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*Erasmus*

**CRIPPLED BY WAR, MARGINALIZED FROM HEALTH CARE:  
THE REALITY OF WOMEN WITH DISABILITY ACCESSIBILITY  
OF HEALTHCARE SERVICES IN POST-CONFLICT GULU IN  
UGANDA**

A Research Paper Proposal/Design

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## List of Acronyms

CAO	Chief Administrative Officer
FGD	Focus Group Discussion
GRRH	Gulu Regional Referral Hospital
GROW	Gulu Referral Orthopedic Workshop
HC	Health Centre
LRA	Lord's Resistance Army
LSMH	Lacor St Mary's Missionary Hospital
NGO	Non-Government Organisation
NRH	National Referral Hospital
NUWODU	National Union of Women with Disabilities of Uganda
PFPPs	Private for-Profit Practitioners
PNFP	Private Not for Profit
RRH	Regional Referral Hospital
UBOS	Uganda Bureau of Statistics
UNFPA	United Nations Population Fund
VHT	Village Health Team

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## **Abstract**

This research sought to explore the ways through which the experiences of women with conflict-related challenges are shaped by health services offered in post-conflict northern Uganda. To achieve this aim, the research main research question was further abridged into four research questions. In order to answer these research questions, the researcher employed qualitative research design. To gather the data, the researcher used focus group discussions and interviews. The participants of the study included 20 women with disabilities, six health workers and two representatives from the National Union of Women with Disabilities of Uganda. From the findings of the study, it was concluded that there are different healthcare services available for women with disabilities in Gulu district. However, these services are unequally distributed in the district, limiting access for the disabled women who come from the areas of the district where there are no health facilities. Furthermore, the findings reveal that there are various, social, economic and cultural challenges that hinder the accessibility of the available health services by women disabled by the conflict. Following the findings of this study, it is perceived that development and implementation of inclusion policies is an effective strategy to improve access of health services by disabled women. When making laws the Ugandan government and international partners should consider incorporating issues that touch on disabled people. Also, the society should encourage the participation of disabled women in politics. Therefore, political parties ought to embrace disabled women in their political ranks. When they become active politically, they will speak about the issues affecting them in accessing healthcare.

## **Keywords**

Women with Disability, Uganda, Gulu, Health Care, Post-Conflict, Disability, Holistic Health



## Chapter 1 Introduction

### 1.1 Background to the Research Topic

#### 1.1.1 Uganda's Healthcare System

Uganda's National Healthcare System is comprised up of many enterprises, actors as well as structures with the primary aim of attaining alongside maintaining dependable healthiness. All over the country, the provision of healthcare interventions follows a de-centralised system where localities and health sub-districts play a vital part in the delivering and managing healthcare at lower tier levels. Uganda's healthcare systems are organised in; nationwide referral or provincial referral hospitals, general hospitals, and health centres (HC) IV, III, II & I (Chi et al., 2015: 2). Primus argued further that, the general hospitals do offer helpful, preventive, surgery, healthful maternity, and transfusion of blood, in-patient health services, lab and health imaging services including the provision of in-service sessions, practical and operative enquiries supporting the community-based health platforms. While the provincial referral hospitals do provide specialised clinical facilities, for instance, ophthalmology, psychiatry, higher level surgical services, Ear, Nose and Throat, and medical support facilities adding to training and research. Uganda has two nationwide referral hospitals; one is Mulago, and the other is Butabika, which are meant to provide all-inclusive specialist amenities, and they also provide health research and teaching (Chi et al., 2015:2-3).

More so, the HC IV is a mini hospital which offers promotive, therapeutic maternity, preventive, necessary surgery, in-patient health services, laboratory services and blood transfusion. On the other hand, the health centre (HC) IIIs provide primary promotive, preventive and healthful care, maternity care, laboratory diagnostic and initial referral services insurance for a sub-county. While the HC IIs offer initial communication connecting official health division and populations. They provide exclusive out-patient care as well community outreach facilities. Lastly, HC Is do not have practical constructions; however, they contain squads of local people commonly named as the Village Health Teams (VHTs) who plays the role of connecting health facilities with individual communities.

Generally, by 2010, a total of 2,242 healthcare facilities had been built, 56 hospitals opened to the public in Uganda (including two national referral hospitals (NRHs), 11 regional referral hospitals (RRHs), and 43 general hospitals). Uganda's private sector has a significant part in providing and delivering health services because it covers almost 50% of the reported health outputs. It is made up of Private For-Profit Practitioners (PFPPs), Private Not for Profit Organisations (PNFPs) as well as the Traditional and Complementary Medicine Practitioners. By 2010, the PFPPs owned 269 health centres and eight hospitals, while the PNFPs were in charge of 613 healthcare facilities and 46 hospices.

In 2001 the Ugandan government abolished user fees making promotive, preventive, curative, rehabilitative health services in all public health centres free of charge, though the private sections in the general hospitals charges patients. This led to the hindrance of the availability and utilisation of services caused by scarcity of medicines and other health supplies, poor infrastructure, low salaries, lack of accommodation in health facilities, shortage of human resources mostly in public sector, and other challenges that limit accessing of quality health service delivery.

During the war in northern Uganda, many health facilities were destroyed this led resulted in many health issues including limiting access, many health workers fled to the region and decided to go to war free regions, others were even forced in to go and work in neighbouring countries. As a result, the region suffered a big deal in issues of accessing essential health services for both men and women because finding opportunities for good health services was critically challenging which led to bad health results. However, the war starting 2007, the Ministry of Health with assistance from Non-Governmental Organisations (NGOs) and donors embarked on reconstructing and rebuilding the health system in Northern Uganda in order to deliver essential health services thus, increasing the usage of health services and reduces the major health-related problems of women in the region (Mulumba 2014). This study seeks to examine the current state of health systems in Gulu District in a post-conflict context with the intervention of both the government and non-government organisations.

### **1.1.2 The Forgotten and Discounted in Post-Conflict Health Care Intervention**

Without a doubt, the 20th and 21st centuries will go down the memory lane of human history as an era that witnessed a significant amount of devastating armed conflicts that occurred in numerous low- and middle-income countries (Okello et al., 2019). An example of legacy left behind by many of these conflicts is that of Afghanistan where there was a plethora of different forms of disability, in particular, loss of limbs and other physical mutilation on both men and women (Bilukha et al., 2007, 2008, 2011). The scars of the extreme ferocity of the conflicts are something that remains etched on bodies, represented in “people’s psyche and deep-rooted within the social fabric of society” (Hollander & Gill, 2014: 217).

By and large, a visit to the majority of these post-conflict areas will be greeted with the sight of several young men and women moving around with wheelchairs, ill-fitting or broken prosthetic limbs, and makeshift crutches on the street as a testament of the permanent effect of the conflicts (Okello et al., 2019:1). While men (naturally are combatant) are believed to be the primary direct victims of military operations, as “ex-combatants are increasingly prone to injury, disability and mental health problems” (Rockhold & McDonald, 2009:5). Wars and conflicts increase the disability incidences for the women in general, and those women with disabilities get additional or severe disabilities (Ostoleva, 2010:84). This is because women suffered both directly and indirectly consequences of armed conflicts on provision of

public health, and social order which is most often underappreciated and overlooked more than men (Plümper & Neumayer, 2006:723-734). Able-bodied women that become disabled as a result of the conflict are ostracized from society and they experience drawback support from the broader community (Ostoleva, 2011, 2010).

War and armed conflict, in general, create instability and, in most cases, results to resource breakdown and collapse of infrastructures which in turn forced a reevaluation of priorities by the state (Cornelsen, 2012:111). Even when the conflict demises, most of the people stay in refugee camps, and the armed groups stay in possession of weapons (Cahn, 2006:341-342). Therefore, making it uneasy to immediately remedy infrastructure that broke down during the conflict (Cahn, 2006:344-345). Unfortunately, it is within this framework of insecurity and government breakdown that women with disabilities are forgotten continuously and discounted (WRC, 2008:2). Usually, women with disabilities are not recognized in the mix; they were forgotten in many post-conflict arrangements from justice and peace building to healthcare services, from socio-economic to education because of the disruption of resources together with reevaluation of preferable (Ostoleva, 2011). Therefore, it becomes much easier to miss them out since their support systems are lost during the conflict as many of them were forced to abandon medications, wheelchairs, or other similar essential assistive devices that are crucial to their survival (Ostoleva, 2010:85).

From experiences gathered by various studies (Gill & Schlund-Vials, 2016; Knight, 2008; Olsen et al., 2003; Meier & Smith, 2002) in post-conflict settings from Uganda to Nepal, from Liberia to Sierra -Leon, it shows that the response of international and national agencies in the aftermath of conflict which is usually driven by emotional wave (and visibility) created by the modern media is usually to suite the instant essentials of victims. However, the time of intervention is limited, and the responsibility for providing for the conflict-related permanent disability as suggested by (Meier & Smith, 2002: 175-180) henceforward falls practically completely on national governments. These national governments in various occasions are neither prepared nor reequipped with resources to take up the responsibilities of addressing the conflict-related disabilities effectively (ibid). It has a significant transformational effect on the victims' lives as well as their families and the society at large (Ohara et al., 2014) because those crippled by war will have to struggle to access health care with members of the community that have other serious health issues because of the complications related with malignancy, peripheral vascular disease, and diabetes (Okello et al., 2019).

It is against the milieu of the above discussion that this study will focus on Uganda, a country that has experienced civil wars since it got its independence in 1962 (Liebling-Kalifani et al., 2007:1). The conflicts, in particular, the Northern region of the country witnessed series of gross violations of human rights that led to continuing health needs for women war-torture survivors of the civil war years after the end of the war (McElroy et al., 2012; Wegner, 2012; Spitzer & Twikirize, 2013; Vindevogel et al., 2013; Branch, 2013). "The conflict also caused injuries such as blindness and the loss of limbs from landmines and mutilations.

International donors have worked to address the needs of many vulnerable groups, but serious challenges remain” (HRW, 2010:7). During the armed conflict in Northern Uganda, over 14% of civilians obtained injuries on an annual basis with a death rate of 7.8/1,000 yearly and the disability rate of 11.3/1,000 (Lett et al. 2006: 7-51). From all the women survivors, the experiences of those that suffered direct physical disability as a result of the conflicts in their attempt to access healthcare services in post-conflict Gulu district will be analyzed. The analysis will help in having a clear insight into the reality of women that suffered life-changing consequences of conflicts when they attempt to access healthcare.

## **1.2. Problem Statement**

In northern Uganda, the consequences of more than two decades of violent conflict (1986-2007) between the Lord’s Resistance Army (LRA) rebel group and the government of Uganda were endured mostly by the civilians living in the region (Hollander & Gill, 2014: 217). Gulu district in Northern Uganda, however, became the epi-centre of the Uganda civil war in 1986 (Liebling-Kalifani et al., 2008:175). The district experienced the lengthiest armed conflict in Uganda history, a 20-year long war between the Ugandan government force and the Lord’s Resistance Army (LRA) rebels (Mulumba et al., 2014:3). Although, the district was recognized as a post-conflict environment after a peace treaty between the Government and LRA in 2006 (Wegner, 2012), the devastating effect of the conflict lingered on the wellbeing as well as the health status of the Gulu population till the present day.

The settlers of the Gulu tribe suffered from permanent disability resulting from rape and gendered crime, injuries that were from landmines, bombing, gunshots, torture, and mutilation (Spitzer & Twikirize, 2013; Vindevogel et al., 2013). Countless others became permanently deaf or blind due to the effect of the rocket-propelled grenades and permanent disability from serious physical and sexual crimes by different armed forces that were participating in the war (Hollander & Gill, 2014:218). Mutilation and maiming became the order of the day that armed groups used in sending the message of fear to the public during the war. According to Vinci (2005),

“The LRA’s brutality allows it to use mutilation as a method of communication and control over the population. Ears and lips are cut off as a signal to beware of informing on the LRA. Bicycle riders have their legs cut off because bicycles, a major mode of transportation, also bring communication” (Vinci, 2005:370).

The neglect of women with conflict-related disability is also evident in the National Disability-Inclusive Planning Guidelines for Uganda released in December 2017. In general, the experience and challenges encountered by women with a disability that hindered their access to health care are not homogenous, most especially disability that is conflict related. According to Pons (2017), there is robust

documentation of complications suffered by individuals who had disabilities that were caused by the war and thus needed several intervention programs and internal legislature, inclusive of treaties, to ensure that their protection was put in place. Be that as it may, these interventions need to encompass the mindset of the members of the community suffering from disabilities caused by the war activities, who also have to deal with challenges of fitting in the society as well as coping with a new environment. Those that have disabilities that are of this nature share common problems with others that had disabilities early on in their lives that may have come due to natural causes. There are many communities and settlements that treat individuals with disabilities as charity cases, as if they cannot fend for themselves. Cultural education change of mindset and physical support structures are inhibited by this kind of discrimination. In the end it actually prevents those suffering from disabilities to form independent lives. Those that gain disabilities due to man-made causes such as war, find it even harder to do so (Pons, 2017).

### **1.3 Rationale and Significance of the Research**

Unarguably, the conflict severely damaged the health system in northern Uganda due to higher levels of insecurity, limited medical supplies and medicines, restrictions on travel (Vinck et al., 2007). The conflict in Northern Uganda affected provision of healthcare services through the increase of needs as a result of violence coupled with increasing spread of infectious disease which reduced the opportunities of accessing healthcare service because of destruction of health infrastructures, loss of health workers (personnel), and inability to reach health facilities (Kickbusch and Buss, 2014). Regardless of the rebuilding interventions on optimising security, the infrastructure as well as the livelihoods of the multitude of impacted communities in the Gulu district and the Northern region in general (McElroy et al., 2012; Branch, 2013), the weak economy status of Gulu has hindered such efforts (Mulumba et al., 2014).

While many women today still find it hard to access health services in Gulu District (Saile et al. 2014: 46-135). Disabled women have an exclusive set of physical as well as mental healthcare specifications from as early as their teenage years (Piotrowski, 2007:79). These individuals need health interventions that are specific to the victim and compassionate to their practical disability in order to ensure that it does not get worse. The unfortunate bit is that there are multitudes of barriers that range from mental stigma to social banishments (Piotrowski, 2007:79). Other barriers are perceived lack of skilled staff in public facilities, late referrals, health worker attitude, costs of care and lack of knowledge (Kiwanuka et al., 2008). Also, the impact of gender stereotyping and the double discrimination against women with disabilities face due to both their gender and their disability limit women to access health care (Ostoleva, 2010:84). Most importantly, due to patriarchal ideology that is deeply rooted in the traditional societies such as Northern Uganda, women with disability are not considered in decision making process as regards their health needs

Importantly, there is a need to pay close attention to those with newly acquired disabilities from conflicts experiences because they are not used to the challenges, struggle and experiences of those with pre-existing disability (Pons, 2017). The disability terrain is alien to them, and without serious attention to their predicament, they stand the risk of falling into depression as depression is common among women with a physical disability than the general population (Noh et al., 2016:1). Therefore, understanding the women's point of view on how they navigate the new terrain of disability in a post-conflict setting is crucial to the understanding of the kind of health care services they require to survive, the challenges they encountered and how they are dealing with such challenges.

## **1.4. Research Questions and Objectives**

### **1.4.1. Objectives of the Research**

The overall objective of this study is to develop appropriate health interventions and support services for women in Uganda who have experienced physical disability as a result of conflict. In this process, the research aims to identify the underlying factors that shaped these experiences and adopted coping mechanisms and strategies deployed by the women with conflict related disabilities in managing and navigating their experiences in accessing healthcare. In addition, the research examines the interventions provided by the Ministry (with donor, NGO) to tackle major health problems that women with conflict related disabilities encountered and to a large extent how effective are these intervention in addressing the health concerns of women with conflict related disabilities

### **1.4.2. Research Questions**

#### **Main Research Question**

In what ways have the experiences of women with conflict related physical disability challenges shaped and are shaped by the health services in post conflict northern Uganda.

#### **Sub-Questions**

1. What are the health services available to women with physical disability as a result of deliberate mutilation during the conflict?
2. What are the challenges women with such disabilities face in their everyday lives and how do they cope?
3. What is the role of health care services in providing support to women with such disabilities?
4. What are the experiences of women with such disabilities in accessing health care services?

## **1.5 Organization of The Study**

The study will be organized into six chapters in which the first chapter focus will be on the discussion on the research problem, questions, objectives and the context of the research problem. In the second chapter, literature review from previous sources on the research topic and theoretical framework applicable to the research topic has been discussed. Chapter three is dedicated to the methodology section where the research design, data collection methodologies, data collection process and data analysis process are presented. Chapter will present results of the data analysis process and study's findings. Chapter five presents a discussion of the findings in relation to the theoretical frameworks applied to analyse the research topic and research questions. The sixth chapter presents the conclusions of the present study, derived from the findings of this study.

## **Chapter 2 Theoretical Approaches and Literature Review**

### **2.1 Theoretical Framework**

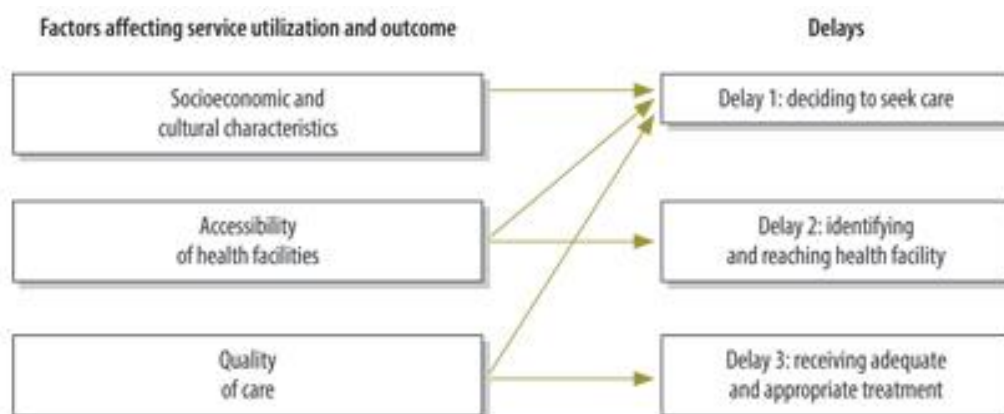
According to Maslach and Schaufeli (2017), a theoretical framework is made up of concepts, whose definitions and reference to appropriate scholarly sources, which are utilized in a particular study. The theoretical framework helps demonstrate an understanding of concepts and theories that are relevant to the phenomenon or topic under investigation and that are associated with the wider areas of knowledge being deliberated. Van de Ven and Johnson (2006) explains that theories are formulated to predict, explain, and understand a phenomenon and in most cases extend or challenge the prevailing knowledge regarding the assumptions of the topic or phenomenon under investigation. It is important for any research to have a theoretical framework that introduces and describes the theory that explains the existence of the research problem of any given study. For the current study, two theories are considered namely three days model of Thaddeus and Maine and the Holistic Healthcare Approach. These two theories form a background for the discussion of how women disabled because of war and conflict in Gulu, Uganda has difficulties accessing health care. These two theories help in the conceptualization of the nature of the research problem and also in understanding the perspective and context of the study.

#### **2.1.1 Three Delays Model of Thaddeus and Maine (1994)**

Three Delays Model of Thaddeus and Maine (1994) is one of the theoretical approaches adopted in this study. This concept defines three things that cause delays which results into health problems: delaying identifying and to reach the health facility, decision making on when to peruse care and getting proper care and treatment while in the health facility (Mbaruku et al., 2009). It is an approach that considers the integral entities that catalyse the delays and provides a couple of solutions to every delay stage and change the current condition. Take for example many critical entities to the delays is deciding whether or not to look for health services. Another example is the provision of poor-quality health care, information regarding the major symptoms to look out for and which locations are best equipped to deal with them, provision of adequate health budgetary estimation. When one looks as the second delay, there are factors to consider that include transportation, security, supportive infrastructure such as roads and even the distance to the healthcare centres are all entities that need to be considered (Mbaruku et al., 2009). In the third, critical actors of consideration begin with inappropriate health facilities, low and delays of medical supplies, less motivated trained medical personnel and limited referral systems (Thaddeus and Maine (1994). Thus, armed conflicts encompass an impact on all the mentioned entities that influence the application of good quality care as well as their outcomes in the post-conflict context such as severe looting and destruction of health facilities.



According to Calvello (2015:418), in the three-delay model, the contributing factors to the delays are not limited to emergencies during maternity period but can be applied to medical needs in general. Following this proposition, in this study the three delays model was applied to identify the factors affecting service utilization and outcome for the disabled women participants which in turn result in three delays.



**Figure 1: The Three-Delay Model in Care for the Disabled**

Source: Calvello (2015)

The factors that impact the utilization and outcome of services and consequently result into delays in the three-model are categorized into three categories, including cultural and socio-economic factors, quality of care, and accessibility of health facilities -Figure 1. The researcher used the three delays theoretical framework to categorize the reasons why women in Gulu, Uganda are having problems with accessing health care services and the interventions that can be put in place in order to help enhance accessibility and usage of health care services. The model is relevant for this study as it is appropriate for focusing on women, and particularly those who are disabled as a result of the war and conflict.

### **2.1.2 Holistic Healthcare Approach**

The knowledge that a human being is a combination of various aspects including physical and psychological has been in existence in literature for the last century (Huljev et al., 2016). The term ‘holistic’ was coined to reflect this understanding of the nature of mankind. The term was devised by Jan Smuts who was the Prime Minister of the South African Republic in the late 1880s. At the time holism was defined as a theory that the whole is a sum of its systemic components. This concept has been applied in the field of healthcare with the fundamental definition being that an individual is made up of the body, mind, and spirit. These components interact in a balanced and harmonious manner resulting in the normal functioning of a person. The concept of health is also introduced here with the definition that a healthy person is one whose physical, cognitive, emotional, and spiritual aspects are at a state of well-being (Poore

et al., 2013). From this definition, it is seen that the health aspect considers all the components that make up a human being.

According to Ventegodt et al. (2016), holistic approach to healthcare refers to the consideration of a complete person; psychologically, physically, spiritually, and socially, in the prevention and management of ailments. All these different states are essential to the wellbeing of the individual and hence should be managed together as the person is given health care. A holistic approach means that the medical personnel are informed of the whole life situation of the patient. Studies exploring the concept of holistic healthcare approach have determined that the general principles of this model are: all persons have innate powers of healing, the patient is not just a disease but a person, patient and medical personnel are partners in the healing process, relevant healing treatment requires a team approach, and that treatment entails addressing the cause of the illness and not just relieving the symptoms (Maizes et al., 2009; Puchaski and Ferrell, 2011; Huljev et al., 2016). This approach to healthcare is recommended for treating all forms of ailments affecting a person.

Holistic healthcare has been described as an approach of analysing illness and providing healthcare that acknowledges and responds to all factors relevant to the health (or illness) of a person (Derick, 2009: 34). This type of care is suitable for treating the disabled women found in Gulu, Uganda. As is explained in chapter 1 of this paper, survivors of armed conflicts, especially those that suffered disabilities required a whole package of health care from psychosocial to physical health care services. Therefore, both state and non-state actors as suggested the Poore et al. (2013) must be able to respond to a multiplicity of needs with a variety of healing paths (Poore et al., 2013: 4). The unattended war physical injuries are proving to be a major impediment to post-conflict situation mostly in Northern Uganda due to the constrained physical ability of affected individuals which limits their productivity (Kasozi, 2017). The needed interventions to heal this trauma include plastic surgeries, palliative care, hip replacement, hypertrophic scars (keloids repair surgeries). Therefore, if rehabilitation coupled with healing is not emphasized in areas/communities affected by armed conflict, it negatively affects life expectancy in such areas. Unaddressed war injuries can continuously inflict suffering, premature death and vulnerabilities on affected people; increasing government expenditure if those wounds are not treated for a long time even after the conflict ended because they lead to complicated and chronic cases increasing health requirements and visits to facilities (Kasozi 2017). Addressing these needs have been suggested to follow a holistic approach that will provide holistic health care for survivors.

Holistic healthcare is a fully-fledged intervention perspective that takes into consideration the essentialities of an individual ranging from their practical, spiritual, communal, emotional and economic necessities. It also includes their psychological state and how they are dealing with their sickness and prospects of being independent. Take for instance, those with mental and developmental challenges often have clinical

comorbidities that need interventions that touch on several specialisation. It includes prospects of long-term support and care as well as support from the communities and societies they come from (Ventegodt et al., 2016). As such they need a level of integration and collaboration that is structured around changing their health state in a positive manner, take care of their wellbeing, while still ensuring that it does not cause a financial burden. This type of care comes with an array of disciplines and coordination among both the healthcare service provider and the patient as well as their next of kin, family and friends (Ventegodt et al., 2016). Depending on the experiences of the women with conflict-related disabilities, holistic healing approaches can be incorporated into the work of various health centres and hospitals in a wide variety of ways from simple community referrals to in-house practitioners to culturally specific programs that focus mainly on traditional healing practices (Poore et al., 2013: 5). Therefore, this is seen as an appropriate model for application in Gulu for treatment of women disabled in the conflicts and war. The holistic healthcare approach was used to analyse whether the healthcare services provided for the disabled women meet the physical, emotional, social, economic, and spiritual needs of the women in order to achieve a holistic health. The holistic healthcare approach was applied in the analysis of the provision healthcare services for the disabled women, to examine whether the services meet the physical, emotional, social, economic, and spiritual needs of the women in order to achieve a holistic health.

## **2.2 Risks and Vulnerabilities Faced by Women in Times of Conflict**

In crisis-affected communities, women along with children are the most vulnerable groups of people (Rohwerder, 2017). The focus of the study is on women and hence the review will disregard the plight of children for the moment. Women are at an increased risk of exploitation, discrimination and violence in times of conflict and war. Furthermore, the women also face constraints in access to health and social care services because of attitudinal, communication, and environmental barriers inherent in their communities. Age and other diversity factors may also impact on the discrimination that women face in such situations.

### **2.2.1 Discrimination and Vulnerability**

During times of war, women often face discrimination on the basis of their gender (Ortoleva, 2011: 9). The United Nations posits that the level of vulnerability in times of disasters or emergencies is dependent on social and civic empowerment, socioeconomic conditions, and access to relief and mitigation resources (Dunn and Sygall, 2014: 50). From this description, it is seen that women often have a greater level of vulnerability before times of crisis as they fare worse in term of health, education, employment and social status (Cornelsen, 2012: 106). In some communities, women are already at risk of gender-based and sexual violence in times of peace and this is exacerbated when the conflict period begins

(Pearce et al., 2016: 120). Ortoleva (2011) concurs with this assertion and adds that armed conflicts amplify the numerous issues that affect women and girls disproportionately compared to men. A study by Jerry et al. (2015) on the impacts of violence on women in Nigeria also determined that the violence experienced by women and girls were associated with oppression and marginalization that these persons face in their daily lives.

### **2.2.3 Risks During Displacement**

There is also evidence of higher levels of risk of violence and exploitation for women in migration or fleeing from areas of conflicts to safer areas (Dowling, 2016: 2). The most common challenge that women encounter in unsafe migration is associated with discrimination and stigmatization based on gender. The women have limited access to health care, participation in helping activities, and issues with identification and registration (UNHCR, 2016: 21). In the situation of crisis, it is the women who take care of the children and continue to act as caregivers until they reach a safe place. In trying to provide for their children in such circumstances, the opportunity for exploitation for such women is augmented (Jerry et al., 2015: 17). During the displacement, these women face immense psychological pressure in providing care to their offspring. In most cases, they may be separated from the children or even lose others to death further enhancing the psychological trauma. Refugee camps are also problematic for women because of the lack of support systems, violence, and problems in accessing facilities and services they need (Ortoleva, 2011: 17). Safety is a big issue for women in refugee camps with congestion also increasing their risk for the spread of diseases. The women are also sexually assaulted by men in the refugee camps and with no proper forms of administration, the vice goes unpunished.

### **2.3 Problems with Access to Services in Conflict Areas**

According to Handicap international (2015), the majority of respondents reported that they did not have enough access to fundamental assistance such as food, shelter, water, and health. Moreover, those people that have disabilities also reported that they do not have access to particular services that they need including assistive devices, access to interpreters and social workers, and rehabilitation services. This further impedes the access of these people to mainstream assistance. The report further explains that the main barriers to accessing aid in situations of war and crisis are lack of access to important information concerning services as well as difficulty in accessing the services themselves (Handicap International, 2015: 4). Other challenges that people encounter include lack of financial or physical access, lack of staff trained in providing appropriate services, and distance to the locations the services are provided (Rohwerder, 2017: 8). According to Rohwerder (2017), only a few people reported that they had access to services provided by humanitarian and health agencies.

Because of the history of marginalization of women in such societies, most of them do not know that they have a right to access emergency aid and health services and they even lack the confidence to speak up and demand such services (Dunn and Sygall, 2014: 50). Because of this attitude and misconception, most of the women will not receive supplies, foods, health services, and other services as they would wait at the back of queues. There are also some cultural norms that may bar women from speaking up or demanding things that they need. Such cultural practices further curtail their access to humanitarian and health services. Such situations are worsened when the things needed by the women are more sensitive or private, for example, hygienic items such as sanitary pads (Rohwerder, 2017: 8). Moreover, discrimination and stigma can also lead to more marginalization of women who are denied services by neighbours, strangers, and even family members.

In most developing countries ravaged with conflicts, women remain largely left out from gender-based violence prevention initiatives that are meant to break the aspect of vulnerability when it comes to sexual violence. These women face barriers that hinder their involvement in such initiatives. The barriers include stigmatization and discrimination by family members, the wider community, as well as service providers (Pearce, 2015: 17). There are also physical barriers that hinder the accessibility of women to these services including high cost or lack of transportation. These barriers affect the ability of women to access services such as raising community awareness and learning about income generation activities. For these women, having fewer financial resources would make them not seek the services of humanitarian aid providers as well as health care. Lack of financial resources means that these women would not afford the cost of transport to go seek such services if they are offered at a distant location.

## **2.4 Factors Affecting Women's Accessibility to Healthcare Services in Conflict Area**

There are also many factors that affect the ability of women in conflict areas to access healthcare and humanitarian services. These factors may be based on the community practices, irrelevant or lack of good policies, and poor healthcare systems. This section presents a discussion of some of the factors that hinder access to healthcare services by women in areas of conflict or war.

### **2.4.1 Poor Policies**

There are usually no specific references to women in the organizational, national, and global policies on the empowerment and protection of affected populations (Sherwood and Pearce, 2016:13). Moreover, there are few globally endorsed operational guidance that supports humanitarian and health actors in implementing commitments and policies related to providing women with more consideration, especially in conflict-afflicted areas. Sherwood (2016) explains that it is necessary to strengthen staff

knowledge, attitudes, and practices in regard to the plight of women. There should also be more focus on ensuring the rights of women are upheld and enforced in policies at all levels.

#### **2.4.2 Negative Attitudes of Community and Family Members**

The ‘attitudes of community and family members’ is considered a significant challenge that women in conflict areas face in striving to access health and humanitarian services (Sherwood and Pearce, 2016: 14). Humanitarians and health providers reported that efforts to change the attitudes of people in such areas are often met with resistance as the people insist it is their culture (Rohwerder, 2017: 11). Moreover, language and cultural barriers may also prevent these women from engaging directly with foreign aid and health care services providers. Ensuring meaningful and active participation of women in making decisions about their wellbeing and lives, and also that of their communities and families is significantly impacted by the discrimination and stigmatization they face.

#### **2.4.3 Limited Knowledge, and Poor Attitudes and Practices of Staff**

Humanitarian and health personnel often report that they are not properly equipped to make sure that women in conflict areas get the best possible services (Sherwood and Pearce, 2016: 14). Because of the low social status associated with women, some health and aid actors may perceive them as objects of protection or charity instead of active participants and actors of change in their communities (Rohwerder, 2017: 11). In this thinking, the health and humanitarian actors do not consider the social factors that have put women in the position they occupy in those societies. The actors do not realize that with the proper approach they can help these women understand their rights and enhance their living conditions. Such situations highlight the poor skills and attitudes that health and humanitarian personnel have, and which impacts the effectiveness of the services they provide.

#### **2.4.4 Lack of Local Partners and Champions**

Without strong accountability at the ground level, women always find themselves having to rely on other people, especially men, to advocate for their needs and rights (Sherwood and Pearce, 2016: 15). In most conflict areas, there is a minimal representation of women advocates leading to lack of championing for their requirements. Even if a few women may be included in advocacy roles, these roles are often male-dominated and the voices of the few women advocates will not be heeded. Moreover, a lack of understanding of the processes and architecture health and humanitarian services makes it difficult for women advocates to articulate and effectively communicate issues affecting them (Pearce, 2014: 15). This underscores the need to have more representation of women in advocacy positions in conflict-afflicted areas so that they may champion for the needs of fellow women.

## **2.5 Research Gap**

While the topic of healthcare challenges for women with disabilities has been widely discussed, only few studies have focused on the case of Uganda, particularly, Gulu District. This research aims to fill in this gap. The reviewed literature discusses several factors that hinder accessibility to health services in conflict areas but the present study looks at the same topic at a post-conflict situation in northern Uganda and only focuses on women who became disabled as a result of the conflict. It is anticipated that findings of this study will help inform policy content and development, and thereby to address the health needs of women with disabilities in Uganda's Gulu District.

## Chapter 3 Research Methodological Strategies

### 3.1 Study Area: Description of Gulu District

Gulu District is one of the districts in the Northern part of Uganda. The district is one of the districts that constitute the Acholi sub-region. Pader District borders it to the east, Lamwo District to the north, Nwoya District to the southwest, Oyam District to the south, and Amuru District to the west. Gulu district is composed of Omoro County, Aswa County, and Gulu Municipal Council. The district has a population 468,407, 240,226 are feminine, and 228,181 being Masculine. Common linguistic; Luo. Farming where the key crop specialisations include millet, cassava, cow Pease, potatoes, beans, Simsim and sunflower. Economic plantations are inclusive of cotton, tobacco, sugar cane, vegetables and cabbage. One can also find fishing on the western end of the district in the River Nile (UBOS, 2013:1). Below is a map of Gulu District.

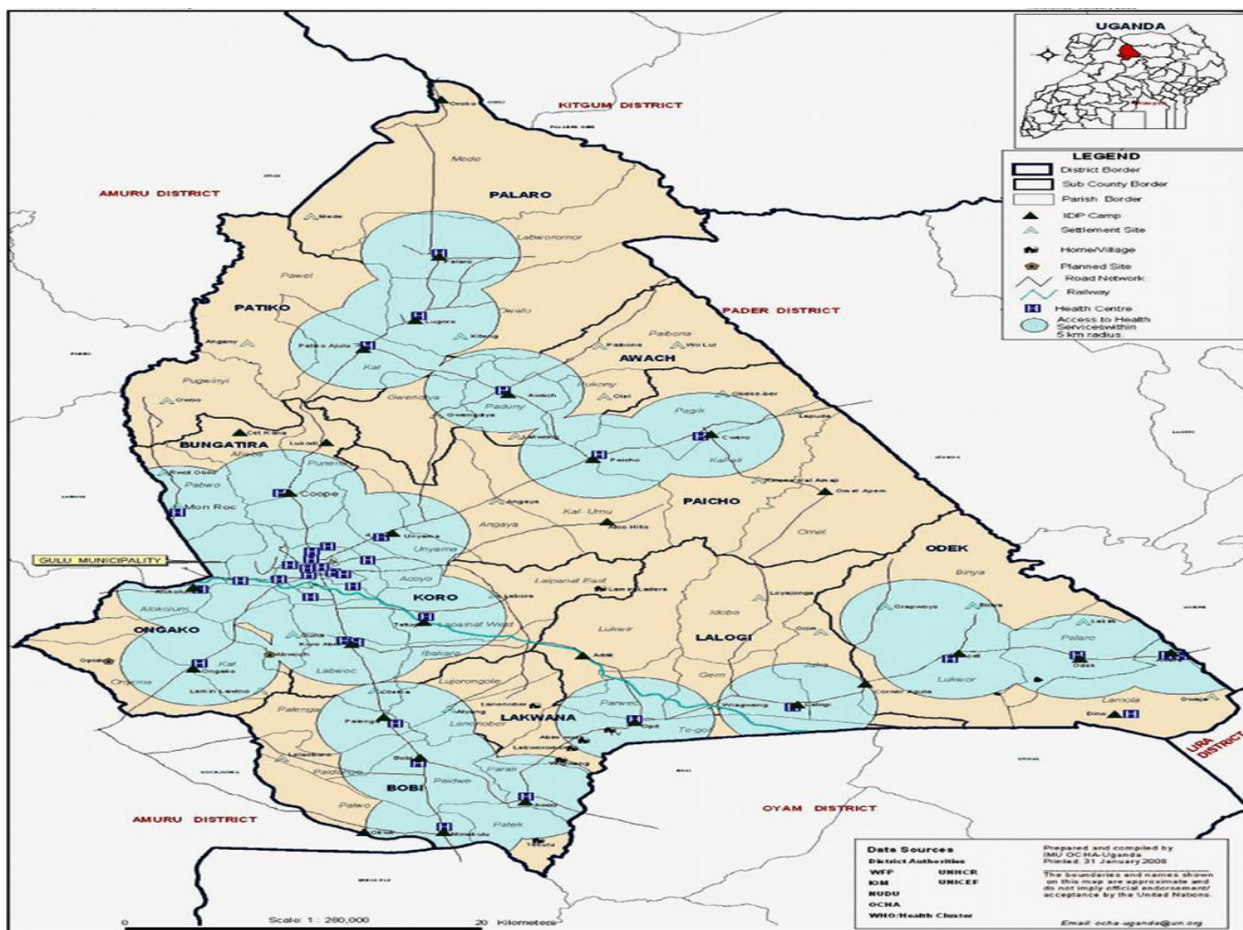


Figure 2: Map of Study Area

Source: Google Map



The district is governed in line with the Constitution of the Republic of Uganda (1995) bolstered by the Local Government Act of 1997 as it was revised back in 2001. Gulu District consists of 12 Sub-counties and 4 Divisions (16 Lower Local Governments). There are other administrative entities that are inclusive of two counties and 1 Municipality (UNFPA, 2013: 5-7). In regard to health infrastructure, apart from 2 private/NGO dispensaries, Gulu in its part has forty five government healthcare service providers, that are made up of 26 levels two units, 14 level-3 health units, three level-4 health centres, a general hospital and a regional referral hospital (Mulumba et al., 2014:3).

The main underlying factor leading to bad health incidences is poverty, and extreme level of illiteracy with special consideration of women, the emergence of illnesses of lifestyles, high prevalence of preventable diseases, limited provision and distribution of health services such as safe water supply and sanitation facilities (UBOS, 2013). Thus, finding proper healthcare interventions is inadequate in Gulu District in general because almost thirty seven percent of the community still commutes over 5km searching for health services. Though, the providing of healthcare service interventions focuses on families and individuals; it is difficult to determine the quality and satisfaction with the service delivery to the community. In conclusion, the awareness of the fundamental patient rights is poor, with weak feedback networks from the public (UBOS, 2013: 60-70). Moreover, there are few health care facilities resulting in inadequate services provided to the people of this area (Nyeko et al., 2016). The study obtained data from rural areas in Gulu District mainly from Omolo and Aswa County.

### **3.2 Data Collection Tools**

For data that will be collected to answer the research questions for this study, the qualitative method of data collection was explored to acquire relevant primary data for the study. The choice of the qualitative method was because the method offers the space where the researcher can participate actively in the process of the data collection, an opportunity that might not be possible in a survey. Moreover, it gives ample room for flexibility that allows the researcher to adjust the research design should, in case there is the emergence of unforeseen circumstances (Wimmer & Dominick, 2013). Qualitative research also helps the investigator understand perceptions and views provided by the respondents and hence allows for deeper analysis of problems affecting society. This is because qualitative research is used to answer questions regarding the perspective, meaning, and experience of the participants. Therefore, this is seen as the most appropriate method for the current research.

#### **3.2.2 Focus Group Discussion**

Considering that data required for this study deals with personal experiences which are not homogenous, a qualitative approach remains the most plausible approach can allow an in-depth

understanding of what the women that suffer disability as a result of conflict in Northern Uganda, Gulu, in particular, go through in their attempt to accessing health care in post-conflict situation. There are several forms of qualitative approach; however, semi-structured interviews and Focus Group Discussion (FGD) methodological approach will be adopted for data collection. FGDs encourages participants to share experiences and interact, give room to seek further clarification on issues that are not clear (Belzile & Öberg, 2012).

The aim of the current study was to explore the experiences of women with a disability as a result of the conflict in Northern Uganda. In this endeavour, the adoption of FGD enables the researcher to understand the sudden transition that occurred in the women lives. The transition involved moving from somebody who could access health care as an able body into finding it difficult to access health care because of the disability they suffered during the conflict. Besides, “focus group interviews, in particular, are capable of bringing into play important discourses that people use to establish social bonds and identities” (Kvale & Brinkmann 2009: 158). This approach offered a rare opportunity for the researcher to access more information and gave the researcher the close opportunity to varieties of experiences and also give the opportunity for other women keeping silence on their challenges to share their experiences when they listen to others speaking. The implication of this is that many of the women with a conflict-related disability had the opportunity to determine if their experiences before, during and after the conflict is having a significant impact on their ability to accessing health care or not and what experience they want to share.

### **3.2.3 Semi-Structured Interview**

To complement the FGDs, face to face semi-structured interviews with sets of predetermined questions on sub-topics were deployed to get the views of NGOs and government officials of the topic of research. This approach is essential in ensuring that the interviewees stay on the topic of discussing and not digress from the main points needed to address the objectives and research questions of the study. This is something that is lacking in an in-depth interview because interviewees tend to go beyond the specific target the fact that they assume they have plenty of time. Besides, it allows the researcher to crosscheck if the research questions have been answered by the database of the guiding questions (O’Leary, 2014). As the researcher may ask a question professionally, there will be some leeway allowed for supplementary questions on top of the ones that have already been predetermined. It will make the exercise less formal and communicative, enabling the respondent to provide answers beyond those that are expected.

### 3.3 Sample and Selection of Respondents

Access to respondents was done primarily through the National Union of Women with Disabilities of Uganda (NUWODU), which is an organization I worked with in the past on a project to raise awareness about issues affecting women. NUWODU is a National NGO that brings together women and girls with disabilities to have a unified stronger voice in advocating for their issues and rights. It has earned the trust a lot of people in Uganda and in particular the women. Besides, the organization has unrestricted access to the targeted respondents for this study. NUWODU is a woman-led disabled people's Organisation, founded in 1999 due to the violation of the rights of the girls and women with disabilities, discrimination, barriers to different services, torture with core values that also focus on building strong communities from society conflicts based on gender and accompanying affiliations as well as offering non-discriminatory help these minority individuals in society. The choice of NUWODU is germane because NUWODU leads the Uganda women with disability movement and the organization remains the leading worthwhile voice that is advocating for women with disability rights and equal opportunities in Uganda (Guzu 2013:3). It is essential to know if they prioritized those that suffered disabilities due to conflict or they address concerns of all women with disabilities with the same approach.

The selection of the respondents for the FGD interview and semi-structured interviews was done through purposive sampling selection method. "The purposive sampling technique is a type of non-probability sampling that is most effective when one needs to study a certain cultural domain with experts within" (Tongco, 2007:147). Since the targeted respondents of this study must meet specific criteria (the disability must be physical and conflict-related, age, marital status), are aimed at answering the research questions and addressing the study objectives, selecting respondents purposely for such purpose seems plausible and germane for the collection of the required data for the study. Besides, purposive sampling guarantees the quality, reliability and competence of the respondents that will be partaking in the study. Moreover, it is useful in circumstances where the population is too small for a random sample (Tongco, 2007:147).

However, those that were selected as respondents are women that suffered permanent physical (amputees, paralyzed and disabilities that requires the uses of the wheelchair, crutches, and prosthesis) as a result of the conflict in Gulu region. Women that were disabled before the conflicts or born with a disability before the conflict or that their disability is not as a result of the conflict will not be considered. Also, women below the age of 18 years were not be considered as they are considered to be children still under the guidance of adult and permission will be needed to conduct the study with them as well as ethical issues in dealing with children. Young people(abavubuka) from 30-45 and older(abakadde) from 46-60 were selected for the interviews, this because those who are 30-45 now were 17-32 by then(during

the conflict) and those of 46-60 were 33-47, so they could still have clear memories about the conflict and will provide clear information. Below is a profile of the research participants. The names are not given as a measure to uphold confidentiality.

**Table 1: Sub Questions, Information Collected, Sample Population and Size**

<b>N0</b>	<b>Research Questions</b>	<b>Method of Data Collection</b>	<b>Source of Data</b>	<b>Sample size</b>	<b>Remark</b>
1	What are the several health services available	Interviews	Health Providers; Midwives, nurses, and doctors from all levels of health facilities; dispensaries, HC III and Iv and hospital (government and private)	6	To identify Specific services available to deal with mutilating injuries
2	What are the challenges women with such disabilities face in their everyday lives and how do they cope?	Focus Group Discussions (FGDs)	Women with Lower Limbs conflict related disability (Double and single Amputee, Spinal Injury/Paralysis that affected limbs	10 participants for FGD (Amputees)  10 participants for FGD (Spinal injury/Paralysis)	To identify life challenges the women with the disabilities encounter and how they cope with the challenges

3	Among the coping strategies what is the place of health care services in providing support to women with such disabilities?	Interviews	Health Providers (as 1 above)  Official Representatives  NUWODU	Same participants as 1 above  2	To identify the relevance and effectiveness of the available health services provided for the women in dealing with their challenges
4	What are the experiences of women with such disabilities in accessing health care services?	FGDs	Women with Lower Limbs conflict related disability (Double and single Amputee, Spinal Injury/Paralysis that affected limbs	Same participants as 2 above	Experiences these women go through to access health care services

### 3.4 Justification for targeted respondents and the procedure of access

The narrowing down of respondents through the stated criteria is due to several reasons. First, disability is extensive (vision impairment, acquired brain injury deaf or hard of hearing, mental health conditions, intellectual disability, physical disability, etc.) and considering the limitation of time. It was not possible to accommodate all types of disability. For instance, there was the exclusion of women with disabilities before the conflict or those who suffered disability not linked to the conflict situation. The reason for this is that the focus was meant to discuss the experiences of formerly abled women who are now disabled because of the conflict. The experiences discussed by the FDGs involved their ability to

access health care and this highlighted the experiences of the doubled life they have lived; the non-disabled life and the disabled life. Exploring these categories of women experiences will go a long way to have a clear understanding of the living reality that people with disability in post-conflict situation contend with accessing health care and other social amenities that is critical to their survival.

To be specific, 20 women with physical disabilities were selected to participate in 2 FGDs. The selection involved getting their names from NOWUDO which is an organization most of the disabled women in the area are registered with. The questions that they were asked was unstructured and a day each was dedicated to the organization of each FGD. The decision to organise two FGDs were influenced by a zeal to understand the heterogeneity of the women experiences since they suffered from different forms of physical disability as a result of the injury suffered from the conflict. In addition to the two FGDs, 6 health providers were purposely selected from health centres, private clinics and referral hospitals. They include midwives, nurses, doctors and all other health personnel is in two constitutes; Aswa County and Omoro, as well as, two official representatives from National Union of Women with Disabilities of Uganda (NUWODU).

I also obtain data from all levels of the health facilities in Gulu, namely; dispensaries, health centres (III), health centres (IV), general hospitals for both government and private. The data involved the number of disabled women and the type of services they sought when visiting these facilities. When I reached the health centre, hospital and clinic I presented an introductory letter from the local council to obtain permission from the head of that particular institution to enable an appropriate staff to take part in this research. Selection of women respondents was made within the communities in Gulu District. I also visited the NUWODU offices where I met with the Chairperson and a staff of the organization. She acted as the coordinator and interpreter for the research and was paid for her services. Together we were able to select the 20 women who were members of NUWODU. Because of familiarity with the women, she was able to coordinate meetings for the focus group discussions offering transport fees for the women.

### **3.5 Navigating the Filed Challenges**

I arrived in Gulu on a sunday and had to meet staff from NUWODO, who acted as the coordinator and interpreter, to discuss on how the exercise was going to be carried out and laying out a work plan on how the entire exercise was going to take place, measures on how to collect the data from the different forms of the respondents which were the women with disabilities, health providers, official representatives and the focus group discussions (FGDs) which were going to be carried out respectively. My team was composed of the coordinator /mobiliser, she was the interpreter as well and myself where everyone had duties to execute respectively. After coming up with the planning, on Monday morning we had to report to the head office of Gulu district in order to see the CAO. He forwarded me to his secretary to process

me a letter referring me to the sub-counties with approval of the CAO's signature approving my fieldwork practice.

During the interviews with the women, I moved with the interpreter/ translator who helped to interpret from English to the local language (Luo/Acholi) because majority of the women were illiterate and did not understand English language nor speak it, so he played a very big role in interpretation as I asked the question respectively to the respondents who were the women with disabilities. Our Movements were also accompanied by the LC1s of different areas /villages where we went to and the LCIs played a role of security to ensure that no dirty work was happening in their wards. We moved to different villages /wards of Awach, Ayul C, Ayul A, Layibe, Patiako, Lacho and other respectively. The security person was not involved in collecting data as a measure to uphold confidentiality.

We also engaged interviews with the health providers of St. Joseph, Gulu regional referral hospital, Awach health center iv and Nimaro hospital where I engaged nurses, Doctors in interviews basing on the interview guides designed on the particular data collection. So I basically had a 40-minute interview with health providers and looking forward on how the women with disabilities were to be helped and improve on the accessibilities of health services to women with disabilities, we carried out interviews which were conducted in the different health units mentioned in the paragraph above. Although the names of the institutions are provided, the names of individuals interviewed are withheld for the purpose of confidentiality. I was accompanied by the coordinator in all the interviews and she helped in recording them. The interviews were then reflected in the daily journal and these were conducted in English.

I carried out interviews with the official's representatives at the National union of women with disabilities of Uganda. (NUWODU) where I engaged in the interviews also basing on the interviews were successful because measures and recommendations were made by the officials to the health providers and the health units. The exercise was carried out at the (NUWODU) office branch of Gulu district (Northern). And it was at NOWODU where they directed me to villages where I could get/find the women.

The interpreter mobilized the women with disabilities since he could communicate so well with them(in the local languages they understood), we meet on the focused group discussions (1 focus group per day, totaling to 2) The mobilization was successful, the women turned up for the meeting and here again we had to use the local language (Luo/Acholi) respectively because the locals do not understand nor speak English, so due to the language barrier I had to again help from the interpreter to translate to the local language as i asked the questions respectively. These sessions also had pictures /images taken after seeking consent from the individuals. The women explored the challenges they faced and made suggestions, recommendations and advice to the health providers, ministry or NGOs on improving on

their health challenges. The women were all happy to have such a study data collection where they went back to their homes convinced that something was going to be done. This is because I informed them that the research would highlight their plight and reveal them to relevant authorities, and this would trigger actions to remedy the issues.

After all these different forms of interviews on different respondents respectively, I made a formal report which reflects all the entire data which was collected in the region Gulu for the respective study topic.

### **3.6 Ethical and political choices and personal involvement (positionality)**

I decided to look at the experiences of women in the post-conflict situation and how the conflict-affected the health systems in Northern Uganda in Gulu district because I worked with an NGO advocating for rights of the vulnerable and needy. We used to visit different districts of Uganda, so when we visited Gulu district, I met these women that were dehumanized during the conflict and still faced with other post-conflict health consequences. This motivated me to do this academic research in addition to what has been done by other researchers.

The research needs to uphold a spendable level of autonomy as well as beneficence, and justice. Permission from Gulu District to conduct the study was obtained from the local authority as well as the informed consent of the FGDs participants and semi-structured interviews respondents was secured before they were finally picked for the research program so as to ensure their identities and privacy was considered a top priority. Informed consent was obtained in oral form. It was a part of the exercise that needed to respect the traditional communal practices of the area. A good example is that consent needed to begin with the leaders of the village before obtaining it from the respondents (Weijer and Emanuel, 2000: 44.). Conclusively, consent procedurals encompassed the essentialities listed below:

- Inclusion of the local communities in the selection procedures;
- Communicating information in local language and according to the cultural values;
- Obtaining consent in local language and according to the cultural values;
- Ensuring withdrawal from taking part in this research.

Every consent form that was completed, alongside the recordings of FGDs, and the semi-structured interviews were secured in a way that the researcher was the only one who had access. It was important that any publication that would as a result of this study was genuine as agreeable to the researcher.



## Chapter 4 Data Analysis

### 4.2 Health Services Available to Women with Physical Challenges Because Of Deliberate Mutilation During the Conflict

From the answers provided by the respondents, the healthcare services available for women with conflict-related disabilities included rehabilitative care such as therapies, medical care, surgical services counselling services and reproductive services.

The rehabilitative services that were mentioned by the respondents included occupational, physical and psychological therapy.

One of the health providers mentioned that

“the rehabilitative care we offer focuses on returning the women to full functionality and dependence through helping them regain recently lost abilities such as motor skills.”

As part of rehabilitative services, x-ray and pharmaceutical services were also some of the mentioned healthcare services available for the disabled women based on the findings. A respondent in the focus group mentioned that

“after experiencing some sharp pain in my leg, the nurse sent me to take some x-ray scan so that the doctor could assess what was wrong with my leg. After the scan is when it was noticed that there was a bone fragment still in leg that was causing the pain. I had to get a surgery for the pain to go away”

Another respondent from the disabled participants said that

“My leg injury healed from the medicine given time by the hospital, but after this, I had to take several therapy sessions in order to restore balance to my legs since I could not be able to walk properly without losing balance and falling.”

Maternal health services were also identified as one of the services available for the disabled women. These include maternal clinic service and family planning services. Despite the availability of sexual and reproductive health services in hospitals, women with disabilities stated that it was hard for them to visit health centres and get information about their sexual and reproductive health because of the negative attitudes people have towards them. When these women went to the hospital for a general check-up or when pregnant female nurses insulted them. A 33-year-old mother of four with conflict-related physical disabilities and working as a vendor said:

“When I was pregnant with my last child, I went to the hospital and the nurse was very rude to me. She said I was giving birth like a dog and she even pitied the man who introduced me to sex. She further stated that I could not control my sexual feelings. I will never go back there again.”

A physically impaired 31-year-old pre-school teacher also went through the same thing. She said: “I went to the clinic to check which family planning method was good for me, but the nurse was so arrogant and told me that sex was not for the disabled, so she did not understand what brought me to the clinic.”

In addition, one of the disabled participant reported that she delivered her first baby from home due to lack of enough support from members of her family because her husband was not home and her mother was unwell. However, for her second child, she delivered in hospital because she received care from her first child as she was in hospital. Nevertheless, reports from many of the interviewees hinted to the fact that negative perceptions and beliefs on disability and reproduction collectively weaken the help that disabled women get, particularly in times of pregnancy and childbirth.

The findings generally demonstrate that even though there is availability of different health services for the disabled women, these services are not evenly distributed in Gulu District. This finding is also evident in the report by Barriga and Kwon, (2010) which mentions that the Peace, Recovery, and Development Plan (PRDP) has mainly ignored vulnerable groups who require protection, including women with physical disabilities. Consequently, a lot of women with disabilities are perceiving that they are better off remaining in displaced persons camps, where medical services are offered, instead of returning home or relocating to another place where the services are not available.

### **4.3 Challenges Women with Disabilities Face in Their Everyday Lives and How They Cope**

#### **Stigma**

Stigma and marginalization were common difficulties reported by the research participants, including the healthcare providers and official representatives.

One of the official representatives said that

“women who are disabled are not treated the same as other women. They are segregated and often marginalized, and this greatly affects their health.”

In this study, the respondents perceived their disability as a barrier to good health. The participants who had disability reported that they experienced discrimination that is very much entrenched in the local culture and community.

One of the healthcare providers mentioned that

“the discrimination facing the disabled women is perpetuated by the attitudes of community members who treat the disabled as worthless individuals. This leads to feelings of despair among the disabled.”

Furthermore, one of the disabled people said that

“the manner in which we are treated in a community is the result of ignorance from other community members on the fact that we can also work and perform just like others. Most of them view us as monkeys on trees.”

The findings of this study regarding stigma are similar to that by Barriga and Kwonn (2010) report which highlight stigma and discrimination as one of the problems suffered by women in the internally displaced camps. The report mentions that a high proportion of disabled women face abuse from family members, neighbours and strangers. Furthermore, their children also experience discrimination from parents of other children who feel that the children of disabled mothers will spread their mother’s disabilities.

### **Difficulties in Pregnancy and Birth**

The findings of this study demonstrated that the disabled women have the desire to get children but face several difficulties that hinders them from achieving this desire. The participants said that their desire to give birth was based on the fact that only by getting children would they perpetuate their lineage and have their future years secured. Truly, the women’s views show that apart from the strong desire to become a mother, and which is based on cultural and social traditions that require married women to have children, there are fears concerning the future and lack of financial support in old age and the need to fight the stigma and stereotypes placed on disabled women. These two factors played a role in pushing these women to want to get their own children.

Another participant reported,

“In my society it is expected that a married woman should give birth. Therefore, if you are a woman who has a husband, but you are without a child then it is difficult for you. That is the reason I want to get a child.”

While one more said that

“For me, I have a great desire to become pregnant and deliver a baby...I seriously desire a baby boy...a person who will look after me in my old age.”

The desire to get pregnant and have children among the disabled women is also expressed in one of the participant’s response that

“Becoming pregnant and getting a baby is a sign that I also can do it. In our community, if one is disabled it is believed that you are abnormal...if you are female, they imagine you can’t or shouldn’t

get pregnant, but you should focus on your disability. So, if I am able to give birth and bring up my child, I will use that to silence those who think I am abnormal just because I am disabled.”

Since many of those interviewees placed emphasis on childbirth and portrayed a desire for having healthy children, they said they desired to get maternal health care so that they could deliver safely. One of the disabled women said

“We who are disabled need special healthcare in the pregnancy period so that we deliver well. I believe all women must get antenatal care.”

### **Mobility Challenges**

When the disabled women were interviewed, they reported that they experienced transportation problems from their homes to healthcare facilities to get attention for serious health problems. Many of the women having physical challenges and those living in rural areas were hit hard by this problem. It could be so because getting healthcare requires one to travel far. For instance, one of the women mentions that;

“When I was expectant, I planned to go to the health center to be seen by a midwife but due to this disability I was unable to go.”

Another woman said:

“I am willing to go and have my leg checked. I am not able to move from my home to the hospital. Since the health centre is far, I cannot get there on my wheelchair. If I had the means I could go by taxi...I cannot go by public means because boarding the bus is difficult and also the bus does not have space for keeping wheelchairs.”

Although many disabled participants said they were not deterred by the cost of maternal care due to the free policy covering maternal healthcare, they still had problems with mobility and the high costs of organizing for transport stopped them from getting health healthcare. This finding is similar to that of (Rugoho and Maphosa, 2017) which demonstrated that disabled women are increasingly faced with mobility challenges when seeking medical help.

### **Unsupportive Healthcare Infrastructure**

One major challenge faced by disabled women when trying to access skilled care is the hostile nature of healthcare infrastructure. One of the interviewees said:

“If I want to go to the health centre, it is not easy for me to enter the facility. The doorway has a high staircase that I cannot climb using my wheelchair. I cannot enter some of the offices as well because it takes time before a nurse can assist you to enter. The last time I went to be checked, I had to wait for 30 minutes.”

Another woman with a physical impairment reported:

“Because I only have one leg, I cannot move without my husband’s help, healthcare personnel also don’t help...when I last visited the hospital I almost fell from the stairs. These are the difficulties I experience.”

She also reported receiving no help from the health personnel because she almost fell from the stairs the last time she went to hospital. Several women especially those with physical disabilities said that many healthcare facilities do not have ramps, people to help disabled women climb the stairs, delivery beds, and wheelchairs, separate washrooms for disabled people, disability-friendly delivery beds, and examination tables. A combination of these problems discouraged some disabled women from trying to get skilled healthcare.

### **Physical Barriers**

Another problem was the distance of the health facilities from the homes of the respondents. They complained that they had to walk for long distances before they got to the nearest facilities. It was even harder for those who had walking assistants because every time they used public transport, they had to pay for two seats to accommodate for their assistants. They even had to pay for their wheelchairs. Again, buildings with most health facilities were inaccessible to people with disabilities. They were not constructed in a way that could accommodate these people. An example of the stated health facilities is those in Gulu, Uganda. A 39-year-old woman who injured her spine during the conflict said:

“Most of the clinic lack ramps to accommodate those using wheelchairs like me. One day I needed to go to the hospital to ask about my sexual and reproductive health and I found it hard to find my way around the buildings. I tried to get help from nurses, and they told me that if I knew I was coming to the hospital I should have brought my relatives. I got humiliated and frustrated and developed a headache. I ended up getting treatment for a headache instead of the sexual and reproductive health that had brought me to the hospital.”

Another problem the people with disabilities met in sexual and reproductive health hospitals was user-unfriendly toilets that were always dirty. Uganda is facing water problems and the hygiene of the citizens is usually compromised. Citizens have died due to cholera and hygiene-related diseases. Women with disabilities find it hard to use dirty toilets in public facilities and they may hence choose to stay at home other than look for the help they need. The complaint was from a 42-year-old female who uses a wheelchair to move from one place to another.

“The toilets are very dirty and that is not healthy.... you can even die from going to those toilets. It is very difficult for people with disabilities to use these toilets Imagine I had to step in human

faeces and urine before I reached the toilet seat. Days after visiting the public toilets I got diarrhoea and I think it was from contaminated hands.”

A 36-year-old physically impaired female participant also said:

“How do they expect physically disabled people to use toilets with human faeces and urine all over the floor? Imagine one day I went to those toilets and stepped on human faces by mistake. I never noticed I had stepped on anything. I was told by other people. It was very embarrassing for me.”

A 29-year-old respondent also had something to say. The woman is paraplegic and uses crutches as a result of injuries sustained from the conflict. She said:

“Some health facilities ask patients to bring their water if they want to use public toilets. No water, no toilet. This is a big challenge for women with disabilities. It is very hard for us to carry water in our condition and it is not all the time that we have people to help us around.”

The responses given for questions related to daily challenges facing women who got disabled during the northern Uganda conflict demonstrate various challenges that range from emotional challenges such as stigma and discrimination, to economic challenges such as lack of income due to loss of ability to work. The coping strategies used by the women mainly involved seeking help from family members as well as healthcare facilities and professionals.

#### **4.4 The Place of Health Care Services in Providing Support to Women with Disabilities Among the Coping Strategies**

##### **4.4.1 Healthcare Services are Available but Short-term or Unreliable**

With the help of several international non-governmental organizations, the government of Uganda established Gulu Referral Orthopedic Workshop (GROW) at GHRR (Okello et al., 2019:2). The main aim of GROW is to offer relatively comprehensive prosthetic limb and rehabilitation services immediately after the war in 2006 targeted primarily at the victims of the conflict. To complicate matters, the cost of operations and maintenance of the GROW facilities rest on the donor agencies' shoulders. As the donor agencies scaled down their operations in the region, it was the patients that are reliant on the services that the donor agencies will suffer the brunt (Okello et al., 2019:2). One of the respondents was injured in 2006 when she stepped on a land mine claimed that she was a beneficiary of the GROW service in 2006. She explained how she was treated with urgency and the proper treatments she received the few years that follow but is not getting more help now that she is off the priority list.

"I lost hope when I stepped on the land mine, but I got treatment and care at the GRRH. However, the good treatment only lasted for two years, because there are lots of people that were injured, so I am no longer on the priority list and I have to struggle to get medical help presently."

Another woman that refused to give her name testified to the early day's proper treatments. She was also a double lower-limb amputee like that respondent and got injured in 2007 when the warring faction of LRA raided her village as retaliation against supporting the Uganda government. She was able to enjoy easy access to medical treatments after her surgery for about three years but now it has become difficult for her to access health care

"The problem is the number of people with a disability that required special assistance is more than the available resources. When I got injured, I was treated at GGRH, and the government provided a wheelchair for me, and after that I am on your own because there are many people in the queue. "

From the available primary data collected during the interviews and focus group discussion, the women with disabilities are enjoying equal rights to access healthcare services like any other member of the society. They can get treatments for a general illness that non-disabled people can also contract, for example, malaria and fever, sexual reproductive health services, pain, and headache, just to mention a few. In general, healthcare services in the study area is not quality and not suitable for adequate healthcare for anybody. However, the health needs of people with a disability come with specificity that requires a medical specialist to look into them (Yee & Breslin, 2010; Krahn et al., 2015; de Vries McClintock et al.,2016; Vergunst et al., 2018).

However, there is no provision or capacity to accommodate the unique needs of the women with conflict-related disability health needs at the nearest healthcare center to the villages that this study was conducted in Uganda. The nearest medical facilities, Gulu Regional Referral Hospital (GRRH) and Lacor St Mary's Missionary Hospital (LSMH); which are the two major hospitals in the Acholi sub-region that offers surgical services (orthopedic, trauma, and general treatments) during the conflict and post-conflict period is about 20 kilometer to the nearest. Therefore, the women have no other option other than making use of Awach health center IV, Unyama health center III, and St Joseph Hospital that is much closer. One of the respondents said;

"Other than a basic health issue that affects everybody such as malaria, fever, STDs, and others diseases, the health center closed to this village is not well equipped, we only go to St Joseph, and in most cases, they will refer you to GRHH if your cases if your condition warrants specialist"

The deduction from the opinions of all the women and medical practitioners' testimonies is that the level of your disability will shape your experiences in accessing healthcare. For example, one respondent (age 60) whom her right hand was amputated after she was injured in 1998 does not need referrer to GHRR or follow up treatment. All her treatments and medication were done at the St Joseph hospital.

The GRRH might be well equipped with a department to provide all sorts of treatments for women with conflict disability, and as a result, the women can get any treatment they want. However, the problem is GRHH, and to some extent, LSMH is the only two medical facilities that can attend to critical cases and they are not accessible to many women with conflict-related disability.

Regardless of the non-proximity to a specialist hospital that can adequately address the specific needs of the women, many women still manage to find their way to the GRRH and LSMH for treatment. Unfortunately, only a few of the women acknowledged the effectiveness of the treatment on their bodies. For example, a woman that identified herself as Mabel painted a sympathetic picture of the inadequate treatments received at GRRH, she emphasized that GRRH is just enjoying a past glory.

"I have been going GRRH for more than three years now; I have not seen any improvement in my condition. They will make you wait for a very long time just to come and tell you that you should come back another time and that time can be four months. I only manage to see a doctor twice in my eight attempts, and they will continue to give you pain killer as if you complain to them that you are suffering from a headache."

Lack of access to appropriate medical treatment and services can discourage women with a physical disability to seek medical care (Mulumba et al., 2014; Nosek et al., 2008). A significant number of women expressed the idea of not wasting time for a service that did not meet up with their expectations as the reason for losing hope in seeking healthcare. However, some shared a contrary opinion on the subject matter. One participant (age 53) suffers a spinal injury during the conflict was referred to GRRH for treatment, and she claimed that after going for treatment at GRRH, she experienced some changes. She believed that many people would claim the treatment they got at the hospital is not sufficient or appropriate because they might not know that some disabilities cannot be reversed.

"I cannot say that I was not treated well; I have accepted my faith since I have the back injury; the back cannot be repaired. Many people have hopes that they will get heal and go back to normal, so when they don't see changes, they want to think that the treatment is not effective."

In general, urban and city centers attract more attention from the government in terms of provisions of social amenities. Consequently, specialized rehabilitation services are typically offered in urban hospitals, making people with disabilities residing in the rural areas finding it difficult to access (Lightfoot, 2004). It is evident in the findings of this study that, the majority of the women with disability (conflict-related or not) living the rural villages find it difficult to travel far distance to the city center for medical treatment. Similar studies conducted in Northern Uganda revealed that because the victims of war are predominantly



located in rural areas, they are more inclined to use inferior government health services (Mazurana et al. 2016). In most cases, they forgo specific treatments that are expensive due to poverty (Mazurana et al. 2016). In general, this study found that clinical services are of low quality and they do not meet the expectations and needs of the women with conflict-related disability.

#### **4.5 The Experiences of Women with Disabilities in Accessing Health Care Services**

##### **Lack of Support From Family Members**

The challenge of mobility that women experience is connected to another problem which is the lack of enough support from the family, members of the community and healthcare givers especially when a disabled woman gets pregnant. There were reports that members of the family and the community were not supportive enough towards a disabled woman who got pregnant. Based on the women's account, disabled women who became pregnant were normally ridiculed because of their disability and the need to concentrate on their disability instead of wanting to get pregnant.

“I have not refused to go to hospital. The issue is that without help I cannot move and there is nobody to help me. They say that since I knew my condition, I needed not have gotten pregnant.”

A woman complained that she needed to go for antenatal, but her problem was that she cannot move around because she has no support and people are unwilling to help her. She was concerned that people were asking her why she got pregnant and yet she knew she cannot walk to the clinic. The failure to get support was a big problem for women having disability because they needed to get direct help from other people if they want to get healthcare. In the same way, many disabled women who were single said they got little support from their families and members of the community. Educated women who were married but were disabled and those with children said they had received better support systems.

“I gave birth to my firstborn at home because my family members did not provide the needed support and my husband was away from home and my mother was sick. However, for my second child I gave birth in the hospital because my firstborn looked after me when I was in hospital.”

##### **Insensitivity of Healthcare Staff to the Needs of the Disabled Women**

Out of all the disabled women interviewed for the study, 15 said that healthcare personnel were insensitive and lacked knowledge on how to give care. They cited that as a major hindrance to their desire to get skilled healthcare services. One woman reported:

“There was a time I was expectant, and I went to visit a midwife. When I arrived at the health centre one nurse called out on her colleagues, ‘come and look at this expectant cripple’. It was so embarrassing. Since then I never went back to the health centre.”

Another physically impaired woman said:

“I suppose many of the nurses lack understanding that we how are disabled have special needs. Sometimes back I visited a midwife. She told me to lie on top of the table...but it was a high table. I requested another nurse to help me, but she burst out shouting at me...she asked why I was not able to climb on the table on my own. She could not understand that I was unable to stand without support. She even told me if I knew I was unable to climb on the table then I had no business getting pregnant. She also told me that she was not employed to help cripples climb and lie on tables. That gave me a very bad feeling.”

Some of the participants said they got irrelevant information from care givers.

“At times, nurses just refuse to consider my situation. When I get pregnant and went to be checked, the nurse told me to do physical exercise by walking on daily basis. But see how I am, I cannot stand, and I cannot walk. All I can do is to move around in this wheelchair. So how does this advice help me?”

Many of the accounts given by the women showed that some nurses were rude and not sensitive at all and they were also not ready to handle the maternity needs of disabled women. Accordingly, many of the caregivers lacked the necessary training for understanding disability and to give care to disabled pregnant women. True to the fact, some women said that some caregivers showed nervousness and discomfort when examining them. One woman said,

“Sometimes it is clear that the nurse is unwilling to help. other times they are filled with fear as if they will be hurt but that is not the case. As a person I have feelings and when nurses treat me badly, I stay away from them.”

### **Service Costs**

Respondents in the study said that all health centres, even those owned by the government and local authorities require women to pay consultation fees of between 10,000 Ugandan shillings–20,000 Ugandan shillings. Apart from the consultation charges, patients are also charged for the supplies and services given. Prior to the 2008 economic meltdown, the Ministry of Social Welfare used to extend social grants to disabled women. The distribution of the funds is very unpredictable, to the extent that there are some disabled women who have not been given any money in the last 10 years. Participants said that since they cannot afford the charges, they are unable to go for medical attention. A 24-year female respondent who suffers from physical disabilities and is being supported by relatives had this to say:

“Clinics and hospitals demand that we pay 10 dollars as for consultation. How do they expect us to get the money? I don’t have a job. I live with my relatives and I find it hard to ask them to give me money for hospital fees because they are supporting me in many different ways.”

Her sentiments were echoed by another female respondent aged 36 years and physically impaired.

“Many women with disabilities have no employment. The government and private employers are not willing to employ disabled women and yet we are not allowed to get treatment in hospitals without paying for it. I should not be misunderstood to be opposing the idea of us being charged for reproductive and sexual health treatment. Some disabled women just don’t have that money. We must cater for our other needs such as paying rent and buying food and all the money we earn is not even sufficient for those needs. When a person is concerned about her daily basic needs, she does not think of going to hospital for health services because that need becomes of less significance.”

### **Provision of Insufficient Information in The Healthcare System**

The respondents said that disabled women got information about reproduction and sexuality from different sources such as parents, peers, health institutions schools among others. Nevertheless, there are elements in many of these information sources that make them difficult to access. Disabled people in **Uganda** lack equal opportunities of attending school together with other people, and therefore, they miss out on information about reproductive and sexual health which others are taught in school. Parents don’t give their disabled children information about sexual and reproductive health.

Social media which today provides information easily and cheaply on different issues gives disabled women the platform for discussing matters of sexual and reproductive health with others. A female vendor aged 39 years walking with artificial legs said:

“I am in a WhatsApp group whose members are disabled women. In this group, we discuss different matters concerning us. In that group, we have some women with disabilities who are knowledgeable about reproduction and sexual health matters. Therefore, I obtain most of the knowledge I have about from friends on WhatsApp.”

Another social platform from which disabled women acquire information about reproductive and sexual health is Face book. This was also confirmed by a 36-year-old disabled woman:

“Face book contains sites that a person can like then follow. The site will then give the person a lot of information about health and wellbeing. We also get some knowledge from Wikipedia and Google. Through the internet we have obtained a lot of information although some of it may not be authenticated. We make use of mobile phones to get into the internet but there are friends of mine who for lack of smartphones they cannot use the internet.”

Other social groups such as social clubs and groups in the church can provide information about reproductive health and sexuality as well. While disabled women get support from social groups, they also said they face marginalization in those groups. An airtime vendor aged 39 years old and callipered as a result of an injury suffered in the conflict said:

“I am a member of a women’s group from my church and in the group, we talk a lot. However, I noticed that when I am in the group, women refuse to talk about health matters related to disabled people.”

### **Lack of privacy**

Disabled women need privacy at hospitals and the lack of it was reported to be a hindrance for those wishing to visit healthcare facilities. The respondents say that health staff is in the habit of violating their privacy. This point was raised by a 31-year-old physically disabled participant who begs on the streets. She said:

“I had a boil in my genital z and I visited the hospital. When I was being examined by the nurse in one of the hospital rooms, other people entered the room. Their thinking was that since I could not see, I had no right to privacy. I heard them walking in and out of the examination room and I became so uncomfortable. I also heard other nurses come in and start talking about me.”

These claims were confirmed by another physically impaired lady aged 34 years old and working as a teacher in a certain private school.

“If you are physically impaired, the hospital staff do not accord you any privacy....When I was expectant so many people would come to examine me, even those who are not healthcare staff because the nurses often allowed their friends to come into the consultation.”

### **Lack Of Knowledge On Caring For Disabled People Among Healthcare Staff**

The participants also noted that healthcare staff lacked knowledge on how to handle disabled people, more so, when their helpers were present. Mostly, they talk to the disabled person through another person and not directly. This denies people with disabilities the freedom to share private information about their sexuality and reproductive health with healthcare staff. These concerns were raised by a 37-year-old woman who has been amputated and as a result she is on a wheelchair:

“When I last went to a clinic my friend was being questioned by nurses about my condition instead of asking me directly. I had a feeling that they were treating me as a child because of my disability. I was embarrassed because I had to reveal to my friend the problem that had brought me at the hospital.”

Similarly, another lady aged 39 and, on a wheelchair, and takes part in wheelchair gaming competitions said:

“They discussed with my mother about the most appropriate method of family planning without my input. I remained sitting as a zombie as they talked about matters pertaining to my health.”

#### 4.6 Suggestions of Improvement of Health Services for Physically Disabled Women

An analysis of the suggestions to improve the health services for women disabled as a result of the conflict in Gulu district demonstrates a myriad of proposed recommendation measures. For instance, one of the healthcare providers mentioned that

“The government in conjunction with other relevant organizations and groups ought to deal with the problems affecting disabled women when seeking health services. Non-governmental, private healthcare facilities and companies should support the government to finance health requirements that disabled women have. As stipulated in the country’s constitution, the government and its partners in development ought to do more to improve the availability of health services to disabled women.”

One of the disabled female participants proposed that

“There is need to improve infrastructure so that disabled people can have their needs met. Ramps and toilets designed for disabled people should be available in every public place, especially in clinics and hospitals. All new hospitals and clinics should be constructed in a design that is friendly to disabled people.”

Another participant from the official representative group mentioned that

“Healthcare facilities should also lower their consultation fees so that disabled women can access health services.”

This respondent went on and mentioned that

“Also, there should be more information sources that disabled women can use. The government needs to finance programmes targeting women with disabilities so that they obtain information concerning their health.”

One of the participating health providers said that

“Organizations supporting disabled women should be capacitated so that that they can provide holistic information on women’s health.”

Due to the issues related to mobility that disabled women are having, one of the healthcare providers recommended that

“present and future transport facilities, health facilities and hospital wards need to be made in a way that they are disability friendly. For example, public transport and healthcare facilities could have wheelchairs, ramps, and adjustable beds that are specially designed for disabled women.”

The importance of a holistic healthcare approach is highlighted in some of the responses of the healthcare providers, official representatives and disabled women regarding what is the most appropriate way to address the challenges faced by disabled women in accessing healthcare services. For instance, one of the participating healthcare providers mentioned that

“it is important for the disabled women to get all-round care that ensures their good health and wellbeing”

When it comes to negative attitudes of healthcare personnel, it was mentioned that necessary for provisions within the Uganda Disability Act to get full implementation. One of the official representatives mentioned that

“The Ministry of Health in the country should also studies on disability and similar issues in the training curriculum for healthcare personnel so that they acquire human resources to attend to women needing specialised and general rehabilitation services. Specifically, both training for health workers before and during service provision should place emphasis on care that is centred on the family, communication with customers, especially sign language.”

As studies done before in Uganda reveal, focusing on healthcare workers training for public relations skills can be used to restore trust and confidence in the nation’s healthcare system (Rohwerder, 2018: Barriga and Kwon, 2010). Furthermore, as a study done by Mulumba et al.(2014) recently recommended, the Ministry of Health in Uganda must make sure that in all hospitals and at all levels such as national and regional, there are healthcare providers who are trained to attend to people with disabilities, especially pregnant women.

## **Chapter 5 Discussion of Findings**

From the study findings, it is evident that women disabled from the northern Uganda conflict go through many problems as they try to access health services in Gulu district. A comparison of these findings with other studies (de LaRoche, 2017: Ganle et al. 2016: Rugoho, 2017) shows that these issues are also experienced in other nations across the globe.

Physical challenges are identified in this study as one of the major hindrances in the lives of disabled women when seeking for healthcare. In this study, physically challenged women cited physical obstacles and clean washrooms as an impediment when they go to hospitals. These physical obstacles get complicated when the bad attitudes of nurses are added to them. Evidence from the study also shows that disabled women normally get no privacy. Since mobility is a big hindrance to many people taking part in the study, the study participants gave the suggestion that the Health service in Uganda and the ministry of health provide subsidized or cost-free ambulance services for disabled women who have a desire to get skilled maternal healthcare. This recommendation resembles that which was made in a certain study from Uganda suggesting that the Uganda Health Service provides mobile health vans so that people living in rural areas can get healthcare ( Ahumuza et al., 2014).

The difficulty of accessing transportation services and health facilities by disabled women is a crucial challenge that was reported by participants in this study. This lack of accessibility does not align with the provisions of Disability Act in Uganda, which require disabled people to have access to services and public areas and the incorporation of these people's needs into the designing, constructing and operating transport networks. The lack of accessibility by these women to healthcare facilities amounts to social exclusion which violates their rights of getting suitable and quality healthcare as shown by certain studies done earlier in Uganda. This can work against the efforts Uganda is making to improve healthcare access to all people by reducing the physical distance.

The findings of this study also suggest that there is scarcity of knowledge on issues pertaining to disabled women seeking healthcare. The Ugandan government is obligated to show respect to the rights of disabled people as stipulated in religious and international laws. The constitution of the country and other local legislations also requires the same. Since Uganda government is a state party to the Convention on the Rights of Persons with Disabilities, the country must make sure that disabled women get their rights just as others are doing (Mulumba et al., 2014). Practically, the Ugandan government should work harder towards law implementation for protecting disabled women in the Northern part of the country from violence and to help them get basic services.

Research results indicated that disabled women are just as sexually active as other women and they want to get children just as other women without disability are doing. To add to the belief that getting pregnant and having children helps them to actualize themselves, the need to fight stigma and bad stereotypes about disabilities and concerns about the future and economic insecurity during old age drove women towards desiring and getting children even with their disabled situations. The discovery that many disabled women want to have children, participate in sexual activities and many of them have been in marriages is an indication that we must direct attention at the peculiar sexual and reproductive health problems and needs of disabled women in Uganda. To add to the focus given to disabled women to provide them with current family planning and contraception services, the study findings show that it is necessary to fight the common misconception that these disabled women are 'asexual' and they can only be helped, or they are 'sick' and not able to marry or give birth.

### **Discussion of the Findings Using Three Delay Model and Holistic Healthcare Approach**

An analysis of the data gathered regarding challenges the disabled women encounter in accessing healthcare services shows the presence of several contributing factors to the three delays model.

From the findings of this study several factors that contribute to the delay in seeking care among the disabled women have been revealed. These factors include women needing permission as well as assistance

from family members and the inability to afford healthcare services. One of the disabled women mentioned that:

“I cannot go to the hospital alone because I cannot use the wheelchair on the roads we have here. To go to the hospital, I have look for days when I can find a family member or friend who can help me get to hospital”

The findings are similar to those of (Berhan and Berhan, 2014) who found that needing assistance and permission from family members delays disabled women from seeking medical help in Ethiopia.

Delay in reaching care is contributed to by such factors as inaccessibility of transport, lack of transport, of confidence in healthcare services, and lack of adequate healthcare facilities in an area (Berhan and Berhan, 2014). In the present study, it was found that factors that contributed to the ability of the disabled women to reach healthcare facilities included lack of adequate medical facilities in Gulu District, lack of transport and inaccessibility of transport mean.

This finding is derived from such responses as

“I have challenges when trying to reach the health centers because the public transport means that I should use to get to the hospital does not accommodate my wheelchair”

Another respondent mentioned that

“The facility that offers physical therapy sessions is very far from my home, so I have to start my journey very early in the morning if I am to get there on time. Sometimes, I arrive late after the doctor has gone and I miss the treatment.”

Delay in obtaining adequate and appropriate treatment is contributed to by such factors as lack of understanding by medical staff, lack of suitable medical supplies and inadequate number of trained medical personnel based on the findings of this study. For instance, one of the healthcare providers mentioned that

“sometimes we have to send some women home without treatment because we do not have adequate staff to offer treatment for all the patients who come in”

The application of the three-delay model in interpreting the findings of the present study demonstrate the presence of the model’s proposed factors in the accessibility of healthcare services among disabled women.

The need for holistic care approach is highlighted by the findings of this study. An analysis of the challenges that the disabled women encounter in their daily lives, challenges in accessing healthcare and their experiences in getting healthcare services demonstrate that the care they are receiving is does not promote holistic health. For instance, while the medicines that they receive from the hospital helps alleviate



the physical pain the women suffer, they still undergo emotional suffering as a result of self-loath stigma and discrimination. For instance, one of the disabled respondents mentioned that

“even though my leg is completely healed after the surgery, I experience emotional and mental problems because of the abandonment and discrimination I get from my family. After being crippled from the war, my husband left me because he thought I could no longer give him children. After he left, I have been feeling less of human being and sometimes I wish I could just die.”

Furthermore, another challenge identified shows that the women lack economic wellbeing as they are not able to work and hence do not have money for the healthcare services they require. One of the official representatives mentioned that

“the disabled women do not only face physical pain as a result of the injuries from the war, but they are also faced with marital and emotional problems which gives them a lot of stress to the extent that some of them are contemplating on suicide”

Some social needs of the women are also not met some of them are discriminated against by strangers, and even family. Furthermore, the desire of some women to have children and be like other mothers in the society is not fulfilled as a result of the belief that disabled women should not get pregnant and lack of access to proper reproductive care. Therefore, the findings of this study identify a need for a holistic approach which can cater for the health and wellbeing of the disabled women by attempting to cater for their physical, emotional, social, economic, and spiritual needs.

## **Chapter 6 Conclusions of the Study**

### **Abstract**

The main aim of this research was to explore the ways through which the experiences of women with conflict-related challenges are shaped by health services offered in post-conflict northern Uganda. To achieve this aim, the research main research question was further abridged into four research questions: 1) What are the health services available to women with physical disability as a result of deliberate mutilation during the conflict? 2) What are the challenges women with such disabilities face in their everyday lives and how do they cope? 3) What is the role of health care services in providing support to women with such disabilities? And 4) What are the experiences of women with such disabilities in accessing health care services? To provide answers to these questions and hence achieve the research aim, qualitative research was employed where data was gathered through focus group discussions and interviews. The identified health services available for women in the northern Uganda conflicts include maternal health services, rehabilitation services and medical services. However, it was noted that these services were not evenly distributed in Zulu district since some of the disabled respondents had to travel

to far distances to reach the healthcare facilities. The study discovered that challenges the disabled women face in their daily lives included stigma, physical barriers, mobility challenges, unsupportive healthcare infrastructure and difficulties in pregnancy and birth. Furthermore, the findings of the study revealed that while healthcare services are available to the disabled women, they are short-term and unreliable.

The experiences of women in accessing healthcare services reveal several issues including mobility challenges, lack of support from family members, insensitivity of healthcare personnel, high service costs, lack of adequate information by healthcare professionals and lack of knowledge. The suggested ways of improving the women's access to healthcare services by the respondents included subsidizing of treatment costs, improvement of infrastructure in health facilities to be more friendly and training of medical professionals on how to address the needs of the disabled women. Following these findings, the study concludes that women disabled from the northern Uganda conflict go through many challenges as they try to access health services in Gulu district. While there are various services available for these women, these services are short-term and often unreliable. Furthermore, the challenges facing the women in their daily lives are preventing them from accessing the medical health services.

From the findings of this study, it has been deduced that although the disabled women desired to live productive lives many women taking part in the study said that their being disabled coupled by that fact that they were attended to by people who are insensitive to disabled people made it hard for them to get access to quality healthcare services. Although some women said they had positive experiences they still had challenges in accessing healthcare services. Another recommend change in this study is the introduction of a disability-related cultural competence education for nurses and other healthcare givers. This would make healthcare facilities more friendly and helpful for disabled people by emphasizing on patient focused care and strategies for change in the behaviour of healthcare givers as well as the public.

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## **APPENDIX I: INTERVIEW GUIDE FOR THE WOMEN WITH DISABILITIES**

Dear Respondent,

I am Ronah Cissy Nassaku a student from International Institute of Social Studies pursuing a Master of Arts in Development Studies. As a requirement for the partial fulfillment of the above award, I am undertaking a study on **challenges that women with conflict related disability encounter in navigating the health care service in post-conflict region of Gulu**. I kindly ask you to respond to this interview: all your responses shall be kept confidential and used only on academic purposes, your rights will be respected and accepted. Your cooperation is highly appreciated.

### **A: Background information on the respondent**

1. Name/Code name
2. Age
3. Gender
4. Marital status
5. Occupation
6. Place
7. What is the type of injury, when did they get it etc?

### **B: Several health services available to women with physical challenges**

8. Did you visit any of the health facilities? When, why, how did you know about it, did you go alone or with someone; which level of health services? Were you referred to a higher level?
9. If you did not get any care, why do you think it was so?
10. Did you get any change after getting these services? Explain please
11. How did/do health providers treat you,
12. Why do you think they treated you the way they did?

### **C: Challenges women with such disabilities face in their everyday lives and how do they cope**

13. Have you ever encountered negative attitudes from individuals or anywhere because of your disability? Please tell me more
14. How do you cope with such challenges?
15. Have you ever been denied treatment?
16. If yes, describe what you experienced and explain why you think you were denied treatment
17. What are the other challenges you encounter in accessing regular treatment or to hospital apart from negative attitudes from health providers or the community as a whole?
18. Is your family aware of your health problem? If Yes, How do, they support you?
19. Is there anyone else that has supported you (informally or formally)? Who and how have they supported you?

### **D: Place of health services in dealing with providing support to women with disabilities**

20. Is there any health institute that has helped you?
21. If Yes, which and when did they start helping you?
22. Please describe how they have helped you
23. If No, Which health service do you think is suitable to help you?
24. How can they help?

25. Are they still helping you?
26. If Yes, have you benefited from their help? Please explain
27. If No, why did they stop?

**E: Women's experiences in accessing health services**

28. Have you ever searched for medical or health service?
29. If Yes, from where and did you access the services? Please explain the service you received
30. How did/do the health providers treat you?
31. How often do you receive or go for health services?
32. If you have never sought for help with your health, please explain why?
33. Did get any improvement or feel helped after accessing the health services? More information please.
34. Did/do you still go to that particular or any other health provider? If No, why? And if yes, how is the process moving?
35. Did/do you ever try out other health services, NGOs or hospitals around Uganda or elsewhere?
36. How was the process?

**F: ADVICE AND RECOMMENDATIONS**

1. Do you have any suggestion for improvement? to Health service providers or the ministry (with donor NGOs) on how or which policies that can help them to address the health problems related to women with conflict related disabilities?
2. Which kind of programs or activities can you recommend health service providers or the ministry (with donor NGOs)?
  3. Which health centers or organizations that address women with disabilities' health problems should be supported?
  4. Which kind of campaigns or awareness should be boosted by the government and health providers to aid the women with physical disabilities' access health services?
  5. Which kind of support should the health providers ensure?
  6. Any questions you would like to ask health service providers and ministry or NGOs about health support for the women with conflict related physical disabilities?

## APPENDIX II: INTERVIEW GUIDE FOR THE HEALTH PROVIDERS

Dear Respondent,

I am Ronah Cissy Nassaku a student from International Institute of Social Studies pursuing a Master of Arts in Development Studies. As a requirement for the partial fulfilment of the above award, I am undertaking a study on **challenges that women with conflict related disability encounter in navigating the health care service in post-conflict region of Gulu**. I kindly ask you to respond to this interview: all your responses shall be kept confidential and used only on academic purposes, your rights will be respected and accepted. Your cooperation is highly appreciated.

1. Background information on the respondent
2. As a health provider, how do you understand conflict related physical disabilities?
3. How often do you attend to conflict related physically disabled women compared to the disabled male?
4. How does this difference in numbers come?
5. Do these women autonomously seek health support?
6. How can you explain the health service system in Gulu regarding conflict related physically disabled women? Why?
7. From experience of working with conflict related physically disabled women, what is your say about their level of seeking, accessing health services and their health improvement?
8. As a health worker, what the determinants of full accessibility or reasons for failure to access health services?
9. Do you think that disability influences or changes a woman's life? how
10. Do you think that disabled women perceive challenges differently from disabled men? why?
11. Do these women show any hesitation or fear to talk about their challenges?
12. Do those women ever complain that the different experiences affect them psychologically in seeking medical care? More information please?
13. Can you notice misery or suffering, even if a woman does not report it?
14. Have you ever observed such cases that were not reported?
15. How do you medically refer to the conflict related physically disabled women?
16. Which health services are appropriate for these women?
  
17. In your own opinion, how do you think these women should be stimulated to report and advance their efforts to seek and access health support?
18. How do the other patients or individuals look at the disabled women conflict survivors?
19. Has the government (with donor NGOs) intervened to support these women?
20. If Yes, How and what have they done?

21. Are they still providing the support?
22. If No, How would you like to see the ministry (with donor NGOs) intervene or support the women with conflict related disabilities to tackle their health problems?
23. Any important information to concerned stakeholders to ensure that they support these women to access medical or healthcare services?

### **ADVICE AND RECOMMENDATIONS**

The intention of this part is to get an understanding of the authentic and instinctive devotion to making health problems that women with conflict related disabilities encounter visible and how they can be addressed.

3. How can you advice Health centers or the ministry (with donor NGOs) on how or which policies that can help them to address the health problems?
4. Which kind of programs or activities can you recommend health service providers or the ministry (with donor NGOs)?
  3. Which health centers or organizations that address women with disabilities' health problems should be supported?
  4. Which kind of campaigns or awareness should be boosted by the government and health providers to aid the women with physical disability access health services?
  5. What kind of support should the health providers ensure?
  6. Any questions you would like to ask other health providers and ministry or NGOs about health support for the women with conflict related physical disabilities?

**APPENDIX III: INTERVIEW GUIDE FOR THE OFFICIAL REPRESENTATIVES  
(Uganda Ministry of Health and National Union of Women with Disabilities of Uganda  
(NUWODU))**

Dear Respondent,

I am Ronah Cissy Nassaku a student from International Institute of Social Studies pursuing a Master of Arts in Development Studies. As a requirement for the partial fulfilment of the above award, I am undertaking a study on **challenges that women with conflict related disability encounter in navigating the health care service in post-conflict region of Gulu**. I kindly ask you to respond to this interview: all your responses shall be kept confidential and used only on academic purposes, your rights will be respected and accepted. Your cooperation is highly appreciated.

1. For how long have you worked with NUWODU?
2. How do you understand physical disability?
3. Have you had any cases of violence or abuse against women with disabilities and how many cases have you dealt with?
4. How can you describe the health care services regarding women with conflict related physical disabilities?
5. Are there steps that have been taken to include women with conflict related physical disability in accessing health services?
6. What policies are in existing to advance proper responses to health problems regarding women with conflict related physical disability?
7. How have the existing programs been effective at identifying and addressing the accessibility of health services and needs of women with conflict related physical disabilities?
8. Which factors affect the accessibility and utilization of health services by women with conflict related physical disabilities?
9. Are there any steps that have been taken to bridge the gaps?
10. What recommendations can you give to health service providers, the ministry (with donor NGOs) in addressing health issues encountered by women with conflict related physical disabilities?

## **APPENDIX IV: INTERVIEW QUESTIONS FOR THE FOCUS GROUP DISCUSSIONS (FGDS)**

- Qn1. Background information, names and what they do to earn a living, consistency.
2. What are challenges you as woman with disabilities face physically in the community.
3. What are challenges you face in the community regarding your disabilities?
4. How have you managed /coped with those challenges.
5. When you go to the health center to access health services, how do the health providers at the health units treat you?
6. Are you freely allowed to access the health facilities/ hospital facilities while at the hospitals or health centers?
7. Do you have negative attitude from the community about your disabilities.
8. Do you have any side business to support you at your homes financially and health wise?
9. What are suggestions you would give to the health providers, ministry or NGOs on improving the health services issues to the women with conflict related physical disabilities.
10. Which kind of programs or activities would you like to advice or recommend the health providers, ministry or NGOs.
11. What would you want the health providers, ministry and other stakeholders to do to help minimize /do away with the challenges you face?
12. What are some of the questions you would ask the health providers, ministry or NGOs about the health support for the women with conflict related physical disabilities.

## APPENDIX V: CONSENT FORM

I am Ronah Cissy Nassaku a student from International Institute of Social Studies pursuing a Master of Arts in Development Studies. As a requirement for the partial fulfilment of the above award, I am undertaking a study on **challenges that women with conflict related disability encounter in navigating the health care service in post-conflict region of Gulu**. I kindly ask you to respond to this interview: all your responses shall be kept confidential and used only on academic purposes, your rights will be respected and accepted. Your cooperation is highly appreciated.

I agree to the following:

Personal interview

Focus group participation

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Interviewee signature

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date