Personal reflections on data gathering process

Covid-19 challenges notwithstanding, being reflexive enabled me to maintain research rigour and safety for myself and my study participants. I was continually reflective of my feelings, what went well and what could have gone better at each stage during the data gathering process as I worked towards improvement.

How I felt before commencement of field work

Before fieldwork commencement, I was anxious and uncertain of how the data gathering process would end and how the covid19 situation would unfold along the way. My worst-case scenario would have been contracting covid19 while in the field, thus exposing the participants and my uncle's family who were accommodating me at the time. Fortunately, by the time of my data gathering, there was no case of covid19 registered in Shema district. I completed data gathering with no incident. However, I was worried about my family that I had left in Kampala during the covid19 crisis. I was also worried that my data gathering would be interrupted by the general government elections that were scheduled for 14th January 2021 and the possible post-election violence. Nevertheless, I completed the data gathering before the day of elections and I felt relieved to join my family.

What went well during the data gathering process

I had adequately prepared for the field, and I had a well laid out Risk Management Plan (RMP) for minimising the transmission of covid19. I ensured that the Standard Operating Procedures (SOPs) were followed as guided by the Uganda Ministry of Health. In addition, the participants were vigilant about the prevention of covid19 and were willing to observe the SOPs during the interviews and FGD.

I had good reception from the district officials, the Community Development Officers (CDOs) and the health managers. I feel that they understood me and treated me as a research student who needed their assistance but also as a colleague who usually works with them in supervising Kyambogo University students of Community Based Rehabilitation and Community Development and Social Justice during their community practice/ field work.

Sharing the same social cultural beliefs and values, including language helped me to gain entry to the study area with ease. Speaking and understanding the local language helped me

in creating rapport, effectively communicate with the participants during our face-to-face conversations and in interpreting the collected data. Sharing the same sociocultural background (my insider positionality) is part of this study's strengths (see Chapter Eight, section 8.4.1).

During the data gathering process, I ensured that each interview was treated independently for each participant. However, where some interview questions or words would seem unclear to the participant, these would be rephrased for clarity. The rephrased question(s) or word(s), that appeared clearer, were used in the subsequent interviews.

What could have gone better

At some point, I felt that I would not realise the sample size for women with physical disabilities. Given the fact that many community activities were suspended due to Covid19 pandemic, CDO were not engaging persons with disabilities for almost a year. This made the identification of women with physical disabilities a bit cumbersome. It would have been better if there was no public gathering restrictions due to Covid-19 and the CDOs were having community engagements, actively mobilising and sensitising persons with disabilities. This and other limitations of this study are explained in detail in Chapter Eight, section 8.4.2.

Appendix XVI: Approvals timelines and Covid-19 implications on this study

HREC 644-2019: Access to and utilisation of antenatal care services by women with physical disabilities in rural south-western Uganda

PI: A/Prof Sheila Clow

Co-supervisor: Prof Theresa Lorenzo

PhD student: Ponsiano Kabakyenga Nuwagaba (Number: NWGPON001)

Table 1: Approval timelines and the implications of Covid-19 on the implementation of this study

Date	Institution	Comment	Annexures
06.12.2019	UCT HREC	Approval for study 644/2019	Appendix XV
17.03.2020	UCT HREC	Institutional research restrictions imposed	Appendix XIX
18.03.2020	Sheema district authorities	Administrative approval to access the study area (access to facilities, staff & community / field workers in the district where research to be undertaken)	Appendix XX
19.03.2020	Uganda Christian University (UCU) REC	Local Institutional REC approval	Appendix XXI
27.03.2020	Uganda National Council for Science and Technology (UNCST)	Research restrictions imposed nationally	Appendix XXII
04.06.2020	UNCST	Research restrictions lifted with provision to heed Ministry of Health guidelines for prevention of transmission of COVID-19. Actions:	Appendix XXIII

		1. Develop a risk management plan (done for UCT FHS HREC) 2. Send risk management plan to UCU REC for approval (sent and approved)	
24.07.2020	UNCST	Country approval granted for study, until 30.04.2023	Appendix XXIV
21.09.2020	UCU REC	COVID-19 transmission risk management plan approval	Appendix XXV
28.10.2020	UCT HREC	Approval to re-open the study to recruitment obtained	Appendix XXVI
15.11.2020	UCT HREC	Approval renewal for study REF644/2019, until 31.01.2022	Appendix XVI
14.12.2021	UCT HREC	Approval renewal for study REF644/2019, until 31.01.2023	Appendix XVII
13.12.2022	UCT HREC	Approval renewal for study REF644/2019, until 31.01.2024	Appendix XVIII

Delaying data gathering in Uganda during the Covid-19 pandemic

In Uganda, the first case of COVID-19 was registered on 21st March 2020. Prior to registering the first case of Covid-19, the Government of Uganda had imposed a lock down on 18th March 2020. As of 1st April 2020, Uganda had 44 COVID-19 cases, no death registered and a cumulative total of 1334 individuals had been tested. (Ministry of Health, 2020a). The map in figure 9.1 below shows the area of study (Sheema district) in South-western Uganda and the distribution of COVID-19 cases in the districts of Uganda (Ministry of Health, 2020b).

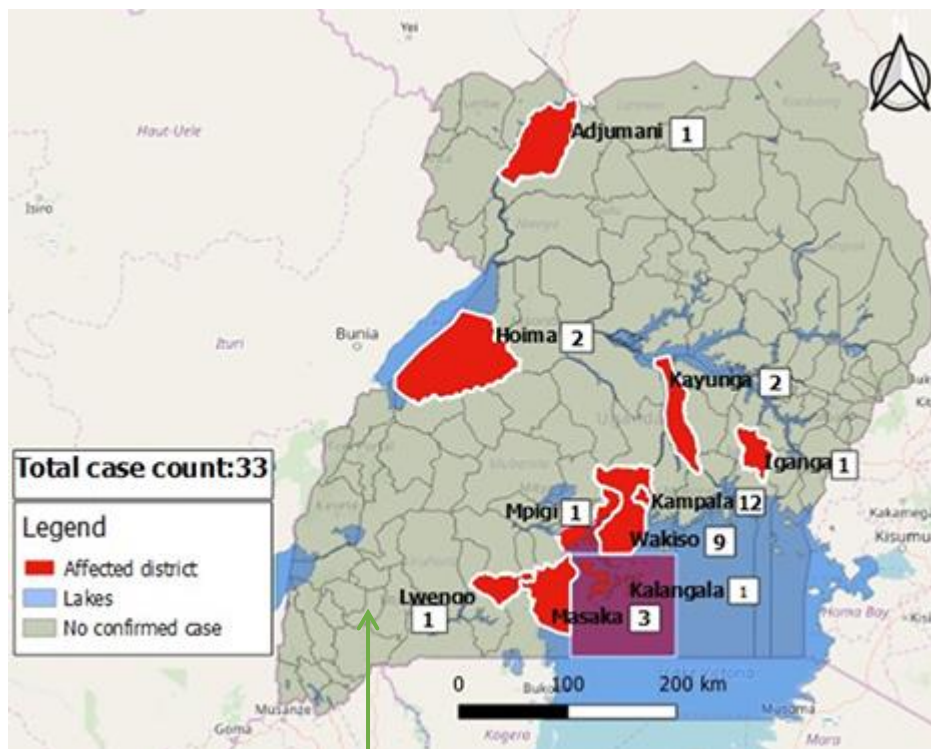


Figure 1: Map of Uganda showing the location the area of study in South-western Uganda and the distribution of COVID-19 cases in the districts of Uganda as of 1st April 2020.

Sheema district in south-western Uganda

Measures put in place by the Government of Uganda to prevent the spread of COVID-19

The government of Uganda had put in place drastic measures as presidential directives to prevent the spread of COVID-19. On the 30th of March 2020, the President of the Republic of Uganda gave a third speech, addressing the nation and gave directives with regard to minimising transmission of Covid-19. Some of the directives that were pertinent to this study included:

- All people-to-people movements by everybody in the country including those using their private vehicles were prohibited for 14 days, starting with the 1st of April 2020.
- Gatherings of more than five persons were prohibited.
- Starting with the 31st of March 2020, at 1900 hours, the President ordered that there should be a curfew throughout the whole of Uganda. All movements were to stop, people to stay in-doors (in their homes) except for the cargo-transporters.
- In order to deal with some unavoidable health issues like mothers in childbirth or very sick people, permission can be sought from the Resident RDC to use private transport to take such a person to hospital.

Decision to delay data gathering

During the COVID-19 pandemic crisis, data gathering for my PhD study had potential to cause risk during data collection. The participants and the research could be exposed to the Corona Virus in the process of identifying and recruiting participants as well as during face-to-face interviews and focus group discussions. More so, the risk of exposure to COVID-19 and the socio-economic risks involved would reduce the level of my concentration and engagement with the participants during data collection. As a researcher, it was my duty to promote and safeguard the health, well-being and rights of participants by abiding by the research ethical principles and standards as provided for in the Declaration of Helsinki by the (World Medical Association, 2013).

Option appraisal was done. Other than delaying data collection, the following options were also appraised.

- 1. Changing the study area and or population:** this was not feasible because Sheema district (study area) was still free of COVID-19 cases. More so, this option would require more movement in the process of applying for new ethical approval and clearance. This movement would expose me and my family to COVID-19.
- 2. Changing the mode of data gathering:** to understand the experiences, view and opinions of the participants regarding the phenomenon under study, a phone interview and possibly a video call to observe non-verbal cues would be appropriate. This would limit exposure of the participants and the researcher to COVID-19 and also abide to government guidelines on social distancing to prevent the spread.

However, option 2 required a good network/internet connection, good amount of airtime/data for both participants and the researcher, smart phone/computer for both the researcher and each participant as well as the researcher to have identified and recruited participants' and got their contact details before movement was restricted, which I had not. I had received ethical approval by a Uganda Institutional Review Board (IRB), awaiting ethical clearance by Uganda National Council for Science and Technology (UNCST). Given that this study was to be conducted in a rural setting in Uganda – which is a low-income country- the mode of data collection that requires such technology in communication was not viable.

My target population included pregnant women with disabilities and health workers. Pregnant women are more vulnerable and are at risk of COVID-19 than the general population since

pregnancy impacts on their immune system. There was need for social distancing and self-isolation for this category of people. However, this risk may reduce when the epidemiologic curve descends and/ or when they give birth and their immune system builds up. The health workers were pre-occupied with responding to national health emergencies and preventing the spread of COVID-19.

In addition, moving away from home i.e Kampala (my place of residing) and back at that time when there was total lockdown and need for social distancing would put my family at the risk of exposure to COVID-19 and other socio-economic risks. I needed to be available for them so as to give a hand in case of an emergency like sickness or theft (house break-in). In such crisis with restricted movement and no means of transport, pregnant women with physical disabilities are put in a more precarious situation as they already have mobility challenges. Therefore, it was imperative to investigate and understand the experiences of these women with regard to the topic for my PhD study at the end of the crisis.

Conclusion

Based on all the above, I delayed data gathering for my PhD study until the end of the lockdown in the country (up to November 2020) when I was able to move to and from the study area, when COVID-19 had been controlled and with no or minimal risk of exposure. The guidelines and regulations changed to allow movement and social interaction and gathering as the situation of COVID-19 changed in Uganda and more evidence unfolded.

During time of data gathering, I still practiced social distancing to continue protecting myself and the participants to prevent the spread of COVID-19. The following under listed measures were continually observed with respect and consideration for cultural values within the study area.

- Maintaining a minimum of two metres from the participants and other people.
- Hand washing with soap and water or use of hand sanitizers with more than 60% alcohol.
- Wearing a face mask
- Greeting people without physical contact (no shaking hands).

Appendix XVII: UCT HREC approval for the study for 2020



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

06 December 2019

HREC REF: 644/2019

Prof S. Clow
Department of Health and Rehabilitation Sciences
F46 OMB GSH

Dear Prof Clow

PROJECT TITLE: ACCESS TO AND UTILIZATION OF ANTENATAL CARE SERVICES BY WOMEN WITH PHYSICAL DISABILITIES IN RURAL SOUTH-WESTERN UGANDA (DEGREE - MR P K NUWAGABA)

Thank you for submitting your response to concerns raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study subject to:

1. The reference MacKenzie is spelt incorrectly and should be McKenzie
2. In point 3, please clarify further what the scope of the case study is- what does it include and exclude?
3. In point 4, please ensure that assumptions about people with other disabilities are addressed- the reason for excluding them is convenience rather than their lack of competence.

Approval is granted for one year until the 30 January 2021.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period. (Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledges that the student: Mr P Nuwagaba will also be involved in this study.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC REF in all your correspondence.

Yours sincerely

PROFESSOR MARC BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

HREC/ref: 644/2019
OL

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code of Federal Regulation Part 312.41, 312.56 and 312.62.

Appendix XVIII: UCT REC renewal for study approval for 2021

	UNIVERSITY OF CAPE TOWN FACULTY OF HEALTH SCIENCES Human Research Ethics Committee	
FHS016: Annual Progress Report / Renewal		
HREC office use only (FWA00001637; IRB00001938)		
This serves as notification of annual approval, including any documentation described below.		
☒ Approved	Annual progress report	Approved until/next renewal date 30.01.22
☐ Not approved	See attached comments	
Signature Chairperson of the HREC/ Designee		Date Signed 7/11/2020
Note: Please note that incomplete submissions will not be reviewed. Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za. Please clarify your plan for research-related activities during COVID-19 lockdown		
Comments to PI from the HREC		
This study was suspended due to the Covid-10 pandemic. Following a motivation to have this lifted and submission of country specific information and updated approvals this suspension was lifted and formal notification (28 October) was received 4 November 2020. The HREC as requested fortnightly reports once recruitment commences. Due to contracting malaria in the interim, Mr Ponsiano is currently convalescing and will shortly travel to the district in which the study is situated. Recruitment is planned to begin on 16th November 2020		
Principal Investigator to complete the following:		
1. Protocol Information		
Date (when submitting this form)	29 th October 2020	
HREC REF Number	644/2019	Current Ethics Approval was granted until 30 th January 2021
Protocol title	Access to and utilization of antenatal care services by women with physical disabilities in rural south-western Uganda.	
Protocol number (if applicable)	Not applicable	
Are there any sub-studies linked to this study?	☐ Yes ☒ No	
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.		
Principal Investigator	A/Prof Sheila Clow	

25 March 2020 Page 1 of 8 FHS016

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Appendix XIX: UCT REC renewal for study approval for 2022

UNIVERSITY OF CAPE TOWN RESEARCH ETHICS COMMITTEE		HEALTH SCIENCES FACULTY OF HEALTH SCIENCES RESEARCH ETHICS COMMITTEE
HUMAN RESEARCH ETHICS COMMITTEE 14 DEC 2021		
FHS016: Annual Progress Report / Renewal		
HREC office use only (FWA00091637; IRB00001938) This serves as notification of annual approval, including any documentation described below.		
☒ Approved	Annual progress report	Approved until/next renewal date 30.01.2023
☐ Not approved	See attached comments	
Signature Chairperson of the HREC/ Designee		Date Signed 14/12/21
Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za . Please clarify your plan for research-related activities during COVID-19 lockdown. Please use the latest form found on our website: http://www.health.uct.ac.za/research/humanethics/forms		
Comments to PI from the HREC		
Principal Investigator to complete the following:		
1. Protocol information		
Date (when submitting this form)	08.12.2021	
HREC REF Number	644/2019	Current Ethics Approval was granted until 30.01.2022
Protocol title	Access to and utilization of antenatal care services by women with physical disabilities in rural south-western Uganda.	
Protocol number (if applicable)	Not applicable	
Are there any sub-studies linked to this study?	☐ Yes ☒ No	
If yes, could you please provide the HREC Reference number for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.		
Principal Investigator	A/Prof Sheila Clow Department of Health and Rehabilitation Sciences (Nursing and Midwifery Division), F45 Old Main Building, Groote Schuur Hospital, Observatory 7925 Tel: + 27 (0) 21 406 6449 E-mail: sheila.clow@uct.ac.za	
Department / Office Internal Mail Address		

29 June 2021 Page 1 of 7 FHS016
 (Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Appendix XX: UCT REC renewal for study approval for 2023



FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRS00001938)			
This serves as notification of annual approval, including any documentation described below.			
☒ Approved	Annual progress report	Approved until/next renewal date	30/01/2024
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed 13/12/2022	

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.

Please clarify your plan for research-related activities during COVID-19 lockdown.

Please use the latest form found on our website:

<http://www.health.uct.ac.za/fhs/research/humanethics/forms>

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	12.12.2022		
HREC REF Number	644/2019	Current Ethics Approval was granted until	31.01.2023
Protocol title	Access to and utilisation of antenatal care services by women with physical disabilities in rural South-western Uganda		
Protocol number (if applicable)	N/A		
Are there any sub-studies linked to this study?	☐ Yes	☒ No	
If yes, could you please provide the HREC Reference number for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	A/Prof Sheila Clow		
Department / Office Internal Mail Address	Department of Health and Rehabilitation Sciences (Division of Nursing and Midwifery) F45 Old Main Building, Groote Schuur Hospital, Observatory 7925 Tel: + 27 (0) 21 406 6449 E-mail: sheila.clow@uct.ac.za		

5 July 2021

Page 1 of 6

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)



Appendix XXI: UCT HREC institutional research restrictions imposed due to Covid-19



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room G50 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone (021) 406 6626
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

17th March 2020

Dear Heads of Departments, Department Research Committees, Researchers and Members of the Research Community

COVID-19: FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE RECOMMENDATIONS FOR RESEARCH STUDIES AND RESEARCH SITES INVOLVING HUMANS

We are anticipating community spread in South Africa. Therefore, all research activities where people are brought together for research purposes, where research participants and research staff and students are placed at risk by virtue of the nature of data collection, or where specimen collection poses transmission risk should be urgently reviewed to determine the risk for COVID-19 transmission. Our duty is to ensure the protection of UCT staff and students; as well as reducing the risk of transmission.

In line with recommendations to practice social distancing, we want to minimise the risk of transmission at research sites and in the context of research studies involving human participants.

Over the next week, we recommend each research study or study site develop a plan to de-escalate or suspend research activities. Limiting infections and protecting research participants and research staff and students should be the priority.

Therefore, the HREC recommendations are as follows:

1. Limiting infections and protecting research participants and research staff and students should be the priority.
2. All non-therapeutic research involving human participants should be stopped. Exceptional reasons for research to continue can be discussed with the HREC.
3. For therapeutic research and clinical research trials:
 - a. All therapeutic research and clinical research trials should be placed on hold and research activities should be suspended where possible.
 - b. Whenever possible, telephonic visits or follow-up should occur.
 - c. Principal investigators and study sites should implement measures to ensure that there is no interruption of required medication or monitoring of adverse events.
 - d. Only critical study visits where benefits significantly outweigh the potential harm of COVID-19 infection take place going forward. Study visits for critical medication or monitoring purposes should continue in consultation with the HREC.
 - e. New enrolments to studies should be suspended. Potential exceptions to this recommendation can be discussed with HREC.
4. Recommendations regarding hand hygiene, cough etiquette and social distancing should be implemented immediately at study sites.
5. Researchers and study sites should develop a 'in the time of COVID-19' template register in case retrospective contact tracing becomes necessary.
6. Should any research staff, students or participants develop signs or symptoms suggestive of COVID-19, please call the National Coronavirus Hotline (0800 029 999), the Provincial hotline (021 928 4102), or WhatsApp "Hi" to 060 012 3456.

All precautions to prevent transmission and reduce risk need to be urgently implemented.

The HREC will continue to function administratively, as well as the reviewing of new submissions.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Appendix XXII: Administrative approval to access the study area



THE REPUBLIC OF UGANDA

SHEEMA DISTRICT LOCAL GOVERNMENT

Office of the Chief Administrative Officer,

P.O Box 160, Kabwohe

e-mail: dembedavisbey@gmail.com

Tel: 0782-666686

Your Ref:

Our Ref: CR/D/302

March 18, 2020

The Executive Secretary,
Uganda National Council for Science & Technology
Kampala.

**RE: ADMINISTRATIVE CLEARANCE LETTER FOR MR. NUWAGABA
KABAKYENGA PONSANO TO CONDUCT RESEARCH IN SHEEMA
DISTRICT**

Mr. Nuwagaba is a student pursuing a Degree of Doctor of Philosophy (PhD) in Disability Studies at the University Cape Town, South Africa. His PhD research is on "Access to and utilization of antenatal care services by women with physical disabilities in rural south-western Uganda". His area of study is Sheema District. He has been permitted to conduct this PhD study by the University of Cape Town, Human Research Ethics Committee (HREC REF: 644/2019).

He is conducting research on an important aspect of health services provision and his findings will be helpful in improving antenatal care service delivery to this vulnerable group of mothers in Sheema District and Uganda at large. This office has granted him permission to conduct his study in Sheema District.

The purpose of this letter, therefore, is to forward him to your office for consideration of his study for research ethics approval and final clearance.



Chief Administrative Officer
Sheema District Local Gov't
Date:

Dembe Beyeza Davis
Chief Administrative Officer
Sheema District Local Government

Copy to: The District Health Officer, **Sheema District**
The District Community Development Officer, **Sheema District**

Appendix XXIII: Local institutional REC approval



UGANDA CHRISTIAN UNIVERSITY

A Centre of Excellence in the Heart of Africa

19th March, 2020

Nuwagaba Kabakyenga Posiano,
Kyambogo University,
P.O. Box 1, Kyambogo, Kampala
+256(0) 781644616
nkponsy@gmail.com

UG-REC-026 APPROVAL NOTICE

To: Mr. Nuwagaba Kabakyenga Posiano; Principal Investigator
Re: UCUREC Application titled *"Access to and Utilization of Antenatal Care Services by Women with Physical Disabilities in Rural South-western Uganda"*.

Application Number: 271-604-010

Version: 2.0

Type: ☒ Initial Review
☐ Protocol Amendment
☐ Letter of Amendment (LOA)
☐ Continuing Review
☐ Material Transfer Agreement
☐ Other, Specify: _____



I am pleased to inform you that the UG-REC-026; UCUREC approved the above referenced application.

Approval of the research is for the period from 19th March, 2020 to 19th March, 2021

This research is considered minimal risk category.

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and additions to the protocol or the consent form must be submitted to the REC for re-review and approval prior to the activation of the changes. The REC application number assigned to the research should be cited in any correspondence.
3. Reports of unanticipated problems involving risks to participants or other must be submitted to the REC. New information that becomes available which could change the risk: benefit ratio must be submitted promptly for REC review.

4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by subjects and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Regulations require review of an approved study not less than once per 12-month period. **Therefore, a continuing review application must be submitted to the REC eight weeks prior to the above expiration date of 19th March, 2021 in order to continue the study beyond the approved period.** Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study, at which point new participants may not be enrolled and currently enrolled participants must be taken off the study.
6. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by UG-REC _026:

	Document Title	Language	Version	Version Date
1.	Research Proposal: Access to and Utilization of Antenatal Care Services by Women with Physical Disabilities in Rural South-western Uganda	English	1.0	27 th January, 2020
2.	Appendix I: Positionality in Research	English	1.0	27 th January, 2020
3.	Appendix II: Request Letter to Community Development Officers	English	1.0	27 th January, 2020
4.	Appendix III: Face-to-Face interview guide for women with Physical disabilities	English	1.0	27 th January, 2020
5.	Appendix IV: Translated face-to-face interview Guide for women with Physical disabilities.	Runyankore-Rukiga	1.0	27 th January, 2020
6.	Appendix V: Face-to-face interview Guide for health workers.	English	1.0	27 th January, 2020
7.	Appendix VI: Focus Group Discussion Guide for women with Physical disabilities.	English	1.0	27 th January, 2020
8.	Appendix VII: Translated FGD guide for women with disabilities.	Runyankore-Rukiga	1.0	27 th January, 2020
9.	Appendix VIII: Non-participant direct observation checklist.	English	1.0	27 th January, 2020
10.	Appendix IX: Letter to Sheema District Administrative Authorities.	English	1.0	17 th March, 2020
11.	Administrative Clearance	English	1.0	18 th March, 2020
12.	Appendix XI: Translated Information Sheet for women with physical disabilities.	English	1.0	27 th January, 2020
13.	Appendix XII: Information Sheet for	English	1.0	27 th January, 2020

UCU REC Approval Version 2.0

19th March, 2020



	women with physical disabilities			
14.	Appendix XIII: Information Sheet for Health workers.	English	2.0	27 th January, 2020
15.	Appendix XIV: Informed Consent Form (ICF) for participants.	English	2.0	27 th January, 2020
16.	Appendix XV: Translated ICF	Runyankore-Rukiga	2.0	9 th March, 2020
17.	Appendix XI: Thesis timeline	English	1.0	27 th January, 2020
18.	Appendix XVII: Budget summary	English	2.0	9 th March, 2020
19.	Human Research Ethics Committee approval (University of Cape Town)	English	1.0	6 th December, 2019
20.	UCUREC Approval Letter	English	2.0	9 th March, 2020
21.	UCUREC Review Report	English	1.0	20 th February, 2020

Signed and Stamped



Prof. Peter Waiswa
UCUREC Chairperson,
pwaiswa@musph.ac.ug



Appendix XXIV: Research restrictions imposed nationally in Uganda due to Covid-19



Uganda National Council for Science and Technology

NEW PROCEDURES ON RESEARCH REGISTRATION AND CLEARANCE DURING THE CORONA VIRUS (COVID-19) PANDEMIC

March 27, 2020

Dear Researcher,

Uganda National Council for Science and Technology (UNCST) would like to inform you that in light of the COVID-19 pandemic, the following new procedures have been made on research registration and clearance by UNCST.

a) **Use of the online research application portal:** All new/initial research permit applications should be made through the online portal at <http://research.uncst.go.ug>, instead of the hard copy delivery of documents to UNCST. Researchers with continuing studies whose initial research permit application had not been made online should use the same portal to submit their Research Material Transfer requests, progress reports notification, requests for extension and notification of amendments.

b) **Halting of recruitment of study participants.** All researchers are encouraged to suspend recruitment of new study participants because of the additional risks the clinical teams and patients at the hospitals, recruitment facilities and sites are likely to face. Participants already recruited and require follow up should not be invited to hospitals or recruitment sites, but rather use telephone call based follow up to complete follow up procedures. Study teams are also encouraged to provide research participants with enough supplies during this quarantine period.

In addition to the above guidance, you are encouraged you to observe the already existing Ministry of Health guidelines on prevention of COVID-19 in order to stay safe. For any further assistance or clarification please do not hesitate to call us on telephone: +256 414 705 500 /+256 414 705 513, Mobile: +256 755 423 321/ +256 788 744 067/ +256 772 620 279 or send an email to info@uncst.go.ug.

We are looking forward to your continued collaboration as we move towards a prosperous Science and Technology led Ugandan society.

Dr. Peter Ndemere
Executive Secretary

Appendix XXV: Research restrictions lifted in Uganda



Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

4th June 2020

Research Ethics Chairpersons
Researchers

RESUMPTION OF RESEARCH ACTIVITIES DURING THE COVID-19 PANDEMIC

Uganda National Council for Science and Technology (UNCST) on 27th March 2020 provided guidance on procedures for conduct of research during the Corona Virus Disease 2019 (COVID-19) Pandemic. In the notice researchers were discouraged from recruitment of new study participants because of the additional risk the clinical teams and patients at the recruitment sites would have while conducting their activities. Researchers were also encouraged not to invite the already recruited participants that required follow up to hospitals or recruitment sites.

UNCST held a stakeholders consultative meeting on 1st June 2020 that provided advice on how best research can be conducted in the country in line with the Ministry of Health guidelines for prevention of COVID-19, without compromising the rights, welfare and safety for both the research participants and research teams.

It is against this background and the need to support research activities in the country that the moratorium that UNCST had put has now been lifted, but we would like to encourage the research fraternity to observe the following guidelines as they conduct their research:

1. Screening of research teams and participants with a temperature monitor at research institutions or recruitment entry points. The main purpose of screening is to identify, isolate and refer suspected cases with Corona Virus infection to prevent transmission and optimise case management.
2. Research teams should be familiar with the common signs and symptoms of Corona Virus infection so as to immediately identify, isolate and refer suspected cases to the Ministry of Health or District COVID-19 Taskforce teams.
3. Key preventive measures such as use of Personal Protective Equipment (PPE), mandatory wearing of face masks, washing hands with soap and water or hand sanitizer and physical distancing must be adhered to throughout the implementation of research activities. Research teams should avoid hand-shakes and hugging at all times.
4. A distance of at least two metres should be ensured during research procedures and activities such as consenting, focus Group discussions and trainings to

LOCATION/CORRESPONDENCE

Plot 6 Kimera Road, Ntinda
P. O. Box 6884
KAMPALA, UGANDA

COMMUNICATION

TEL: (256) 414 705500
FAX: (256) 414-234579
EMAIL: info@uncst.go.ug
WEBSITE: <http://www.uncst.go.ug>

prevent person- to- person spread of the Corona Virus while conducting research activities.

5. Research projects that involve community engagement must carry with them educational materials on prevention of COVID-19 in a language understood by the community as guided by the Ministry of Health. The materials should be displayed in places that are easily visible such as notice boards and doors, etc.
6. Administrative measures to minimise risk of Corona Virus infection such as surface disinfection at least once a day with sodium hypochlorite, alcohol based disinfect or other WHO recommended disinfectants should be done in addition to daily cleaning of research institution and recruitment site surfaces. Research institutions should provide enough PPEs and adequate waste management facilities.

In addition to the above guidance, you are required to develop Risk Management Plans (RMPs) to ensure that research teams and study participants' safety as you implement your activities. The RMPs should be submitted to the Research Ethics Committee (REC) and National Drug Authority (NDA) where applicable for advice and approval, and to UNCST for acknowledgment. We also encouraged you to observe the already existing Ministry of Health guidelines on prevention of COVID-19 in order to stay safe.

For any further assistance or clarification, please contact us on telephone: +256 414 705 513/ +256 414 705 525, mobile: +256 788 744 067/+256 755 423 321/ +256 772 620 279 or send an email to info@uncst.go.ug or research@uncst.go.ug.

We look forward to your continued collaboration as we promote ethical research in the country.



Dr. Peter Ndemere
EXECUTIVE SECRETARY

Appendix XXVI: Country approval for the study



Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS 5262

24th July 2020

Mr. Ponsiano Kabakyenga Nuwagaba
Principal Investigator
Kyambogo University
Kampala

Dear Mr. Nuwagaba,

Re: Research Approval: Access to and Utilization of Antenatal Care Services by Women with Physical Disabilities in Rural South – Western Uganda

I am pleased to inform you that on **30/04/2020**, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of **30/04/2020** to **30/04/2023**.

Your research registration number with the UNCST is **SS 5262**. Please, cite this number in all your future correspondences with UNCST in respect of the above research project. As the Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

1. Keeping all co-investigators informed of the status of the research.
2. Submitting all changes, amendments, and addenda to the research protocol or the consent form (where applicable) to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval **prior** to the activation of the changes. UNCST must be notified of the approved changes within five working days.
3. For clinical trials, all serious adverse events must be reported promptly to the designated local REC for review with copies to the National Drug Authority and a notification to the UNCST.
4. Unanticipated problems involving risks to research participants or other must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST notification after review by the REC.

LOCATION/CORRESPONDENCE

Plot 6 Kimera Road, Ntinda
P.O.Box 6884
KAMPALA, UGANDA

COMMUNICATION

TEL: (256) 414 705500
FAX: (256) 414-234579
EMAIL: info@uncst.go.ug
WEBSITE: <http://www.uncst.go.ug>



Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records.

6. An annual progress report and approval letter of continuation from the REC must be submitted electronically to UNCST. Failure to do so may result in termination of the research project.

Please note that this approval includes all study related tools submitted as part of the application as shown below:

No.	Document Title	Language	Version Number	Version Date
1.	Research proposal	English	N/A	January 2020
2.	Face – to – face interview guide for women with physical disabilities	English and Runyankole – Rukiga	N/A	January 2020
3.	Face – to – face interview guide for health workers	English	N/A	January 2020
4.	Focus group discussion guide for women with physical disabilities	English and Runyankole – Rukiga	N/A	January 2020
5.	Non – participant direct observation checklist	English	N/A	January 2020
6.	Information sheet for women with physical disabilities	English and Runyankole – Rukiga	N/A	January 2020
7.	Information sheet for health workers	English	N/A	January 2020
8.	Informed consent for participants	English	N/A	January 2020

Isaac Makhuwa

For: Executive Secretary

UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Copied: Chair, Uganda Christian University, Research Ethics Committee
LOCATION/CORRESPONDENCE

Plot 6 Kimera Road, Ntinda
P.O.Box 6884
KAMPALA, UGANDA

COMMUNICATION

TEL: (256) 414 705500
FAX: (256) 414-234579
EMAIL: info@uncst.go.ug
WEBSITE: <http://www.uncst.go.ug>

Appendix XXVII: Approved Covid-19 transmission risk management plan

UNIVERSITY OF CAPE TOWN
FACULTY OF HEALTH SCIENCES
DEPARTMENT OF HEALTH AND REHABILITATION SCIENCES



21st September 2020

The Chairperson
Uganda Christian University Research Ethics Committee
Mukono, Uganda

Dear Sir,



**RE: COVID-19 TRANSMISSION RISK MANAGEMENT PLAN FOR MY
PhD RESEARCH FIELDWORK IN SHEEMA DISTRICT**

I am a PhD Student at University of Cape Town, South Africa. My research protocol was approved by University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (HREC REF: 644/2019), Uganda Christian University Research Ethics Committee (UG-REC-026) and Uganda National Council for Science and Technology (UNCST) (REF: SS 5262) on 6th December 2019, 19th March 2020 and 24th July 2020 respectively. It is titled: *“Access to and Utilization of Antenatal Care Services by Women with Physical Disabilities in Rural South-western Uganda”*. It is a qualitative study involving women with physical disabilities and health workers. Data will be collected using direct non-participant observation, face-to-face interviews and focus group discussions.

The purpose of this letter is to submit my Risk Management Plan for prevention of transmission of COVID-19 during fieldwork for my PhD research for your approval. This is in response to UNCST circular dated 4th June 2020; allowing resumption of research activities in Uganda during the COVID-19 pandemic. During my research activities, I undertake to adhere to the Uganda Ministry of Health guidelines for prevention of transmission of COVID-19.

Please, find hereto attached my Risk Management Plan.

Yours faithfully,

Nuwagaba Kabakyenga Ponsiano

Principle Investigator/ UCT PhD Student No: NWGPON001

Mobile Tel: +256 781 644616; Email address: nkponsy@gmail.com



Study Approvals:

Uganda National Council for Science and Technology - UNCST REF: SS 5262

Uganda Christian University Research Ethics Committee - UCU REC REF: 026

University of Cape Town Human Research Ethics Committee - UCT HREC REF: 644/2019

**COVID-19 TRANSMISSION RISK MANAGEMENT PLAN FOR MY
PhD RESEARCH FIELDWORK IN SHEEMA DISTRICT**

Research Title: *“Access to and Utilization of Antenatal Care Services by Women with Physical Disabilities in Rural South-western Uganda”*

Task/ activity	Action to be taken to reduce/ remove the risk of COVID-19 transmission	Person responsible
Travel from Kampala to Sheema	A. Deep cleaning and sanitization - This will involve deep cleaning and disinfecting of the car (private) before leaving Kampala to Sheema and before leaving Sheema after fieldwork. - I will ensure that all my clothes are cleaned/washed and ironed. - I will also clean and/or disinfect the pens, papers, notebooks, phone, laptop, recorder and any other materials that I will use in data collection. - I will frequently clean and disinfect frequently touched surfaces like doorknobs/handles, table and chair surfaces etc during research activities. - I will consistently wash my hands with soap and water whenever I can access a hand washing facility/point and participants will be encouraged to do the same. - I will also carry with me a hand sanitiser that I will consistently use in case there is no accessible facility/point for washing hands (along the way to Sheema and within Sheema) for myself and the participants their carers.	Researcher Participant
Travel within Sheema during fieldwork		
Identification and recruitment of participants		
Data collection		
Travel from Kampala to Sheema	B. Wearing face masks and physical distancing - Wearing of face masks will be ensured. - I will ensure that we (participants, their carers and myself) consistently wear face masks during all the research procedures and activities such as consenting, interviews and focus group discussions to prevent person-to-person transmission of COVID-19. - A physical distance of at least two meters will be maintained during research procedures and activities. - I will avoid handshakes and hugging at all times during greetings. - I have secured accommodation at a relative's (my uncle's) home in Sheema for the days I will be in the field. This will reduce the risk of interacting with many and different people in a hotel when seeking accommodation.	Researcher Participant
Travel within Sheema during fieldwork		
Identification and recruitment of participants		
Data collection		
Researcher's accommodation during fieldwork		



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Study Approvals:

Uganda National Council for Science and Technology - UNCST REF: SS 5262

Uganda Christian University Research Ethics Committee - UCU REC REF: 026

University of Cape Town Human Research Ethics Committee - UCT HREC REF: 644/2019

Task/ activity	Action to be taken to reduce/ remove the risk of transmission of COVID-19	Person responsible
Travel from Kampala to Sheema	C. Self-quarantining and self-monitoring - Before leaving for Sheema, I will quarantine myself at home for two weeks. - During the two weeks, I will monitor my body temperature to observe for fever (above 37.2°C) and any other COVID-19 symptoms like cough, flue, sore throat etc. - I will also do daily self-monitoring for symptoms (chills, cough, flu, shortness of breath, general body weakness, sore throat and diarrhoea) of COVID-19 and document my COVID-19 status during the fieldwork. This will be done before leaving Kampala for Sheema and when I am in Sheema before going to the field.	Researcher
Travel within Sheema during fieldwork		
Identification and recruitment of participants		
Data collection		
Travel within Sheema during fieldwork	D. Identification and referral In case of any suspected case of COVID-19 during my fieldwork, they will be referred to the nearest health facility for further assessment to prevent transmission and optimise case management.	Researcher
Identification and recruitment of participants		
Data collection		
Identification and recruitment of participants	E. Awareness raising I will carry with me educational materials on prevention of COVID-19. These materials will be in Runyankore-Rukiga (the language understood by the community) as guided by the Ministry of Health. They will be displayed on the doors or any visible place where the research activities will be taking place.	Researcher
Data collection		

RESEARCHER'S NAME: **Nuwagaba Kabakyenga Ponsiano**
(UCT PhD Student No: NWGPON001)

SIGNATURE:  DATE: 21/09/2020

SUPERVISOR: A/Prof Sheila Clow

CO-SUPERVISOR: Prof Theresa Lorenzo



Appendix XXVIII: UCT HREC approval to re-open the study to recruitment



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

28 October 2020

HREC/REF: 644/2019

A/Prof S Clow

Department of Health & Rehab Sciences
F-45 OMB
Email: shello.clow@uct.ac.za
Student: nkponsey@gmail.com

Dear A/Prof Clow

Project Title: ACCESS TO AND UTILIZATION OF ANTENATAL CARE SERVICES BY WOMEN WITH PHYSICAL DISABILITIES IN RURAL SOUTH-WESTERN UGANDA (DEGREE - MR P K NUWAGABA)

Thank you for your letter to the Faculty of Health Sciences Human Research Ethics Committee dated 09 October 2020.

The HREC has approved your request to re-open the study to recruitment.
Please supply feedback every 2 weeks for 8 weeks.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020 & 06 July 2020.

Please quote the HREC REF in all your correspondence.

Yours sincerely

PROFESSOR MARC BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

HREC/REF: -644/2019sa

Appendix XXIX: Thesis title amendment approval



UNIVERSITY OF CAPE TOWN
UNIBESITHI YASENATHE • UNIVERSITEIT VAN KAPSTAD

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee



Form FHS006: Protocol Amendment

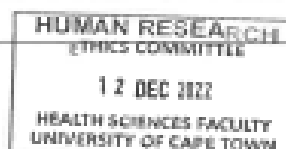
HREC office use only (FWA00001837: ~~844~~ 20001938)		
☒ Approved	☐ Type of review: Expedited	☐ Full committee
This serves as notification that all changes and documentation described below are approved.		
Signature HREC Chairperson / Designee		Date 12/12/22
Note: All Major amendments must include a Cover Letter and a local PI Synopsis justifying the changes for the amendment. Please note that incomplete amendment submissions will not be reviewed. Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za with subject line: FHS006 + (HREC Reference number). The latest forms are found on our website. http://www.health.uct.ac.za/hrs/research/humanethics/forms Please also clarify your plan for research-related activities during COVID-19 lockdown.		
Comments from the HREC to the Principal Investigator:		
Note: The approval of this protocol amendment does not grant annual approval. Please complete the FHS016 / FHS017 form for annual approval at least one month before study expiration.		

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	08.12.2022	
HREC REF Number	844/2019	
Protocol Title	Access to and utilisation of antenatal care services by women with physical disabilities in rural South-western Uganda	
Protocol Number (if applicable)	N/A	
Principal Investigator	A/Prof Sheila Clow	
Department / Office Internal Mail Address	Department of Health and Rehabilitation Sciences, F45 Old Main Building, Groote Schuur Hospital sheila.clow@uct.ac.za	
1.1 Is this a major or a minor amendment? (see FHS006h ₁) Major (tick box) Minor (tick box)	☐ Major	☒ Minor

5 July 2021
FHS006



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1.2 Does this protocol receive US Federal funding?	☐ Yes	☒ No
1.3 If the amendment is a major amendment and receives US Federal Funding, does the amendment require full committee approval? Note: Any protocol amendments for Full Committee Review MUST be submitted on the monthly HREC submission dates. (Please email an electronic copy to hrec-enquiries@uct.ac.za)	☐ Yes	☐ No
1.4 Did the initial study require UCT No-Fault Insurance	☐ Yes	☒ No

2. List of Proposed Amendments with Revised Version Numbers and Dates

Please itemise on the page below, all amendments with revised version numbers and dates, which need approval.
 This page will be detached, signed and returned to the PI as notification of approval. Please add extra pages if necessary.

1. Proposed amendment of the thesis title: Revised version – 01 (08th December 2022)

Old title: Access to and utilisation of antenatal care services by women with physical disabilities in rural South-western Uganda.

New title: The mixed experiences of pregnant women with physical disabilities in accessing and utilising antenatal care services in rural South-western Uganda.

3. Protocol status (tick ✓)

☐	Open to enrolment
☐	No participants have been enrolled
☐	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
☐	Research-related activities are complete, long-term follow-up only
☒	Research-related activities are complete, data analysis only

4. Proposed changes will affect: (tick ✓ all the categories that apply)

Protocol	
☐	Study objectives, design (including investigator's brochure, clinical activities, study length)
☐	Study instruments, questionnaires, interview schedules
☐	Sample size
☐	Recruitment methods



☐	Eligibility criteria (inclusion and exclusion criteria)
☐	Drug/device (composition, amount, schedule, route of administration, combination with other drugs/devices, safety information)
☐	Data collection/ analysis
☐	Principal Investigator. (Please attach revised conflict of interest and PI declaration statements. Refer: sections 7 and 8.4 in the New Protocol Application Form FHS013)
☐	Consent form and information sheet
☐	Recruitment materials (e.g. advertisements)
☐	Administrative (e.g. change in sponsor's name, change in contact information)
☒	Other. Please specify: This is a title change only and there is no change to the protocol itself. There is no impact on participants safety and the overall risk: benefit ratio of the study.
<i>*Note: Amendment changes involving study length, sample size, additional sites and eligibility criteria (i.e. inclusion of minors and /or pregnant women) need to be declared to the Insurance office. Please liaise via fhs.sponsorship@uct.ac.za regarding the required documentation and information to be submitted to obtain an updated UCT No-fault Insurance Certificate- it should be included herewith</i>	
4.1 In your opinion, will there be any increase in risk, discomfort or inconvenience to participants?	
☐ Yes	☒ No
If yes, please provide a detailed justification/explanation:	

4.2 What follow-up action do you propose for participants who are already enrolled in the study?	
☐	Inform current participants as soon as possible
☐	Re-consent current participants with revised consent/assent forms (append)
☒	No action required
☐	Other. Please describe:

5. Detailed description of the change(s)

Please attach, for each amendment, a summary of all changes which clearly indicates:

- Old wording (e.g. strikethrough text, CHANGED FROM and CHANGED TO)
- New wording (e.g. italicized, bold, tracked)
- Detailed rationale/ justification/ explanation for each change

6. Ethics Review for Amendment Levy – cost including vat

Amendment Review Costs including VAT

Please tick amount to be billed:

Submission Type	Description	New fee (Vat incl.)	tick ✓
Research funded solely from UCT departmental/divisional/group budget	Major/Minor Amendments	R0,00	☐
Non-sponsored student research for degree purposes at UCT/Other Universities & Colleges	Major/Minor Amendments	R0,00	☒
Protocol amendment - Major (FHS006 Form)	Clinical Trial & International Grant Funded Research - Any changes to the protocol that requires Full Committee review	R8 000,00	☐
Protocol amendment - Major (FHS006 Form)	Clinical Trial & International Grant Funded Research - Any change to the protocol that requires Expedited review that does not require Full Committee Review	R5 000,00	☐
Protocol amendment - Minor (FHS006 Form)	Clinical Trial & International Grant Funded Research - Minor amendments, administrative changes that do not affect study design e.g. changes to informed consent form, changes in study staff, etc.	R2 350,00	☐
Protocol amendment - Major (FHS006 Form)	National grant funded research - Any change to the protocol that requires Full Committee review	R7 000,00	☐
Protocol amendment - Major (FHS006 Form)	National grant funded research - Any change to the protocol that requires Expedited review that does not require Full Committee review	R2 500,00	☐
Protocol amendment - Minor (FHS006 Form)	National grant funded research - Minor amendments, administrative changes that do not affect study design e.g. changes to informed consent form, changes in study staff, etc.	R1 000,00	☐

NB: Protocols funded by UCT (e.g. departmental funding / student research) and by certain grant funding organizations (e.g. MRC, NRF, CANSA,) are exempt from these charges.

Please provide details for invoicing, either complete section 1 or 2 :

1. Invoice billing – Directly to Sponsor

Sponsor's name	
Billing Address of Sponsor:	
Vat Number:	
Contact person:	
Telephone number:	
Email Address:	

2. Internal Journal Billing:	
Fund Number:	
Cost Centre Number:	
Account Holder Name:	
Division of Account Holder:	

7. Amendment Submission checklist (tick ✓)

7.1 Please tick that all the documents are attached before submitting to the HREC. NB: Incomplete submissions will not be processed	
☒	Latest FHS006 form completed with all sections completed as per our website
☒	Cover Letter
☒	PI Justification/ Summary for the reasons for the amendment
☐	Protocol - Track changes & Clean Copy (where necessary)
☐	Informed Consent Forms (ICF), if applicable (Any changes made to ICF tracked & clean copy)
☐	Any other additional documentation in support of amendment
☐	Updated no fault insurance certificate (if applicable)

Please email this form and supporting documents (if applicable) in a combined pdf-file to enquiries@uct.ac.za with subject line: FHS006 + (HREC Reference number). The latest forms are found on our website.

8. Signature

My signature certifies that I will maintain the anonymity and/ or confidentiality of information collected in this research. If at any time I want to share or re-use the information for purposes other than those disclosed in the original approval, I will seek further approval from the HREC.			
Signature of PI		Date	08.12.2022