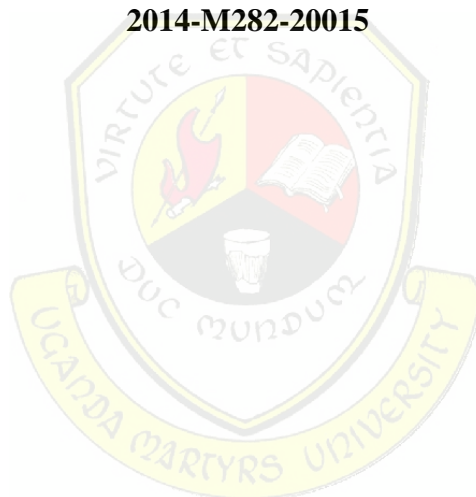


**LIVED EXPERIENCES OF PEOPLE LIVING WITH DISABILITIES AND  
HIV/AIDS IN KAMPALA: A CASE FOR THE DEAF AND BLIND**

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**2014-M282-20015**



**UGANDA MARTYRS UNIVERSITY**

**NOVEMBER, 2016**

**LIVED EXPERIENCES OF PEOPLE WITH DISABILITIES AND HIV/AIDS IN  
KAMPALA: A CASE FOR THE DEAF AND BLIND**

**A POSTGRADUATE DISSERTATION**

**PRESENTED TO**

**THE FACULTY OF HEALTH SCIENCES IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE AWARD OF THE DEGREE  
MASTERS OF PUBLIC HEALTH-HEALTH PROMOTION**

**UGANDA MARTYRS UNIVERSITY**

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## **DECLARATION**

### **DEDICATION**

I dedicate this work to my mother Juliet Bitarabeho whose values of dignity, decency, and patience have always been an inspiration, also to my respondents the deaf or blind people who are living with HIV, my fiancé, my brothers, sisters, friends and all that have made my education life a success

I cannot forget to dedicate this research to daughter Akatunda Nicole; I remember very well all your cries of parting with a dad going to school.

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## **LIST OF ABBREVIATIONS**

<b>HIV:</b>	Human Immune Virus
<b>AIDS:</b>	Acquired Immune Deficiency syndrome
<b>ARVs:</b>	Anti Retrial Viral drugs
<b>PWDs:</b>	Persons with Disabilities
<b>WHO:</b>	World Health Organizations
<b>NUDIPU:</b>	National Union of Disabled Persons of Uganda
<b>UNAIDS:</b>	United Nations Programme on HIV/AIDS
<b>UN:</b>	United Nations



## **KEY WORDS AND THEIR DEFINITIONS**

**The Blind:** Blindness is lack of vision. It may also refer to as loss of vision that cannot be corrected with glasses or contact lenses (Kraut, 2013, 124:45). The researcher in this paper used the word visual impairment to also mean blind.

**The deaf:** Deafness is the hearing loss that bars the learning of the language through hearing (Northern et al, 1991, 13:185). According to HRSA (2001, as cited in David, 2003, P.2), the deaf people have a wide range of hearing loss, ability to process sound, and to understand speech. They have varying abilities to produce speech, related to the degree and frequency range of hearing loss and their age at its onset.

According to Finger man (2001, p.89), the deaf and blind people are naturally defenseless humans that make them undergo various experiences in their lives as regards to HIV/AIDS.

**Lived:** A happening in the universal self of a person which marks that he/she can remember very well

**Experiences:** What an individual went through which affects in his or her life.

## ABSTRACT:

**Back ground:** Although efforts have been made through establishment of programs and campaigns to make sure that the spread and effects of HIV/AIDS is minimized among people living with disabilities, it is so unfortunate that such information has been rarely accessible by the blind or deaf community due to the formats in which such information is disseminated does not favor the deaf or blind people. (Wangulu 2009) This study brings out the voices of the deaf or blind people, their experiences with HIV/AIDS virus including the access to health services and the challenges they encounter while trying to live positively with the virus or accessing the information and treatment as regards to HIV/AIDS.

**Objectives of the study:** The study specifically thought to understand the experiences of the deaf and blind people living with HIV/AIDS and explore the challenges they face while accessing HIV treatment. The study sought to generate evidence from the true life experiences of a category of population which may in one way or another be thought not to be sexually active and not vulnerable to HIV due to their impairments, yet in actual senses they are exposed and vulnerable.

**Methodology:** Phenomenological approach into qualitative research was used. Purposive sampling was used to identify respondents. There after a list of cases in the phenomenon was obtained from various health facilities in Kampala Capital City Authority where the respondents are getting HIV/AIDS care, in total they were six respondents. Data tools used were audio recording, notes writing, and observations. Data was analyzed using thematic analysis where themes and sub-themes were developed through data categorization.

**Results:** The findings revealed that, the deaf or blind people who are living with HIV/AIDS had stigma and discrimination both at community and family levels. All respondents disclosed that they experience limited access to HIV/AIDS information in the format that suits their disabilities, such as sign language and braille. The study findings also revealed that some Nurses are very rude and stigmatizing the deaf or blind people living with HIV/AIDS. On the other hand, the study found that life experiences with HIV show positive influence in areas of skills development as the deaf or blind learnt how to generate income through activities like kick boxing, playing keyboard and guitar.

**Conclusion:** The findings revealed that, communication gaps, stigma, poor adherence and limited access to HIV/AIDS related information were most pressing among the deaf or blind people living with HIV/AIDS. The study findings also revealed that some of the respondents still lack confidentiality as a result of low education levels. The overall implications of living with HIV/AIDS have both positively and negatively influenced the deaf or blind HIV victims.

**Recommendation:** The deaf or blind need to be empowered through forming their own peer networks with support from partners or relatives, so that they share experiences and strengthen their confidence. The deaf and blind should be provided with appropriate, equal and similar services and information tailored to suit their special needs to ensure observation of their rights to health.

## CHAPTER ONE

### 1.0 Introduction /Background.

Despite the growing recognition of HIV/AIDS prevention needs among the people with disabilities, there is still lack of evidence related to experiences of the people with disabilities who have become HIV positive (Nixon, et al, 2014). However, evidence indicates that persons with disabilities are at the same risk of contracting HIV as the non-disabled because of the many vulnerabilities they face such as; feeling inferior, poverty, lack of education, lack of sex education, lack of knowledge about HIV and safe sex practices, sexual violence and abuse, poor access to health as well as stigma and discrimination (Philander and Swartz, 2006). The exclusion of persons with disabilities is worsened with the beliefs and myths that they are asexual, unlikely to use drugs and alcohol, less at risk of violence or rape than their non-disabled peers thus at no risk of HIV contraction (Elisabeth, 2006). The health practitioners who would provide the information and services to them, lack the necessary skills for dealing with this category of people, while the counseling, testing and support services are rarely modified to suit the needs of say the blind people (Wangulu, 2009). Therefore lack of information, education and communication materials in accessible formats for the disabled community, means that this group of the population has little HIV related knowledge, including how to prevent transmission of HIV, how to live positively in case one is infected and how to care for others living with the disease (Yungungu, et al, 2013,p.169).

Nduta, et al (N.D) further noted that programs and campaigns to create awareness on how to prevent, manage and live positively with HIV have been rarely accessible by the visually impaired persons. These programs do not seem to recognize the role that the visually impaired persons can play in the fight against HIV/AIDS. The visually impaired/blind people should not be just seen as beneficiaries, but rather essential players in HIV/AIDS programs as this makes

such programs more acceptable and effective. Nduta, et al further adds that although the Disability People organizations have published Information, Education and Communication (IEC) materials on HIV&AIDS in Braille, not all blind people can read Braille. In addition, there is not yet enough research that has been written and published on the intersections between blindness and HIV.

On the other hand, Groce (2007, p.3) stipulates that the deaf community offers a clear example of the limitations faced by those with disabilities in the face of HIV&AIDS epidemic. Groce argues that the only way through which information about HIV can be delivered to the deaf is by sign language, which is mostly learnt in school unless when the family members are deaf and already use sign language at home. The people to deliver this information to the deaf or blind are not experienced enough due to the unique needs and there is no clear exploration of what methods work best for delivery of health care to the deaf or blind. For example the study conducted by Groce (2007, p.6) in Swaziland revealed that 32% of the deaf population were likely to purchase newspapers as compared to 63% of the hearing community. In addition, purchase of radios among the deaf community was at 40% as compared to 90% of the hearing group. Hence, the lower access to both printed materials and radios increases the spread of AIDS among the deaf in Swaziland, as these are the notable sources of information. Groce (2007) adds that the gossip and folklore that are part of the deaf communities complicate the discussion of AIDS and as a result there tends to be confusion caused by actual translation of HIV/AIDS messages into sign language.

This study therefore aimed at understanding the experiences of the deaf or blind people living with HIV in Kampala. By hearing the voices of the participants, the study was in position to identify the needs and challenges faced by the deaf and blind while accessing HIV/AIDS information and services. The study also brought out the possible recommendations that can be

used to assess the existing HIV programs and policies and their concerns towards the lives of the deaf and blind living with HIV.

### **1.2 Problem Statement.**

According to the World Health Organization 650 million people or 10% of the world's population have a disability and four out of every five disabled persons live in developing countries. (Disability and Rehabilitation WHO Action Plan 2006-2011) In Africa, the population of people living with a disability is more than 10%, but only a few studies are available about the lived experience of the deaf or blind who living with HIV/AIDS. According to (Andersen, 2006), it was estimated that there are approximately 2.5 million disabled persons in Uganda

The problem is that the proportion of the deaf or blind people who are living with HIV/AIDS has not been documented. Yet this presents a double burden of powerlessness and helplessness as much as it presents threat to future economic development. Despite some interventions by the government, deaf or blind people have been left out, (Wangulu, 2009,p.1) meaning that the public health promotion core values of like meaningful involvement, equity, helping the most at risk and empowerment have not been well addressed yet.

A major hurdle is the lack of information or data regarding the quality of lives the deaf and the blind living with HIV/AIDS. The Ugandan survey conducted by Hanass-Hannock and Jias (2009) revealed that out of the 371 people with disabilities who participated in the survey perceived themselves as at a risk of contracting HIV. The participants had limited factual HIV knowledge and on how to make choices as regards their sexual behavior. Therefore, if there is no intervention to educate, protect and help the deaf and the blind, they will continue to suffer silently to the levels that the government, health policy makers, health workers and associated bodies about disability and HIV/AIDS may find it difficult and expensive to address. Thus, a

need for this study to help all the concerned authorities understand the lived experiences of the blind and deaf living with HIV and AIDS, such that proper and tailored measures can be taken to reduce the virus among this section of the population. However this study focused on the blind and deaf within the urban and peri-urban areas of Kampala city. This was due to the reason that Kampala being a city accommodates people of all kinds including the deaf and blind.

### **1.3 Research Question**

What are the lived experiences of the deaf or blind people as regards to living with HIV/AIDS while accessing HIV care?

### **1.4 Theoretical framework**

There are several theories which match well with my study, like the grounded theory through which a researcher derives a general abstract of theory of a process, action or interaction grounded in views of participants. But this may not be suitable for my study since grounded theory explores processes, activities and events yet the main focus of this study is personal lived experiences. (Crewswell, 2009)

A phenomenological approach was used to understand the lived experiences of the deaf or blind living with HIV. This approach to the study gave the researcher a privilege to understand the nature of the meanings that the deaf and blind gave to their lives and such meaning determine their actions. This is in line with the statement of Mcphail, 1995, p.160 when he wrote that human consciousness should be the primary unit of analysis in the study of human life. This means that there is no way through which the outside world can understand a human being as a whole, without hearing their voices. Through their voices, one can understand how they feel about a particular situation. Therefore the study emphasized hearing from the first person to get their voice, which is critical in understanding how the blind or deaf living with HIV feel.

Phenomenology is considered as a process as well as a method, and the procedure which involves studying a small number of subjects via extensive and prolonged engagement to develop relationships and patterns of meaning. In this process the researcher set aside his own experiences in order to understand those of the participants in the study. (Creswell, 2009)

Phenomenology theory came up as a philosophy before World War 1 and has continued to exist prominently in modern society as challenging to dominant views on the origin and nature of truth of time. Phenomenon comes from a Greek word *phaenestai*, to flare up, to show itself to, to appear. (Dowling, 2007)

Transcendental phenomenology an original form of phenomenological philosophy advanced by Edmund Husserl (1859-1938) advocates for applying the phenomenological attitude over natural attitude with the main interest being to discover and discuss the 'lived world'. Edmund Husserl's theory aims at identifying the structure of experiences as described by the research participants and hence it is descriptive in nature. (Kafle, 2011)

The focus of phenomenological research is on what the person experiences and its expression in language that is as loyal to lived experiences as possible, hence phenomenological inquiry attempts to describe and explain the meanings of human experiences beneath how people describe their experiences to the structures that underlie consciousness to the essential nature of ideas. (Rudestam, 2007)

Hermeneutic phenomenological theory advanced by Martin Heidegger a disciple of Edmund Husserl and his school of phenomenology puts an effort to get beneath the subjective experience and find genuine objective nature of things as realized by an individual. Hermeneutic phenomenology is concerned with human experience as it is lived with a focus toward illuminating details and seemingly trivial aspects within experience that may be taken

for granted in our lives, with a goal of creating meaning of the phenomenon. (Kafle, 2011) Phenomenological research characteristically starts with concrete descriptions of lived situations, often first-hand accounts, set down in everyday language and avoiding abstract intellectual generalizations thus enabling the researcher to reflectively analyze these descriptions by offering a synthesized account and thereby identifying general themes about the essence of the phenomenon. (Finlay, 2009).

Therefore, in this study the researcher was guided by the hermeneutic phenomenological theory, by focusing on the subjective experience of individuals and groups, because the study was concerned with human life as it is lived. Therefore, the study clarified in detail and some aspects within the deaf or blind experiences that may be taken for granted in their lives, with a goal of creating meaningful impact (Wilson and Hutchinson, 1991) as cited in Kafle (2011,p.191). For example this hermeneutic theory helped the researcher to unveil some of the misconceptions that society has towards the deaf and blind living with HIV. In this the researcher was able to understand the world as experienced by the deaf or blind through their life world stories (Kafle, 2011, p.186). This is because *phenomenological research makes a distinction between appearance and essence, as well as between the things within our experiences and what grounds things within our experience* (Ehrich, 1999, as cited in Kafle, 2011, p.189). The study therefore used hermeneutic phenomenological theory in order to help find out the experiences of the deaf or blind people with HIV/AIDS go through during the course of their life.

### **1.5 Goal**

The main goal of this study was to explore the lived experiences of the deaf and blind with HIV/AIDS. The study findings would help the deaf or blind people to be empowered knowledge on HIV/AIDS care so that they can make healthy decisions with in their society.



## **1.6 Purpose of the study**

The purpose of this study was to understand the lived experiences of the blind or deaf living with HIV/AIDS. The researcher aimed at finding out the nature of life and its trend, which the deaf and blind people living with HIV/AIDS undergo throughout their life... This is because there is little information reflecting on the quality of life regarding the blind and the deaf living with HIV/AIDS in Uganda.

## **1.7 Specific Objectives**

1. To establish the experiences of the deaf or blind people as regards to living with HIV/AIDS in Kampala
2. To understand the challenges faced by the deaf or blind living with HIV/AIDS while accessing HIV/AIDS care in Kampala.

## **1.8 Justification for the study**

According to the National Union of Disabled Persons of Uganda (NUDIPU, 2014), there was not much literature on the incidence of HIV/AIDS among people with disabilities in Uganda. This is mainly because those who have been charged with HIV/AIDS control had not yet considered HIV/AIDS people with disability. What is known however, basing on information derived from those working and interacting with Persons with Disabilities (PWDs) is that the incidence is high and yet no mechanisms have been put in place to reduce HIV/AIDS prevalence among this section of the population. Therefore, since the information written on the deaf and blind living with HIV is limited the findings to this study contributed to the existing body of knowledge as regards the deaf and blind people living with HIV.

### **1.8.1 Significance to public health and health promotion practice**

The findings of this study brought to light the perceptions and knowledge the deaf and blind

people living with HIV have towards living positively with the virus

The findings shall empower the deaf or blind in finding better ways of addressing their experiences especially those regarding HIV/AIDS. They now understand the challenges they face and how these challenges can be addressed to improve on adherence.

Furthermore the blind and deaf deserve different treatment and care compared to the other disabled people. Therefore, basing on public health promotion practices, the deaf and blind people deserve special tailored services towards addressing their problems especially in line with HIV. Therefore the findings availed health service providers with the best practices and ways on how to access the HIV/AIDS services and information by the blind and deaf.

Finally, the recommendations brought forward by the interviewees are of paramount importance to policy makers and programmers towards amending existing or developing new policies that respond to the needs of the blind and deaf. Through engaging the deaf and blind living with HIV during planning and implementation processes.

## **CHAPTER TWO**

### **2.0 Literature Review:**

Literature review helps the researcher with the insight into the field of study he or she is aiming at. Therefore, building upon the previous knowledge and current global momentum, this study is important to inform the national AIDS programmers and health service providers to enable them respond effectively to HIV/AIDS among the deaf and blind people. Although, the researcher's target was the deaf and blind community, it became appealing to the researcher to give a brief overview of HIV/AIDS among the disabled in general before narrowing it to the target group. This is due to the fact that there is still limited literature written on the deaf and blind as a specific category of the disabled community. This explains why the deaf and blind have been neglected as regards planning and implementing HIV/AIDS policies and programs. When reviewing different articles, the researcher gets to understand more about the topic under study and also how best the scope of the study can be limited. Important to note is that this paper may not have given a comprehensive and exhaustive body of all literature that has been written on deaf and blind, but rather, a reflection on what has been written and studied on the topic. It is for this reason that the researcher used articles as far as 2006 rather than the recommended from 2011-2016.

### **2.1 HIV/AIDS and the Disabled**

People with Disabilities have continued to be a marginalized population in international and national responses to HIV/AIDS (UNAIDS, 2009). According to a WHO and the World Bank World Report (2011), persons with disabilities represent approximately 15% of the world's population with 80% of them living in low and middle-income countries. Although there has been significant progress around the world in recent years towards providing universal access to HIV prevention, treatment and support programs, the organization of Human Rights Watch

(2014) revealed that such progress has excluded the people with disabilities due to lack of adequately targeted and accessible services for such persons. Persons with disabilities are often more vulnerable to HIV infection than anyone else because of their lower education and literacy levels, higher poverty and greater risks of physical and sexual violence (Human Rights Watch, 2014,p.1). However, Tun et al (2016), states that in order to address the needs of the persons with disabilities living with HIV, HIV services must be inclusive, addressing their specific needs to ensure early diagnosis and timely initiation of HIV treatment and also to promote retention and adherence in care and treatment. This can be done by understanding the unique experiences of persons with disabilities living with HIV from their own perspectives and experiences in accessing HIV services and information. But also the effectiveness and success of the awareness campaigns and intervention programs can only be measurable when the pandemic's prevalence in a targeted population is known. It is unfortunate though that, there seem to be no clear facts on the prevalence of HIV/AIDS among people with disabilities in the available literature (Chireshe et al, 2010,Yungungu et al, 2009 and Human Rights Watch, 2014). This study therefore endeavored to assess whether information about HIV prevalence among the people with disabilities is clear through talking to some case.

In order to curb the increasing number of people with disabilities living with HIV, so many initiatives have been launched among which is the African campaign on disability and HIV/AIDS. The Campaign was launched with the objective of promoting a coordinated response involving persons with disabilities in African countries to achieve inclusive national HIV and AIDS policies and programs and equal access for persons with disabilities (The World Bank, 2010,p.2). Since then, the subject of disability vis-à-vis HIV and AIDS has received greater attention due to the increasing cases of the epidemic in the marginalized populations. People with disability are often the least educated and among the poorest sections in most

societies. (WHO 2010) This makes them unable to speak out strongly about their rights as regards the inadequacies in interventions by the government and health service providers.

According to the World Health Organization 650 million people or 10% of the world's population have a disability and four out of every five disabled persons live in developing countries. (Disability and Rehabilitation WHO Action Plan 2006-2011) In Africa, the population of people living with a disability is more than 10%, but only a few studies are available about the lived experience of the deaf or blind who living with HIV/AIDS. According to (Andersen, 2006), it was estimated that there are approximately 2.5 million disabled persons in Uganda

A NUDIPU's baseline study as cited in the World Bank Report (2010) on HIV and the disabled in Uganda revealed that, a high percentage of persons with disabilities were suffering from sexually transmitted infections including the deaf and blind. While a localized test that was conducted among women in one of the sub counties in Gulu revealed that 25% of the women with disabilities were confirmed to be HIV positive (The World Bank, 2010). The UNAIDS (2009) report gives some reasons as to why the disabled people may be at a higher risk of contracting HIV/AIDS virus as compared to the able bodied community. Below they are mentioned;

**HIV risk behaviors:** There is a possibility that many people with disabilities engage in behaviors, which put them at a risk of contracting HIV infection such as unprotected sex, male-to-male sex, injecting drug use among others (UNAIDS, 2009). Since people with disabilities also belong to the socially marginalized groups, they do face compounded stigma and discrimination. This makes them feel inferior and they may end up spreading HIV virus to people they are having sex with. A study carried out by Mprah (2013) in Nigeria revealed that 98% of the deaf people engaged in risky sexual behavior because they were unaware of the

consequences. They did not have knowledge on the use of condoms as a safe measure against sexually transmitted diseases, hence lacking measures on how they could prevent it (Mprah, 2013, p.30). Groce (2007) states that disability among adolescents, compounds many of the risks related to HIV transmission. Disabled adolescents are frequently excluded from social activities, thus limiting their opportunities to learn, set boundaries hence lowering their sense of self-worth. In the end, this often compromises their ability to refuse when pressured to have sex or even try drugs.

**Sexual Violence:** Larger percentages of people with disabilities are more likely to face sexual assault during their lifetime than those without disability. (UNAIDS, 2009) A study carried out by Hanass-Hancock (2009,p.6) across the three African countries indicated that disability contributed to 70% of the cases of sexual assault. The Uganda Demographic and Health Survey (2006) noted that more than two thirds of Ugandan disabled women with HIV, experienced violence from their partners as sixty eight percent had been harassed or beaten by their partners. The situation becomes worse for the deaf and blind that may not be in position to defend themselves. According to Hanass-Hancock (2009), the deaf are soft targets for sexual assault since it is believed that they cannot shout for help or even talk about the abuse, while the blind are not in position to recognize the person who may assault them, hence making it difficult to report the case.

**Access to HIV education, information and prevention services:** There are higher chances that people with disabilities are turned away from HIV education forums or not invited by outreach workers because of assumptions that they are sexually inactive or they do not engage in HIV risk behaviors (UNAIDS, 2009,P.3). The UNAIDS report further explains that even in circumstances where information on HIV among people with disabilities is high, it is not always translated into use of HIV testing and counseling services. For the blind and deaf people

according to the World Bank report (2010),the format through which HIV/AIDS information is disseminated is a crucial barrier as it is not accessible to the deaf (sign language and television subtitles) or the blind (such as Braille). Yungungu et al (2013,p.169) sides with the World Bank report when in the study noted that, the traditional methods used to disseminate HIV/AIDS information are not visual impairment friendly. The large print materials are not translated into Braille format hence preventing the blind people from accessing HIV information. Moreover, the HIV campaigns that are run through newspapers and billboards put the blind at a disadvantage. While in circumstances where these campaigns are run over radios, the deaf are left uninformed. Lack of information is compounded by low levels of literacy among the persons with disabilities (World Bank, 2010,p.20). Therefore sexuality and HIV information on radio and televisions should incorporate elements that make it accessible to individuals with sensory impairments (deaf and blind), such as self-explanatory audio-visuals. (Aderemi, et al, 2013)

Similar to the above, is the communication barrier faced by the deaf and blind while accessing information on HIV/AIDS, prevention and treatment services. The World Bank report (2010), states that the deaf and blind people rely on tactile communication, which requires patience and skilled interpreters who are hardly available at clinics and hospitals. This leads to extremely negative experiences for the deaf and blind people with HIV. A World Bank study in South Africa reported a deaf person having his HIV positive status disclosed to him by a doctor writing in large letters on a piece of paper and holding it up in front of his face, without being counseled or even explained on how to use the medications (World Bank, 2010). In the same line, there is a specific communication problem in the translation of the language and concepts of HIV/AIDS into sign language, especially the notion of being HIV positive and HIV negative. For example, there is a misconception that being HIV positive is a good thing because the word

positive indicates a good outcome, and HIV negative is a bad thing especially among the deaf community (World Bank, 2010,p.25)

In addition, there are few legal consequences for those who abuse people with disabilities in most of the countries (Groce, 2005). In her explanation, Groce writes that the police, judges and social workers relate accounts of abuse or rape with disability to confusion. That is the reason as to why individuals with disabilities fail to submit police reports or even give testimony because they will always be, misunderstood (Groce, 2005,p.219). They also fear to take cases to court due to the costs involved in filing cases and yet most of the disabled people are defined to be the poorest. Taking an instance where a case has been filed to the police or in court, there is still a challenge of lack of sign language interpreters who would explain the case in simpler terms for the people in the above designations to understand. (Groce, 2005) The study drew attention to policy makers, implementers and other service providers on issues related to deaf service delivery.

### **2.1.1 Stigma and Disability**

Further is the issue of stigma and discrimination that is faced by the disabled population thus hindering many of them from accessing HIV services Tun et al (2013,p.3) revealed that persons with disabilities experience multiple dimensions of stigma, which compound each other to result in social isolation and being cut off from sources of information and services. He further adds that this double stigma of being HIV positive and having a disability discourage people to get tested for HIV because they fear the potential results and related consequences for example who to take care of them. In a World Bank study conducted across three African countries (Uganda, Zambia and South Africa), the findings revealed that fear of stigma prevented persons with disabilities from accessing HIV services, disclosing their HIV status, and seeking treatment and support. In particular the blind and deaf people reported



discriminatory attitudes from the medical personnel, who instead of speaking to them directly, they would address the personnel accompanying them to the health center (World Bank, 2010,p.24). Additionally, stigma and discrimination is not only confined to the clinics and hospitals, but also pervades family and the community. Elisabeth (2006,p.34) identified four types of stigma faced by Persons living with HIV/AIDS whether disabled or non-disabled;

Stigma from family members; According to Elisabeth's (2006) research in Uganda about the access of HIV services among the disabled, the study found out that HIV/AIDS related stigma is evident with family members. Those feelings of rejection and segregation are common. In the belief and fear that HIV is contagious, the families of the disabled refuse to share household utensils with them, while others are moved out of the family home for the same reason. Under circumstances where poverty exists, family members believe that the costs of caring for a person who is ill could have lasting consequences and would make the life of other family members difficult. Although HIV services are free in most of the countries including Uganda, they come at a cost in terms of feeding, which may not be affordable by the poor. For example in an interview by Tun et al (2016) in Uganda a deaf respondent mentioned poverty as one of the reasons as to why they fail to access HIV services. According to him, the medicines provided require something to eat, and that's why some disabled people are reluctant to take the medicines because they do not have the money to buy the food to accompany the medicines. Thus they end up not taking medicines at a regular basis as prescribed by the doctors (Interview by Tun, et al, 2016). This study therefore, intended to assess the challenges faced by the deaf or blind as they are trying to access HIV care.

Stigma from the friends and community; Rankin et al (2005) as cited by Elisabeth (2006) narrates that, in most African villages, the identity of an individual is tied to that of the family, community and tribe. Therefore HIV/AIDS related stigma does not just affect the person

infected and his family, but the whole clan or even the village and that is why a person living with HIV may be excluded (Elisabeth, 2006). Tun et al (2016) confirms this in a study conducted in Uganda among the blind, where a blind person raised a concern of stigma from the community. Tun et al said that the guides who direct them do not want to guide them to areas where the HIV services are offered simply because they fear the community associating them with HIV/AIDS (Interview, Tun, et al, 2016). Matters become worse for the case of the deaf and blind that need a third party for interpretation while accessing HIV/AIDS services. In this stance, confidentiality is compromised, as you can never be sure whether the third person will not tell others.

Stigma from their sexual partners;The need to be loved by their partners has deterred many people from testing for HIV in fear of knowing their status and of course losing their loved ones. For example a woman may fear to disclose her status to the husband due to fear of being abandoned and perhaps to be condemned as being a prostitute. Elisabeth (2006), states that due to fear of stigmatization, many African women are tested for HIV during pregnancy, but they rarely return to the testing site to find out about their test results. However to my personal analysis, this seems to have changed as the increased number of health centers and hospitals give people the advantage of choosing where to test from, and of course which health center to go to in order to access HIV/AIDS services if found positive.

Stigma at the place of work;considering the condition of the person with any forms of impairment, who tested HIV positive, It becomes doubled stigma. First of all, their physical condition puts them in a pitiable condition and of course no employer will be willing to retain someone who is believed to be about to die especially if the symptoms have already manifested

on the person. However, the most significant consequence of stigma in the work place is the inability to find work at all (Elisabeth, 2006).

Extreme poverty associated with disability is also another factor that discourages people with disabilities from accessing HIV/AIDS information. The World Bank (2010), estimates that people with disability make up 20% of the world's poor. Although such services are free of charge in government-aided hospitals, there are still other costs that a person has to incur such as transportation costs; interpreter costs for deaf and of course the costs of feeding after accessing HIV medication. Taking an example of Uganda, most of the government hospitals are situated in urban centers, which mean that people in rural areas have to incur transport costs to get to these hospitals. As result their concerns about HIV/AIDS are overshadowed. Similarly, Groce (2005) revealed that some parents in Thailand were selling off their deaf daughters to brothel operators in exchange for money. This is because among the brothels there is no one who can speak sign language, and therefore there was no way out for the girls to call for help from authorities or even discuss their situation with people in the surrounding community, thus putting them at a risk of contracting HIV/AIDS. Similarly Touko's (2010) study in Nigeria revealed that 55.1% of the deaf participants were engaged in commercial sex as a means of earning an income. Therefore contexts of poverty increase the vulnerability of persons with disabilities to HIV/AIDS. (World Bank, 2010,p.19).

The end result is that many individuals with disability are not reached with HIV/AIDS messages, they are not aware of the symptoms of HIV/AIDS besides not understanding the implications of the symptoms should they appear yet a reduced ability to recognize symptoms of HIV/AIDS for example by members of the deaf community, may delay appropriate care and management of the infection (Groce, 2007,p.10) while those who may be in position to understand the symptoms are limited by other factors to access medication. Among others is

the issue of confidentiality. For example a deaf and or blind individual may need to take along a friend or relative with him or her as a sign language interpreter to communicate health concerns. This compromises their confidentiality thus discouraging them from visiting hospitals for treatment (Groce, 2007).

Therefore, the African Campaign on Disability and HIV&AIDS (2008) stipulates that, people with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programs, including those that directly affect them. In fact they should have access to the physical, social, economic and cultural environment, to health and education and to the information and communication in enabling them to enjoy all human rights and fundamental freedoms in their fullness. A global survey on HIV&AIDS conducted by the World Bank 2004, found out that people with disabilities (concern on the deaf and blind) are not yet factored in the HIV sector, despite their vulnerability to a variety of known risk factors (Wangulu, 2009,p.1).

## **2.2 Social interpretations surrounding disability and HIV/AIDS**

There are common myths the community has developed in regard to the disabled people living with HIV and AIDS. Such myths increase the vulnerability of the deaf and blind community to unwanted sexual attention and shape the often-negative attitudes of the service providers and society at large. The World Bank (2010,p.22) report describes four commonly known myths as follows;

Persons with disability are not sexually active and are thus HIV free: This misconception shapes people's attitudes especially the caregivers towards persons with disabilities regarding access to HIV/AIDS services. They believe that since they are not sexually active, then there is no need of including them in the programs and campaigns fighting AIDS or even

accommodating them in the voluntary counseling and testing and treatment programs. To the contrary, people with disabilities are as sexually active as their non-disabled peers, have feelings like any other normal human being and can of course be infected with HIV/AIDS (see Human Rights Watch, 2014,p.21, World Bank, 2010).

Sexual intercourse with a woman who is disabled can cure AIDS: Many men and women have taken advantage of the deaf and blind by having sexual intercourse with them in the guise that they will be cured of the disease. In fact women with deafness or blindness are taken to be women of chaste before God and that once you have sexual intercourse with them they will also be chaste (Groce, 2007). In Groce's study among the seropositive persons in Cameroon, Adonis et al (2010,p.5) noted that the seropositive that engaged in rape believed that by having sexual intercourse with people with disability, the virus would be purged from their systems. Personally I do not agree with such a misconception. The number of people with HIV is just increasing day by day, and if surely sleeping with a disabled person would heal AIDS, so many people would be willing to do it for their health to be well.

Lastly is the misconception that a child with any form of disability is a curse/punishment from God. Many of our societies have condemned people who give birth to children with impairments that they must have committed a sin before God and the only way God would punish them is by giving them a disabled child (Groce, 2007). This makes such children to be abandoned by their own family, thus making a child vulnerable to sexual abuse, which in the end may result into contraction of the HIV virus.

Basing on the findings from this study all the above are real myths not reality. It was revealed that whether disabled or able bodied the sexual feelings or desires are experienced by everybody. In fact among all the six respondents only one male aged 25 years was not yet

married but he has hopes to marry in future.

### **2.3 The Deaf and HIV/AIDS: What are their experiences and challenges?**

The deaf exist within a unique and vibrant culture, a fact not always appreciated by the hearing individuals. (Wangulu, 2009) However many advocates believe that the acceptance by the hearing population that a deaf culture exist, is a very important step towards educating the nation about the needs of the deaf who are living with HIV (The Health Resources and Services Administration Report (2008). Several arguments have been raised on the possibility of the deaf people being contracted with HIV/AIDS epidemic. Adonis (2010,p.6) reveals that there is converging information that the general population's social perception of the deaf constitutes elements that weaken the ability of the deaf in making safe sexual decisions. The belief that the deaf are asexual yet they are more exposed to sexual risks than the hearing persons increases their vulnerability to contraction of HIV/AIDS. This marginalization is evident in the domain of research with limited information available while the few efforts that have been undertaken to integrate the deaf in the fight against HIV/AIDS are unequally dispersed in different parts of the world (Touko, et al, 2010).

Further the deaf people depend greatly on visual elements for learning new information. For example pictures, slides, videos and live presentations used in HIV education as they provide a greater impact on their lives. However Roberts (2006) as cited in Mprah (2013) reveal that even the visual information the deaf receive from the above sources is not translated into sign language. Thus, in the view of difficulties the deaf face while accessing information from formal sources such as the health professionals and media, they often turn to informal sources such as families and friends for information which is reported to have factual errors (Mprah, 2013). In the end, the deaf are in danger of becoming infected with HIV because they are not only unaware of the ways through which the virus can be transmitted, but also the symptoms

should they occur. For example Aderemi (2013) tried to assess the HIV transmission knowledge among people with different forms of disability in Nigeria. The deaf believed that AIDS would be transmitted through sharing a toilet or a cup. This means that there are higher chances that the deaf would involve themselves in behaviors that would infect them with HIV unknowingly.

Important to note however, is that, the prevalence of AIDS epidemic among the deaf community differs from that of the hearing community. This is because the deaf lack public forums devoted to educating them about the virus, yet the brochures that would be available for them to learn may only reach a small segment of the population of the deaf who have acquired some literacy skills.

### **2.3.1 Challenges**

Deaf people face greater access problems than other people due to the fact that mainstream sources of information are inaccessible to them (Mprah, 2013). The particular barriers the deaf face in learning about HIV protection range from inadequate schooling about human sexuality to the scarcity of locally available education programs thus increasing their vulnerability to contraction of HIV. For example HIV prevention and treatment materials are culturally inappropriate and linguistically incomprehensible for the deaf and hard of hearing (The Health Resources and Services Administration, 2008). This lack of information in accessible formats is that HIV/AIDS programs and campaigns may pass over people with sensory disabilities especially those who have not been to school and or live in rural areas (World Bank, 2010). In the end the deaf rely on informal sources of information such as friends, family who tend to have factual errors (Mprah, 2013,p.23). On the other hand, Roberts (2006 as cited in Mprah, 2013,p.23) emphasize that even the visual information that the deaf receive from the televisions may not be accurate and at times it is incomplete and meaningless because most of it is not

translated in sign language. Groce (2007) adds that, there are no programs on television targeting only sign language users. Besides, the amount of factual information on HIV/AIDS available to the deaf audiences based on visual interpretations of television programming is open to questions and deserves further investigation. (Groce, 2007)

The study carried out by Nduta (n.d, p.7) in Maryland USA revealed that that deaf people are 2 to 10 times as likely as their hearing counter parts to be HIV positive, which has been attributed to poor access to information, inadequate treatment programs, issues of confidentiality within the community, difficulty in accessing information from the media and lack of prevention programs aimed specifically at them. While Heuttel and Ronstein (2001) as cited in Mprah (2013,p.23) noted differences in the levels of knowledge pertaining to HIV/AIDS between deaf American students and their hearing counterparts. The authors noted that the deaf students were less likely to have accurate knowledge because information from informal sources such as friends and family tended to have more factual errors, while hearing students obtained information from their teachers, TV and reading materials. There is therefore, need to make services available in accessible formats to the deaf community at all levels such as training health service providers at the hospitals to interpret the medication/prescription of drugs to the deaf patients.

Related to the above are low levels of literacy among the deaf population. While schools play an important role in addressing the knowledge gap in HIV prevention among children and young people (Human Rights Watch, 2014). However it is unfortunate that that deaf have always been left out which makes them to unable to access HIV prevention information on an equal basis with others. The Human Rights Study in Zambia (2014) noted that children with disabilities are almost three times more likely to have never attended school that children without disabilities in the same household. An example of the deaf youth explained that his



father refused to pay for his school fees before his hearing siblings could accomplish school (Human Rights Watch, 2014,p.28). While under circumstances where children with disabilities are able to attend school, they are often left out of instruction on HIV because the teachers think that they do not need to learn about HIV.The Health Resources and Services Administration Report (2008) concludes that this lack of knowledge about HIV disease contributes that the deaf are often not diagnosed with HIV until symptomatic hence dying sooner than the hearing individuals.

Care, treatment and support services are not easily accessible to the deaf persons. The nurse-patient relationship is very instrumental in achieving total healing of the patient. This smooth relationship between the two parties gives patients a shoulder to lean on, and in this way they believe they have someone to trust, and to whom they can express their deeper feelings. However, this relationship sometimes requires specific skills such that the vulnerability of the patient is decreased. Such kind of relationship is lacking among the deaf HIV patients and the caregivers, just because most of the service providers lack knowledge about disability issues (Tun et al, 2016,p.5, Yungungu, 2009).

Further, the findings from Tun et al (2016) revealed that the deaf participants felt it was difficult for them to receive counseling and instructions for taking medications, and facilities lacked informational materials in accessible formats. While others reported that, when doctors see a deaf person approaching, there is always a communication breakdown, and they instead ignore them (Tun et al, 2016). Similarly, the Health Resources and Services Administration Report (2008) noted that the doctor-patient communication is severely limited for the hearing impaired, leading to the negative perceptions of the health care system, difficulty in making appointments, increasing anxiety and medication dosing errors. There is therefore a need to initiate training programs for the health care providers targeting people with specific disability

issues.

Limited research on the deaf with HIV; There is still little literature collected in regard to the experiences of the deaf people living with HIV (Touko, et al, 2010). This information may not only be important to the policy makers and health service providers, but also to the deaf and other disabled population to provide insight to them on how they can prevent themselves from contracting HIV or even on how to live positively with the virus (Tun et al, 2016,). In reading the different stories from different research related articles, they will come to understand the safe ways of having sexual intercourse and with which kind of person. The deaf will also understand their legal rights, where to run to in case a situation of vulnerability comes their way, among other lessons. However, this is one of the more serious challenges to responding adequately to the needs of the deaf and entire disabled community as few countries refer to the need to collect data and information on aspects of disability (Liesl, et al, 2010,34)

The deaf often experience lack of confidentiality in HIV testing and treatment because of communication barriers and the need to involve a third person for interpretation. Confidentiality of HIV test results is a cornerstone of medical ethics recognized as the best practice (Human Rights Watch, 2014,p.36). The deaf people are often reliant on relatives or other people (say friends) to take them to the hospital for medical appointments and as well communicate the information to them. This means that they will have to tell them about their status, thus depriving them of confidentiality. This discourages them from going for voluntary counseling and testing. The fact that a third party has known their HIV status increases their stigmatization thinking that may be the third person has spread the news to the rest of the community members. Therefore it is a call for the government and organizations in charge of persons with disabilities to carry out programs and conduct campaigns that will help to raise public awareness, in order to combat stereotypes, and prejudices relating to people with

disabilities.

#### **2.4 The Blind and HIV: Experiences and challenges**

There has been a major difference between what has existed in the policies, programs and public speeches on HIV and AIDS among the blind, and what is actually on the ground. There is almost no research that has been carried out on the intersections between blindness and HIV. This situation is compounded by stigma blind people suffer from society and the negative attitudes from service providers, which inhibit their uptake of the HIV/AIDS services (Nduta, N.D, P.16). This section discusses the experiences the blind people have lived with the HIV epidemic.

The most powerful weapon a man can ever have is information. Once an individual is informed, there are higher chances that whatever decision he or she takes is based on facts. In the same way, inaccessibility of information about HIV and AIDS among the blind means that they have limited knowledge on how to live positively with HIV and AIDS, or how to care for others who are either infected and affected (Yungungu, et al 2013,p.169). Besides the traditional methods used to disseminate HIV and AIDS information are not visual impairment friendly. For example the textbooks in print, diagrams, billboards, video shows, newspapers, magazine and television adverts do not make sense to the blind people. Whereas the safe use of a condom, which is one way of preventing HIV/AIDS, is difficult for the blind. It is actually more difficult to teach a blind person how to use a condom since they only have to touch (Human Rights Watch, 2014). This means that they cannot know whether it is damaged or even expired.

In relation to the above, Yungungu et al (2013) highlights cases of illiteracy among the blind especially those living in the rural setting. The blind have not been adequately educated about this deadly disease yet a reasonable number of them die of illness similar to HIV/AIDS. Due

to their social situation, the blind cannot read or write hence cannot address the available literature on HIV&AIDS, while those who are educated, still face a challenge of limited information and communication materials in Braille format (Yungungu, et al, 2013,p.169)

The blind people need services on HIV and AIDS in a manner accessible to them. Yet, there are limited policies, strategies and or guidelines to mobilize stakeholders in a coordinated manner such that they incorporate the population of the blind (Yungungu, et al, 2013). This is because policy makers have rarely considered the needs of the blind when formulating policies in relation to HIV and the blind, and in this way they lack services that best suit their needs.

The vulnerability of the blind persons to HIV and AIDS is further exacerbated by traditional beliefs and myths that assume them to be at no risk of contracting HIV and AIDS. In such circumstances they are excluded from voluntary counseling, testing, treatment facilities and other supportive services. For example, a study carried out by Yungungu, et al (2013) in Kenya among the Samburu people depicted the perceptions the society has towards the blind. According to the Samburu culture, the blind are seen as an outcast and therefore keeping such a person in a community brings bad omen to the community. This is why the blind are not accepted and have to live in isolation, hide in houses, hence making it hard for the blind people to access HIV/AIDS information and services. Due to cultural factors, ignorance and superstition, the blind are largely perceived as a curse from God, subhuman and unfit to participate in society's mainstream activities (Yungungu et al, 2013). Such stigmatization and discrimination makes the blind people live a life of no one to care, no one to talk to in case of any problem, which results into, continued trauma and depression.

## **2.5 HIV/AIDS and Disability journey in Uganda: Where are the deaf and blind?**

In history, Uganda has been at the forefront of the disability movement in Africa with one of

the most vibrant movements in the whole continent (Lang and Murangira, 2009,p.24). For example the fundamental human rights of people with disabilities are explicitly recognized within the 1995 constitution of Uganda, the people with disabilities Act of 2006,the country's ratification of the UN convention on the rights of persons with disabilities in 2008, election of people with disabilities at all levels of political life from the village to parliament among others bring us to a conclusion that Uganda fully endorses the rights and needs of people with disabilities (Lang and murangira,2009 ; Ochom and Mannan,2014). It is however unfortunate that the processes of policy formulation and implementation are totally divorced from each other, as there is lack of coordination between different government ministries on cross cutting issues like those of disability which is compounded by lack of statistical data about the people with disabilities in the country (Lang and Murangira, 2009). The World Bank Report (2010) indicates that persons with disabilities in Uganda are among the poorest and few are employed. Most of them have little or no education and are not considered as a priority group to receive education; they face barriers in accessing health centers due to transport costs, as most of the government hospitals in Uganda are located in urban centers

The study conducted by Chireshe et al (2012,p.19) in Uganda about the availability and awareness of HIV/AIDS among the PWDs revealed that the deaf and blind are excluded from HIV/AIDS awareness and intervention programs and only the PWDs who can hear and see benefit from them. While the deaf had problems in getting the HIV/AIDS messages due to lack of sign language interpreters, the blind were left out on the messages displayed on billboards, newspapers and televisions. Additionally Nantumbwe (2010,p.18) noted that, many deaf persons in Uganda are confined in enclosed places where they are cared for by relatives or friends, thus making it difficult for them to access HIV/AIDS information through the media and of course campaigns, yet HIV/AIDS information especially through public campaigns

contributes towards HIV/AIDS prevention efforts used around the world to disseminate messages that encourage people to change their behaviors.

The most recent study carried out by Chireshe et al (2016) in Uganda confirms the situation of the deaf and blind. One of the blind participants informed them that when they go to the hospitals they are ignored and are not provided with services while the deaf respondent narrated that when a doctor sees a deaf person, there is a communication breakdown, as the doctor does not know sign language. This has been largely due to lack of statistical data for the deaf and blind. The numbers of the deaf and blind affected by HIV/AIDS is not known, and that is why they are suffering un noticed.

Important to note is that, of all studies that the researcher managed to come across, only one study by Nantumbwe (2010), which was a dissertation had talked about the deaf and their access and utilization of HIV/AIDS services, although focusing on women. This means that the men were left out. This explains the possible reasons as to why the needs of the deaf and blind as regards HIV/AIDS information and services have been neglected. Thus this study aims at bringing out the voices of the deaf and blind through understanding their lived experiences with HIV/AIDS virus. This in the end will help policy makers and implementers, as well as the advocates for people with disabilities to mainstream the deaf and blind into HIV/AIDS programs to ensure that communication between them and service providers is improved, more workshops and seminars in the rural areas with different formats of HIV information are conducted to close the gap created by the media.

### **2.5.1 Reaching the Deaf and Blind. The role of the community, Government and other stakeholders as regards HIV among the deaf and blind:**

Reaching the deaf and blind with HIV/AIDS messages is complicated because of their nature of impairment. For example, high illiteracy rates are a common challenge among the deaf and

blind. Even where HIV/AIDS education is provided in say schools and public campaigns, the deaf and blind are left out as educators think they do not need the information.

For any policy or program to be successful, it has to bring on board the people that are going to be affected by that particular policy. This is however a challenge in most of the countries that use the top-bottom approaches towards solving development problems. The challenges faced by the blind and deaf people regarding HIV are not identical. This means that there needs to be establishment of policies and programs that are disability specific and will be in line to address the challenges faced by a specific category of people with disabilities. The following are key issues of concern that need to be addressed if the community, government and Non-government organizations (that advocate for the rights of the blind) need to put into consideration if we are to ensure complete access of HIV services to the deaf and blind.

Due to their special needs while accessing HIV services, the deaf and blind should be given larger role in the design and provision of HIV/AIDS education, training and counseling services. The World Bank (2010) study in Zambia, Uganda and South Africa, showed that, in situations where the persons with disabilities were engaged as counselors and educators, the disabled with HIV were reached who might not have been reached if the services and information had been spread by the non-disabled persons. This is because when given the upper hand, persons with disabilities are in better position to mobilize, understand and encourage persons with disabilities in the need of counseling and HIV services. They will be able to raise disability awareness among medical personnel who lack skills to handle health related issues of the disabled, and also to ensure that appropriate forms of communication are in place.

Many programs and campaigns that exist do not seem to recognize the role the deaf and blind can play in the fight of AIDS. They should not be only beneficiaries but also essential players

in HIV/AIDS programs as this makes programs more acceptable and effective. For this reason therefore, the government and other institutions need to extend their support and assistance to programs that involve and work with the deaf and blind. Such support in the end will ensure sustainability and effectiveness in implementing HIV/AIDS programs. ADD (2005) as cited in the World Bank report stipulates that “unless the persons with disabilities are themselves integrated as active participants in planning, coordinating and implementing health programs that affect them, they are bound to be perpetually on the margins of health policy and service provision”.

Related to the above is the need to expand HIV and AIDS related training for all health care workers and other professional, to enable them to better realize the uniqueness of the deaf and blind while administering medication and treatment of HIV information and services to them. As discussed earlier, most of the health workers lack skills to effectively communicate with these categories of people, they end up at times ignoring them or even requesting them to get a third person for interpretation which disguises the patient confidentiality, especially during voluntary counseling and testing situations. In circumstances where the patient and doctor speak the same language, it raises the confidence of the patient, and they will be able to talk freely about private life.

Besides training the health workers, there is also need to train and sensitize the whole community at large about the rights of the deaf and blind. They should be able to understand that the deaf and blind have the same and equal rights as everyone else in the society. This will not only help in correcting the misconceptions the community has against this category of people, but also reduce the discriminations the community has towards them. In the end the confidence and self-esteem of the deaf and blind will be raised, and will have no fear to visit health centers for any health related information regarding HIV.



The inability of the health service providers to respond to the needs of the deaf and the blind has been due to limited research regarding this category of people living with HIV. Lack of data means lack of knowledge and information on how to prevent the virus. It is therefore a call for researchers to investigate more in the area of HIV and the deaf/blind people. The data collected will be very useful in answering the questions the community has as regards HIV, the deaf and the blind. The data will also help policy makers and implementers who have been neglecting.

There is need to adopt and appropriate disability sensitive channels of communication to disseminate HIV/AIDS information to the blind and deaf. As discussed previously, most of the campaigns are run through newspapers and billboards, which put the blind at a distinct disadvantage. On the other hand the deaf individuals will also miss out in case the campaigns are concentrated on radios. There is a need for appropriate messages and methods of communication as recognized by the Kampala Declaration on Disability and HIV/AIDS, which calls for HIV prevention specialists and service providers, to develop targeted prevention messages and methods, that are tailored to meet the specific disability form, gender, age and adapted to cater for all local languages and various cultures (World Bank, 2010,p.20)

Conclusively, it is important to actively and effectively involve not only the blind and deaf, but also people with disabilities in general, in the programs of prevention, management, care and support services that relate to HIV/AIDS. There is also need for the blind and deaf themselves to openly acknowledge that HIV concerns them. This will help them develop self-confidence and esteem.



## **CHAPTER THREE**

### **3.0 METHODOLOGY**

#### **3.1 Introduction**

This chapter is one of the most important parts in a report, as it stipulates the ways through which the facts and doubts of the researcher were confirmed. It brings out the methods, tools design through which data was collected. Choosing the right methods to the study yielded the right data needed, the reverse is true. Briefly this chapter presents the study area, design, study population, sampling techniques, the sample size, methods of how data was corrected and analyzed, the ethical considerations that the researcher considered in mind and of course the limitations to the study. It also discusses the intended ways of disseminating the results.

#### **3.2 Study area**

The study was carried out in four of the five Divisions of Kampala, while visiting health centers that offer HIV/AIDS information and services. Important to note is that the researcher was not in position to interview all the blind and deaf living with HIV across all divisions since it was quite hectic, and besides Kampala is a big city with several health centers. For that reason the researcher had to use exclusion method to get the exact respondents following point of saturation.

#### **3.3 Research Design**

The researcher employed a phenomenological design through employing unstructured interviews with a particular number of people, thus employing qualitative research methodology. Bryman (2008, p.31) The researcher adopted this type of research to help him study things in their natural settings. In addition, qualitative methodology involves face-to-face

interactions with the respondents, which helped the researcher in interpreting the body language actions that may have been missed only through words. Lofland and Lofland (1995, as cited in Bryman, 2008, p.385) The researcher was also able to dig deeper into the case in the phenomena since the study was exploratory in nature.

This in the end empowered individuals as they shared their stories; as they knew that someone was hearing their voices. Therefore, since the researcher aimed at understanding the lived experiences of the blind and deaf living with HIV/AIDS, it was of paramount that the researcher adopted the qualitative phenomenological study that involves a close relationship between the researcher and the respondents.

The researcher also adopted this design, simply because phenomenology calls for thick description and close analysis of lived experience, to understand how meaning is created through embodied perception.(Creswell, 2009) This helped the researcher to understand deeper the lived experiences by exposing taken for granted assumption about the ways of knowing. It was therefore needful for the researcher to adopt the phenomenological approach to first of all, expose the misconceptions the society has towards the deaf and blind as regards to HIV/AIDS, and also to understand the experiences that these category of people go through while accessing HIV information and services.

### **3.4 Study population**

The study population was the deaf and the blind people who are living with HIV/AIDS in Kampala Capital City Authority. Participants were located through personal contacts in their organizations where they receive their HIV/AIDS treatment.

### **3.5 Sampling procedure**

The researcher intended to interview between 5 to 25 participants. However due to the fact that some respondents lacked proper physical address and active telephone contacts in their HIV care files, the researcher managed to reach six respondents. And this was in line with Creswell (2007,p.120) who stated that phenomenological research method can recruit a minimum of five and maximum of twenty- five respondents. The researcher followed the principle of saturation point as per qualitative studies. The researcher also aimed at exhausting all the information about the case in the phenomenon.

### **3.6 Sampling technique**

The participants to the study were purposively selected from the health facilities that which were accessed by the researcher. Bryman (2008, p.458) asserts that purposive sampling is the most commonly applied sampling technique in qualitative research. Bryman writes that this type of sampling is to do with the selection of units, which may be people, organizations, documents, and departments with direct reference to the research questions being asked. This method was chosen because it enables the researcher to identify the exact participants that suites the study. For example, the researcher visited health centers, which provided him with a list of the deaf and blind people accessing HIV services from that particular health Centre.

### **3.7 Data Collection methods-**

In-depth interviews were conducted as the main source of collecting data in this study. The researcher chose this method of data collection because of its flexibility. Bryman (2008) says that the advantage with this method is that it gives room for questions that are not included in the guide to be asked, as the interviewer may pick up on things said by interviewees. This

means that the researcher was at higher chances of digging deep into the area of study. The use of in-depth interviews also helped the researcher to have room to clarify, explain or rephrase statements that appeared unfamiliar to the respondents. Similarly it also gave an advantage to the researcher when respondents gave brief responses to some questions; through probing, more information was gathered

### **3.8 Data Collection tools**

For the case of the in-depth interviews, the researcher developed an interview guide with questions about the topic under study. This however was edited time to time, as new concerns kept arising from the respondents and was useful to the researcher when data on such upcoming issues was received.

Besides the interview guide, the researcher had a notebook that helped him in writing down the views of the respondent. This was because there are some key issues that, respondents hinted on and were useful in either data analysis or even recommendations for further research.

The researcher also used a recorder so as to accurately capture information. Being that this study involved a third party (Interpreter), it was propelling for the researcher to use a recorder to capture the responses as said or translated by the interpreter. Bryman (2008,p.443) states that, the procedure of recording is important for detailed analysis as required in qualitative research. It ensures that interviewee's answers are captured in their own terms. This is because qualitative researchers are not only interested in what people say, but also in the way they say it. Unlike taking notes as it is easy to lose the phrases and language used.

### **3.9 Data analysis and presentation methods**

Thematic analysis was used in the analysis of the data collected. Bryman (2008, p.554) This method was used because, thematic analysis does not have distinctive cluster of techniques from other methods of data analysis since the use of themes has been applied in most approaches to qualitative data analysis. Although most people are used to coding, to the researcher a theme is more or less the same as a code (Bryman, 2008, p.554). This includes, transcriptions of the audio recordings, formulating clusters of them and finally generating meaning out of them.

Data collected were kept confidential. Data was transcribed into verbatim by playing the audio recordings and writing what was recorded. On completion of the transcription process the researcher rechecked for accuracy of the transcribed data to see if it was in line with the narration of the respondents.

Furthermore, after collecting data from the field, the researcher had to look for arguments recurring which helped to build up themes. However these were only specific to the research questions because huge amounts of data were collected of which some was not relevant to the topic under study.

### **3.10 Quality control**

To ensure quality control the researcher developed an interview guide to use during the data collection process. This helped in guiding the researcher on which questions were to be asked and also helped not to lose track as some respondents could go astray in answering some questions. More so the researcher also noted down the respondent's replies as exactly as they were which was at times impossible due to the limited time the researcher was given by respondents to carry out the interview, thus recording was used in conjunction with writing notes. Not doing so could have resulted into the researcher distorting the respondent's answers

and probably writing mixing answers for different questions. It would also not look good among the respondents, so, the researcher used a recorder to avoid respondents feeling tired of him if he was to keep asking for pardons for the same question.

### **3.10.1 Transferability**

This is an extent to which the research findings can be transferred to other participants, settings, detail data collection as well as process of analysis. The researcher achieved this through use of quotations and presentation of findings.

### **3.10.2 Validity**

Validity means confidence of data and it happens when the research findings reflect the experiences of people under study. This was achieved by continuous engagement with the respondents during data collection process and consulting the supervisor during analysis process.

### **3.10.3 Reliability**

This calls for accuracy and consistency of data in research. Reliability in this study was achieved through inquiry audit by the supervisor.

## **3.11 Ethical Considerations**

Seeking the respondent's consent on whether to participate in the study was put into consideration. It is the Participant's right to know the benefits of his or her participation in a certain study. (Bryman, 2008) The researcher introduced himself as a researcher to the participants and shared what the research was all about, told them the amount of time it was



going to take to end an interview. According to the Social Research Association guideline to ethical considerations in research, subjects should not be treated with the impression that they are required to participate. *They should be aware of their entitlement to refuse at any stage for whatever reason and to withdraw data just supplied.* Thus participation in the study was based on the freely given informed consent of those being studied (Bryman, 2008, p.121).

In addition, seeking respondent's consent was done during recording. This was because some respondents had little time for the interview and yet were very important to the study. In such a case the researcher used a recorder to make use of the little time provided. But prior to that the researcher asked for permission from the respondents whether they were comfortable for their voices to be recorded and the five respondents agreed to be recorded. This availed the researcher with detailed information.

With reference to the topic under study that seeks to investigate the experiences of the deaf and blind people living with HIV/AIDS, it necessitated the researcher to emphasize the issue of confidentiality. Because, subjects had a choice to accept to participate in the study, and they were to some extent made aware that they had a right to refuse to answer some questions basing on a feeling that those questions may be intruding in their private realms and may not want to make it public even when the interview consisted of two people (Bryman, 2008, 123). Therefore the researcher assured the respondents that he will maintain maximum confidentiality of the information provided through not recording names and not using the for any other purpose other than academic.

The researcher also made sure that questions asked did not harm the respondent. Given that the topic under study was sensitive, the researcher in one way or the other avoided questions that may upset the respondent or even psychologically harm them.

### **3.12 Plan for dissemination of results**

The results were submitted to the Faculty of Health Sciences of Uganda Martyrs University for the academic award of Master of Public Health-Health Promotion. After final approval, a copy was submitted to the KCCA authorities as one of the key authorities that granted me access to the health facilities within Kampala. The researcher also retained a copy for future reference.

### **Conclusion**

Through the voices of the deaf and blind living with HIV/AIDS, this study highlighted specific challenges this category of the population face while accessing HIV treatment, care and services. This is because these challenges/barriers exist at many levels. While some of them are individual such as limited knowledge about HIV/AIDS virus, others are psychosocial (stigma), economic (poverty) and well as those that are as a result of the health systems like the attitudes and lack of interpreter skills by the health service providers (Tun, et al, 2016). Therefore changes are needed at every level to ensure that the persons with disabilities (deaf and blind in particular) have access to HIV services including provision of accessible services specifically appropriate to the deaf and blind, ensuring collaborative planning and establishment of the HIV/AIDS policies and programs for the people with disabilities and of course making sure that the government trains more health service providers in skills that can address the challenges of the deaf and blind in the hospitals.

## **CHAPTER FOUR**

### **PRESENTATION OF RESULTS**

#### **4.0 Introduction**

This chapter presents the research findings as per the objectives. The results were analyzed and presented according to the specific objectives, that is to say, the lived experiences of the deaf and blind with HIV/AIDS, and the challenges they face as they stay with the Virus. Additionally, this presentation is based from the themes and subthemes that emerged from the questions asked.

In this chapter also, when quoting verbatim, the respondents were described by the sequence in which the interviews were conducted and form of disability, age and gender. “R No 1-DF”. This means respondent number one- who is deaf and is a female or R No 4-BM, meaning respondent number four who is blind and is a male. For purposes of confidentiality the health facilities where the respondents are getting medical care are not disclosed.

#### **4.1 Participants’ characteristics.**

The presentation of the background information of the respondents was considered important as this may provide a basis for the interpretation of the findings as well as essential for drawing conclusions to this study. For example the age, levels of education, economic status and of course their marital status. Six respondents were interviewed with the majority aged between 35-45 years except one respondent who was aged 25 years. Two respondents were female while four were males. Five respondents were married with only one being single.

As far as their education is concerned, it was varying for the six respondents interviewed. One respondent (deaf) had obtained a bachelors degree, one (blind) had completed senior four, one (deaf) studied up to primary six while the rest of the three respondents (1 deaf and 2 blind) did not attain any education at all. Important to note is that all these respondents have averagely lived with HIV for at least eight years.

The respondents in this study were both males and females whereby three were deaf and three blind which made a total of six. Of the six, four were male and two were females and the two females were all deaf , the total of deaf respondents were three and the blind were three as well. Five of the respondents were married and only one male (deaf) respondent was not married yet to him is positive living life style. (Tun et al, 2016,) The educational levels of the six respondents who were interviewed varied. Only one respondent (deaf) had bachelors degree, One respondent (blind) completed senior four, one respondent (deaf) primary six, the other three respondents (1 deaf and 2 blind) did not attain any education at all. All the six respondents have averagely lived with HIV for at least eight years. (Yungungu et al, 2013). None of the respondents had formal employment by the time interviews were conducted. However, some of the respondents had skill related activities on which they earn a living from rather than depending on relatives or begging.

#### **4.2 Lived experiences with access to HIV/AIDS information and services among the deaf or blind people.**

Both deaf and blind respondents described life with both disability and HIV as a double burden. Majority of the participants reported that it is better for one to be blind or deaf without HIV or have HIV alone without being deaf or blind.

It was while interviewing and interacting with the respondents that a number of sub-themes came up which needed the attention of the researcher. The study intended to find out how the deaf and blind have managed to live positively with the virus, and also how they access HIV/AIDS information and services. These issues were translated into three themes that affect the life of the blind and deaf living with HIV/AIDS.

#### **4.2.1 Fear of stigma and discrimination**

Both the blind and deaf respondents complained about being discriminated against not only at the community level but also by their fellow family members. Discrimination manifested itself at the hospitals especially where doctors and nurses do not want to work on them due to the fact that they need a third person to interpret for them. One of the deaf respondents was quoted saying;

*“People like me suffer a lot in the hospital. No doctor is willing to work on you. When they see you approaching them that is when they feel like taking breakfast. Matters become worse when you have no one to talk on your behalf, you can spend the full day in the hospital without being worked on. It hurts, and that’s why when I go there and I see a sign of ignoring me, I go back home, after all I have no hopes of living longer” (R No 1 DF)*

On the other hand, respondents raised the issue of stigma they face during their lifetime of living positively with the virus. Being HIV positive and at the same time blind or deaf, is double stigma. A blind respondent narrated;

*“When people see you in this condition they think no one can admire you, hence cannot contract HIV. But it is not the case, we are also normal human beings with feelings, although the difference comes in that some people take advantage of us. Now for my situation, because am blind, there is a woman in our village who used to help me with household chores. She seduced me and we ended up having sex. After some time, I felt like fever and went to the hospital that is when I was told I was HIV positive. I feel sorry for myself as well” (R No 5 BM)*

While R No 6-DM had this to say about stigmatization from the community;

*There is a neighbor who saw me when I went to get medicines at the window, hohohoho, it seems she published the information in the whole village. Now days I see people looking at me and laughing (tears flow on his face),I feel very bad and lock myself in the house always. I think that when I get out, people will mock me”*

#### **4.2.2 Vulnerability and powerlessness**

Both the blind and deaf people are vulnerable which puts them at a risk of being more powerless. Some people in the community take advantage of their disability. One of the blind male respondents revealed how a female community member and a family friend took advantage of him and ended up getting HIV.

*[.....]I know how I got HIV, some woman in this village took advantage of my blindness, she was a family friend and she used to help me with house work because my wife and children were always away during the day. So she could cook and we eat it is unfortunate she died but she was very beautiful and kind we ended up having sex several times, though she could bring condoms I had no eyes to see if they were expired or not. (R No 2-BM)*

Being powerless means one cannot make his or her own decisions. This came out clearly in the findings where a female deaf respondent is suffering the consequences of the decisions made against her will by her husband and doctors.

*[...] I gave birth to my second born normally and the child was ok, but after one months and a half my child died, the doctor told my husband that it was pneumonia. It hearts me up to now because I would be playing with my two children this one child that remained is lonely but it is unfortunate the doctor put a stick in my arm to stop me from having more children and I know my husband was behind it. But now it is making me to over bleed, blood come out like this brick for three weeks now I want to have more three children at least.(R No 3-DF)*

#### **4.2.3 Internal perceptions about HIV and individual disability**

Under this theme, the following sub themes emerged suicidal following feelings of isolation and hopelessness, death and double burden.

Suicidal feelings were prevalent among the respondents basing on the nature of HIV/AIDS disease as a chronic illness. This made some of the respondents feel hopeless and isolated in the society.

*‘..... I came to know that I was HIV positive in 2015 February and I became so heart broken. Because I am fighting with the stigma of deafness and here come HIV, remember the story of my step mothers that I told you ..... (Tears roll on her face) how will I face my father that am HIV positive? I felt isolated, hopeless to the extent that I thought of committing suicide.’ (R No 1-DF)*

Fear of death was common to majority of the respondents. Bellow, are some of the responses quoted verbatim directly.

*[.....]I have gone through a lot of challenges from the day I got to know that I have HIV yet am blind I already knew I was going to die and that was over ten years ago but here am still leaving. The most challenging part was how I was going to tell my wife that I have HIV, it was a serious battle in my heart and this affected me so much because I had fears that she could leave me alone and take my children with here yet my family has always been my joy. (R No 2-BM)*

Double burden was predominantly experienced by the respondents. To other respondents it was shocking news in their ears and were wondering how they were going to handle the burden of disability and HIV at ago.

*It's when this second wife was pregnant that I came to know that I am HIV positive. She went for Antenatal and when they found her with HIV she was asked to bring her husband. She came and told me I was needed at the hospital but she did not tell about her HIV results I thought maybe since she was in her late 40s there could be a problem with the baby. [...] I tested HIV positive too, this was shocking news to me, because I had a burden of blindness and now I have added another burden of HIV. (R No 4-BM)*

However others did not experience the double burden alone but they also had fears that they might not marry nor have children in future.

*[.....] It was in 2009 when I was diagnosed with HIV, this was very challenging the fact that am blind, I was wondering how I was going to handle the two burdens (blindness and HIV) I was not even married and had no child yet. (R No 5-BM)*

#### **4.2.4 Social support**

Because of their disability situation, they always need someone to help them in their day-to-day life, which has been difficult for them. Respondents reported to have gained hope, happiness and joy in relation to the care and support given to them by their family members as well as medical doctors.

*Am happy that the doctors and nurses at the hospital where I pick my ARVs are my friends. They always consider me first whenever I get to the hospital. They take me through the hospital while holding my hand just in case there is any laboratory test that is needed to be done. (R No 2-BM)*

#### **4.2.5 Access to HIV/AIDS information and services by the deaf and blind**

Different responses were received from the participants as regards the means through which they receive HIV/AIDS information is concerned. The deaf informed the researcher that the only means through which they could access information is through newspapers and billboards. Newspapers are not free of charge while most of the bill boards are located in the City Centre, so it is hard for those who stay in the peripheral areas of Kampala to access such information.

*If am to read about HIV it's only through newspapers.... but the problem is the money to buy them. I can't afford buying them daily...this means that may be once or twice a month...so this means that I sometimes miss some important information (R No 1 DF)*

While the blind respondents interviewed gave radios as the main source of information;

*At least these days there are cheap radios that are affordable, and of course you can tune to the language you better understand. Having bought a radio has helped me know more about HIV/AIDS, and when I started developing the symptoms I knew it was AIDS and had to run to the hospital immediately to be tested and if positive begin medication”(R No 2 BM)*

#### **4.3 Challenges faced by the deaf and blind while accessing HIV/AIDS services and information**

Respondents raised a number of challenges they face while accessing HIV/AIDS information and of course services at the health centers. The researcher developed themes for the different challenges raised. Below they are discussed;

##### **4.3.1 Poverty and lack of support from family members**

Poverty was common among all the six respondents. The respondents attributed poverty to many cases. For example, while taking ARVs, the respondents informed the researcher that they need to eat a balanced diet such as eating a fruit every day, plenty of oral fluids, which is quite expensive. While on the other hand some of the respondents reside far from the medical centers hence need to incur transport costs to reach the hospital.

*“I got to know that I was infected with HIV in 2002, and I have been on treatment since them. Unfortunately my brother who has been taking care of me abandoned me. Life is hard for me that I*



*even lack money for transport to go for treatment. Concerning meals, those I left to God, as I just thank God for even the very little that I get (provided by neighbors)”—R No 6 DM*

Furthermore, the findings revealed that poverty contributed to poor adherence of HIV drugs among respondents.

*[.....] Sometimes i miss my appointments when I have no transport to take me to the hospital. In fact, for the last one and half {1 ½} months I have not been swallowing my ARVs, because my brother who always help me and takes me to the hospital was sick and I was not on good terms with my husband. But now my brother is well and last week he came here and took me to the hospital am swallowing my ARVs now.’-R No 3 DF*

The results revealed for some respondents who were staying with family members to support them, were seen as a burden to them;

*“Like you see am blind, I need to go with someone to the hospital. Days of my appointment reach when everyone at home is busy or even they don’t want to go to the hospital. I either hire someone to take me or I miss the appointment. Being in this condition necessitates you to be with enough support from your family which lacks at times.” (R No 5 BM)*

#### **4.3.2 Attitudes of the health service providers**

Although this was not common among the six respondents interviewed, two of the respondents interviewed had been victims of negative attitude from the nurses where they used to go for treatment. They reported that such attitude prevented them from accessing HIV services and information from hospitals. In fact one of the respondents reported to have missed three months without going for treatment waiting for the change of attitude of the Nurse.

*“I have spent three months without going for treatment because the nurses that work on me are very rude. I am actually waiting for all this time thinking that may be by the time I go back she has been changed to another hospital, or even she has forgotten me and treat me as a first time person to meet. She barcks at you as if you are a child. I even don’t know whether these tablets will work for me because of this time I have spent without swallowing them” (R No 3 DF)*

However this was not the case with the other four respondents. To my personal analysis, this could have a relationship with the level of education because the participants that I interviewed who had achieved some level of education reported a different case. They were treated well regardless of the form of disability. For example a deaf respondent who had obtained a bachelors degree was quoted to have said;

*“To be sincere the health workers treat me very well. They make sure I get everything I need without any difficult” R No 1-DF*

Besides attitudes of the medical personnel, is the factor of lack of special skills to attend to the deaf and blind accessing HIV services at the health centers. Some deaf respondents interviewed reported that most of the nurses that attend to them in the health centers they access HIV services lack sign language skills.

*“I face difficulties in trying to explain the doctors my condition especially when I go alone to the hospital. The nurse that usually attends to me doesn’t know sign language. Whenever I go there alone, once she sees me she begins smiling and disappears. This necessitates me to go along with someone who will help me interpret to her my situation...” (R No 1 DF)*

#### **4.3.3 Lack of confidentiality**

This was commonly raised by the deaf participants especially those who had not obtained any education. For those with literacy skills could read and understand what the doctors wanted to communicate to them. However it was quite challenging for the non-educated as they needed a third person to interpret for them the doctor’s information.

*“It makes me feel small that issues concerning my private life are first explained to someone before I get to know it. This isn’t fair, the government should help us and deploy health workers with special skills to attend to the deaf”(R.No 3 DF)*

#### **4.3.4 Information access barriers**

The means through which the information is delivered to the deaf and blind community is quite challenging. Below is what the respondents revealed to the researcher;

*“I always miss HIV related information which is published in papers because I cannot read and I do not have braille skills. This is among the challenges I am facing as a blind person with HIV, I always have to depend on second hand information unless it is audio message. (R No 4-BM)*

Some other respondents revealed to the researcher to have been given wrong medicines as a result of misdiagnosis.

*“There is a time I went a lone and I had developed diarrhoea but when I tried to explain to the doctor, he showed me a sign that he had understood and he wrote for me medicines to swallow. Reaching at the at medicine window, they gave me small red tablets which I used to take when I was pregnant and I knew they were for improving blood. So this indicated that the doctor perceived me wrong may be he thought I was telling him that I was bleeding. [...] I went back to the doctor and explained more but nothing until they get a telephone contact of my husband from my file and he told them that I have been with diarrhoea for two days. There I was given the right medicine but after some good hours. It is so challenging to be deaf and with HIV which need regular visits to the hospital for the rest of my life”. (R No 3-DF)*

Despite the planned objectives some respondents revealed to have experienced discrimination due to societal beliefs.

*“My parents did not look at me as a useful person simply because of my deafness and to make matters worse a girl child with no mother in the house but rather with step mothers. I went through all that when I was only deaf, but I do not know how it would be if it was like now when I have HIV too”. (R No 1 D F)*

#### **4.4 Summary of key findings**

This study generated a lot of information in relation to living with HIV/AIDS while you are deaf or blind. Key issues which came up basing on the objectives of the study were;

**Objective 1:** The study findings revealed that the deaf or blind people who are living with HIV/AIDS had stigma and discrimination both at community and family levels. The deaf or blind people also had limited access to HIV/AIDS information in the format that suites their disabilities, such as sign language and braille.

**Objective 2:** The study findings also revealed that some deaf or blind people living with HIV/AIDS are still facing negative attitudes from health care providers. However, this was not so common with most of the respondents who were interviewed.

## **CHAPTER FIVE**

### **DISCUSSION OF RESULTS, CONCLUSION AND RECOMMENDATIONS**

#### **5.0 Introduction**

This chapter discusses the findings of the study in relation to other studies conducted by other scholars. Key issues which the study found were discussed in comparison with other studies. In the conclusion section, a summary of key findings were pointed out and appropriate recommendations were made to the responsible authorities.

#### **5.1 Discussion of results**

The study questions and the hermeneutic phenomenological theory guided the study. The themes developed were in one way or the other found to be fitting into hermeneutic phenomenological theory which focuses on the subjective experience of individuals and groups. This probably could be because both the study and the theoretical framework are focusing on human life and how it is lived. However, this Hermeneutic phenomenological theory, gave broader understanding on what it entails to be a deaf or blind person at the same time having HIV. Unlike other studies which focused on HIV/AIDS and disability (Groce, 2006), knowledge and attitudes towards HIV/AIDS among the deaf (Mprah, 2013) and sexual vulnerability and HIV sero prevalence among the deaf (Touko, 2010), this study explained the lived experiences of the deaf or blind people in general in relation to living with HIV/AIDS.

The study discovered that some of the major challenges to access were systemic in nature. Among these include sign language among health care providers, and poor access to health promotional messages related to HIV. Though the deaf benefit from audio visual messages, they lack sign language interpretation and the blind also lack messages in Braille format. This implies that the deaf or blind will always feel left out and vulnerable. Hence, they need support

so that they can easily get accurate, appropriate and timely information. This will help the deaf or blind people living with HIV to make their own decisions and choices for better health.

The theme of fear for stigma and discrimination was in agreement with (Tun et al, 2013,p.3) who revealed in his study, that persons with disabilities experience multiple dimensions. When there is fear among the patients poor health seeking behaviors will emanate and patients will lose confidentiality and trust in health care providers. Hence they will die silently with their AIDS which puts both the individual and the community at a very high increased HIV spread. From the findings three respondents (R No 1 DF, R No 3 BM and R No 5 BM) revealed to have experienced stigmatization and discrimination from both health facilities and the communities. This means that the blind are the most affected with stigma. The findings were found to be line with World Bank, (2010,p.24) which indicated that the blind and deaf people reported discriminatory attitudes from the medical personnel, who instead of speaking to them directly, they would address the personnel accompanying them to the health center. Additionally, Elisabeth (2006,p.34) found out that stigma and discrimination is not only confined to the clinics and hospitals, but also pervades family and the community. This exposes the deaf or blind to vulnerability because it lowers their self-esteem and they will not fit in the society as well.

Social support was also reported as very important in giving hope among the majority of the respondents. It was revealed from the findings that by the virtue of being deaf or blind with HIV but with someone in your life helped the respondents to gain hope, happiness and joy in relation to the care and support given to them by their family members as well as medical doctors. This implies that despite getting medical treatment, the deaf or blind need social support in the HIV-positive living life. Similarly, in relation to the health facility management, there is need to put disability specific social support groups like HIV-Deaf or blind clubs, where

such people can meet and share experiences in a way to support each other like it is for other HIV social support clubs.

The study revealed difficulty in communication modes used by health care workers.(Tun et al, 2016) added more evidence and revealed that the deaf participants felt it was difficult for them to receive counseling and instructions for taking medications, and facilities lacked informational materials in accessible formats. Thus this could lead to extremely negative experiences for the deaf and blind people with HIV as they are trying to live positively. Therefore, counselors and mental health professional with special communication skills focusing the deaf or blind are much needed in health facilities to make HIV/AIDS deaf or blind persons access necessary information. When this is done, the deaf or blind will have their right to privacy and confidentiality protected.

Low levels of income were a common characteristic shared among all the disabled HIV participants. And this somehow negatively affected their eating and transportation costs, hence poor adherence to HIV treatment. It was reported from the findings that some participants missed their appointments to the health centers due to lack of transport. While on the other hand other participants reported feeling they are becoming a burden to their family members, because each hospital visit will need to be accompanied and that means transport for two people. However, most of the participants have started doing small income generating activities like, singing, operating food store, Kick boxing to have their own money and support themselves to relief off the burden from the family members. Therefore contexts of poverty increase the vulnerability of persons with disabilities to HIV/AIDS. However, none of the six participants was getting HIV care from a nearby health facility, though this was attributed to fear of stigma. Health promoters or health care workers need to continuously encourage the deaf or blind HIV clients to accept and be transferred to nearby health care center to reduce on

the transport costs.

Negative attitudes of the health service providers were reported though it was not so common among the six respondents that were interviewed. Two of the respondents interviewed had been victims of negative attitude from the nurses where they go for HIV treatment. They reported that such attitude prevented them from accessing HIV services and information from hospitals. In fact one of the respondents reported to have missed three months without going for treatment waiting for the change of attitude of the Nurse. To my analysis this had connection with low literacy levels, those who had some education did not face this challenge. This implies that, deaf or blind people living with HIV will be unable to speak out strongly about their rights for access to health care services.

Besides negative attitudes of the medical personnel, is the factor of lack of special skills to attend to the deaf and blind accessing HIV services at the health centers. Some deaf respondents interviewed reported that the doctors and nurses that attend to them in the health centers where they access HIV services lack sign language skills. This implies that the deaf and blind people rely on tactile communication, which requires patience and skilled interpreters who are hardly available at clinics and hospitals. Hence the hospital authorities and the government should come up with legal consequences for such professionals who discriminated vulnerable persons.

The deaf people were mostly affected by lack of confidentiality because of illiteracy. This was quite challenging for them as they needed a third person to interpret for them the doctor's information. Some of the respondents reported feeling uncomfortable to find that their private life is first explained to a third party (interpreter) in the hospital. It also violates the ethics of medical practice where confidentiality of HIV test results is a cornerstone among medical ethics recognized as the best practice. It is therefore, of great need for the ministry of health

and policy makers to ensure that all medical workers are equipped with special needs skills like sign language to address these challenges that the deaf people face while seeking medical care.

The study also looked at the information access barriers. It was found out from the study that the means through which the information is reached to the deaf and blind community is quite challenging. The most powerful weapon a man can ever have is information, but it is unfortunate that majority of the deaf or blind people do not easily access this weapon. Inaccessibility of information about HIV and AIDS among the blind or deaf, means that they have limited knowledge on how to live positively with HIV/AIDS. The commonest means that people access HIV/AIDS related information, are the textbooks in print, diagrams, billboards, video shows, newspapers, magazine and television adverts which do not make sense to the blind people. However, the other challenge that came up from the blind respondents none of them had braille skills. This was evidenced from the study findings among the blind respondents who were interviewed where one revealed to have experienced limited access to information because he cannot read and he does not have braille skills. This implies that the blind are powerless hence cannot make right decisions when it comes to their health, which is dangerous to them as individuals and to the community at large as HIV spread may increase.

On the other hand also further, findings revealed that the deaf participants felt it was difficult for them to receive counseling and instructions for taking medications, and facilities lacked informational materials in accessible formats. Also the deaf people depend greatly on visual elements for learning new information. Such as pictures, slides, videos and live presentations used in HIV education as they provide a greater impact on their lives. From my analysis, even the visual information the deaf receive from the above sources is not translated into sign language. From the study findings some of the deaf respondents reported facing challenges in



communication since none of the medical workers know sign language skills. It is very unfortunate, that one of the respondents was misdiagnosed (instead of diarrhea the doctor diagnosed vaginal bleeding) and the client was given medicines for bleeding. This is very dangerous to the deaf one can become dehydrated and die. Therefore, such cases can only be addressed when the medical workers are exposed to special needs skills like sign language.

## **5.2 Conclusions**

Conclusively, the findings of the study revealed that, communication gaps, stigma, poor adherence and limited access to HIV/AIDS related information were most pressing among the deaf or blind people living with HIV/AIDS. This implicated that the respondents were powerless and face discrimination. The study findings also revealed that some of the respondents still lack confidentiality as a result of low education levels.

The overall implications of living with HIV/AIDS have positively influenced the deaf or blind HIV victims. The deaf or blind people living with HIV, their experience have caused positive change which is skills centred as well as income creation activities.

## **5.3 Contributions to the body of knowledge**

This study contributed to the body of knowledge in that, the deaf or blind people living with HIV had their skills improved in income generating activities as well as positive attitude in terms of HIV-positive living. This was done during the time of interviews. They too had the willingness to work in a way of getting financial support for their treatment regardless of the double burden of HIV and blindness/deafness.

## **5.4 Recommendations**

### **5.4.1 Recommendations to the public health promoters**

The deaf or blind need to be empowered through forming their own peer networks with support from partners or relatives, so that they share experiences and strengthen their confidence.

Public health promoters need to advocate and support the deaf or blind people living with HIV/AIDS. This can be in form of free training skills, like sign language or braille which is specifically deaf or blind centered.

Public health promoters should advocate for protection of the deaf/blind people by ensuring that they put to task the responsible health institutions to ensure easy access of health related information to the deaf or blind people.

### **5.4.2 Recommendations to the Ministry of Health**

The ministry of health needs to continue sensitizing the public on HIV/AIDS prevention and positive living but also consider sign language use on TV messages to benefit the deaf and braille in print media to benefit the blind.

The ministry needs to ensure that the health services are easily accessible to the deaf or blind as it is to the rest of the population.

### **5.4.3 Recommendations to other policy makers**

Policy makers need to formulate a policy to include sign language skills on the teaching curriculum in all health training institutions. This would cater for the deaf clients have adequate information in health facilities.

The policy makers need to come up with regulations to cater for the blind clients to access information in audio or Braille formats.

Training programs on sign language and braille skill at community levels need to be done to cater for those deaf or blind who cannot afford to go to formal training schools

### **5.5 Suggestions for further research**

There is need for further research on the attitudes and perceptions of the deaf towards the use of an interpreter when communicating to the health worker. Further research needs to be done use of interpreters does not affect the deaf people but also other people with language barriers.

Further research should be done on the safer sex practices and their applicability among the blind people. Safer sex practices is very wide and it can also benefit other people with other forms of disabilities apart from the deaf.

### **5.6 Limitations of the study**

The researcher encountered the challenge of location the respondents mostly the deaf. The researcher had to first contact the family member of the deaf respondents for appointment. This prolonged the estimated period of data collection because most of the contact persons were not staying with the respondent

Limited access to proper sources of information on HIV/AIDS causes unnecessary vulnerability among the deaf or blind community. This study informed the deaf or blind on how to access the information that benefits them as they are trying to live positively with the virus.

The researcher found challenges while studying the experiences of the deaf, not all the deaf respondents understood the sign language. Thus for those who did not understand the sign language, the sign language interpreter employed gestures skills for better communication.

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## **APPENDIXES:**

### **Appendix I: EKIWANDIIKO KYO KUKIRIZANGANYA**

Amanyagangenze**MUHANGI APOLLO** era ngandimuyizi owe byobulamuokuva mu Uganda

Martyrs

University

e

Nkozi.

Nkolaokunonyerezaokumanyaembeerazabantuabatawuliraobangabamuzibe ate  
ngababeerawonakawukakasilimumumukibugakya Kampala.

Oliwaddembeokwetabamukunonyerezakuno ate  
ngabulikimuekinayogelwakokigyakukumibwangakyakyamanyo.

Wobangaolinaebibuuzobyonaebikwatakukunonyerezakuno,  
oliwaddembeokumbuzaobaokukubakusimueno 0782545414

obakumukutugwayintanetiguno- [muhangi\\_appolo@yahoo.com](mailto:muhangi_appolo@yahoo.com)

Nsimyenyooobuddebwo no kwewayookwetaba mu kunonyereza.

### **OKWATULA KWO'YO EYE'TABYEMU KUNONYEREZA**

Nsomyebyonaebikwatakukunonyereza ate  
nganekigenderelwakyakwokinyonyoddwabalungigyendi.

Ntegeddeekigenderelwakyokunonyereza ate  
ngantegezeddwantiokwetabamusikwabuwazzentindiwaddembeokusalawoobutetabamukunon  
yerezanekitakosankolaganayangeno'munonyereza.

Mbaddeno'mukisaokubuuzaebibuuzono'kudibwaamungabwekyetaagisaokumatiza.Nolwenso  
ngaeyonsaze'wookwetabamu'kunonyereza.

Omukonogwe'yetyemu.....

Omukonogwo'munonyereza.....

**WebaleNyo!!!**

## **Appendix II: Interview guide**

**TOPIC:** A phenomenological study of the lived experiences of the deaf and the blind people living with HIV/AIDS in Kampala.

### **INTERVIEW GUIDING QUESTIONS**

1. Please may you tell me more about your experience of being deaf/blind with HIV/AIDS?
2. Since the time you contracted HIV/AIDS to now when you have some challenges in relation to living with HIV/AIDS how is your life?

<b>ACTIVITY</b>	<b>APRIL/MAY/JUNE</b>	<b>July</b>	<b>Aug</b>	<b>Sep</b>	<b>Oct</b>	<b>Nov</b>	<b>Dec</b>
Developing the research topic							
Research proposal writing							
Pretesting of Interview guides							
Submission of 1st draft of the proposal							
Submission of 2 <sup>nd</sup> draft and final copy of the proposal							
Data collection							
Data analysis							
Report writing							
Report submission 1 <sup>st</sup> draft							
Submission of Second draft							
Submission of final draft and dissemination of results							

**WORK PLAN**

## BUDGET

NO	ITEMS	QUANTITY	UNIT COST	TOTAL COST
<b>A</b>	Stationery			
	Reams	1	18500	18500
	Pens	8	500	4000
	File Folders	2	500	1000
	Flash Disc	1	25000	25000
<b>B</b>	Internet Services		100000	100000
<b>C</b>	Airtime		100000	100000
<b>D</b>	Typing and Printing report	50 pages	1000	50000
<b>E</b>	Photocopying the report	3 copies	100	150000
<b>H</b>	Binding			
	Proposal	3 booklets	15000	45000
	Report	3 booklets	15000	45000
<b>I</b>	Meals			
	Breakfast	7 days	6000 per day	42000
	Lunch	7 days	6500 per day	45500
<b>J</b>	Transport	7 days	50000 per day	350000
	Sign Language Interpreter		500000	500000
<b>K</b>	Miscellaneous		80000	80000
	<b>Grand total</b>			<b>1825000</b>