Deaf People in Western Region, Kenya:

Language, Community and HIV/AIDS

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Declaration of authorship

I, Robert Keatley confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Date: 27th April 2016

Abstract

Kenya is contending with a very serious and shifting HIV/AIDS epidemic with marginalized communities, like the Deaf community, traditionally beyond the reach of public health campaigns remaining very much at risk of infection. Whilst some research has considered the sexual and reproductive health needs of the Deaf community, there is a paucity of information about the various subgroups within the deaf population, particularly those marginalized deaf individuals who are on the fringes of the community.

This study explored how much deaf Kenyans know about HIV/AIDS compared to their hearing compatriots in Western Region, Kenya. Qualitative and quantitative data was collected by means of a survey questionnaire administered through semi-structured interviews from a total sample of 160 people, including 82 deaf and 78 hearing people from five counties in Western Region. Data was analysed by means of theme content analysis (qualitative data) and descriptive statistics (quantitative data). The results showed that there are generally lower levels of awareness and uncertainty of knowledge about HIV transmission and HIV prevention in the deaf population as compared to the hearing community with isolated deaf individuals having less awareness and knowledge compared to their deaf compatriots living in urban areas or as part of a Deaf community.

This study has the potential to make a valuable contribution to how people view deafness in developing countries. Too often, the assumption is that deaf people are a homogenous group, conversant with local sign language and Deaf culture. However, this study found that whilst deaf people may be an at risk group, isolated homesigners are a sub-group who appear to have less language and information about HIV/AIDS and this fact may be putting them at greater risk of HIV infection, and thereby making them even more at risk than an already 'at risk' group.

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral Drug
ASL	American Sign Language
AU	African Union
AUB	African Union of the Blind
CBO	Community Based Organisation
CBS	Central Bureau of Statistics
CDC	Centers for Disease Control & Prevention
CEDAW	Convention on the Elimination of all forms of Discrimination Against Women
CODA	Child of a Deaf Adult
CRC	Convention on the Rights of the Child
CSDH	Commission on the Social Determinants of Health
CSW	Commercial Sex Worker
DPO	Disabled Persons Organisation
DHS	Demographic and Health Survey
GDP	Gross Domestic Product
GoK	Government of Kenya
GP	General Practioner
HCT	HIV Counselling and Testing
HI	Handicap International
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug User
ILO	International Labour Office
IPU	Inter-Parliamentary Union

KASF	Kenya AIDS Strategic Framework
KNAD	Kenya National Association of the Deaf
KNADWS	Kenya National Association of Deaf Women Section
KNADYS	Kenya National Association of Deaf Youth Section
KNASP	Kenya National AIDS Strategic Plan
KNBS	Kenya National Bureau of Statistics
KNCST	Kenya National Council for Science and Technology
KSL	Kenyan Sign Language
KU	Kenyatta University
LCD	Leonard Cheshire Disability
LVCT	Liverpool VCT Care and Treatment
MDG	Millennium Development Goal
MoE	Ministry of Education
MoH	Ministry of Health
MSM	Men Who Have Sex With Men
MTCT	Mother to child transmission [of HIV]
NACC	National AIDS Control Council
NASCOP	National AIDS & STI Control Programme
NGO	Non-Governmental Organisation
NHS	National Health Service
NSP	National Strategic Plan
PEP	Post Exposure Prophylaxis
PEPFAR	The President's Emergency Plan for AIDS Relief
PHC	Primary Health Care
PLWA	Person Living with HIV/AIDS
PWD	Person with Disability

SDH	Social Determinant of Health
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNCRPD	United Nations Convention on Persons with Disability
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
VCT	Voluntary HIV Counselling and Testing
VSO	Voluntary Service Overseas
WFD	World Federation of the Deaf
WHO	World Health Organisation

Glossary

D/deaf

Woodward (1972) established today's convention that is prevalent in most of the literature – and used in this thesis - whereby the upper - or lowercase letter D/d is used to classify the status of D/deaf people. 'Deaf' people are those who identify themselves as members of the Deaf community, communicate in sign language, and regard themselves as culturally Deaf; whereas 'deaf' people are those who do not sign and regard themselves as having a hearing impairment and part of the mainstream hearing society.

To avoid any confusion regarding the precise hearing status of someone - for purposes of this study, a deaf person was defined anyone who was profoundly deaf or who used any form of sign language to communicate.

Deaf community

Woll & Ladd (2011) note that it is not always possible to define the boundaries of Deaf communities; however, it is – they suggest - broadly understood to be comprised of those deaf people who use a sign language. For the purposes of the discussion in this thesis, I have adopted this definition of the term.

Acknowledgements

Chapter 1   Introduction

1.1   Background

In 2008, having worked in adult education and public health – and specifically on HIV/AIDS and marginalized groups - for nearly two decades in eastern and southern Africa, I took up a position as a voluntary service overseas (VSO) volunteer at a Kenyan non-governmental organization (NGO), Liverpool VCT Care and Treatment (LVCT) Health, to support their Deaf programme expand to include a wider disability focus. It was in this capacity that I was introduced to the Deaf community. I took Kenya Sign Language (KSL) lessons at the University of Nairobi and qualified as a KSL interpreter. Whilst at LVCT Health, I also qualified as a HIV counselling and testing provider. During this time, I had the opportunity to combine both skills to counsel and test deaf Kenyans for HIV. I met some deaf people who were very proficient in signing and with whom communication was easy. However, there were others with whom communication was much more difficult. This experience stirred an interest in me to consider whether there were some people in the deaf population that had possibly been left behind in terms of HIV/AIDS education and service provision because of the communication barriers they faced.

It was whilst undertaking fieldwork for this study that the reality and impact of communication barriers hit me. On one particular day in the early stages of data collection for this study, a man named George had come to meet us in Kisumu. It was a hot September day and we were about to start our investigation of HIV/AIDS with the Deaf community. George was a Deaf man who had responded to the Deaf Association's call for participants in our study. He had come forward to be interviewed. What George told me during our interview shocked me to the core. During this whole study, I have not really been able to get what George told me out of my mind. His words have kept me going, kept me motivated and given me the strength to keep going when at times I have felt tired and questioned my resilience and energy to see it through. In exploring the situation of HIV/AIDS in his region, George said:

'There is something out there killing us!'

During the interview, it became clear that George did not have much information about HIV/AIDS. For sure he had lived through and seen the destruction and devastation that HIV/AIDS had delivered to communities in this part of East Africa. However, he did not seem to have the information or details about the epidemic and what had been going on around him to fully understand and answer the questions we put to him.

HIV/AIDS first appeared in Kenya in 1984 (NACC, 2014a). If one considers that HIV/AIDS has been in Kenya for at least 30 years and there have been billions of Kenyan shillings[1] poured into massive education, prevention and treatment campaigns, it is hard to justify that there could be a someone like George – or a section of the community - who may not have enough information about the disease to be live safely and well. At the end of 2014, Kenya's adult prevalence rate was 5.3% with 1.2 million Kenyans living with HIV (UNAIDS, 2016). Current surveillance data suggests that the adult HIV prevalence rate in the country is stabilizing (NACC, 2014a) with some marginalized groups within the population showing much higher rates of infection – notably CSWs, MSM and IDUs.

There is a general paucity of information regarding the sexual and reproductive health (SRH) health needs of the deaf people in Africa. Where studies exist, most have engaged with signing deaf people who are easiest to reach in special schools for the Deaf, capital cities or more urban areas (Groce et al, 2006; Groce, Yousafzai & Van Der Maas, 2007; Enwereji & Enwereji, 2008; and De Andrade & Baloyi, 2010). This study, however, aims to understand the nature and extent of HIV/AIDS knowledge of those harder-to-reach deaf people who reside in more isolated and rural areas, and specifically in the Western Region of Kenya that has been so hard hit by the HIV pandemic. The following research question will be explored:

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[1] The 5 August 2015 exchange rates for the Kenyan shilling were: 1 US$ = 101 Ksh; and 1 GB£ = 157 Ksh

- How much do deaf Kenyans (aged 18-35) know about HIV/AIDS compared to their hearing compatriots in Western Region, Kenya?

This study is not a prevalence study and no participants will be asked about their status.

To address the above question, I travelled to Kenya four times over four years. I met and interviewed 78 hearing and 82 deaf individuals. A questionnaire (Appendix 3) was developed and administered during semi-structured interviews. I will argue in the course of this thesis that providing HIV/AIDS information and services for deaf people is far more complex than is being discussed in the literature and the mechanisms needed to ensure that this population is sufficiently equipped to protect itself from infection is more diverse than is currently considered, even when there is an acknowledgement that deaf populations need special attention. This argument, I suggest, could be extrapolated and applicable to all groups of PWD.

1.2 Structure of the thesis

This thesis comprises seven chapters. Chapter 1 introduces the study and describes the overview and structure of the thesis.

Chapter Two presents disability, deafness and HIV/AIDS from a global and Kenyan perspective. Estimates from two Kenyan population censuses - the National Survey for People with Disability (Government of Kenya/Kenya National Coordinating Agency for Population and Development, 2008), and the Population and Housing Census (Government of Kenya/Kenya Bureau of Statistics, 2010) - are provided to set the context and possible extent and distribution of hearing impairment in the country. Data relating to HIV/AIDS are given to establish the context within which this study was undertaken. The Kenya AIDS Strategic Framework (KASF) 2014/15 – 2018/19 is presented (NACC, 2014b) and outlines the Government of Kenya's (GoK) commitment to

reach key and vulnerable populations, including – any as yet - unidentified marginalized and vulnerable groups in the country.

A discussion of social determinants of health (SDH) - including the structural and proximal determinants - and the appropriateness of grounding this study in the SDH framework is developed in Chapter 3. This framework is consistent with the social model of disability that views disability and health outcomes in a broad and holistic way that encompasses the environment and society in which a person lives. The GoK has made some significant steps to address some of the structural determinants of health over the last decade and has included ratification of the United Nations Convention on the Rights of Persons with Disability (UNCRPD), promulgation of a new Constitution and enactment of the Persons with Disability Act 2003. Evidence from the review of available literature that is explored in Chapter 3 confirms that disabled and deaf people have less awareness and knowledge about HIV/AIDS than their non-disabled hearing compatriots, and this lack of information is putting them at risk of infection. However, there is a paucity of information that explores the subgroups within the deaf population. This aims, objectives and research question for the study are presented as well as a reflection on my background and experience in Kenya that has enabled me to undertake this investigation.

The research methodology is outlined in Chapter 4. Grounded theory has been selected and adopted as the most appropriate research methodology to address the aims, objectives and research question for this investigation. The research design for this study is essentially qualitative with some quantitative components contained in the semi-structured questionnaire. A detailed account of the research process, including components before, during and after data collection is given in this chapter. Characteristics of study participants are also reported.

Findings in relation to awareness and knowledge (transmission and prevention) of HIV/AIDS are reported in Chapter 5. The results are presented to each of the three questions that participants were asked, namely: (i) Have you

heard of HIV/AIDS?; (ii) Which of the following are ways that somebody can get AIDS?; and (iii) How can HIV infection be prevented. To explore the data to the optimum, the results to each of these questions are presented by hearing status, gender and various geographical areas.

Chapter 6 explores language, community and HIV/AIDS. The discussion outlines the language options and communication barriers that deaf people face with specific examples and reference to family and engagement with the health service. Once an understanding of the communication barriers and language options has been established, the discussion considers the resultant feelings of isolation and loneliness that many deaf people experience in life. The conclusion that emerges from the discussion is that the focus of any response should primarily be on the development of language as clearly the foundation for bonding and support with friends and family is dependent upon communication. Furthermore, with language proficiency, deaf people will also be able to get the information, develop the skills and be able to access the services required to protect themselves from HIV infection.

Chapter 7 opens by with a discussion of key findings from this study. The first is confirmation that the deaf people have less awareness and knowledge about HIV/AIDS than the hearing community; and second, that there are different subgroups within the deaf population that have varying levels of awareness and knowledge about the disease with isolated, non-signing proficient deaf individuals the most at risk group. The 2008-09 Demographic and Health Survey (DHS) claim (GoK/Kenya National Bureau of Statistics & ICF Macro, 2010) that there is near universal awareness of HIV/AIDS in the country can clearly be challenged as evidence from this study suggests that only 80% of the deaf participants had heard of the disease. The GoK, through the KASF 2014/15 – 2018/19, has pledged to address the needs of any emerging marginalized or vulnerable group. This study shows that deaf people comprise one of these groups. However, it also suggests that deaf people are not a homogenous group of signing proficient urban-based Deaf individuals who are engaged in Deaf culture, but also comprised of isolated deaf people who functionally have very

limited or no language proficiency. The needs of the deaf population are therefore very varied and complex. The response therefore will need to be guided by further research and discussion, some suggested areas of which are presented in this final chapter.

Chapter 2 Understanding disability & HIV/AIDS in the global and Kenyan context

2.1 Introduction

Kenya is located in Eastern Africa and has more than 40 ethnic groups. Each ethnic community has its own language, traditions, cultural values and practices. Whilst the Deaf community comprises people from each of the country's 40 ethnic groups, there are linguistic and cultural distinctions that separate the Deaf community from the hearing majority; and subgroups exist within the Deaf community based on a person's linguistic ability, educational background and where in the country they are from.

This chapter explores HIV/AIDS, disability and deafness from a global and Kenyan perspective to establish the context in which the study is set. Review of available data suggests that very large amounts of money have been spent on HIV/AIDS. Whilst some surveys - notably the 2008-09 Demographic and Health Survey (DHS) - inform us that there is almost universal awareness of HIV/AIDS (99% of women, 100% men) in Kenya (Government of Kenya/Kenya National Bureau of Statistics & ICF Macro, 2010); others suggest that this may not be entirely true, as people with disabilities (PWDs) - and particularly the Deaf Community in Kenya - falling short. Girois[2], cited by Hanass-Hancock & Satande (2010), found only 80% of deaf respondents in her survey had heard of HIV/AIDS. There is a GoK commitment, contained in KASF 2014/15 – 2018/19 to meet the needs of any community in the country that does not have universal access to HIV prevention, treatment and care services (NACC, 2014b). This study explores key issues and challenges related to HIV/AIDS currently facing the different subgroups within the deaf population in Western region, Kenya and to identify any particular group(s) within the population that need special attention. The study does not however seek to determine the prevalence rate of HIV and no participant in this study was asked about their HIV status.

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[2] Attempts to locate the original study have not been successful. However, I will endeavour to locate and review the original source before publication of this study.

2.2 Disability

In order to establish the research background and context, it is important to consider disability from a global and Kenyan perspective.

2.2.1 Global disability

Discussion and controversy about numbers of PWD is not a new debate (Yeo & Moore, 2003). Numbers are contentious because defining and collecting data at the individual and community level is an evolving discipline, and central to any discussion about disability are resources. Current work underway through the Washington Group[3], as well as through major organisations such as WHO and UNICEF, will increasingly allow us to better define and identify disability in the field (CDC, 2009). Currently, however, there is still on-going debate about the specific methodologies to be used (WHO, 2011).

Riddell (2010) acknowledges that it is very difficult to get precise numbers for PWDs in censuses. There can be issues about definition of terms and of family members often hiding disabled family members from census takers (Yeo & Moore, 2003). Socio-cultural values are known to play a major role in determining who is identified (by self, family and others) as 'disabled' and what is counted as an 'impairment' (Johansson, 1991; Turmusani, 1999).

Evidence also informs us that how someone is asked about disability can influence the answer that they give. Riddell (2010) illustrates this point by highlighting the experience of census taking in Zambia, where, in response to a direct question in the 1990 Census about whether someone in the home was 'blind, deaf, dumb' and so forth, prevalence was established to be 0.9%. However, the 2006 Living Conditions Survey asked people a less direct question about whether they had 'difficulties in seeing, hearing, walking and remembering' and the resulting prevalence was 13.3%. Under reporting of

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[3] The Washington Group on Disability Statistics was formed as a result of the United Nations International Seminar on Measurement of Disability that took place in New York in June 2001. The Group comprises representatives from national statistical agencies that address selected problems in disability survey measurement and methodology to facilitate the comparison of data on disability cross-nationally (CDC, 2009).

numbers becomes significant if the impact of doing so means that less attention, and therefore policy, programme and resource focus on this population.

WHO (2011) estimates that 15% of the world's population, or more than 1 billion people, in the world has some form of disability significant enough to affect their day-to-day lives. Women are disproportionately reported to be disabled with 20% of women and 12% of men living with a disability. WHO (2011) also acknowledges that accurate data on disability are lacking for developing countries such as Kenya.

2.2.2 Disability in Kenya

As population statistics for numbers of PWD are contentious, presentation of findings from 2 current information sources are given. The first, the 2008 National Survey for Persons with Disability; and the second, the 2009 Kenyan Population and Housing Census.

The 2009 Kenya Population and Housing Census found the country's population to be 38.6 million (Government of Kenya/Kenya National Bureau of Statistics, 2010). One question in the census related to disability, and it found that 1.3 million people, or 3.5% of the population had a disability. However, the earlier 2008 Kenya National Survey for Persons with Disability estimated 4.6% of the population had a disability (Government of Kenya/Kenya National Coordinating Agency for Population and Development, 2008).

Table 2.1:   Prevalence rates of disability in Kenya

Data Source	Prevalence Rate (%)	Number (million)
National Survey for PWD (GoK/KNCAPD 2008)	4.6	1.8
Population & Housing Census (GoK/KNBS 2010)	3.5	1.3

Adapted from the National Survey for People with Disability, (Government of Kenya/Kenya National Coordinating Agency for Population and Development, 2008, p.8); and the Population and Housing Census (Government of Kenya/Kenya National Bureau of Statistics, 2010, p.399).

Applying the WHO estimate of 15% of the world's population having some form of disability against the 38.6 million population figure from the 2009 Kenya Population and Housing Census, a figure of 5.8 million Kenyans is produced. Whilst this figure may overestimate the number of PWD, evidence from the literature suggests that census figures often yield an underestimate (Riddell, 2010). Therefore, we can conclude that the precise figure for the number of PWD in Kenya is likely to be somewhere between the two survey estimates of 1.5 million and the WHO estimate of 5.8 million. Whatever the exact number is, the point is that there is a sizeable population of PWD in Kenya.

There does seem to be a general consensus that the majority of Kenyans, including the majority of PWD, live in rural areas. The 2009 Kenya Population and Housing Census discovered that approximately 68% of Kenyans, live in rural areas (Government of Kenya/Kenya National Bureau of Statistics, 2010); and the National Survey for PWD informed us that a higher percentage of PWD, estimated at as high as 80%, live in rural areas of the country (Government of Kenya/Kenya National Coordinating Agency for Population and Development, 2008).

2.3 Deafness

2.3.1 Global deafness

The World Federation of the Deaf (WFD) estimates that there are approximately 70 million deaf people in the world (WFD, 2015). It should, however, be noted that this figure includes those individuals who have congenital and acquired deafness. WHO also informs us that 80% of deaf people in the world live in a developing country (WHO, 2006). This, they continue, is because factors such as disease, accidents and environmental influences cause at least 50% of all hearing loss and these are more likely to occur in developing countries.

Poorer countries in the developing world are more likely to have a higher proportion of deaf people in their population than richer countries. Furthermore within a country, poorer people are more likely to be deaf than their more affluent neighbours. The implication from these facts and analysis is that a disproportionate number of deaf people in the world live in rural areas in developing countries, and they live in poverty.

The poor suffer more from hearing impairment because they cannot afford the preventive and routine care to avoid hearing loss such as antibiotics for childhood otitis media. Once a hearing loss has occurred, they often do not have access to ear and hearing care services and are unable to obtain suitable hearing aids to make the impairment manageable. Production of hearing aids meets less than 10% of global need. In developing countries, fewer than 1 out of 40 people who need a hearing aid have one. Where hearing aids and services are available they are generally expensive and often inappropriate for developing communities (WHO, 2005).

The richer industrialised countries of the North have a more developed infrastructure to cope with the challenges of hearing impairment. The less well off countries of the South face a much larger social and economic burden of the impact of hearing loss on individuals, families, communities and countries.

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Deafness is a significant issue in much of the developing world because health systems are often not adequately staffed or equipped. WHO (2005) claim that half of all cases of deafness and hearing impairment are avoidable through primary prevention and a large percentage can be treated through early diagnosis and suitable management. The consequence of weak health systems is that people with hearing problems are not given the care they need at the right time with the result that hearing impairment or a more profound hearing loss is the consequence – for example, Stone (1999) claims that 40% of hearing loss in children in developing countries could be preventable by early identification.

Schirmer (2001) suggests that the road to diagnosis can be a long one. In children, the earlier a hearing loss is identified, the more quickly the child and family can receive early intervention services. Sebald (2008) explains how early intervention reduces stress on families and facilitates communication within the family which is beneficial to the child's development. Although the technology is available in industrialised countries for identifying hearing loss virtually at birth, many hearing losses still go undetected during infancy. The result is that diagnosis can be late. Meadow-Orlans and her colleagues found that a survey of parents of preschool deaf children in North America had a confirmed diagnosis at a mean age of 14.5 months (Meadow-Orlans et al, 1997). This situation is often much more alarming in developing countries. Olusanya, Luxon & Wirz (2005) found that the age of detection for hearing impairment was unacceptably high, up to 5 years in some cases. This was largely traced to the inexperience of most physicians who downplayed parental concern and suggested that babies were too young to be tested or gave false assurance of normal hearing.

The conclusion from this section is that the prevention, diagnosis and management of hearing loss in the global South is further complicated by weak health systems that has resulted in a greater number of people being affected by hearing impairment.

2.3.2 Deafness in Kenya

Deaf population

Young & Temple (2014) inform us that the numbers of deaf people in many developing countries is not known. In some instances, they suggest, the reason is that the population cannot be, or is yet to be, accurately defined or counted. In this section, I present the possible range of numbers of deaf and hearing-impaired people in Kenya.

In 1996, it was estimated that the rate of acquired deafness in Kenya ranged from 2-10% of the population, and largely due to preventable causes such as otitis media, malaria, meningitis and the use of ototoxic antibiotics (Smith et al., 1996). More recently, in the 2008 Kenya National Survey for Persons with Disability Report, it was found that 12% of disabilities are hearing-related (Government of Kenya/Kenya National Coordinating Agency for Population and Development, 2008). Unfortunately, neither of these figures provides us with a precise number of pre-lingually (congenital or early-onset) deaf Kenyans.

Best estimates of congenital and early-onset permanent childhood deafness in countries of the developing world suggest that no fewer than 6 per 1,000 live births (Olusanya & Newton, 2007), but individual country estimates vary (Leigh, Newall & Newall, 2010). The 2009 Kenya Population and Housing Census informs us that Kenya's population is 38.6 million (Government of Kenya/Kenya National Bureau of Statistics, 2010). Applying the 6 per 1,000 live births to this figure produces an estimate of 231,600 deaf people.

Some GoK data relates to the numbers of people who are hearing impaired. Applying the 12% of disabilities being hearing-related percentage against the National Survey's estimate of 1.8 million PWD in the country, it can be suggested that 216,000 Kenyans have hearing impairment. The figures produced from the Population and Housing Census concluded a number with a number of 187,818.

Table 2.2:   Numbers of people with hearing impairment in Kenya

Data Source	Number of PWD (Million)	Number of Hearing Impaired (Thousand)
National Survey for PWD (GoK/KNCAPD 2008)	1.8	216
Population & Housing Census (GoK/KNBS 2010)	1.3	188

Adapted from the National Survey for People with Disability, (Government of Kenya/Kenya National Coordinating Agency for Population and Development, 2008, p.8); and Population and Housing Census, (Government of Kenya/Kenya Bureau of Statistics, 2010, p.399).

Considering that 80% of PWD – including 80% of the hearing-impaired and deaf people in Kenya – might live in rural areas (Government of Kenya/Kenya National Coordinating Agency for Population and Development, 2008), and applying it to the National Survey figure of 216,000 hearing impaired Kenyans, 173,000 would be estimated to live in rural areas. Similarly, applying this 80% estimate to the Population and Housing Census estimate of 187,818 hearing impaired Kenyans, approximately 150,000 hearing impaired people would live in rural areas of the country.

The conclusion from the presentation of the numbers in this section is that precise numbers are hard to confirm. However, it is clear that the number of both deaf and hearing impaired Kenyans is sizeable and should not be ignored.

Organisation

The Kenya National Association of the Deaf (KNAD) was established and formed by the Deaf community in 1987. The Association is an ordinary member of the WFD, and was created to represent deaf Kenyans in national and international matters. KNAD operates programmes that promote and address the education, health and cultural needs of deaf Kenyans. To achieve this, KNAD has 47 branch

associations in the country that are responsible for reaching out to urban and rural communities in their areas.

KNAD suggests that the 2 surveys underestimate the numbers of deaf people in the country. During the early phase of this project, KNAD Senior Management informed me that they use a range of numbers to estimate the deaf and hard-of-hearing population of between 500-800,000 people. The figure for deaf and hard-of-hearing people living in rural areas, calculated using the KNAD estimate would be considerably higher than either of the two surveys, at in excess of 400,000 people.

Cognizant of the varying needs within the deaf population, two new sections were created within KNAD in 2012. The first, the Kenya National Association of Deaf Women Section (KNADWS) was established to advocate for the rights and empowerment of deaf girls and women in Kenya. The second, the Kenya National Association of Deaf Youth Section (KNADYS) was formed to champion the rights of deaf youth and to provide and prepare them with leadership skills.

Kenyan sign language & culture

KSL is the sign language used by the Deaf community in Kenya.

The Kenyan Constitution recognizes culture as the foundation of the nation. Article 11(2) provides that 'the State shall – (a) promote all forms of national and cultural expression through literature, the arts, traditional celebrations, science, communication, information, mass media, publications, libraries and other cultural heritage' (Government of Kenya, 2010, p.16). From this all-encompassing perspective, it can be assumed that Kenyan Deaf culture is part of the diverse cultural composition in Kenya to which this Article refers and commits the State to promote.

Since language is an important component of culture, it is necessary to consider how the Constitution addresses language, and specifically KSL. Under Article 7(3) 'the State shall…. (b) promote the development of use and indigenous

languages, Kenyan Sign Language, braille and other communication formats and technologies accessible to PWD' (Government of Kenya, 2010, p.14). The Constitution acknowledges KSL as a national language in Article 120(2), and grants it one of the official languages of Parliament under Article 120(1).

It is estimated that there are 340,000 users of KSL in Kenya (Lewis, Simons & Fennig, 2015). Lewis, Simons & Fennig (2015) do not estimate the population of deaf people in Kenya so predictions of numbers of deaf people that do not use KSL are unable to be made. However, they do note that usage of the language is increasing. There are some important provisions in the Constitution that are applicable to deaf people who do not know KSL. These Articles illustrate the GoK's commitment to supporting deaf Kenyans, and promoting their culture and language.

Article 44 states, '(1) Every person has the right to use the language, and to participate in the cultural life, of the person's choice. (2) A person belonging to a cultural or linguistic community has the right, with other members of that community – (a) to enjoy the person's culture and use the person's language' (Government of Kenya, 2010, p.31). It would therefore seem that for deaf people who are denied the opportunity to integrate into Deaf society and participate in Deaf culture, their rights under Article 44 are being violated.

The Constitution addresses the rights of deaf people to communication. Provision under Article 54 declares 'a person with any disability is entitled – (d) to use sign language, braille or other appropriate means of communication' (Government of Kenya, 2010, p.37). Therefore, this right to communication would be violated if a deaf person is denied an opportunity to acquire and learn sign language.

Under Article 56, there is provision to address situations where deaf people are denied the opportunity to engage in Deaf culture and learn sign language: 'the State shall put in place affirmative action programmes designed to ensure that minorities and marginalized groups – (d) develop their cultural values,

languages and practices' (Government of Kenya, 2010, p.38). There is therefore scope in this provision to address the language and cultural needs of deaf people who have been denied access to language because of their isolation from the Deaf community.

There is one other provision in the Constitution that is applicable to this discussion and concerns deaf people who are not signing-proficient. Article 31(1) provides that 'every person has the right to freedom of expression, which includes – (a) freedom to seek, receive or impart information or ideas' (Government of Kenya, 2010: p.25). Interpreting this provision widely, it could also include those deaf people who have not had the opportunity to learn sign and engage with other deaf people with whom they can communicate, develop language and express themselves.

There are some KSL dialect differences according to where you live in the country – for example, between Kisumu (Western Region), Nairobi (Central) and Mombasa (Coast). A manual alphabet exists, mainly developed from the American Sign Language (ASL).

The first dictionary for KSL was written in 1988 (Schmaling, 2012). Since then, there have been a number of additional resources published, including a manual of SRH signs to specifically to standardize signs and help address the challenges of communicating about SRH issues, including HIV/AIDS.

Interpreters are rarely available and usually unqualified due to a lack of interpreter training programmes and weak certification process.

Deaf education

Education for deaf children in Kenya is offered in special residential schools, special units attached to regular schools and in integrated settings. However, the exact number of institutions with deaf learners is not known.

Historically, the first Deaf schools were established in Kenya in the late 1950s and early 1960s. The teaching staff in these schools for the Deaf rarely included a deaf person. In the 1990s, the Ministry of Education (MoE) launched a programme to train and get deaf teachers into Deaf schools. The Special Needs Education Policy 2009 acknowledges that the primary or first language of deaf children in Kenya is KSL, and it promotes the development and use of KSL within and outside the school environment (Government of Kenya/Ministry of Education, 2009). However, Kimani (2012) challenges us to consider that KSL may not be developed enough to be able to express all the concepts used in education, and in particular, she cites subjects such as science and mathematics as being particular examples.

Evidence from the literature informs us that the majority of children with special needs and disabilities in Kenya, including deaf children, do not access educational services (Government of Kenya/Ministry of Education, 2009). However, the numbers of children in this vulnerable group of children with special needs that are receiving an education is improving – for example, in 1999, 22,000 learners with special needs and disabilities were enrolled in primary and secondary schools; and this doubled to 45,000 in 2008. Part of this expansion in numbers is attributed to the introduction of free primary education in 2003 (Government of Kenya/Ministry of Education, 2009).

Currently, KNAD Senior Management estimates that there are 45 special schools for the Deaf that are educating deaf children throughout Kenya. Assuming that there are several hundred deaf children in each school, it is possible to conclude that whilst thousands of deaf children are receiving an education through this system, there must be many hundreds, and possibly thousands, of deaf children who do not have access to any form of regular structured formal education that also exposes them to KSL and Deaf culture. Furthermore, it should be noted that failure to access an education, and specifically learn to read and write means that a consequence of being illiterate is that a person will not be able to fingerspell and communicate using the fingerspelling alphabet.

2.4   HIV/AIDS

In order to explore HIV/AIDS with the hearing and deaf populations in Western Region, Kenya, it is important to first set the context of HIV/AIDS, globally and nationally.

2.4.1   Global HIV/AIDS

Sub-Saharan Africa bears an inordinate share of the global HIV burden. In 2013, there were 35 million people living with HIV/AIDS (PLWA) in the world (UNAIDS, 2013). Sub-Saharan Africa is reported as having 24.7 million PLWA or 71% of the global total (UNAIDS, 2013). Although the rate of new infections has decreased, the total number of people living with HIV continues to rise with more women than men infected in sub-Saharan Africa (UNAIDS, 2010).

2.4.2   HIV/AIDS in Kenya

HIV/AIDS first appeared in Kenya in 1984 (NACC, 2014a). Fifteen years after it was first identified, and in 1999, Kenya's then President Daniel Arap Moi, declared it a national disaster and public health emergency. He is recorded as saying:

> 'AIDS is not just a serious threat to our social and economic development; it is a threat to our very existence… AIDS has reduced many families to the status of beggars… no family in Kenya remains untouched by the suffering and death caused by AIDS… the real solution to the spread of AIDS lies with each and every one of us. AIDS is a war that we must win.' (Ndeti, 2011, p.4).

At the same time as the Presidential declaration of HIV/AIDS as a national emergency, the National AIDS Control Council (NACC), under the Ministry of Health (MoH) was established to guide and steer the national response to HIV/AIDS. Together with the National AIDS & STI Control Programme (NASCOP) and other partners, NACC has overseen the development of 4 Kenya National AIDS Strategic Plans (KNASP): KNASP I, 2000-2005; KNASP II, 2005/6-2009; KNASP, 2009/10-2012/13; and the KASF 2014/15-2018/19. Each

strategic plan has prioritized a component on HIV prevention with varying emphasis. The current KASF 2014/15 – 2018 has the overall goal of universal access to comprehensive HIV prevention, treatment and care.

In 2014, the adult prevalence rate was 5.3%, with 1.2 million Kenyans living with HIV (UNAIDS, 2016). HIV prevalence rates vary widely in the country, from 15.1% in Nyanza Region to 2.1% in Eastern North Region (NACC & NASCOP, 2013). There are a number of contributing factors that could explain the regional variance in HIV prevalence rates; however, perhaps of greatest significance in this instance is the fact that Eastern North Region has been isolated from the rest of the country due to its harsh environment and the general insecurity in the region. Furthermore, there can be significant differences within regions – for example, in Western Region in 2012, Nyanza's Homa Bay County was reported to have an adult HIV prevalence of 27.1%, as compared to 18.7%, 70 miles away in Kisumu City (NACC, 2014a).

Despite this, there appears to be an apparent levelling off of the HIV adult prevalence rate in Kenya in recent years; however, vulnerable or marginalised groups at the fringes of society are seeing prevalence rates at very high levels. Key populations identified by the Mode of Transmission Survey 2008, and cited by NACC (2014a, 2014b) include sex workers and their clients, men having sex with men (MSM), and people who inject drugs (IDUs).

Figure 2.1: **HIV prevalence among general and key populations in Kenya (NACC 2014a, p.4)**
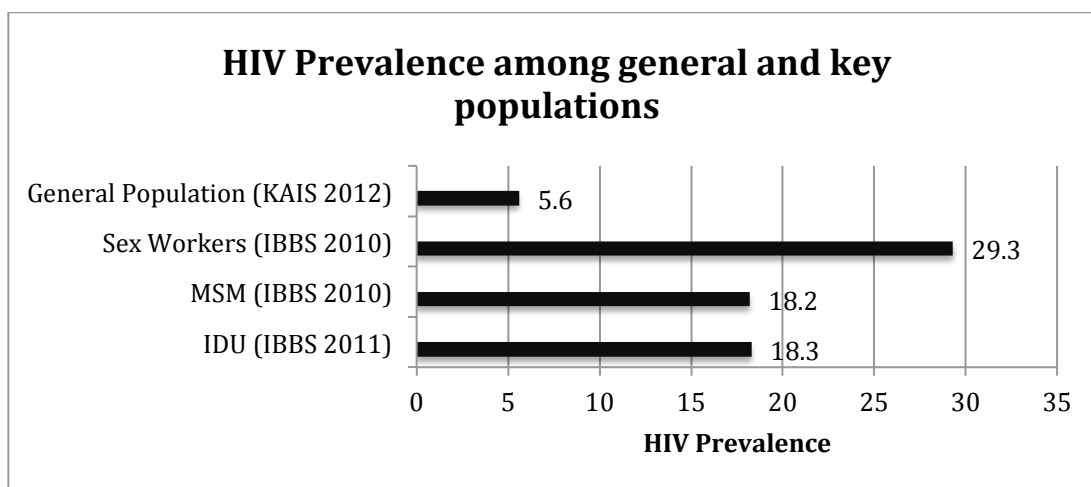
Recent surveys show that prevalence rates in some concentrated groups in the country may be higher than the figures presented above – for example, one study of MSM in Mombasa, gave a rate of 43% (NACC & NASCOP, 2012); and (iii) a study of IDUs in 5 urban areas (Mombasa, Malindi, Nairobi, Nakuru and Kisumu) 42% (Ndetei et al., 2006).

The annual number of new infections is roughly one-third the number recorded in 1993, when Kenya's epidemic peaked (Government of Kenya/Kenya National Bureau of Statistics, 2010). However, the number of new infections remains high, with an estimated 100,000 Kenyans becoming infected in 2013 (NACC, 2014a).

Kenya is recorded as having the third highest number of PLWA in sub-Saharan Africa (Government of Kenya/Kenya National Bureau of Statistics, 2010) with women currently representing 57% of this PLWA population (NACC, 2014a). Whilst antiretroviral (ARV) therapy had successfully reached 83% of all adults who are medically eligible for treatment (NACC & NASCOP, 2012), there were still 58,000 deaths of AIDS-related deaths reported in 2013 (NACC, 2014a). Although the percentage of PLWA in the country has fallen by roughly 40% since 1995-96 (Government of Kenya/Kenya National Bureau of Statistics, 2010), the actual number of PLWA is continuing to increase as effective

treatments help maintain good health and reduce AIDS-related deaths. The result of this more successful treatment campaign is that there are greater numbers of PLWA in communities. Furthermore, although some of this discussion and presentation of HIV-related statistics look encouraging, progress against HIV in other countries has sometimes been followed by a resurgence of the epidemic, underscoring the critical importance of continued vigilance of trends and renewed emphasis on prevention programmes.

2.5 Disability and HIV/AIDS in Kenya

Disability and sexuality makes many people uncomfortable (Shakespeare, Gillespie-Sells & Davies, 1996).

There is large body of literature that informs us that there is a general assumption that PWDs are asexual and that they lack the desire, ability or capacity for sexual relationships (Addlakha, 2007; Anderson & Kitchin, 2000; Becker, Stuifbergen & Tinkle, 1997; Di Giulio, 2003; Groce, 2004; Joseph, Sawyer & Desmond, 1995; Kallianes & Rubenfeld, 1997; Milligan & Neufeldt, 2001; Smith et al., 2004; Wazakili, Mpofu & Devlieger, 2006).

Other studies suggest that society's discomfort in dealing with sexuality issues has resulted in a failure to provide services, including development of HIV/AIDS prevention and treatment programmes (Di Giulio, 2003; Drainoni et al., 2006; Groce & Trasi, 2004; Groce, MacNamara & Mawar, 2006; Nosek & Simmons, 2007; Liu & Clark, 2008; Yousafzai et al., 2005).

There is a general lack of information on how HIV/AIDS is impacting on the disabled community in Kenya. However, Handicap International (HI) proved the asexuality assumption wrong. They undertook a study in 2007 that found that PWDs are sexually active; they are having unprotected sex; and are therefore potentially exposing themselves to HIV/AIDS infection. The study concluded that HIV/AIDS should be a key concern for public health professionals and service providers who wish to improve the lives of PWDs in Kenya (Handicap International, 2007).

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Specifically, the HI study revealed that 100% of deaf respondents said they lacked access to HIV and AIDS information. 37% of deaf respondents in the survey said they engaged in sex before the age of 16, and 34% said they had engaged in sex for money. The HI report cited as an example that 52% of deaf respondents did not know that ARV drugs were available for free in the country. This was in spite of the much publicized announcement 12 months earlier by the then Kenyan President, President Mwai Kibaki, that these life-saving drugs would be provide free in public hospitals and health centres to those people who needed them (BBC, 2006).

LVCT Health is a SRH NGO that was established in 2002 to provide HIV/AIDS information, prevention, counselling, testing, care and treatment to vulnerable groups. In 2004, and in response to the emerging need, a Deaf Programme was initiated with testing centres in Kisumu, Nairobi and Mombasa. Currently, LVCT Health's Disability Programme (formerly the 'Deaf Programme' until 2008) is almost entirely run by deaf Kenyans and delivers HIV/AIDS services to PWDs through 2 centres in Nairobi and Kisumu. These services entail confidential HIV counselling and testing at clinics managed by deaf staff; mobile VCT activity and community mobilization in urban and rural deaf communities; support to deaf clients in need of referral and care; and the establishment of post-test support groups within deaf communities.

From the earlier analysis, it can be shown that the majority (80%) of PWD, including Kenya's deaf population, live in rural areas that place them outside the scope of most disability or deaf-focussed health, including HIV/AIDS, interventions that can often successfully reach the urban-based communities. Evidence from online data informs us that over the initial two-year period (2004 – 05), only 1,709 deaf clients were seen at the LVCT Health deaf-run VCT testing centres (Taegtmeyer et al, 2009). Whilst there is no data to inform us whether these clients were all from urban areas, it is clear that for rural deaf Kenyans to access these services, they will often have to travel large distances to reach the centres. A study by Smith and colleagues (2004) investigated the behaviour of women with disabilities accessing safe motherhood and sexual

health facilities in Zambia. Their study revealed that the cost of travelling to the hospital by public minibus or private taxi was beyond the means of many. The implication from this finding is that if deaf people are unable to fund their travel to the urban-based testing centres, they will have to rely on the off chance of an outreach activity visiting their area through mobile services, door-to-door campaigns or outreach work at community level. This LVCT Health programme, therefore – albeit a model programme – is still probably only reaching a small percentage of all who need it.

2.6 Poverty and risk to HIV infection

Nearly half (46.6%) of all Kenyans were living below the national poverty line in 2005-06, and 40% of the population subsist on less than US$ 2 per day (World Bank, 2010). WHO & UNFPA (2009) suggest that the rate of poverty of PWD is double that of the general population.

One of the consequences of acute poverty is that it can lead to risky behaviours (for example, prostitution) as a means to survive. Risky commercial sex work makes PWD vulnerable to HIV infection (Johnson et al., 2006; Smith et al., 2004). There is a tendency, among other things, for poor people to exchange sex for cash (DFID, 2000). Joffe & Bettega (2003) studied the link between commercial sex work and deafness in Zambia. They confirmed that deaf and hard of hearing adults and adolescents are at risk of HIV/AIDS because of multiple sexual partners, including those acquired through transactional sex. With reference to the HI Kenyan study already mentioned, it was found that 1:3 of the deaf participants had engaged in sex for money (Handicap International, 2007).

2.7 Education and risk to HIV infection

Lower levels of education are associated with poorer health outcomes (Commission on the Social Determinants of Health, 2008). In order to establish the research context and background for this study, it is therefore important to consider access to and quality of education in Kenya.

The 2008-09 Kenyan DHS indicated that 79% of children of primary school age are attending school. The net attendance ratio is slightly higher for girls (80%) than for boys (78%) (Government of Kenya/Kenya National Bureau of Statistics & ICF Macro, 2010). The net attendance ratio for primary school is higher in urban (84%) than in rural (78%) areas. There was no data in the DHS for children with disabilities.

The 2008-09 DHS also informs us that the adult literacy rate (15-49 years) is 86% in women and 93% for men nationwide (Government of Kenya/Kenya National Bureau of Statistics & ICF Macro, 2010). This means that the illiteracy rate in women (14%) is double that for men (7%). Furthermore, there are variations according to geographical area with urban areas faring better than rural ones. There is once again no data in the DHS for children with disabilities.

There is a body of literature that informs us that children with disabilities are less likely to be educated or attend school (Groce, 2003, 2004, 2005; Munthali, Mvula & Ali, 2004; WHO, 2011). Groce (1999) affirms that children with disabilities are disadvantaged as their educational levels are, she notes, often sub-standard, and their dropout rates are double or triple those of non-disabled children. The situation for deaf children is also precarious. The WFD estimates that 90% of deaf children and adults have never been to school and are therefore more or less illiterate (WFD, 2012).

Groce (2013) notes that many developing countries have only few schools for special education. These schools are often located in capital cities and tend to serve children from more affluent families. While such schools are helpful for those who attend, the capacity of these schools is limited. They are usually underfunded and short of staff and facilities. Perhaps most significant of all though is that they can rarely educate more than several hundred children at a time. WHO (2011) cite Karangwa & Kobusingye 2007 who state that in Rwanda only 300 of an estimated 10,000 deaf children in the country were enrolled in primary and secondary schools, with another 9 in private secondary school.

Haualand & Allen (2009) note that almost all countries acknowledge that deaf children have a formal right to enter a school. However, almost none offer an education system whereby education is delivered in the most appropriate language (sign) for deaf students. WHO (2011) explains that the majority of teachers in schools for the deaf lack sign language skills creating barriers for deaf children. The WFD echo this claim by suggesting that most deaf people in developing countries do not receive an education and that only 1-2% of all deaf people get education in sign language (WFD, 2012). The 2009 Deaf People and Human Rights Report highlights the consequence of this educational environment when they concluded that most deaf children and deaf students are illiterate when they have completed their education. Even when deaf children graduate from 12 years of education, reading and writing levels are poor (Conrad, 1979; Van Biema, 1994).

There are a number of consequences of this situation. The first is that many PWDs do not reach the educational level to be fully able to obtain and process much of the mainstream health, including HIV/AIDS, information through the traditional public health prevention campaigns. Stevens (1998) explains that deaf people generally have limited access to mainstream mass-information systems, such as newspapers, magazines, television, commercials and advertisements. Even when mass-information systems are available, articles and advertisements in newspapers and magazines are too difficult to understand because they contain ambiguous messages and thus are not straightforward enough for deaf people. Furthermore, televised HIV/AIDS campaigns and ads are rarely subtitled, captioned, and/or interpreted into Sign Language, especially in resource poor countries like Kenya. Stevens (1998) sums it up by saying that deaf people's right to information is being ignored.

The second is that the education system and quality of education that deaf children experience means that many do not develop the critical thinking, problem-solving and life skills thus impacting on the choices they make, their future behaviour and opportunities (Baker-Shenk & Kyle, 1990; Braswell-Burns, 2010; Haualand, 2009; Lang, 2002).

It should also be noted that the impact of this lower educational status will also be felt later on in life by the fact that PWD, including deaf adults, will very likely experience reduced employment opportunities and decreased productivity in adulthood (Filmer, 2008; Burchardt, 2005). In light of the earlier discussion about poverty and risk to HIV infection, the importance of education is clear.

2.8 International & national commitments: HIV/AIDS & deaf people

The GoK has made significant progress over the last decade to promote and protect the human rights of its all citizens, including PWD. Notable achievements include: ratification of the UNCRPD, promulgation of the new Constitution, and the introduction of the Persons with Disability Act 2003. There are a number of key provisions that need highlighting as they are directly relevant to setting the context and illustrating the commitments that the GoK has made to address HIV/AIDS and the deaf population.

2.8.1 UNCRPD

Under UNCRPD Article 25, PWD have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. The UNCRPD also provides in Article 25 that States parties must "provide persons with disabilities the same range, quality and standard of free or affordable health care and programmes as provided to other persons..." (United Nations, 2006, p.15).

The UNCRPD focuses on geographical access to health care, establishing in Article 25(c) that States parties must "provide these health services as close as possible to people's own communities, including rural areas" (United Nations, 2006, p.15). Provision of health care facilities to individuals in rural areas ensures that everyone is able to physically reach health care facilities. The provision of health services within an individual's community is critical for PWD who have a right to access health services within their community. The UNCRPD further defines accessibility in Article 9 as 'access, on an equal basis with others, to the physical environment, to transportation, to information and

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communications... and to other facilities and services open or provided to public, both in urban and rural areas' (United Nations, 2006, p.8). Interpreting these Articles in the broadest sense, it means that not only must services be available locally, in communities, but also that the facilities provided must be adequately resourced to cope with the language and communication needs of deaf people.

There is a connectedness and very close relation between the different rights – for example, deaf people's right to health is very closely related to full and equal access to health information and services. This connectedness is very clear in the example of HIV/AIDS. Stevens (1998) claimed that 'early HIV/AIDS prevention campaigns in several countries literally fell on deaf ears within the Deaf community' (p.102). This fact meant that deaf people's health was jeopardized and their human rights were 'ignored.' At this time, with the coming into being of the Convention, and the protection provided under Article 25 that state parties provide PWD the same SRH care and programmes as provided to other persons, if deaf people do not have either awareness of or are denied information about the disease and how to protect themselves from infection, their rights would now be violated and not simply 'ignored'.

One other right that is increasingly discussed in the debate of SRH for PWDs is the right to participation. Article 23 of the UNCRPD requires states to eliminate discrimination against PWD in all matters relating to marriage, family, parenthood, and relationships, including in the areas of family planning, fertility and family life. Shakespeare, Lezzoni & Groce (2009) note that participation also means that health professionals should speak directly with the PWD themselves about health matters and health choices, and not speak solely to their carers, relatives or people who accompany them to health appointments. In fact, Article 22 defends the equal rights of PWD to privacy, including privacy of personal health information. In environments where health professionals neither know sign language nor have access to interpreter services, and where deaf people rely on their friends and families to accompany them to health facilities,

guaranteeing the provisions under Articles 22 and 23 becomes very challenging, if not impossible.

UNCRPD Article 19 states that PWDs have the right to live in the community and participate in society as equal citizens. The focus of this Article 19 is to create an enabling social and physical environment so that all persons are able to be included and participate in their community. Article 19 specifically addresses the social, physical, and economic barriers that prevent full participation in the community that lead to exclusion – for example, deaf people who are isolated and unable to access health services, or participate in education and employment in their communities because of a lack of sign language interpreters is a violation of UNCRPD Article 19. Furthermore, Hammarberg (2012, p.5) poses that violations occur: '…when support is altogether withheld, thus confining a person to the margins of the family or society…' For those deaf people – and particularly isolated deaf individuals - who are restricted to staying home or within families because they are unable to communicate with people in communities around them, their rights under Article 19 are also violated.

Governments that ratify the Convention are legally bound to treat PWD not as victims or a minority, but as subjects possessing all human rights, including civil and political rights as well as economic and social rights. The GoK ratified the Convention in 2008. The challenge now for the GoK is to domesticate these commitments into enforceable national laws and policies to ensure that these rights are protected and respected.

2.8.2   The Kenyan Constitution

Kenya gained independence from Britain in 1963. Since independence Kenya has had two major constitutional reforms, in 1969 and 2010.

The demand for a new constitution to replace the 1969 text with a more democratic system began in the early 1990s with the end of the Cold War and

democratic changes taking place. After a lengthy review process, Kenyans endorsed the introduction of the new Constitution in a referendum on 4 August 2010. The Constitution is firmly grounded in the principles of human rights and guarantees the civil, political, cultural, economic and social rights of all Kenyans and provides the framework within which everyone should have the opportunity to reach their full potential.

Article 21(3) of the Constitution establishes a national commitment that 'all State organs and all public officers have the duty to address the needs of vulnerable groups within society, including women, older members of society, persons with disabilities, children, youth, members of minority or marginalized communities, and members of particular ethnic, religious or cultural communities' (Government of Kenya, 2010, p.20)

The Constitution also makes provision to address the past. Article 27(6) commits the State to take legislative and other measures, including affirmative action programmes and policies to address any disadvantage suffered by individuals or groups because of past discrimination. The situation therefore where, for example, deaf people denied HIV/AIDS information, or access to services, could be challenged under this provision. If deaf people can prove that there was a failure of the State to meet their needs and uphold their rights, there is a commitment for action.

Article 26(1) states, 'Every person has the right to life' (Government of Kenya, 2010, p.24). It would therefore follow that any one who does not have the information or services to protect themselves from, and consequently contracts, a potentially life-threatening condition – like HIV/AIDS - may be having this right violated.

Article 43 of the Constitution establishes a right 'to the highest attainable standard of health' (Government of Kenya, 2010, p.31) which explicitly includes the right to reproductive health care. The situation therefore where anyone is

unable to or has restricted access to HIV/AIDS information or services is clearly therefore having this right compromised under Article 43 of the Constitution.

2.8.3   The Persons with Disability Act (2003)

The aim of the Persons with Disability Act (2003) is to provide for the rights and rehabilitation of PWD; and above all to combat discrimination and achieve equalization of opportunities for PWD. The Persons with Disability Act clearly states that all Kenyans should have equal access to health care and treatment, including prompt attendance by medical personnel to PWD, as contained in Article 20(d).

When Parliament enacted the Persons with Disability Act in 2003, it created the National Council for Persons with Disabilities as a statutory organ to oversee the welfare of PWD. The functions of the Council are set out in Article 7 of the Act. Article 7(1)(b)(iii) mandates the Council to advise the Minister on the provisions of any international treaty or agreement relating to the welfare or rehabilitation of PWD.

There are two further significant key provisions contained in the Persons with Disability Act (2003) that support Kenya's implementation of the UNCRPD. The first is creation of a National Development Fund for Persons with Disability. The Fund is administered by the Council through a board of trustees and may fund or contribute to the expenses of organisations of or for the training or benefit of PWD. Therefore, some of the constraints created by a lack of GoK budget allocation may be alleviated by the existence of the Development Fund.

The second relates to the prioritization of action of the implementation of the UNCRPD. Article 7(1)(g) of the Persons with Disability Act states that the Council assess and report to the Minister on the welfare and rehabilitation of PWD and to advise on the relative priorities to be given to the implementation of those measures. In other words, the Council has an important role to play in creating a dialogue from PWD to the GoK to establish priorities for action within the context of implementing the UNCRPD. Without the authority of the Persons

with Disability Act, this function would have been left to Disabled Persons Organisations (DPOs) and other interested parties to advocate and lobby on behalf of PWD. In setting up a communication channel back to the GoK, there is a greater chance that recommendations will be acted upon.

2.8.4   Enforcement

Whilst some important steps have been made to establish human rights principles in the country, it cannot be assumed that all rights are now guaranteed. In addition to the National Council for Persons with Disability, there are other bodies with a disability rights mandate that have been established by the GoK through various Acts of Parliament. One of these, the Kenya National Commission on Human Rights, monitors abuses and violations of human rights in Kenya. The establishment and mandate to perform these oversight functions are evidence of the GoK's commitment to ensure that laws and policies are enforced and human rights respected in the country.

2.9   HIV/AIDS funding in Kenya

Evidence shows that very large amounts of money have been spent in Kenya in recent years to combat HIV/AIDS. A review of two key international funding sources clearly reflects this. The first is the Global Fund, established in 2003 to fight HIV/AIDS, TB and malaria; and the second is the US-government initiative to address HIV/AIDS, called, The President's Emergency Plan for AIDS relief, or PEPFAR.

Table 2.3:   Global Fund grant disbursements to Kenya (Global Fund, 2015)

	Signed (US$)	Committed (US$)	Disbursed (US$)
HIV/AIDS	541,607,793	404,006,070	385,201,320
TB	68,127,216	58,931,501	52,898,713
Malaria	287,193,314	260,370,066	252,225,788
TOTAL	896,928,323	723,307,637	690,325,821

Table 2.4:   PEPFAR grant disbursements to Kenya (PEPFAR, 2012)

Financial Year	US$ in millions
2004	92.5
2005	141.3
2006	208.3
2007	368.1
2008	534.8
2009	565.0
2010	548.1
2011	517.3
TOTAL	2,975.4

To date, Kenya has received 16 grants from the Global Fund with US$ 385 million for HIV/AIDS. The combined total from the Global Fund and PEPFAR that Kenya has received is approximately US$ 3,300 million. Additionally, there are of course many other funding sources that support the implementation of HIV/AIDS programmes in Kenya.

Between 2009 – 2013 and implementation of the KNASP III, spending on HIV increased from Ksh 63 billion (US$ 688 million) to Ksh 72 billion (US$ 786 million) per year (NACC, 2014a). Expenditure levels are planned to remain high

with the implementation of the KASF 2014/15 – 2018/19 costing US$ 5,486 million for 5 years (NACC, 2014b). With such large amounts of money, it would not be unreasonable to expect that all Kenyans should have both awareness and comprehensive knowledge about the disease.

2.10 Kenya AIDS Strategic Framework 2014/15 - 2018/19 and the deaf population

The KASF is aligned to the Constitution of Kenya, the Vision 2030[4], and the African Union (AU) goals on HIV control, and it defines the results to be achieved and offers broad strategic guidance on the coordination and implementation of the HIV response. The goal of KASF is universal to comprehensive HIV prevention, treatment and care.

Table 2.5:   KASF 2014/15 – 2018/19 Key Strategic Objectives (NACC, 2014b, p.11)

1	Reduce new infections by 75%
2	Reduce AIDS related mortality by 25%
3	Reduce HIV related stigma and discrimination by 50%
4	Increase domestic financing of the HIV response to 50%

From the analysis earlier in this chapter, it can be concluded that the HIV epidemic in Kenya is heterogeneous in nature, manifesting differently in different populations and geographic areas. Clearly, if the key strategic objectives (1) and (2) in Table 2.5 are to be met, prevention and treatment programmes and policies need to be more sensitive to the needs of key and vulnerable populations – no group must be left behind in the response, including the deaf population. It is therefore important that an appropriate framework is flexible so that County Governments can adapt and use it to best develop HIV plans relevant and responsive to address their local HIV epidemics.

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[4] Vision 2030 is Kenya's development programme covering the period 2008-2030. It was launched on 10 June 2008 by President Mwai Kibaki.

The KASF is championed as being adaptable so that each county can use it as a guide to develop individual responses that meet the specific needs of its communities.

There is a commitment in the Framework to see that groups that have been marginalized in the past are reached. As the MoH Cabinet Secretary, Hon. James Wainaina Macharia said, 'The KASP emphasizes an equitable HIV response that ensures that no one is left behind (NACC, 2014b, p. vii)'. Professor Mary Gethui, Chairman of NACC, explained, 'The strategic framework requires that all actors pay particular attention to vulnerable and marginalized groups' (NACC, 2014b, p. viii). Essentially, 'The success of the HIV response is dependent on protecting and promoting the rights of those who are socially excluded, marginalized and vulnerable' (NACC, 2014b, p.4).

Whilst there is a commitment in the overall Framework to reach marginalized groups, the question still remains about who are the marginalized groups, and how are they defined at county level. KASF identifies the first group, or key populations, as those who - due to specific higher-risk behaviour - are at increased risk of HIV. They include MSM, IDUs and CSWs. The KASF acknowledges that there are legal, cultural and social barriers related to the behaviour of these groups that increase their vulnerability to HIV infection in Kenya. The second group of vulnerable populations includes those people whose social contexts increase their vulnerability to HIV, and include young girls and women, people in prisons and other closed settings, fishing communities, truck drivers, street children, PWD, migrant populations especially those in humanitarian crisis and mobile workers.

Whilst there is no specific mention of the deaf population in the Framework, PWD are included as a vulnerable national group and the presumption must be that County Governments will consider the needs of the different groups that comprise the disabled community in preparing their local plans. There may however be some concern in assuming that the needs of the entire deaf

population will be met because there is reference to the disabled community being a vulnerable group in national framework document.

The first reason is that deaf people often find itself in a somewhat difficult position. Stevens (1998) refers to an observation by Bengt Lindquist, UN Special Rapporteur of Disability, who, in May 1997, noted at the WFD that deaf people appear to be given less protection than those of people with other disabilities. Lindquist suggested that deaf people are marginalised on two fronts. The first is from the non-disabled community, and the second from the disabled community. In other words, deaf people always tend to fall in the middle between two positions. On the one hand, they are not regarded as 'disabled' enough to be assigned special attention; and on the other, the nature of their disability – deafness – is all too often not understood at all (Stevens, 1998). The fact is that in being in this position, their needs are often not met.

The second reason that the needs of everyone in the disabled, including deaf population, will not be met merely by being included in a general disability group is because of the diverse nature and needs of each of these groups. Clearly, some people within the disabled community will be reached through an all-inclusive approach. However, for many, they wont be unless there are specific efforts to reach and engage with them.

Furthermore, if there is a component in a programme that specifically focuses on deaf people, there are also further subgroups within the deaf population to consider – for example, male/female; signing/non-signing subgroups. The point is that the accumulation of these different groups and subgroups make it very hard to guarantee that a general mainstream HIV programme, a disability programme, or even a deaf programme, can possibly meet all the different needs of all the different groups and subgroups within the deaf population unless all the groups and their needs have been identified and factored in to a programme. This explains why the LVCT Health's Disability Programme - whilst offering an important HIV service to the disabled community - cannot be expected to reach all those people who need it. The question therefore becomes

whether the deaf population, or any of its subgroups, can be confirmed as one of the marginalized groups for whose needs the KASF 2014/15 – 2018/19 is committed to addressing.

2.11 Conclusion

Fifteen years on from President Moi's stirring words, it would perhaps not seem unreasonable to expect that Kenya's entire population would have heard of the HIV/AIDS virus and have sufficient information to protect itself from the disease that, in 1999 the President said, was to threaten the entire nation's existence. However, clearly the 'war' is not yet won as 101,560 Kenyans were infected with HIV/AIDS in 2013 (NACC & NASCOP, 2014).

The conclusion from the Kenya AIDS Response Progress Report 2014 entitled, 'Progress to Zero' suggests that the data on the country's HIV epidemic shows a stabilizing epidemic among the general population and an elevated epidemic among key populations. In summary, the future of Kenya's HIVAIDS epidemic will be determined by the success of efforts to slow the spread of HIV among young people and attention to marginalized communities. It is estimated that 80% of Kenyans are under 35 years old (UNDP, 2013). Three marginalized groups have been identified: CSWs, MSM and IDUs. Whilst the disabled community is mentioned as a vulnerable group, there is a risk in assuming that the needs of the entire deaf population will be met even if County Governments only consider the needs of a broad disabled community. This is largely because the disabled community is wide and varied with each group – like the deaf population - having its own particular characteristics and needs that differ from other groups within the community. The disabled community can therefore be seen to be a very heterogeneous group where one response for a 'disabled community' to a complex issue like HIV/AIDS will unlikely be enough.

The next chapter will explore current literature to establish the current situation, and particularly whether there is any evidence to show that deaf

people have been left behind the mainstream population in terms of awareness and knowledge of the HIV/AIDS.

Chapter 3 Overview of the current discourse on disability & HIV/AIDS

3.1   Introduction

This chapter opens by exploring the conceptual framework of the social determinants of health (SDH) and how it relates to disability. This framework is consistent with the social model of disability. This model, like the SDH, views disability and health outcomes in a much broader and holistic way that encompasses the environment and society in which a person lives. The discussion then expands upon HIV/AIDS awareness & knowledge, key determinants of why deaf people are particularly at risk of HIV infection. The conclusion from a review of available literature is that all studies confirm that PWD, including deaf people, have less awareness and knowledge about the disease compared to their non-disabled and hearing compatriots. Furthermore, there is evidence from North American studies that suggests there are different subgroups within the deaf community that have varying levels of awareness and knowledge about the disease. There were no studies from Africa that explore this issue and this study could help inform this discussion.

3.2   Conceptual framework: The social determinants of health

WHO (1948) defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or illness. In accepting this broad definition of health, we accept that the health of individuals and communities is therefore a result of a complex mix of social, economic, political and environmental factors. These factors are called the SDH.

As outlined in the previous chapter, Article 43 of the Constitution of Kenya establishes a right to the highest attainable standard of health for all Kenyans. Attention to the SDH is required to achieving health benefits. General Comment 14, CESCR (cited in FXB Center for Health and Human Rights & Harvard University 2013, p.9) explains that the right to health is 'an inclusive right

extending not only to timely and appropriate health care but also to the underlying determinants of health'. This connection is also supported by WHO (2013, p.7) when they acknowledge that the right to health and SDH are not mutually exclusive, 'the right to health entails the rights to equity in the SDH'.

In 2005, WHO established the Commission on the Social Determinants of Health (CSDH) to support countries and global health partners to address the social factors, or social determinants, that lead to ill health and health inequities. Their 2008 report, *Closing the Gap in a Generation* concluded that ill health and health inequities were determined by 'the conditions in which people are born, grow, live, work and age' (p.26). The fundamental drivers of these conditions are the distribution of and access to power, money and resources at global, national, community, family and personal levels and are affected by policy or individual choices at each of these levels (Commission on the Social Determinants of Health, 2008). The report provided a comprehensive, evidence-based discussion of the pervasive inequalities of health in many countries, demonstrating the presence of a social gradient in health with higher levels of disadvantage being associated with worse health outcomes.

In the discourse, there are a number of different models used to explain the SDH. The conceptual framework of the CSDH, and the one adopted for this investigation, identifies two main levels at which determinants operate: the structural and proximal levels. To fully address the research question in this investigation, and specifically to explore the SRH needs of deaf people, an understanding and consideration of the SDH at both the structural and proximal levels is necessary.

WHO defines structural determinants as the fundamental structures that generate social stratification or groups, and include both global and national economic, political, social welfare and education systems (Commission on the Social Determinants of Health, 2008). Within a country therefore, the choices that the Government makes through the policies and programmes it implements will result in varying structures of opportunity or access for their

citizens, and these choices will impact upon their citizen's health. If for example, a Government implements an HIV education policy that is not fully inclusive and does not address the specific needs of deaf people with the result that they are unable to access HIV/AIDS information, the result will be a worse health outcome for deaf people. The point being that the lower health outcome in this instance is not a natural phenomenon but rather the result of human action; or in this instance, inaction.

In the previous chapter, the discussion looked at three important measures that the GoK has made to address some of the structural determinants of health: ratification of the UNCRPD; promulgation of the new Constitution; and the enactment of the Persons with Disability Act (2003). Furthermore, in the KASF 2014/14 – 2018/19, the GoK appeals for evidence of any emerging marginalized or vulnerable group to HIV infection. It could be argued that in making this appeal and responding to evidence, together with the enforcement of the UNCRPD, the Constitution and the Persons with Disability Act (2003), the GoK should meet its commitments to address the structural determinants of health that impact upon the health of its citizens, and particularly the disabled community.

Proximal determinants are the circumstances of daily life, from the quality of family environment and peer relationships to availability of food, housing, and recreation to access to education. Proximal determinants are generated by the social stratification that results from structural determinants, but are also generated through cultural, religious, and community factors (Commission on the Social Determinants of Health, 2008). These proximal determinants establish individual differences in exposure and vulnerability to health compromising factors that generate health or ill health. It is possible therefore to have differing health outcomes for individuals in the same family – for example, if hearing and deaf children are raised differently in the same home, their health outcomes will vary.

Within the public health response to HIV/AIDS, education has long been championed as an important means to control the disease. The Inter-Parliamentary Union Handbook for Legislators on HIV/AIDS, Law and Human rights (cited in FXB Center for Health and Human Rights & Harvard University 2013) clearly states the importance of education in the defence of HIV, citing evidence that getting and keeping young people (particularly girls) in school dramatically lowers their vulnerability to HIV. However, there is a more fundamental importance of education that has a particular relevance to this discussion on HIV and deaf people, and that is the development of 'health literacy'. WHO defines health literacy as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health (WHO, 2013). The American Medical Association defines health literacy as 'a constellation of skills, including the ability to perform basic reading and numerical tasks that allow a person to function in the health care environment' (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association, 1999). Safeer & Keenan (2005) suggest that most health care materials are written at 10th grade level. They continue that inadequate health literacy can result in difficulty in accessing health care, following instructions from a physician, and taking medications properly. For optimal comprehension and compliance, they note that patient educational material should be written at sixth-grade or lower reading level, preferably including pictures and illustrations. The point is that people need to have reached a certain level of education to understand, process and act on health information. A deaf person, therefore, who has not been educated to the level whereby they attain health literacy will be unable to protect themselves from HIV/AIDS.

In the absence of published literature on the SDH and deaf people, the example of SDH and adolescence is presented to show how the structural and proximal determinants shape health status. In analysing adolescence and the SDH, Viner et al (2012) note that the health of adolescents and young adults is affected by social factors at personal, family, community and national levels. They show

that the strongest determinants of adolescent health are structural factors such as national wealth, income equality and access to education. Furthermore, they suggest that safe and supportive families, safe and supportive schools, together with positive and supportive peers, are crucial to helping young people develop to their full potential and attain the best health in the transition to adulthood.

Marmot (2009) acknowledges the criticism that the SDH seems to have overlooked individual agency or choice, it essentially being a person's right to chose to be healthy or otherwise – for example, to drink and smoke and have risky sex. He counters this argument by stating that the CSDH put empowerment, having control over one's life, enjoying fundamental freedoms at the centre of its focus. For example, if a deaf individual has all the information, skills, resources and access to services for HIV, it therefore follows that they are empowered, have control over their life and are therefore free to make their own life choices. In a situation where the information, skills, resources or services are not complete – for whatever reason - it can be argued that they are not empowered or free to make an informed decision.

The key point is that Governments are responsible for creating conditions that make it possible for individuals to be as healthy as they can be. To achieve this, equity in SDH to improve individual's capacity to lead a healthy life is required. It therefore follows that for Governments to make the right choices and implement policies and programmes that address inequities and raise the levels of health of the most disadvantaged or marginalized people - notably PWD or the deaf community - more information must be gained and knowledge shared to understand their SDH. It was with this in mind and the need to develop an understanding of how the SDH operate that the SDH was chosen for the conceptual framework for this study to explore the SRH needs of deaf people in Western Region, Kenya.

3.3 Disability models

This study was framed using the social model approach to disability. This defines disability as the loss or limitation of opportunities to take part in everyday life of the community on an equal level with others due to physical or social barriers. This approach to disability is consistent with the SDH that considers a person's health status in a broader sense, being the consequence of the impact of structural and proximal factors rather than relating to the functioning of the body or presence of disease. The premise in this approach therefore is that there are barriers or issues that hinder deaf people from accessing health services, including SRH services, that put them at risk of HIV infection.

The traditional medical and charitable models or approaches to disability tended to focus on the individual, the PWD, rather than on the need for societal change. The medical model defined disability as the loss or reduction of functional ability, and PWD were defined by their impairments. The solution, under this model focused on medical or technical interventions by experts to alleviate the impairment. Therefore, in the example of a deaf or hard-of-hearing person, a medical response to 'fix' the impairment might mean the provision of a hearing aid or the insertion of a cochlear implant. Under the charitable model, PWD were to be pitied and helped, usually by being given financial support. In both the medical and charitable models, issues of the right to full inclusion and participation are not addressed.

The UNCRPD does not provide a definition of disability, but instead provides a broad description intended to be widely inclusive. Article 1 establishes that 'persons with disabilities' includes 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (United Nations, 2006, p.4). This description of disability shifts the focus toward the social and environmental barriers that hinder an individual's participation in society rather than on the individual's impairments.

Shakespeare, Lezzoni & Groce (2009) argue that when disability is over-medicalised by health professionals who focus on individual problems and ignore the structural issues that contribute to health status, injustices increase. They recommend that a human rights-based approach addressing the social and economic determinants of health is one that will create real improvements.

3.4 Lack of HIV/AIDS information

Lack of information about HIV, including how it is transmitted and how it can be prevented, places the person at risk for exposure (Strunin & Hingson, 1987). It is not good enough for someone to obtain only partial knowledge when any knowledge gap can be life-threatening (Baker-Duncan et al., 1997). In order to explore any lack of HIV/AIDS information, I consider two factors: firstly, awareness levels of the disease; and secondly, factual questions to determine comprehensive knowledge of the disease and its transmission to enable someone to protect themselves from infection.

The aim of this section is to review published and grey literature to explore what we know about deaf people and their risks of HIV infection.

The literature review was undertaken using six databases: Medline, Web of Science, Scopus, Embase, Popline and Source. A combination of MeSH and/or key terms was used to define the search. These included references to disability (Deaf*, Hear*); HIV (HIV*, AIDS*) and location (Africa*, Kenya* and sub-Sahara*). These produced a total of 977 references, many of which were discounted as not being relevant to this study. Guided by findings from Groce et al (2013) who found that the number of papers in the peer-reviewed literature was small, with an average of 5 articles published annually 1990 – 2000; rising slightly to 6 between 2000 – 2010, I adopted a different strategy. Literature was identified from working through published journal reference lists, and an in-depth review was also done using available grey literature.

My conclusion from searching available online databases is that there is a scarcity of information available to sufficiently answer this question from

published material for the deaf community in Kenya alone. I have therefore decided to draw on the wider literature that addresses awareness and knowledge levels of HIV/AIDS in the broader disabled community. Having explored the findings for the disabled community, I proceed to consider findings from studies for the deaf community. My conclusion is that in most, if not all, studies reviewed, the disabled community – and within this I include the deaf community - appear to have less awareness and information about HIV/AIDS than the non-disabled community. I will first consider published material for the disabled community.

3.4.1 Disabled community

In this section, I draw on some of the empirical work from 5 studies in eastern and southern Africa over the last decade to confirm that whilst there might be an awareness of HIV, there is a significant body of research to show that PWDs lack comprehensive knowledge and accurate information about the disease.

In 2009, the Journal of the International AIDS Society published a paper, "Disability & HIV/AIDS – a systematic review of literature on Africa" by Jill Hanass-Hancock, a researcher working in South Africa. The review acknowledged that the field of disability in HIV/AIDS had been growing in recent years, and the rationale for the paper was the need to consolidate the available literature in a systematic way to take stock of what research studies had informed us. One of the main conclusions from this analysis was that PWD lack access to HIV/AIDS information, testing and treatment (Hanass-Hancock, 2009).

Yousafzai et al (2004) explored whether PWD face inequalities in accessing health information and services in Swaziland. At the time of the study, Swaziland had a national HIV prevalence rate of 38.6%. This qualitative exploratory study involved 8 focus group discussions, 4 with 56 (non-disabled) adults aged 16-29 years; and 4 with 32 adults with physical or hearing disability (aged 18-32 years). The study found that information and awareness of

HIV/AIDS was good among the non-disabled participants who obtained their information from a number of sources. In contrast, participants with disability obtained information about HIV/AIDS from a limited range of sources, lacked knowledge about HIV/AIDS and were misinformed about modes of transmission. To illustrate this point, only 8% of the PWD (*n*=36) knew that testing for the HIV virus was the only means of determining an individual's HIV status. This can be compared to an awareness rate of 100% in the participants without disabilities (n=56). When one considers that at the time of this study, over one in three of the adult Swazi population was living with HIV, and that 92% of the PWD who participated in this study did not know how to confirm someone's HIV status, this finding is alarming. Not surprisingly, one of the recommendations from this study was for further research to understand the barriers faced by people with different disabilities in developing countries that make them vulnerable to HIV.

Munthali, Mvula & Ali (2004) undertook a study involving 341 PWD and their close family members in 5 districts in Malawi to explore and understand their SRH needs and experiences, perceptions about HIV/AIDS and how best information on HIV/AIDS could best be communicated to them. HIV adult prevalence reached a peak of 16% in Malawi in 1999. Thereafter, the prevalence began to decline steadily to reach 12%, a year before this study. The majority of the participants in this study had physical disabilities; others had hearing, speech and visual impairments. Data was collected through focus group discussions. The main finding was that there was high general awareness of HIV/AIDS; however, consistent with the Swazi study a year earlier, knowledge levels were low. For example, 43% of respondents said that they would be able to tell if someone had AIDS just by looking at them.

The following three studies from South Africa by Philander & Swartz (2006), Wazakili, Mpofu & Devlieger (2006), and Eide et al (2011) inform us that the challenges that PWD face in getting the information and building knowledge and understanding about HIV are commonplace throughout Africa. In no studies

have the researchers been able to confirm that PWD have the same levels of knowledge about the disease as the non-disabled majority population.

Philander & Swartz (2006) undertook a study with visually impaired South African adolescents. The investigation recruited 15 participants (12 with visual impairments), most of whom were in senior positions of organizations and service providers in the field of visual impairment, affiliated with the South African National Council for the Blind and working in 3 provinces in the country. Eighty-seven per cent (*n*=13) said that people with visual impairments were at greater risk to HIV infection because of a lack of information on the HIV pandemic and preventive measures.

Wazakili, Mpofu & Devlieger (2006) undertook a study that explored the experiences and perceptions of sexuality and HIV/AIDS among 15-24 year old young people with physical disabilities in Nyanga Township, Western Cape Province in South Africa. Ten young people and ten parents participated in multiple individual interviews as well as focus group discussions. The results indicated that disabled young people have limited factual knowledge about sexuality and HIV/AIDS.

Eide et al (2011) undertook a study in 3 provinces in South Africa (Gauteng, KwaZulu-Natal and the Western Cape) involving 285 participants aged between 18-75 years old and including a range of disabilities (physical, intellectual, hearing, emotional/psychological, communication, amongst others). Findings showed that there was not comprehensive knowledge of HIV/AIDS. For example, participants were asked about how HIV can be prevented: using condoms (77% confirmed knowledge); abstaining from sex (43%); sticking to one partner (46%); avoiding contact with blood, using gloves when touching blood (35%); not having sex before marriage (26%); not sharing toothbrushes (17%); using drugs to prevent mother to child transmission (17%); taking ARVs (17%); having fewer sexual partners (11%); and male circumcision (6%). Analysis of the data further revealed that gender, level of education and

geographical differences were key predictors for access to information and knowledge about HIV/AIDS among the disabled community.

From analysis of the findings from each of these studies, it is clear that PWD do not have comprehensive knowledge about HIV/AIDS to protect themselves from HIV infection. In the next section, I will explore the findings for studies that have addressed the same issues for deaf people. Since there was a paucity of information from the eastern and southern Africa region, I am drawing on global literature.

3.4.2   Deaf community

In 1992 it was estimated that the deaf population in America was about 8 years behind the hearing population in HIV knowledge and awareness (Bares, 1992). Two years later, in 1994, Time Magazine published an article in which Van Biema offered a stark warning: 'Thousands of deaf Americans have never learned the details about HIV and AIDS, and their ignorance is killing them' (Van Biema, 1994, p.76). In spite of these findings and very clear warning, five years later, in 1999, Gaskins noted that within the disabled community, deaf adolescents were found to have the most misinformation and the largest gaps in knowledge about the HIV/AIDS (Gaskins, 1999). And finally, Winningham et al (2008) discuss some of the lessons learned from more than two decades of HIV/AIDS prevention efforts and the implications for people who are deaf or hard-of-hearing. They confirm that there is an established body of evidence in the literature that suggests that persons who are deaf or hard-of-hearing score lower than hearing populations on tests of HIV knowledge. Essentially, the consistent message over the last two decades is that deaf and hard-of-hearing people do not have the same levels of knowledge about HIV as their hearing compatriots anywhere in the world.

The global published literature helps us understand what more we do know about HIV/AIDS awareness and knowledge levels in deaf people. Seven American studies (6 from North America and 1 from Brazil), and 4 studies from

Africa (2 from Nigeria, and 1 each from South Africa and Swaziland), show that an established body of knowledge suggests that whilst there is awareness of HIV/AIDS in the deaf community, there is also a lack of comprehensive knowledge. The review also shows that there are some subgroups in the deaf community that appear to be more disadvantaged, with less awareness and knowledge about the disease. Most of this evidence is based on findings from North American studies. Research has tended to be on the more educated, urban signing Deaf community, and little is in fact known about the more marginalized individuals who are outside of – or on the fringe of - the Deaf community.

Luckner & Gonzales (1993) undertook a study that included 240 secondary school students who were deaf or hard-of-hearing (109 male, 95 female), aged between 12 to 21 years from the Rocky Mountain region of the United States. Results from analysis of the questionnaires showed that although there was a general awareness, some knowledge and information gaps existed – for example, only 63% (*n*=100) correctly responded that condoms helped prevent AIDS. Males were significantly more aware than females that condoms help prevent AIDS. There were a number of findings that are of concern. These included: 70% did not realize that HIV/AIDS cannot be contracted by giving blood; 46% were unaware that all gay people do not have AIDS, and 62% thought that married people cannot get AIDS. The findings from this study suggest that the situation for the deaf community may be consistent with findings from HIV/AIDS awareness and knowledge studies in the broader disability community studies that found that comprehensive knowledge may be lower in the deaf and disabled populations.

Bisol et al (2008) reported on a study in Brazil that compared HIV/AIDS knowledge and health-related attitudes of deaf and hearing youth. Forty-two deaf students attending a special non-residential public school for the deaf and 50 hearing students attending regular public school, ages 15-21 years, answered a questionnaire on HIV/AIDS. The study confirmed that deaf youth have less knowledge than hearing youth about HIV/AIDS with only 47% of deaf

youth answering questions correctly about HIV. Interestingly, the deaf students were more likely than the hearing students to choose the alternative 'do not know'. There were also differences between the two groups in their answers to open-ended questions about HIV/AIDS prevention. For instance, the use of condoms was mentioned 45 times by the hearing participants and only 15 times by the deaf participants. The finding that the deaf students in this study were more likely to respond 'do not know' is important as it illustrates that the deaf participants were less likely to be confident in their answers.

A North American comparative study of sex knowledge among deaf and hearing college freshmen found that deaf college freshmen lag behind hearing college freshmen in nearly every aspect of sex knowledge examined (Swartz 1993). This study recruited 203 hearing college freshmen from the University of Maryland (*n*=75) and Loyola College in Baltimore (*n*=128) and deaf college freshmen at Gallaudet University (n=38). The results showed that the mean test scores on the SKI (Sex Knowledge Inventory[5]) was 80% correct for hearing participants. The mean score for deaf subjects on the SKI was 71% correct. This study challenges an observation made by Gaskins (1999) in which he suggested that one of the reasons that deaf people had less information about HIV/AIDS was because they are often isolated in communities. Whilst this may indeed be true for many deaf populations, the finding from this study with deaf college freshmen at Gallaudet University reinforces the fact that the reasons that deaf people have less information about the disease are likely to be a combination of different factors. Gallaudet is the world's only university, established in 1864, with programmes and services specifically designed to accommodate deaf and hard-of-hearing students. It is therefore highly unlikely that the reason that the deaf college freshmen in this study scored a lower SKI test result was because the participants were isolated.

Tripp & Kahn (1986) compared the sexual knowledge of 30 hearing impaired participants (11 men, 19 women; aged 25-81 years) with that of 30 hearing

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[5] SKI is a questionnaire developed by Swartz (1990).

participants (12 men, 18 women; aged 19-74 years). Participants completed a sexual knowledge questionnaire covering physiology, slang, general pregnancy and foetal development, contraceptives, and male and female anatomy. Findings showed that the two groups differed significantly: in each section, the hearing participants performed significantly higher than the hearing impaired students. Tripp & Kahn recommended that the adult deaf community was in need of sex education. The study's results are reconfirmed in the later Swartz (1993) study presented above in which it was suggested that it was not only HIV/AIDS in which deaf people may be lacking information, but also the broader subject field of SRH.

Bat-Chava, Martin & Kosciw (2005) undertook a study with groups of people with hearing loss in different regions of New York State. The study set out to investigate the knowledge about HIV/AIDS and barriers to HIV/AIDS education and prevention among deaf and hard-of-hearing people. Focus groups and individual interviews were used to elicit information. In total, 21 focus groups were conducted with 134 participants (74 female, 60 male). Themes elicited in the interviews suggested that deaf sign language users are less knowledgeable about HIV/AIDS than oral deaf and hard-of-hearing participants, and that deaf adolescents have more knowledge than deaf adults. This was a landmark study in the deaf community because it was the first time a researcher looked at the different communication or language groups within the deaf community in relation to HIV knowledge.

Peinkofer (1994), a social worker at the AIDS Center of the Rochester's Strong Memorial Hospital in America, wrote 'HIV Education for the deaf, a vulnerable minority' suggesting that large numbers of deaf and hard-of-hearing people in America are in danger of becoming infected with HIV/AIDS. Deaf people are particularly vulnerable, he suggests, because of (i) the language barriers; (ii) their unique culture; and (iii) the paucity of community services, education programmes and general information directed to this population. Peinkofer noted the barriers that deaf people face in learning about HIV protection range from inadequate schooling about human sexuality to the scarcity of locally

available education programmes outside the cities with high rates of HIV infection. Peinkofer's work helps guide this study in Kenya. Essentially, he observed a difference in knowledge levels about the disease in the deaf population between those deaf people who live in urban and rural areas, with rural deaf people having greater barriers to acquiring information about HIV/AIDS. Whilst my study in Kenya is in very different environments to those observed by Peinkofer, his study was the first to observe a difference in knowledge levels based upon geographical location.

Woodroffe et al (1998) investigated whether the public information being dispensed about AIDS reaches deaf and hard-of-hearing persons to the same extent as the rest of the American population. The study involved 40 deaf and hard-of-hearing and 37 hearing persons in southeast Michigan who were asked to complete a self-administered written survey. There were no significant demographic differences between the two populations but there were differences regarding attitude towards and knowledge about AIDS. Deaf and hard-of-hearing people were less likely to associate sexual contact with drug users and number of sexual partners as high risk sexual behaviours, were more likely to believe that storing blood for future personal use lowers their chances of contracting AIDS, and believe that using public restrooms, kisses on the cheek and visiting an AIDS patient increased their chance of contracting AIDS. Furthermore, they were more likely to believe they did not need to change their sexual behaviour as a result of the AIDS epidemic. Deaf or hard-of-hearing persons also held more negative views than hearing persons towards AIDS patients, such as those with AIDS were not important to the community, dentists with AIDS should not be allowed to continue working, and landlords should be able to evict people with AIDS. Their findings suggest differences in receiving, trusting and/or being exposed to current information about AIDS by deaf people. The finding that the deaf and hard-of-hearing participants scored lower on tests to determine HIV levels of knowledge reinforces all the earlier studies. However, this was the first study to explicitly expose any stigma and prejudice against PLWA by deaf people. These stigma findings are indicative of

the lack of information and knowledge, and the fear of the disease that is manifested in some prejudicial attitudes.

Studies regarding the levels of HIV/AIDS awareness and knowledge levels in the deaf populations in Nigeria, South Africa and Swaziland have been drawn upon to set out what research informs us about deaf populations in Africa. All four studies confirm awareness and a lack of understanding of the disease, its pathology and progression.

Groce et al (2006) undertook a study in Swaziland to determine whether there were any measurable differences in the level of knowledge about HIV/AIDS between hearing individuals and individuals who identified themselves as deaf sign language users. The study involved 191 rural and urban hearing and deaf adults. A structured questionnaire was administered to establish whether there were any statistically significant differences between hearing and deaf populations in their level of knowledge about HIV/AIDS symptoms, transmission and prevention, as well as differences in sources of information about HIV/AIDS. Additional questions were asked regarding differences in accessibility of HIV testing services and HIV/AIDS-related healthcare for the two groups. Significant differences in levels of knowledge about HIV/AIDS were identified between the hearing and deaf respondents with the deaf population significantly more likely to believe in incorrect modes of HIV transmission and HIV prevention. This study confirms findings from earlier studies in America that inform us that deaf people appear to have less knowledge about HIV/AIDS. It is interesting to note here that the deaf participants in this study were all sign language users.

Groce, Yousafzai & Van Der Maas (2007) undertook a study in Nigeria where there was an adult HIV prevalence rate of 5.4%. The aim of the study was to compare HIV knowledge among deaf and hearing individuals in order to inform how effectively deaf members of the community are being reached by HIV/AIDS messages. The study involved deaf and hard-of-hearing adolescents (*n*=50) and young adults (*n*=50). The deaf and hard-of-hearing participants were recruited

from two schools for the deaf in two states. Of the deaf participants, the majority (n=40) were still attending school, while a small number (n=10) were either graduates or dropouts. The comparative hearing population (n=50) was recruited from the same towns at random in the market place where every third person was asked to participate. The results showed that there were significant differences in levels of understanding about certain aspects of HIV transmission – for example, kissing (deaf & hard-of-hearing 44% vs. hearing 20%), touching (deaf & hard-of-hearing 42% vs. hearing 10%), and transmission due to dirty environment (deaf & hard-of-hearing 30% vs. hearing 4%). The deaf and hard-of-hearing respondents were also significantly less likely to be familiar with the possibility of mother to child transmission [of HIV] (MTCT) (deaf & hard-of-hearing 52% vs. hearing 74%).

A study in Nigeria of deaf and people with leprosy also found evidence of misunderstandings and misconceptions about the disease. Some participants believing because they had leprosy, they were protected from HIV infection. It was also found that some participants were of the opinion that testing them for HIV would mean wishing them the infection (Enwereji & Enwereji, 2008).

De Andrade & Baloyi (2010) found that participants in their South African study appeared to have basic knowledge about HIV and AIDS with an understanding that prevention through abstinence or use of condoms could limit HIV transmission; however, gaps in their knowledge were shown by a belief that touching people with HIV or AIDS, or that 'rejecting' a person who was possibly HIV positive was a preventive measure and confusing HIV with other illnesses (e.g., cancer). These results were obtained from interviewing 7 adolescent South African sign language users (aged 15-21 years) who were attending a school outside Johannesburg for hearing impaired learners from lower socioeconomic backgrounds.

Review of the literature in this section included seven American and four African studies of HIV/AIDS and deaf populations. All the studies confirm that whilst there is awareness of HIV/AIDS in deaf populations, there are gaps in

knowledge. Furthermore, evidence from North America suggests that there are subgroups in the deaf community that are more disadvantaged in terms of HIV/AIDS knowledge. The next section in this analysis will consider the situation in Kenya.

3.4.3 Kenya

Before exploring awareness and knowledge levels about HIV/AIDS in the deaf community, it is important to establish a benchmark for the wider hearing society from which comparisons can be made. In this regard, respondents interviewed in the 2008-09 Kenya DHS were asked whether they had heard of an illness called AIDS. Those who reported having heard of AIDS were then asked a number of questions about whether and how AIDS could be avoided.

Ninety-nine percent of women and 100% of men aged 15-49 reported having heard of AIDS (Government of Kenya/Kenya National Bureau of Statistics & ICF Macro, 2010). There is no data for PWD in the DHS; however, HI (2007) found that awareness of HIV/AIDS amongst PWDs in Kenya was 91%. In the DHS, the only groups for which the level of awareness of AIDS fell below 98% were women and men with no education (women 94%, men 96%) and women in the lowest wealth quintile (97%) (Government of Kenya/Kenya National Bureau of Statistics & ICF Macro, 2010). According to this available data therefore, PWD would constitute one of the least aware of AIDS groups in the country.

In the DHS, respondents were also asked a series of questions to determine whether they have 'comprehensive knowledge' of HIV/AIDS. Comprehensive knowledge was defined as knowledge that (i) consistent use of a condom during sexual intercourse and having just one uninfected faithful partner can reduce the chance of getting the AIDS virus; (ii) knowing that a healthy-looking person can have the AIDS virus; (iii) and rejecting the two most common local misconceptions about AIDS transmission or prevention (mosquito bites and sharing food). In analysing the results to this question, it was found that knowledge about AIDS transmission among women and men aged 15-49

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residing in rural areas is lower compared with knowledge among urban counterparts.

Table 3.1: **Knowledge about HIV/AIDS transmission, presented by gender & location (Government of Kenya/Kenya National Bureau of Statistics & ICF Macro, 2010)**

	Urban (%)	Rural (%)
Men	70	51
Women	62	44

62% of women in urban areas (*n*=2,148) have comprehensive knowledge about HIV/AIDS compared with 44% of their counterparts in rural areas (*n*=6,296). Similarly, 70% of men in urban areas (*n*=866) have comprehensive knowledge about HIV/AIDS compared with 51% of those in rural areas (*n*=2,392) (Government of Kenya/Kenya National Bureau of Statistics & ICF Macro, 2010).

In order to develop a more comprehensive understanding of the situation of deaf people in Kenya, I have first drawn on two available published journal articles that specifically address knowledge levels of HIV/AIDS in the deaf community in Kenya. These studies reveal that deaf Kenyans are neither universally aware of HIV/AIDS, nor do they have an entirely comprehensive knowledge about the disease.

In the first, Nyang'aya (1998) found that campaigns against HIV/AIDS in Kenya had failed to address the communication needs of the deaf community. In 1998, Nyang'aya warned, 'Greatly bypassed by the information on AIDS, there is danger that the deaf Kenyan community will be wiped out by the epidemic because of the many obstacles' (1998, p.20). Among the obstacles, he lists: (i) the use of English language in literature on HIV/AIDS; (ii) the lack of KSL interpretation; (iii) exclusion from services – for example, telephone hotlines for counselling services. All of these obstacles exist because of the unique language and communication needs of the deaf community, and society's failure to address these needs.

The second study, Girois (2004, cited by Hanass-Hancock & Satande (2010)) revealed that although 80% of the deaf respondents (*n*=250) in the study were aware of HIV/AIDS and its transmission through sexual intercourse, some still believed in false modes of infection: biting of mosquitoes (41%), kissing (39.6%), and sharing of eating and drinking utensils with HIV positive persons (26.4%) as possible ways of transmission. In other words, there was neither universal awareness nor comprehensive knowledge about the disease. Nyang'aya's earlier observation that HIV/AIDS information was 'by-passing' the deaf community seemed to still hold true at the time of this study for many in the deaf community.

In this chapter, I have reviewed 5 PWD studies from Africa and 11 global deaf studies. The conclusion from this examination of the literature is that deaf people have less awareness and knowledge about HIV/AIDS than their hearing compatriots. Furthermore, there is some evidence from the United States to suggest that different subgroups in the deaf community have varying levels of HIV awareness and knowledge. Peinkofer (1994) observed that urban deaf people had greater access to HIV/AIDS information than rural deaf people; and Bat-Chava, Martin & Kosciw (2005) discovered that HIV knowledge in sign language users was less than oral deaf or hard-of-hearing groups in New York State.

There is a paucity of information about deaf communities in Africa, and particularly regarding the more marginalized deaf individuals who are less proficient in signing and more isolated, and who typically live in rural areas of the continent. One study undertaken by Girois, and cited by Hanass-Hancock & Satande (2010), informs us that having surveyed 250 deaf individuals from across Kenya, there was 80% awareness of the disease at that time. However, this study was completed over 10 years ago and was very broad and did not consider the nature of complexity of context for the deaf community. This therefore prompts us now to consider the deaf community in more detail to determine which subgroup(s) within the community are particularly at risk, and why, since as Kennedy & Buchholz (1995) suggest, it is wrong to consider the

deaf community as one homogenous group. Following the observations of Peinkofer (1994) and Bat-Chava, Martin & Kosciw (2005), urban/rural and signing/non-signing were identified as subgroups from which to start the investigation in Kenya. In addition, it is expected that findings from this study could help address the challenge set by the KASF to identify particular groups for special attention.

3.5 The Study

3.5.1 Broad aim

The aim of the study is to improve the SRH services for deaf Kenyans.

3.5.2 Research question

- How much do deaf Kenyans (aged 18-35) know about HIV/AIDS compared to their hearing compatriots in Western Region, Kenya

3.5.3 Specific objectives

1. To explore deaf young people's access to information and services related to SRH (including HIV/AIDS) in Western Region, and to compare findings with the knowledge base of their hearing peers.

2. To investigate the role of language, communication, isolation and Deaf culture, as well as geographical location and gender upon awareness and knowledge of HIV/AIDS.

3. To establish baseline data from which future studies on SRH information and services (including HIV/AIDS) for deaf young people in Western Region can be compared.

3.5.4 Justification of the research question

Evidence from all studies reviewed clearly shows that deaf people have less awareness and knowledge about HIV/AIDS than the hearing majority. In

addition, the review also revealed that there is a dearth of information about the deaf community in Kenya. The research question therefore sets out to fill this gap in knowledge to establish awareness and knowledge levels about the disease in Western Region in Kenya, with a particular focus to explore evidence of any subgroups within the deaf community. As the discussion progresses, I will draw upon published literature to develop understanding.

3.5.5 Positionality

Singleton, Martin & Morgan (2015) address a range of important issues where hearing and deaf researchers work together. One key recommendation is upon reflection in this kind of collaborative research. Kennedy & Buchholz (1995) suggest that in order to appreciate the magnitude of HIV-related problems facing the deaf community, a researcher needs to gain insights into the deaf community and deaf culture. Harris, Holmes & Mertens (2009) emphasise the precondition of researchers having credibility within the community in which they are carrying out the research. They define credibility as researchers who are Deaf and/or have trusted and verifiable cultural competence to engage in research alongside, with and for deaf people. In response to these suggestions, I feel I need to set out my connection to Kenya, and particularly the deaf community, that has enabled me to do this study.

One of my initial concerns in undertaking this research was the fact that I am clearly an 'outsider' since I am neither deaf nor Kenyan. The main criticism of 'outsider' research is its tendency to produce knowledge or interpret societies from a position or location of power and privilege, and in most cases without sufficient input from local people (Agar, 1980; Grafanaki, 1996). Initially, I tried to counter this belief by considering my background, experience and attachment to Kenya.

I lived in Kenya and worked in public health and adult education for 20 years. More specifically, I have worked around HIV prevention with vulnerable groups in both the NGO and UN sectors. Vulnerable groups have included drug abusers,

prisoners, young people, orphans, PWD and deaf people. I have a long and established connection with the deaf community - I trained as a KSL interpreter at the University of Nairobi and as an HIV counselling and testing provider with LVCT Health. I have been interested to learn and appreciate the language and culture of the deaf community and I hope that this history has enabled me to build up trust that is so essential to this type of investigation. In addition, an old article – but one that I found particularly useful - by Baker-Shenk & Kyle (1990) helped me reflect upon my position and standing with the Community (Appendix 2).

3.6   Conclusion

This chapter has shown, with evidence provided from the current discourse on disability and HIV/AIDS in published literature, that PWD - including deaf people - have less awareness and knowledge about HIV/AIDS compared to their non-disabled and hearing compatriots.   Furthermore, there is emerging evidence of subgroups in the deaf community in North America that have varying levels of awareness and knowledge about the disease. However, little is known about the subgroups in the deaf community in Africa. The next chapter will outline the methodology and methods adopted in this study to address the aims, objectives and research question that have been presented in this chapter.

Chapter 4 Methodology & methods

4.1 Introduction

This chapter presents the methodological approach to the study. It briefly considers the justification behind adopting grounded theory methodology, using a semi-structured questionnaire that incorporates quantitative and qualitative approaches. It also imparts the process and methods used in the collection and analysis of data in this study.

4.2 Research methodology

Broadly speaking, this investigation seeks to explore how much deaf Kenyans know about HIV/AIDS compared to their hearing compatriots in Western Region, Kenya. The literature review concluded that there is a general dearth of information about the SRH needs of the deaf community in Kenya, and especially regarding any subgroups that include the harder-to-reach deaf individuals. It was decided that to best address this research question, an exploratory qualitative approach established in grounded theory was the most suitable type of enquiry.

There are a number of reasons in the literature to support the rationale of adopting grounded theory methodology in this investigation.

Firstly, many studies have highlighted that deaf people have less awareness and knowledge about HIV/AIDS than hearing people. However, upon closer inspection of the findings, it can be seen that many of these studies and their findings are centred upon deaf people in capital cities of larger urban areas where the deaf participants are connected to and part of a deaf community. However, little is really known about the situation and needs of the larger population of isolated and harder-to-reach deaf people who typically live in rural areas of developing countries like Kenya. Considering Crooks's (2001) proposition that grounded theory is ideal for exploring integral social relationships and the behaviour of groups where there has been little

exploration of the contextual factors that affect individual's lives, grounded theory methodology is appropriate for this study.

Secondly, my experience and background in this field have encouraged me to undertake this investigation with the supposition that deaf people have less awareness and knowledge about HIV/AIDS than hearing people, and that deaf people without access to signed or spoken language are more at risk of HIV infection than their signing deaf compatriots. These thoughts will be considered and explored in this study from data collected directly from these communities themselves. Since grounded theory is defined as 'the discovery of theory from data systematically obtained from social research' (Glaser & Strauss 1967, p.2), it can be further be argued that grounded theory is the most appropriate research methodology for this investigation because the study will be undertaken with data collected directly from what is happening on the ground in communities.

Glaser (1978) recommends using grounded theory to get through and beyond conjecture and preconception to exactly what the underlying processes of what is going on, so that professionals can intervene with confidence to help resolve the participant's main concerns. Since a key partner in this investigation is KNAD and one of their main interests in undertaking this study is to be able to take findings to supporters of the deaf community to help raise attention, resources and interventions to support deaf people that have not typically been reached in earlier programmes, grounded theory would therefore appear to be the most apt methodology to best meet this additional aim of the study.

It is the subjective levels of understanding of HIV/AIDS by the deaf community that is the crux of this study. Taking the interpretivist's stance and through the deployment of an appropriate research instrument, my role as the researcher is to grasp the meanings and patterns behind people's behaviours and actions in relation to what they know about HIV/AIDS and how and why they behave the way they do. My role is not to test anyone for HIV or investigate anyone's HIV status to establish prevalence rates.

4.3 Research strategy & study design

Glaser (2001, p.145) famously said, 'All is data'. In saying this, he is essentially encouraging researchers who use grounded theory methodology to adopt a flexible research design to allow more freedom during the data collection process. In collecting data from different sources, he argues, the researcher will develop a deeper understanding, and therefore, a better, more accurate and valid theory will result.

The chosen design, whilst essentially qualitative-based, comprised mixed methods, incorporating both quantitative (questionnaire) and qualitative data collection (interview) components that were contained in a semi-structured interview with participants.

By administering a questionnaire, levels of knowledge can be established, compared and contrasted. For such questions to establish the facts or information levels that participants have about HIV/AIDS, McCoubrie (2004) advises that multiple-choice questions are a good way to determine knowledge levels. However, for this study, with its broader aim to explore people's access to information and services coupled with the role of language, communication and deaf culture upon awareness and knowledge, a mixed methods design was required. This is because whilst multiple-choice questions can test factual knowledge, they do not provide the in-depth details and context that can better explored through a discussion.

4.4 Selection of participants

This study focussed on 4 groups of people: hearing and deaf young people in urban and rural areas in Western Region, Kenya.

A clear and detailed inclusion and exclusion criteria for research participants was developed in consultation with KNAD. Initially the plan was for the study participants to be aged 15-30 years. However, in the early stages of the study, due to industrial action by the teaching union, there was some interruption to

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the school teaching programme mid-2012. This coincided with the early stages of the data collection and meant that some of the anticipated younger participants were not available to be interviewed because the school holidays had been shortened to make up for lost class time during the strike action. After consultation with my supervisor and with support of the study advisory team, the research protocol and plan was amended. The modified age range of 18-35 years was adopted to better reflect the actual ages of participants who could be engaged in the study. This age range, 18-35 years, became consistent with the definition of youth as set out in the recently promulgated Kenyan Constitution. The aim was always to have a gender balance between male and female participants.

4.5 Sampling: Purposive with snowball technique

In designing this research project, some thought had to be given about the sample size. The study is explorative in nature and the precise number of interviews would be determined by when I felt I had reached saturation, with no new data coming from participants. I trusted that by combining the process of sampling, data collection and data analysis during the fieldwork stage of the project, I would be able to gauge when saturation had been reached. However, I needed to plan the data collection phase, and there were obvious time and financial restrictions. I therefore decided to search the literature for some guidance regarding optimum sample sizes for this type of investigation.

The UK's National Audit Office suggests that a sample size of between 50 and 100 should ensure that results are sufficiently reliable; although 30, they suggest, may also be sufficient (National Audit Office, 2001).

Baker and Edwards (2012) gathered and reviewed responses to the 'how many' question from 14 renowned social scientists and 5 early career researchers and wrote a methodological paper entitled, 'How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research'. The riposte answer from many respondents to this

question was 'it depends'. However, other responses recorded in this paper helped guide me through the design process. Becker suggests that a single interview is adequate to establish if something is possible; and a few to demonstrate that a phenomenon is more complex and varied than previously thought. Brannen and Becker warn that a small number of interviews may not enable the researcher to compare groups however. Adler and Adler advise graduates to sample between 12 and 60, with 30 being the mean; and Ragin notes that students are often guided by, '20 for an M.A. thesis and 50 for a PhD. dissertation' (p.33). Flick acknowledges that whilst the inside determinants of projects (methodological and epistemological considerations) should be more important in answering the question of 'how many?', it is often the outside factors that play a more central role.

Finally, I decided that a sample size of 50 hearing and 50 deaf young people in both urban and rural areas – a total sample size therefore of 200 young people – would probably be sufficient to address the research questions. I was, however, flexible and knew that I would be guided during the research data collection process and constraints of time and money.

Since this study is focused on a very specific population with distinct characteristics, purposive sampling, using a snowballing technique, was chosen.

Sadler et al (2010) inform us that snowball sampling was conceptually designed as a sample recruitment method that offered a way to overcome many of the recruitment challenges associated with inviting difficult-to-reach communities. In the process of this review, I became aware that there could also be marginalized, hard-to-reach groups within the deaf community that might not be reached if I did not take measures to ensure they were included – for example, deaf isolates who were detached from the local deaf culture and community. If deaf isolates are not known by other deaf people, there would clearly be limitations in adopting a sampling recruitment strategy like snowballing that is dependent upon the research participants knowing one another. For deaf people who were connected to other deaf people, a

snowballing technique offers the potential to recruit them in an appropriate, culturally sensitive and effective way. However, extra efforts and time were needed to engage deaf isolates. Very often, deaf isolates were reached through engaging with both deaf and hearing communities whereas deaf-signers were reached through networks in the deaf community.

Initially the plan was to have KNAD (the 'Connector') provide a list of 100 urban and rural deaf people who met the selection criteria. The literature on snowballing sampling warn that in this process, there is the potential for bias – for example, the sample might include an over-representation of individuals with numerous social connections who share similar characteristics (Magnani et al., 2005). In this instance, it would mean over-representation of deaf people who were known to KNAD. To address any direct influence on participant selection from a list, and after consultation with my supervisor, it was decided that individuals from this list would be randomly selected for inclusion in the study. This would be achieved by using the random selection function in MS Excel. Thereafter, adopting the snowballing technique, each of these participants (the 'Source' or 'Seed') would be asked to provide contact details of other people in their community who meet the inclusion criteria until a chain of 3 was met. The hearing participants would be selected from neighbouring homes within the same community as the deaf participants. However, in practice this strategy had to be adapted because KNAD did not have an up-to-date register of deaf people in Western Region.

The snowballing recruitment strategy was therefore adopted for this study. The strategy worked through deaf networks and by word of mouth. Sadler and colleagues (2010) acknowledge that there are times when the initial 'connector' (KNAD) might not need to make direct contact, but instead will use their authority to convey approval that the information be shared. Sadler et al (2010) found some advantages to this process and they were borne out in this study. Essentially, KNAD introduced me to a deaf organization in the study area, the Western Kenya Deaf Development Group, who became a key partner in the process. They were very engaged, active and supportive as they had an

appreciation of the value of spreading information about the study and the importance of participation to their community members.

In practice, a representative from the Western Kenya Deaf Development Group and I travelled to a study area in advance of our data collection visit, and got in touch with someone from the local GoK administrative structure and deaf community. These individual contacts were first given information about the study and plans were made regarding a timetable for returning to do the interviews. After introduction and engagement with a local deaf person had been established, they were asked to pass the information along to other deaf individuals whom they knew and for whom the information might be relevant. We stressed the importance of reaching deaf people who were 'off the beaten track' and not just recruiting those who resided in the immediate vicinity or area that we had visited. Information given was about when and where the semi-structured interviews would take place. Deaf participants were asked to come with a hearing friend or neighbour who was of the same gender and age.

Sadler et al (2010) warns that one limitation of snowball sampling is the fact that there is no statistically reliable way to estimate whether 'saturation' of the sample has been reached. This is particularly important in qualitative research because, in that body of work, 'saturation' is defined as when no new information is forthcoming from the participants in the sample that has been recruited already. Therefore, it is not possible to know whether new or other information could be gleaned had a random sample been recruited. In view of the limited time available, guided by the Baker and Edwards (2012) discussion, together with the UK Audit Office recommendation, and after agreement of the study advisory team and consultation with the Kenyatta University (KU) Ethics Committee, the research protocol and plan was amended so that the sample size for the study readjusted to include 40 urban deaf, 40 urban hearing, 40 rural deaf and 40 rural hearing. The objective in designing the research in this way was to reduce the chances of discovery failure by cutting the sample size any more, as warned by Sadler and colleagues (2010).

4.6   Study area

4.6.1   Statistical information

The study area was Western Region, Kenya.

Figure 4.1:   Map of Western Region, Kenya

(Google Maps, 2016)

This region was chosen because it has both high concentrations of HIV prevalence and high numbers of PWD and hearing-impaired people in the country (Government of Kenya/Kenya National Coordinating Agency for Population and Development, 2008; Government of Kenya/Kenya National Bureau of Statistics and ICF Macro, 2010).

Table 4.1:   Prevalence of disability and hearing impairment in Western Region (Nyanza & Western Provinces) (Government of Kenya/Kenya National Coordinating Agency for Population and Development, 2008, p.8)

	Nyanza	Western
Prevalence of Disability (%)	6.8	3.3
Prevalence of Hearing Impairment (%)	0.8	0.7

Table 4.2:   HIV/AIDS prevalence rates for the 10 counties of Western Region (NACC & NASCOP, 2014, p.5)

County	HIV Adult Prevalence Rate (%)
Bungoma	3.5
Migori	13.4
Siaya	17.8
Kisumu	18.7
Homa Bay	27.1
Kakamega	5.6
Vihiga	6
Nyamira	6.9
Busia	7.1
Trans Nzoia	7.2
Kisii	8.9

The precise study areas in the region were guided by study advisory team and included a range of different communities from across the region, including one area with a concentration of deaf people near a Deaf school in a rural area (Rongo). Guided by the findings from Bat-Chava, Martin & Kosciw (2005) that the presence of the National Technical Institute for the Deaf in Rochester, New York, meant that local deaf communities were better exposed to information about HIV/AIDS, the study advisory team decided to explore a deaf community near a Deaf school in this study region to see if there was any impact created by the presence of a deaf educational institution in this context.

The predominant ethnic groups of people are the Luhya and Luo. These communities include different clans and sub-clans, many of whom speak different vernacular languages.

4.6.2 Negotiating access

The Kenyan co-researcher partner organisation was KNAD and the academic partner was the Special Needs Education Department at KU.

The decision to partner with KNAD was in an attempt for the Deaf community, through its own administrative structure, to benefit as much as possible from this study's process and outcomes. There is some literature to support this incentive. Dalrymple and Burke (1995) suggest that researchers who consider research participants as true partners are an essential component of cultural sensitivity and a crucial element in anti-oppressive practice. This is also borne out by Patel (1999) who recommends that to improve sensitivity, researchers should always consult members of the community or group to be studied while being aware that minority ethnic groups are not homogeneous nor can their members be entirely representative of all those belonging to their community.

Harris, Holmes & Mertens (2009) advise that in Deaf-friendly research, the Deaf community should be considered as hosts or gatekeepers and the researchers as visitors. Furthermore, they recommend that the Deaf community should be

collaboratively involved in the design, decision-making, and monitoring of research projects from beginning to end.

Hall (1975) explains that a research process should be of some immediate direct benefit to a community and not merely the basis for an academic paper. This means, for example, that the young people, the participants, should – as a result of participating in the research process – be more able to articulate problems themselves and to initiate the process to find solutions. It was with this in mind that this study was conducted in partnership with KNAD and overt access was employed so that the deaf community were fully informed and engaged in the investigation. My aim throughout was guided by Singleton, Martin & Morgan (2015), who said that in community-engaged research, Deaf people are seen not only as informants but also as collaborators.

The Kenya National Council for Science and Technology (KNCST) made the necessary introduction to the GoK's County administrative structure and personnel in Kakamega and Kisumu. Meetings were held with the relevant authorities and time taken to explain the aims and objectives of the study. A leader from the Western Kenya Deaf Development Group accompanied me to each of these meetings and the reception was always very positive and helpful.

4.6.3   Study advisory team

KNAD were a co-researcher and involved in the study from the outset. My decision to embark on this study was in fact guided by the connection and input I had from KNAD and people in the deaf community when I was employed and working in Kenya. At a very early stage, the roles of each partner were agreed to establish and ensure that equal and consistent partnership was achieved.

A study's advisory team was created and included representatives from KU, Leonard Cheshire Disability (LCD) and KNAD. One of the main aims of this body was to foster teamwork between UCL and Kenyan colleagues to ensure consensus in decision-making and to strengthen partnership and ownership of the project. In Kenya, collaboration was fostered through meetings. At other

times, when I was in the UK, communication was maintained through email, Skype and SMS to ensure that all members of the team were fully informed and participating throughout the study.

4.7 Study approval and ethical issues

4.7.1 Ethics approval

Singleton, Martin & Morgan (2015) are interested in how researchers can work best with Deaf people, Deaf schools, Deaf children and families, and other professionals who work in the area of deafness. They advise that research funding agencies expect ethical compliance, good quality dissemination, and knowledge exchange, as well as evidence of how the research will actually make an impact on the everyday lives of the participants and on wider society.

Ross et al (2010) advise that researchers – regardless of their discipline - who include Deaf participants in their research to conduct their investigations in an ethical manner, protecting the integrity of their research and the individual rights of the participants regardless of age, ethnicity, cultural and linguistic background and respecting and protecting the Deaf community by understanding broader concerns of community-engaged research.

In research, special attention must be given to assuring adherence to national and international ethical guidelines (Brody, 1998; Claudot et al, 2009). Since the study was in Kenya, both the British and Kenyan guidelines had to be followed and standards maintained throughout. In this regard, the research protocol was approved by the Research Ethics Committees at UCL (3600/001) and KU (PKU/046/E06). Once ethics approval was granted, a research license for 3 years was secured from KNCST.

Both Ethics Committees, as well as the KNCST, had their own procedures and reporting guidelines that were adhered to throughout.

4.7.2   Ethical issues

Voluntary participation

Participation in the study was entirely voluntary. There was no financial remuneration for involvement in the study. However, in the early stages of the investigation, some participants started to complain that they had expended their time, and sometimes money for transport, to participate in the study. After consultation with KNAD and the research advisory team, it was decided that it would be fair and best that participants should be given something to acknowledge their time and commitment to the study. It was therefore deemed an appropriate goodwill gesture that participants be given a soda and some cake.

Informed consent

Participants were informed of the purpose of the study (i.e., research project for a PhD thesis and the broader aim of improving the SRH services for deaf young people in Kenya) and the rights of each participant explained. This information was contained in the 'information sheet' that was explained fully – in spoken or signed languages - and left with everyone who participated in the study (Appendix 6).

Singleton, Jones & Hanumantha (2014) discuss the importance of offering informed consent documents translated into the deaf individual's native sign language in order to ensure comprehension for deaf participants with limited spoken or language proficiency. To be more as inclusive and culturally appropriate as possible, the informed consent procedure was translated into sign at the start of each interview with deaf participants. In some instances, where the deaf participant was not proficient in KSL, the support of a member of Western Kenya Deaf Development Group was called upon to translate. There is a body of literature that includes work by Young et al (2006) that notes that not everyone has had experiences of autonomy and rights, nor necessarily possesses the self-esteem, to enact personal choices like deciding to participate in a research study or not. It was with this in mind that a member of the

Western Deaf Development Group accompanied us on data collection trips to help support us in the consent procedure.

Special permission had to be granted by the KU Ethics Review Committee to video the deaf interviews because of the additional concerns about anonymity and protection of participants. This was consistent with previous work by Roald (2002), and Singleton, Jones & Hanumantha (2014) and was necessary because of the fact that sign is a visual language and therefore participants could easily be identified if the tapes got into the wrong hands. A signed consent form to participate and be recorded/filmed was requested from each participant (Appendix 7).

Confidentiality and anonymity

The protection of confidentiality and anonymity of the participants was a priority throughout this study[6].

Discussions were held with the study advisory team as to how best ensure that all participants were safe and in no harm as a consequence of participating in the study. In this regard, a number of measures were taken to ensure the confidentiality and anonymity of participants. Confidentiality was assured in that no names of participants have been revealed in any report or dissemination of data. Recordings and field notes were stored in a safe place. Recordings were destroyed after the interviews had been translated. Furthermore, at no time was or will any video material be made available for public use or incorporated into any presentation of the research findings.

Support

Discussing issues related to HIV/AIDS could have been an upsetting experience for some participants. Whilst this study did not ask any participants directly to divulge their HIV status, it was felt that we should be ready to support

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[6] While all the information presented in this thesis is as it was relayed to me, some names and identifying details have been changed to protect the privacy of the people involved.

participants as much as we could. In this regard, a list of contacts for professionally trained personnel who could offer participants further information and support was contained in the information sheet.

4.8 Methods of data collection

For this study, primary data was generated through formal semi-structured interviews, focus group discussions, field notes and informal conversations during the two phases of data collection, and secondary data generated from the literature review.

4.9 Preparation for primary data collection

4.9.1 The semi-structured interview

There are a number of reasons why semi-structured interviews were used in this study. Cohen, Manion & Marrison (2007) explains how semi-structured interviews allow participants and interviewers to discuss their interpretation of the world in which they live and to express how they regard the situations from their point of view. Walker in Ritchie & Spencer (1994) informs us that this data explains why participants behave in the ways that they do, to describe 'the world view' (p.174). At first reading therefore, this seems to fit the demands of the semi-structured interview in this study. However, in this particular study, there was another requirement relating to flexibility and adaptability. Drever & Scottish Council for Research in Education (1995) outlines that semi-structured interviews are a technique that has an inherent flexibility.

Mall (2012) cited research by Storbeck, and Storbeck, Magongwa & Parkin that found the low levels of literacy in the deaf and hard-of-hearing communities in South Africa meant that she adopted joint interviews and focus groups discussions as opposed to a self-administered questionnaire for her enquiry with the deaf community in that country. For this study, it was decided that collecting data through individual semi-structured interviews as opposed to joint interviews or focus group discussions was preferable because participants

in this study would have very different levels of communication as a key focus of this study was in reaching isolated deaf people living in more remote areas of the country. The concern being that a group discussion of deaf people might not create equal opportunities for everyone to participate as group conversation would inevitably suit the more competent signers who could dominate the communication.

One example from this study highlights how the process had to be adapted for one participant who was not very familiar with KSL, but who did, however, know some homesigns. For this interview, it was necessary to have a team of interpreters (relay interpreters) whereby I voiced the questions in English, they were translated into KSL (by the KSL interpreter), then on into homesigns for the participant to respond to (by a signing Deaf person from the Western Kenya Deaf Development Group). The response was then translated back along this line of communication for me to record and note. It should be noted that the interpreter/research assistant was not able to communicate in homesigns. There were some instances where I called upon the assistance of a deaf member of the study advisory team to look at some video clips help confirm the accurate translation of some homesigns.

In preparation of this study, a general structure was established in advance that set out the ground to be covered and the main questions to be asked during the semi-structured interview. However, the detailed structure was left to be worked out during the interview so that both the interviewer and person being interviewed had a fair degree of freedom in how to communicate, what to talk about, how much to say, and above all, how to say it. The role of the interpreter in this process was to transfer meaning between languages: English and sign language; English and Kiswahili. The key domains to be asked, however, related to the participant's background socio demographic personal data (age, gender, hearing status, language, information about family background); education; employment; income; social networks & support; and knowledge and perceptions about HIV/AIDS (sources of information, transmission and prevention, testing). The other areas of focus in the semi-structured interview

were guided by key issues identified during the literature review for this study and included: poverty, language, self-esteem, lack of education, lack of HIV information, deaf sexuality, sexual abuse, substance abuse, stigma, health care, deaf culture and the criminal justice system.

Initially, the plan was to interview deaf people in their homes. However, in the interests of time and money, it was decided that a more efficient and effective way to conduct the interviews would be to convene the meetings at venues that were more central and accessible to reach more deaf people in a shorter amount of time. Venues included local primary schools, churches or other community buildings identified by the local GoK administrative officers or Chiefs.

The interviews were conducted in English, Kiswahili, KSL or homesigns. In this way, the participants were able to use the language that they were most comfortable with to communicate without compromising the validity and reliability of their responses as a result of communication barriers and different literacy levels (Peinkofer, 1994; Doyle, 1995; Bat-Chava, Martin & Kosciw, 2005). Most interviews lasted approximately 1 hour; however, for those participants that could not communicate in KSL, the interviews were shortened or were simply abandoned because there was no communication.

Some interviews were facilitated by me, and others by the interpreter/research assistant. The rationale for two facilitators was to address any form of bias or influence by having only one interviewer and to facilitate the generation of more complex data in having two. In this way a deeper understanding of the issues emerged thereby improving the quality of the study (Liamputtong & Ezzy, 2005). In sharing the facilitation roles, 'investigator triangulation' (Patton, 2002) was achieved. Denzin (1989) has noted the challenge in triangulating data in qualitative studies and suggests that whereas in more scientific quantitative studies triangulation refers to accuracy of data, in qualitative studies, a more appropriate interpretation of the concept could be to improve understanding.

4.9.2 Development of the questionnaire

The framework for the study's semi-structured interview centred around a questionnaire that was developed and used by Yousafzai AK, Dlamini PJ, Groce N, Wirz S (2004), *Knowledge, personal risk and experiences of HIV/AIDS among people with disabilities in Swaziland*, International Journal of Rehabilitation Research, Vol 27(3), 247-251. Since this original questionnaire was developed, it has been adapted and used in Cameroon, Haiti, Jamaica, Nigeria and South Africa. However, for the development of this survey instrument, reference was made to the original questionnaire that was used in Swaziland. Some of the questions were relevant to this study and were incorporated into the semi-structured questionnaire (Appendix 3). Others were expanded or left out altogether. The questionnaire that was developed in this way was a draft instrument that was ultimately reviewed by the study advisory team in Kenya and piloted in the field. In addition, once the data collection had started, some additional questions were added to the instrument – for example, in exploring communication options, it became important and necessary to know when participants became deaf (pre- or post- lingually). The questions that were added to the research instrument are contained in Appendix 4.

4.9.3 Topic guide

It was important to develop a topic guide for the interviewer to ensure that correct, consistent and comparable procedures were followed during the investigation.

The Guide outlined how to do the introductions; give information about the study and consent procedures; administration of the research tool (questions, prompts and probes); as well direction on how to conclude and round up the interviews (Appendix 5). The Guide also authorised the interviewer the flexibility to change the direction of the interview – for example to follow up on any noteworthy issues that emerged during the interview. In addition, because of the difference in the participants' communication skills and language

proficiency, the Guide also allowed for the rewording or restructuring of questions to elicit responses from participants.

4.9.4   Reflexivity

Chambers (1983) explains that qualitative research is an approach that offers an opportunity to explore social relationships such as reciprocity, dependence and exploitation, amongst others to gain an insight into the lives and conditions of different people in society. It provides a deep and rich insight into the personal, historical, economic, social and political relationships in society through observation, questioning and discussion. To truly allow this process to develop, Parahoo (2014) suggests that the researcher needs to reflect on how their own value perceptions, behaviour or presence, and those of the respondents, can affect the data they collect. The concern being that failure to be reflexive could lead to me imposing my beliefs, values and patterns of behaviour and therefore the production of invalid data (Leininger, 2002).

Hunt & Bhopal (2003) state that it is adequate for researchers to simply be cognizant of customs, values and beliefs of the target group. However, Apentiik & Parpart (2006) offer some strategies and mechanisms for researchers, and I incorporated some of these into the process.

One key strategy was the selection of the interpreter/research assistant for the study. To ensure that I got the best person I could find for the job, I came up with some key qualifications, skills and attributes needed for the position. Essentially, I needed a good interpreter and someone who was somewhat of an 'insider' to the Deaf community so that they could both help me with cultural issues and also ensure that the deaf participants felt confident and comfortable participating in the study. To meet these requirements, and after discussion with the advisory team, it was decided that a child of a deaf adult (CODA) would be best because a CODA, having grown up with at least one deaf parent, would be both socially aware and have first hand knowledge of the Deaf community, culture and sign language. In addition, I decided that a female CODA would be

preferable because, as Sollis & Moser (1991) advise, women researchers are better at obtaining sensitive information about and from other women.

In addition, another key strategy that I incorporated throughout the study, was to participate in some of the recreational, social and cultural activities of the Deaf community. However, I was always aware of balancing participation in a research community's activities (Wilson, 1992) and the methodological imperative of objectivity (Devereux & Hoddinott, 1992). Singleton, Martin & Morgan (2015) explore maintaining professional relationships between researchers and informants in studies with Deaf communities. They suggest that the dynamics of these relationships may vary depending on the researcher's age and gender, and on whether the researcher is Deaf or hearing, and on values held within the host community. Ultimately, my motivation was to make meaningful connections with participants in order to develop and shared understanding, and this was made possible largely by my attachment to the Deaf community and knowledge of KSL.

4.10 Recruitment & training of the interpreter/research assistant

Although equipped with KSL and Kiswahili language skills, I had to address the need for an interpreter/research assistant who would assist with language and cultural issues. I needed someone who was familiar with Deaf, Luo or Luhya cultures, and fluent in English, Kiswahili and KSL.

The research advisory team was asked to source CVs of suitable people. This call for CVs resulted in the submission and review of three CVs by the research advisory team, and one being selected. In the event, a female CODA, who had been raised in the region by two deaf parents and resident in Kisumu, was selected.

In order to prepare a training programme for the interpreter/research assistant, I read some material by Yin. Yin (2009) explains that the goal of the training is to ensure that those engaged in the investigation understand the

basic concepts, terminology, and methodological issues relevant to the study. According to Yin, the interpreter/research assistant therefore needed to know:

- Why the study was being done

- What evidence was being sought

- What variations could be anticipated (and what should be done if such variations occurred) and

- What would constitute supportive or contrary evidence for any given proposition.

In addition, I decided that additional topics needed to be covered to build the skills and confidence of my interpreter/research assistant. A structured training programme including the aims of the project and the roles and responsibilities was developed. We went through the consent procedure, conducting and recording the interview, keeping field notes, and translating the interviews. The training also discussed some of the findings from the literature review and research studies with deaf communities in other countries to highlight the possible range of issues and findings that this type of research can produce. To develop teamwork, skills and confidence, practice interviews were conducted and feedback encouraged. Particular attention was given to ensure that the interpreter/research assistant knew and could follow the lead questions with relevant probing to avoid taking what was said for granted. The interpreter/research assistant was encouraged to become reflexive and to keep field notes of interviews regarding anything that could be discussed in subsequent meetings. The process enabled the interviewer/research assistant to discuss any problems she had encountered and to explore solutions or alternative ways. In fact, the interviewer/research assistant provided useful insights and made practical suggestions, which improved the data collection process – for example, handling some of the sensitive issues created by internal politics within the Deaf community. Towards the start of the project, for example, the interviewer/research assistant was able to share some

background knowledge and historical information about the development of Nyaweri VCT, including which organisations and who was involved in its establishment. In being given this information, I was able to approach the centre and engage with key persons right from the start, and in the right way.

Initially the interpreter/research assistant interpreted the interviews for me so that she could see first hand and gain experience of the procedure and process of conducting the semi-structured interviews. When her confidence was established, she progressed to facilitate interviews herself.

4.11 Piloting the research instrument

After training the interpreter/research assistant, the research instrument and topic guide were piloted with 3 participants (2 Deaf and 1 hearing person) and checked for content, format and engagement to ensure the questions and approach were right for the study. Oppenheim (1992) advises that this is an important process even when questions have been 'borrowed' from other surveys to confirm that they would work for our participants. Furthermore, we needed to clarify and confirm how we would sign each question in the instrument.

During the piloting of the questionnaire, we initially tested the multiple-choice question response options with two Deaf men by asking the question in 'open' form to discover how respondents spontaneously interpreted the question. In this way, we were able to modify the questions by offering additional answer categories that we had not considered. This process also highlighted the importance of the 'other' category in the answer list of options.

In the piloting stage, when misinterpretations became evident, we did amend the questionnaire. One example was of an edit to the question, 'Do you have friends outside the home?' In trying out the questionnaire, it became clear that people were interpreting this question to mean whether they had any 'clandestine' boyfriends or girlfriends outside of their main relationship or home. To counter this interpretation, we had to clarify exactly what we meant

by the question we were asking. In this example, we were in fact asking about support and friendship networks and not about sexual relationships. In short, the piloting enabled some minor edits and a final version of the instrument was prepared. In collaboration with my supervisor, it was decided that if there were any problems or issues that emerged during the data collection phase of the study, the instrument could still be reviewed and amended.

Another issue that came up during the piloting of the instrument was the issue of taboos. According to Pratt & Loizos (1992), some questions often go unasked as the researcher does not know how to tackle the topic because they may consider it too sensitive or highly contentious. In this study, an example of such a sensitive issue was rape and sexual abuse. In piloting the instrument, a Deaf pilotee could see our discomfort in dealing with the issue directly as we were scouting around the topic a bit. He advised and reassured us that discussion of rape and sexual abuse would not be an issue for people in the Deaf community and that we should not shy away from addressing it but rather confront it head-on. Through the passage of time with the Deaf community, I was able to discern what was important, delicate and controversial, and to appreciate how sensitive and contentious information can vary in different language settings.

4.12 Interviews

The table below summarises the number of interviews completed in this study:

Table 4.3:   Number of study interviews completed (with language preference) by hearing status, gender & geographical area

	Hearing		Deaf		Total
	M	**F**	**M**	**F**	
Urban	10 (Eng: 7)* (Swa: 3)*	28 (Eng: 28)	25 (KSL: 23)* (Iso: 2)*	15 (KSL: 14) (Iso: 1)	78
Rural	19 (Eng: 16) (Swa: 3)	21 (Eng: 21)	26 (KSL: 15) (Iso: 11)	16 (KSL: 10) (Iso: 6)	82
Total	29	49	51	31	160

* Eng: English; Swa: Swahili; KSL: Kenyan sign language; Iso: Isolate

Table 4.4:   Age breakdown of study participants by hearing status and gender

	Hearing		Deaf		Total
	M	**F**	**M**	**F**	
18-20	10	19	5	4	38
21-24	7	15	9	6	37
25-30	11	15	32	16	74
31-35	1	0	5	5	11
Total	29	49	51	31	160

Interviews were conducted in the communities in which the participants lived. Participants were invited to come to a central venue that had been agreed by the local administration, usually during the week before the interview dates. Interviews were generally held over a 2-3 day period in each geographical area, and the interviews ran most of each day.

The interviews were conducted in English, Kiswahili or sign. After consultation and agreement with the study advisory team, it was decided that if a participant

did not know either a spoken or signed language, we would thank the participant for their time and terminate the interview. Furthermore, I used branching in terms of who gets asked questions – for example, participants who had not heard of HIV/AIDS were not asked follow up questions.

On days where there were many participants or I was sick, the interpreter/research assistant conducted some interviews. The interviews were recorded, either by video or audiocassette.

4.13 Data management and analysis

4.13.1 Data management

The UCL research ethics framework and the provisions set out in the United Kingdom's Data Protection Act were complied with throughout the study.

To protect participants and uphold their right to anonymity and safety, it was very important to store and keep all recorded data safe. Recordings were destroyed after interviews had been translated.

Papadopoulus (2006) warns that skipping the translation and back-translation process must be avoided as crucial meanings can be missed. To avoid this pitfall, plenty of time was made to translate the material as soon after the interview as possible.

Young & Temple (2014) note that signed languages are only translated and not transcribed. Temple & Young (2004) explain that historically, transcription was a problem in studies where data was collected in sign languages. The reason is that transcription generally refers to a change in modality, that is, writing down what has been said in the original language. However, in data collected in sign, the change in modality is accompanied by a change in language, something that is usually defined as translation and not transcription. For this reason, the terminology adopted for the process in the study is translation.

Bujra (2006) advises that translation is more than a technical exercise. She suggests that it is also a social relationship involving power, status and the imperfect mediation of cultures. I could see that this was especially true when body language and facial expressions have to also be considered in translating from sign language. Clearly, a challenging task during the translating process was to capture and maintain the essence of participants' views. To address the challenges of translating the material, not only did I decide to write the sign language directly into English, but I also decided to be open with my interpreter/research assistant about some of the concerns that I was facing – for example, the fact that I was anxious that she was making some judgments about the messages received, filtering out some material that she considered unimportant whilst I had felt that it was precisely something that the study needed to know. I think the point was that because I had signing knowledge, and in doing the translating work together, I could see some of our different conceptual judgments regarding the video text. After an open discussion about how to deal with differences, it became an advantage to work on the translations together as we were able elaborate and explain some of the areas that we had trouble understanding. In one instance where we could not agree, to avoid destroying the trust we had established on both sides, I cited some advice from Birbili (2000) who said that it is good practice to verify the accuracy of the translations of tape-recorded interviews from other sources when unsure. In doing so, we were able to defer the evaluation and translation of the videoed text to a deaf member of our study advisory team to clarify for us. Furthermore, in another instance where a deaf participant was known and easily accessible for clarification, the findings were taken back to the participant in order to be verified, a process called respondent validation (Silverman, 1993).

4.13.2 Data analysis

Quantitative data analysis

Three questions in the questionnaire were asked to determine levels of HIV/AIDS awareness and knowledge (transmission and prevention).

To determine levels of awareness, participants were asked, 'Have you heard of HIV/AIDS?' with the options of answering 'yes' or 'no' (appendix 3, question 24).

Knowledge about modes of transmission were tested by providing participants with 12 statements about 'the ways that somebody can get AIDS' with options of responding 'true, false or don't know' (Appendix 3, question 27). To determine levels of knowledge about ways to prevent getting HIV/AIDS, participants were provided a series of 9 statements about how infection can be prevented (Appendix 3, question 29), and again participants were asked to respond, 'true, false or don't know'. Each statement was given the same value with each correct score being awarded one point. The responses for each participant were entered in to a spreadsheet and scores totalled using Microsoft Excel. Using the software, mean test scores for different participant groupings (for example, geographical areas: urban – rural – Rongo) were calculated, and a number of tests of statistical association conducted. The results are displayed using bar charts and tables, and are presented in chapters 5 and 6 of this thesis.

Qualitative data analysis

As data was collected through a variety of methods, a range of different ways to analyse the data was required. In fact, some researchers advocate that there is no single or correct way of analysing qualitative data (Robson, 2002; Cohen, Manion & Marrison, 2007). Yach (1992, p.605) describes the process as being 'discovery oriented' which further implies the individuality of the process. It was with this spirit of freedom that I embarked on the analysis of the data in this study.

Qualitative research develops theory inductively (Leach, 1990). This is the opposite approach to that adopted in traditional social science research where the process starts with the researcher choosing a theoretical framework and then applying this model to the phenomenon to be studied (Allan, 2003). Martin & Turner (1986) emphasizes that grounded theory as a research methodology involves the discovery of theory through the analysis of data collected. Because of grounded theory's unique approach - and the validity of the theory being

dependent upon the procedures involved - a more thorough discussion of the data analysis process in this study is presented.

Allan (2003) elaborates on the process of handling the data in grounded theory investigations. It was Allan's process that I followed during the data handling and analysis parts of this study. Allan (2003) explains how the process can be viewed in terms of 4 stages. The aim of each stage is to reorganize increasing amounts of data to make it more workable. Once the data has been collected, the first part of the process involves the marking or labelling of key points extracted from the transcript texts to create codes. These codes are the anchors to which subsequent data is initially grouped. The second part of the process is when collections of codes of similar context are then merged into concepts. The third part is the development of categories where broad groups of similar concepts are assembled and used to generate a theory. The creation of the theory, or fourth stage, comprises a collection of categories that detail the subject of the research.

The following table outlines how 6 things that people said (items) initiated the creation of the structure suggested by Allan (2003) and outlined above for this study. The data only concerns one part of one category, Deaf culture.

Table 4.5: Coding items in the Deaf culture category

Item	Code	Concept	Category
'The Deaf don't help one another. Some Deaf want to show their richness or their better position'.	Showing off	Deaf Behaviour	Deaf Culture
'When a Deaf person is rich, he oppresses others because of competition.'	Competition		
'If you are deaf and positive, everybody will know'.	HIV status gossip	Deaf Grapevine	
'Deaf girls ignore me and they always cheat me. They go hide and make stories and gossip me'.	Gender		
'Deaf people should be faithful to one another and not sleep around'.	Deaf promiscuity	Deaf Sexuality	
'We take it that because they [deaf people] don't communicate, they don't have sex'.	Deaf asexuality		

In this study, the data was analysed according to the 12 categories identified in the literature review and upon which the questionnaire and topic guide was developed. These issues included poverty, language, self-esteem, lack of education, lack of HIV information, Deaf sexuality, sexual abuse, substance abuse, stigma, health care, Deaf culture and the criminal justice system. Within these 12 categories, 60 concepts were established; and within each of the 60 concepts, there were approximately a dozen codes created to 'house' items said by the 160 participants in this study.

Dey (1999) suggests there are 'probably as many versions of grounded theory as there were grounded theorists' (p.2). However, Charmaz (1990, 2006) identifies 7 features that all grounded theorists have and these are outlined and

expanded upon below. In order to not get distracted by focusing on these types of grounded theory and which one this study fits, I discuss the elements of Charmaz's framework to explain key components of the research process from data analysis to the creation of the theory in this study.

1. Simultaneous collection and analysis of data

The fieldwork part of the study was a constant process of data collection and analysis. This is one of most important components of the grounded theory research process. Initially, grounded theory method was called the constant comparison method because the hypothesis is generated by constantly exploring the data (Glaser & Strauss, 1967). The question I repeatedly asked myself in this study was 'what's going on?' and 'what is the participant's main problem and how are they trying to resolve it?'

Calman (2006) explains how concurrent data collection and analysis in her study enabled her to become theoretically sensitive to the data. During my study, there were 2 phases of data collection. In each phase of data collection, every interview was translated and written up within about a week of being held. After interviews were completed in one area, time was taken – sometimes a week or more - to reflect upon the data collected and how it related to emerging concepts and categories before moving on to the next area. In this way, I was developing theoretical sensitivity by immersing myself in the data and trying to understand patterns in what the participants saw as being significant and important. During this time, I discussed preliminary ideas, findings and developments with the study's advisory team to get a broader understanding and appreciation of the data.

2. Creation of codes, concepts and categories developed from data and not by pre-existing conceptualisations

Upon first reflection, it appears that this second feature suggests that the ideal situation is to begin a study without any predetermined ideas or hypotheses to allow the development of theory to simply emerge from the study's data. In

practice, however, this is probably an unrealistic interpretation of the feature. For example, in this study, one of the reasons that I was able to do this work was because of my background and experience of working with the deaf people. Some might suggest therefore that I cannot claim to be completely unbiased or influenced by this prior knowledge or experience. Dey (1993: p.63) offers an explanation by suggesting that 'there is a difference between an empty head and an open mind' as prior knowledge can be used to inform analysis rather than direct it. This suggestion is supported by Glaser (1992) who notes that literature can be 'used' as data and constantly compared with the emerging concepts and categories to be integrated into the theory. In this study, existing literature and my prior knowledge and experience helped to inform the development of concepts and categories.

Using Nvivo 10 software, I coded the written data from field notes and interview transcripts. This process involved me reading and labelling everything in the data, line by line. The intention was to 'break open the data to consider all possible meanings' (Corbin & Strauss, 2008, p.59). The labels that were assigned helped to create codes from which collections of codes could be grouped together into concepts.

3. Discovery of basic social processes in the data

This was an exploratory stage where I familiarized myself with the data, explored it and began to understand possible linkages and emerging patterns. During this part of the process, I developed a greater appreciation of the issues and how the participants see and resolve their problems. The codes were constantly compared, re-coded and merged into new concepts that were in-turn renamed and modified. The connections between the concepts began to emerge – for example how communication could impact upon a person's connection to their family. This connection would then influence how someone views themselves in their environment and therefore have a bearing upon their self-esteem. In exploring the data in this way, I developed a more sophisticated appreciation of the research questions and how this study could address them.

4. Inductive construction of abstract categories

Strauss & Corbin (1990, 1998) refer to this part of the process as 'axial coding'. For Glaser (1978), it was called 'theoretical coding'.

During this stage of the process, I reorganized the data through making associations and connections between the categories. I began to define and recognize the core categories and main concerns in the data. At this stage, open coding stopped and a process of selective coding started where I used my skill and knowledge of the subject to reorganize and code for the core and related categories.

As has been explained in this chapter, I developed the research tool around 12 issues that emerged from the literature review. These issues included poverty, language, self-esteem, lack of education, lack of HIV information, deaf sexuality, sexual abuse, substance abuse, stigma, health care, Deaf culture and the criminal justice system. Whilst the initial coding of the data in this study was not grouped according to these themes, during this part of the process, it could be seen that categorizing according to these themes could help explore the problem. However, there were other issues that emerged from the data – issues that centred around new categories – for example, family. It became important to set these issues apart for consideration in order to develop and understand the phenomenon.

5. Theoretical sampling to refine categories

Glaser and Strauss (1967) indicate that theoretical sampling is a process of data collection for generating theory whereby the researcher jointly collects, codes and analyses data and decides what data to collect next and where to find them, in order to develop theory as it emerges.

During this process, it became clear that using the deaf community networks to find deaf participants to work with in this investigation meant that the process would inevitably reach those deaf people who were connected to other deaf

people. However, in order to balance the investigation, it was necessary to explore ways to reach those deaf people who lived in the more remote and harder to reach areas of the study region and who were therefore more isolated and could better reflect the situation of deaf isolates. This was achieved, not through the sending of SMS messages to deaf people which was one of the more familiar means of communication in the deaf community in the earlier stages of the investigation, but by actually sending someone out into the community to do house visits to identify homes of isolates that I could follow up with and visit.

Charmaz (1990) suggests that theoretical sampling is best used when some key concepts have been discovered. Theoretical sampling is then used to generate further data to confirm and refute original categories. In this study, it became clear that rural communities could be divided into two categories. Initially the plan was that the distinction for this investigation could be made with deaf urban and deaf rural. However, after reflection, that was redefined to include 2 subsets within the rural distinction. The first, those who live in a rural area in which there is a Deaf community – for example, a rural community near a Deaf school; and the second, rural areas in which deaf people are isolated and live in homes that are geographically detached from other deaf people.

6. Writing analytical memos as the stage between coding and writing

During this research, I kept a field diary that included notes about interviews and conversations held in the field. I also asked my research assistant/interpreter to do the same. As the process shifted to a more formal analytical analysis that involved the creation of codes, concepts and categories, I started to write personal notes in memos to record emerging ideas and track thinking. It was important to have a reference of how my thoughts developed and changed during the analysis process because codes were continually compared with other codes, grouped into concepts, modified and reorganized throughout the analysis. The memos enabled me to document and therefore remember the reasons and rationale for steps taken during the process.

7. The integration of categories into a theoretical framework.

To develop a theoretical framework, data from the quantitative and qualitative components of the investigation needed to be compared, contrasted and linked together to further explore and understand the situations and issues under investigation. To facilitate this, different software packages were used. Data from the close-ended questions was analysed using Excel and SPSS, and independently checked for reliability.

4.14 Feedback and dissemination of findings

On completion of the fieldwork component of the study, 2 feedback meetings for key advisors to the study were convened with representatives from KNAD, NGOs (LCD, Undugu Society of Kenya, LVCT), Higher Education (University of Nairobi's KSL Research Project) Civil Society Organisations (Western Kenya Deaf Development Group). One of the aims of the feedback meeting was to present preliminary findings and to provide an opportunity for discussion, reflection and validation.

In order to ensure that their research findings were widely disseminated and accessible Singleton, Jones & Hanumantha (2014) published their research findings in two languages: English (2014) and ASL (2012). Singleton, Martin & Morgan (2015) argue that it is critical for researchers to give back to the Deaf community by disseminating the findings through newsletters, posters, research debriefing, websites, and conference presentations (both research and community-based ones).

Papadopoulos (2006) recommends some strategies for reporting and disseminating research findings in ways that are sensitive and inclusive, and these will be followed for this final part of the research process.

Copies of the final version of this PhD thesis will be given to KNCST, KU and KNAD. It is also expected that opportunities will be explored to present findings in conferences, workshops and in peer review journals. A key strategy will be to

use extensive direct quotations and case studies to allow the voices of the participants to be heard.

4.15 Conclusion

In this chapter, once the rationale for adopting a grounded theory methodology to this study was established, a detailed account of the research process was presented that included components before, during and after data collection. The next chapter will present the results from the questionnaire that was administered to determine awareness and knowledge levels of HIV/AIDS before exploring language, community and HIV/AIDS.

Chapter 5 Results: HIV/AIDS awareness and knowledge

5.1 Introduction

All the comparative studies reviewed in preparation for this investigation found that deaf people have less awareness and knowledge about HIV/AIDS than their hearing compatriots. In order to explore the research questions in this investigation, and specifically to determine levels of awareness and knowledge about HIV/AIDS, participants in this study were asked three questions about HIV/AIDS:

- Exploring awareness of HIV/AIDS, asking: 'Have you heard of HIV/AIDS?'

- Knowledge of HIV/AIDS transmission, asking: 'Which of the following ways can somebody get AIDS?' in a 12-statement test; and

- Knowledge of HIV/AIDS prevention, asking: 'How can HIV infection be prevented?' in a 9-statement test.

Each correct answer was awarded one point, and the mean test scores calculated. The results from these questions are initially given for both the hearing and deaf participants in the study so that comparison and analysis on any similarities and differences regarding HIV/AIDS awareness and knowledge between the two populations can be explored. Results for the deaf respondents are then presented by gender and location. Locational results are presented by the groupings of urban and rural; and then further by urban, rural (no Deaf school), and Rongo (a rural location near a Deaf school) to enable an assessment of the impact of being engaged in Deaf culture and community upon a deaf person's awareness and knowledge levels of HIV/AIDS.

5.2 Awareness of HIV/AIDS

To determine baseline levels of awareness of HIV/AIDS in hearing and deaf groups, participants were initially asked if they had heard of a disease called

HIV/AIDS. 100% of the hearing participants (n=78) and 80% of the deaf participants (n=82) reported having heard of HIV/AIDS (X^2= 16.911, p<0.001) (Figure 5.1).

Figure 5.1:   Have you heard of HIV/AIDS? by hearing status
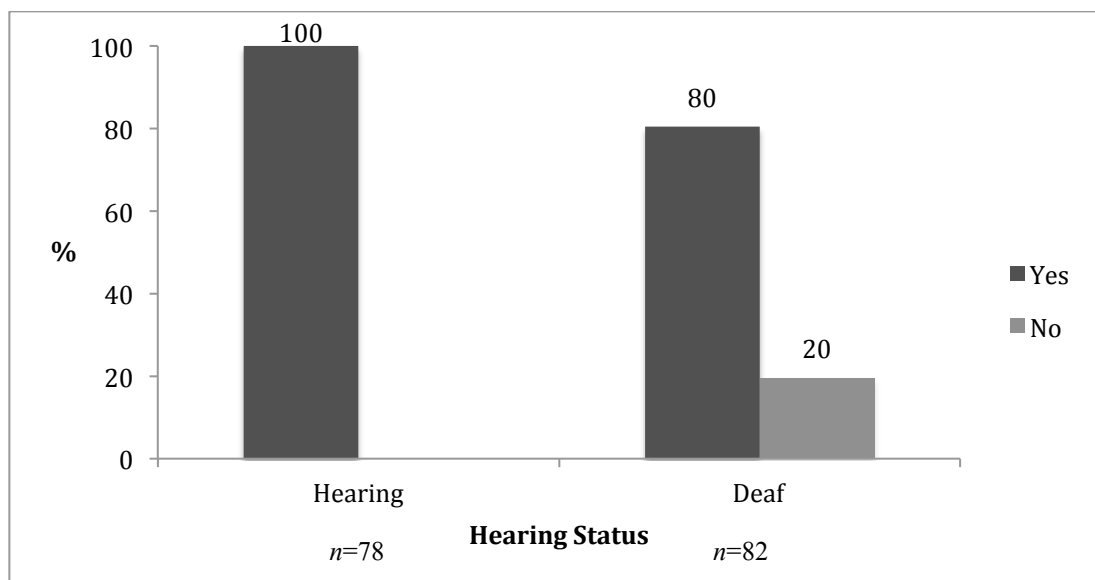
While there was no statistically significant difference between deaf men and deaf women in awareness of HIV/AIDS (X^2= 3.070; p=0.093), there was a statistically significant difference between rural and urban participants. Fewer rural participants (70%, n=42) than urban participants (93%, n=40) had heard of HIV/AIDS (X^2=7.175, p=0.007) (Figure 5.2). However, Table 5.1 stratifies the data by locational subgroups of urban – rural (no Deaf school) and Rongo (with Deaf school) and gender: this shows that awareness rates of the rural deaf group dropped to 50% (verses 93% in urban areas) for those deaf individuals; and awareness rates for Deaf people who live in the community surrounding the Deaf school, increased to 100%, outstripping even their urban counterparts (X^2=22.942, p<0.001).

Figure 5.2: Have you heard of HIV/AIDS? Deaf participants by urban-rural geographical area
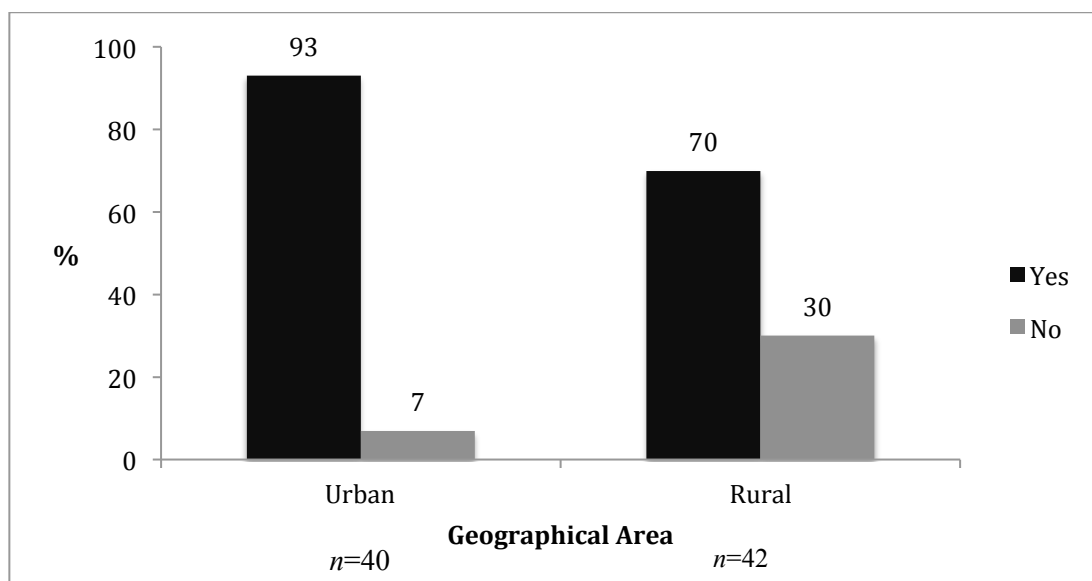
Table 5.1: Have you heard of HIV/AIDS? Deaf participants by gender & urban-rural (no Deaf school)- Rongo (with Deaf school) geographical area

		Male	**Female**	**TOTAL**
Urban	**Yes**	22	15	37
	No	3	0	3
	TOTAL	**25**	**15**	**40**
Rural	**Yes**	8	5	13
	No	10	3	13
	TOTAL	**18**	**8**	**26**
Rongo	**Yes**	8	8	16
	No	0	0	0
	TOTAL	**8**	**8**	**16**
TOTAL	**Yes**	38	28	66
	No	13	3	16
	TOTAL	**51**	**31**	**82**

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All the deaf respondents (8 male, 8 female) in Rongo (rural area with a Deaf school) had heard of HIV/AIDS (Table 5.1). However, only 8 out of 18 deaf men, and 5 out of 8 deaf women, in rural areas (with no Deaf school) in this study had heard of HIV/AIDS. Statistically significant results of geographical location upon awareness levels of HIV/AIDS were found in deaf men (X^2=13.699, p=0.001), and deaf women (X^2=9.549, p=0.008).

5.3   Knowledge of HIV/AIDS

In this study, participants were given 12 statements about HIV/AIDS and its transmission, and asked to respond 'true', 'false', or 'don't know'. The aim was to gauge knowledge levels about disease transmission. A detailed statement-by-statement analysis is contained in Appendix 9.

Fifteen deaf participants (18%, *n*=82) could not respond to these questions because they did not have enough language (spoken or signed) to engage in these questions about HIV/AIDS. For this reason, these interviews are not included in the statistical presentation of findings in this section. Table 5.2 shows the age, gender and location for each of these 15 deaf participants: 12 were male and 3 were female.

Table 5.2: Non-respondent deaf participants by age, gender & urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area.

Age Gender	Geographical Area			Total
	Urban	Rural (no Deaf school)	Rongo (with Deaf school)	
18-20				
Male	1	3	0	4
Female	0	0	0	0
Total	1	3	0	4
21-24				
Male	1	1	0	2
Female	0	1	0	1
Total	1	2	0	3
25-30				
Male	0	5	0	5
Female	0	0	1	1
Total	0	5	1	6
31-35				
Male	0	1	0	1
Female	0	1	0	1
Total	0	2	0	2
Total				
Male	2	10	0	12
Female	0	2	1	3
Total	2	12	1	15

5.3.1 HIV transmission

Figure 5.3 outlines the mean scores for the hearing and deaf respondents for the 12 statements that they were asked about HIV transmission.

Figure 5.3:   Knowledge (HIV transmission (out of 12)) by hearing status
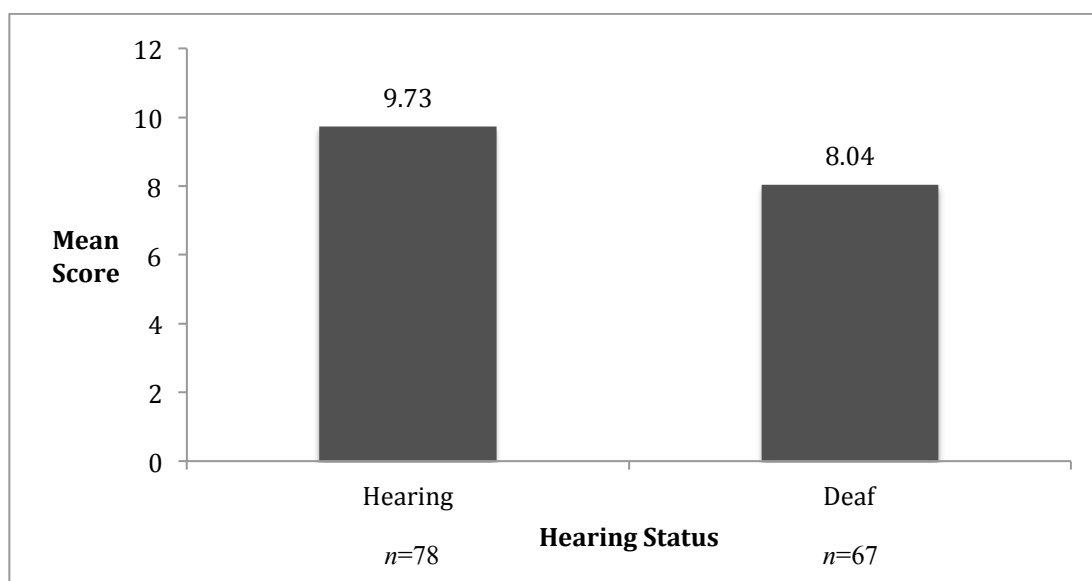
Table 5.3:   Knowledge (HIV transmission (out of 12)) by hearing status

	Number of participants	Mean, (SD)	Variance, Range
Hearing	78	9.73, (1.99)	3.96, 12
Deaf	67	8.04, (3.25)	10.56, 12

There was a statistically significant difference in knowledge levels of HIV transmission between the deaf and hearing populations in this study, with the hearing population (n=78) scoring a higher mean score of 9.73 compared to the deaf population (n=67) of 8.04 (t(106)=3.86,p<0.001) (Figure 5.3; Table 5.4).

The mean scores for the deaf male (n=39) and deaf female (n=28) participants on the facts about HIV/AIDS transmission (Table 5.5) showed no statistically significant difference.

Table 5.4:   Knowledge (HIV transmission (out of 12)), deaf participants by gender

	Number of participants	Mean, (SD)	Variance, Range
Male	39	8.05, (3.08)	9.49, 12
Female	28	8.03, (3.53)	12.46, 11

Table 5.6 presents the knowledge of HIV transmission for the deaf respondents by geographical areas urban – rural (no Deaf school) – Rongo (with Deaf school). No statistically significant difference was found between these geographical areas and knowledge of HIV/AIDS (transmission) for deaf respondents in this sample (Fisher's Exact 1.407 (df=2), p=0.252).

Table 5.5:   Knowledge (HIV transmission (out of 12)), deaf participants by urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area

	Number of Deaf participants	Mean, (SD)	Variance, Range
Urban	38	8.10, (3.26)	10.63, 12
Rural	14	6.92, (3.42)	11.70, 10
Rongo	15	8.93, (2.93)	8.58, 10

Table 5.7 tabulates the results for deaf men and deaf women by the geographical areas of urban – rural (no Deaf school) – Rongo (with Deaf school). No statistically significant differences were found for either deaf men (Fisher's Exact 0.667 (df=2), P=0.520), or deaf women (Fisher's Exact 2.481 (df=2), p=0.104) and knowledge of HIV (transmission) by these geographical groupings.

Table 5.6: Knowledge (HIV transmission (out of 12)), deaf participants by gender & urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area

	Male Mean, (SD) Variance, Range	Female Mean, (SD) Variance, Range
Urban	7.65, (3.47)[a] 12.04, 12	8.8, (2.95)[d] 8.70, 11
Rural	8.13, (2.85)[b] 8.12, 8	5.3, (3.72)[e] 13.84, 8
Rongo	9.13, (1.96)[c] 3.84, 6	8.17, (3.95)[f] 15.60, 10

The following total N was used to calculate the means: [a], N=23; [b], N=8; [c], N=8; [d], N=15; [e], N=6; [f], N=7.

5.3.2 HIV prevention

To determine how much the participants knew about how to protect themselves from HIV infection, they were given 9 statements about HIV prevention, and asked to respond, 'true', 'false' or 'don't know'. The tables below reflect the mean scores for the different population groups in the study. A more detailed statement-by-statement presentation and analysis of responses is contained in Appendix 10.

From the deaf population in this study, 19 (23%) deaf people could not answer this question because they did not have sufficient language (spoken or signed) to engage in the conversation. It was interesting to note that 19 deaf people - 4 more deaf participants - gave up trying to answer this question than the earlier question about HIV/AIDS transmission. As in the previous section, participants who did not answer any of the parts to the question are not included in the statistical analysis that is presented below. Table 5.8 shows the age, gender and location for each of these 19 deaf participants: 12 were male and 7 female.

Table 5.7: Non-respondent deaf participants by age, gender & urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area

Age Gender	Geographical Area			Total
	Urban	Rural (no Deaf school)	Rongo (with Deaf school)	
18-20				
Male	1	3	0	4
Female	0	0	0	0
Total	1	3	0	4
21-24				
Male	1	1	0	2
Female	0	2	0	2
Total	1	3	0	4
25-30				
Male	0	5	0	5
Female	2	0	1	3
Total	2	5	1	8
31-35				
Male	0	1	0	1
Female	0	2	0	2
Total	**0**	**3**	**0**	**3**
Total				
Male	2	10	0	12
Female	0	4	1	7
Total	**4**	**14**	**1**	**19**

Figure 5.4:   Knowledge (HIV prevention (out of 9)) by hearing status
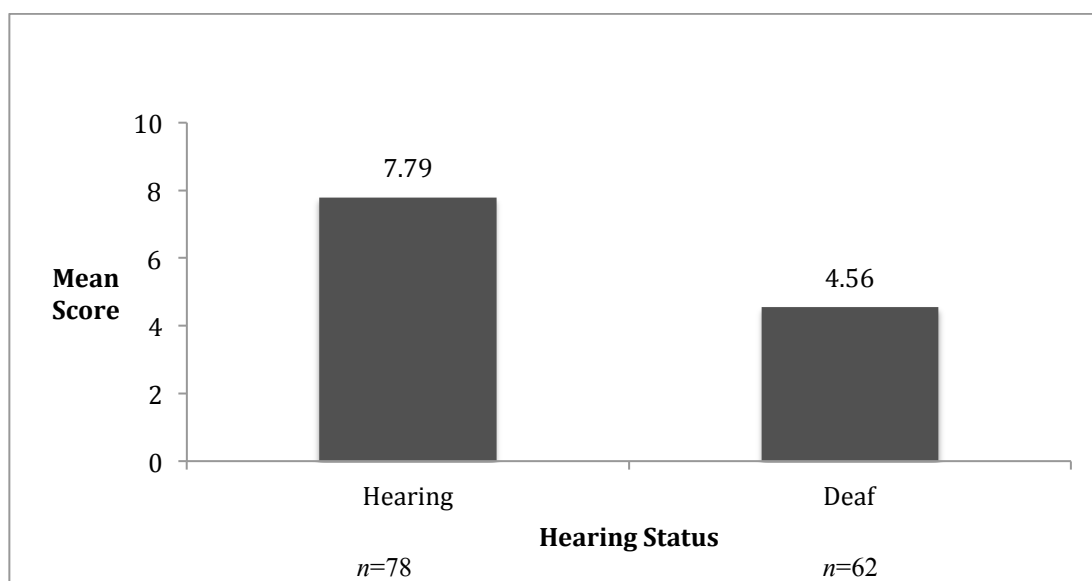
Table 5.8:   Knowledge (HIV prevention (out of 9)) by hearing status

	Number of participants	Mean, (SD)	Variance, Range
Hearing	78	7.79, (2.2)	4.84, 10
Deaf	62	4.56, (2.91)	8.47, 11

There was a statistically significant difference in knowledge levels of prevention and HIV/AIDS between the deaf and hearing populations in this study, with the hearing population having a higher mean score on the knowledge scale than the deaf population (hearing: 7.79; deaf: 4.56) (t(7.47)=138; p<0.001) (Figure 5.4, Table 5.9).

There was no significant difference between the mean test scores between deaf men and deaf women t=0.812, df=60, p=0.4 (Table 5.10).

Table 5.9:   Knowledge (HIV prevention (out of 9)), deaf participants by gender

	Number of Deaf participants	Mean, (SD)	Variance, Range
Male	39	4.33, (3.17)	10.05, 11
Female	23	4.95, (2.42)	5.86, 8

The highest mean test score in the deaf population in this study was achieved by Rongo (with a Deaf school: 6.21); then, rural (no Deaf school: 4.83); and finally, urban (3.83) (Table 5.11). A one-way ANOVA test was conducted: Fisher's Exact 3.74 (df=2), p=0.03. The post hoc test (Bonferroni correction) confirmed that urban contrasted with Rongo (with a Deaf school) was the only statistically significant difference (p=0.024).

Table 5.10:   Knowledge (HIV prevention (out of 9)), deaf participants by urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area

	Number of Deaf participants	Mean, (SD)	Variance, Range
Urban	36	3.83, (2.69)	7.24, 11
Rural	12	4.83, (3.63)	13.18, 11
Rongo	14	6.21, (2.11)	4.45, 10

No statistical significance was found for either deaf men (Fisher's Exact 3.062 (df=2), p=0.059) or deaf women (Fisher's Exact 1.107 (df=2), p=0.350) and knowledge of HIV/AIDS prevention stratified by the geographical areas of urban – rural (no Deaf school) – Rongo (with a Deaf school) (Table 5.12).

Table 5.11: Knowledge (HIV prevention (out of 9)), deaf participants by gender & urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area

	Male Mean, (SD) Variance, Range	Female Mean, (SD) Variance, Range
Urban	3.56, (3.01)[a] 9.06, 11	4.30, (2.05)[d] 4.20, 6
Rural	4.25, (3.77)[b] 14.21, 11	6.00, (3.55)[e] 12.60, 8
Rongo	6.62, (1.99)[c] 3.96, 7	5.67, (2.33)[f] 5.43, 7

The following total N was used to calculate the means: [a], N=23; [b], N=8; [c], N=8; [d], N=13; [e], N=4; [f], N=6.

5.4   Conclusion

This chapter set out to determine the levels of awareness and knowledge of HIV/AIDS over three levels:

- Exploring awareness of HIV/AIDS, asking: 'Have you heard of HIV/AIDS?'

- Knowledge of HIV/AIDS transmission, asking: 'Which of the following ways can somebody get AIDS?' in a 12-statement test; and

- Knowledge of HIV/AIDS prevention, asking: 'How can HIV infection be prevented?' in a 9-statement test.

It further explored whether there are any subgroups in the deaf population that lack awareness and knowledge about the disease through stratifying data by gender and different geographical areas.

The findings presented in this chapter are consistent with other studies (Bat-Chava, Martin & Kosciw, 2005; Bisol et al., 2008; De Andrade & Baloyi, 2010;

Enwereji & Enwereji, 2008; Groce et al., 2006; Groce, Yousafzai & Van Der Maas, 2007; Luckner & Gonzales, 1993; Peinkofer, 1994; Swartz, 1993; Tripp & Khan, 1986; Woodroffe et al., 1998) that found the Deaf community does not have the same awareness or knowledge levels about the disease as the hearing community. Furthermore, findings in this study suggest that there are some language and communication issues that are affecting the potential for deaf people to get the necessary information about HIV/AIDS to protect themselves from HIV infection. This is demonstrated by:

1. The discovery that approximately 20% of the deaf participants recruited in to this study did not have enough language (KSL) to be able to engage and fully participate.

2. 20% of the deaf participants in this study had not heard of HIV/AIDS; and

3. The deaf population in this study scored statistically significant lower test scores than the hearing population on both HIV/AIDS awareness (Figure 5.1) and facts (transmission and prevention) about HIV/AIDS.

To further explore the issues raised in this section, the next chapter will consider the issues of language, communication, family, isolation and engagement with Deaf culture to determine if there may be a link between these issues and a deaf person's level of HIV/AIDS awareness and knowledge.

Chapter 6 Results: Language, community and HIV/AIDS

6.1 Introduction

The previous chapter showed that the deaf participants in this study have less awareness and knowledge about HIV/AIDS compared to the hearing participants in this investigation. Groce (2005) noted that one of the main reasons that deaf people have less awareness and knowledge about HIV/AIDS is because of the existing language and communication barriers. Since 100% of the hearing (*n*=78), and only 80% of the deaf (*n*=82) participants in this study had heard of HIV/AIDS, the focus of the discussion in this chapter starts by exploring the language and communication barriers that confront deaf people, and obstruct their access to getting information about HIV/AIDS. Evidence from experiences from HIV/AIDS training programmes, family background and engagement in with the health service are presented to explore the issues. Once an understanding of the communication challenges has been established, the conclusion from the discussion – and supported by literature – is that deaf people need to interact with other deaf people and engage in Deaf culture to develop language, and in doing so, build knowledge about HIV/AIDS.

6.2 Deaf people and communication

Communication – and how we communicate – is central to all our lives, whether hearing or deaf. However, options and potential for communication are very different.

A person's experience of hearing impairment is largely dependent upon at what age they develop the hearing loss and where in the world they live. Essentially, there are two types of deafness: congenital (at birth) or acquired (after birth). Congenital deafness is either a hereditary or genetic condition or caused by a problem during pregnancy or childbirth. Acquired deafness, however, can be result of a number of different factors that include: an infectious disease (measles, mumps, rubella); a chronic ear infection; the result of a drug (ototoxic

drugs, anti-biotics or anti-malarials); excessive noise; head or ear injury; tumour or aging.

Acquired deafness can occur pre-lingually (before speech and language development) or post-lingually (after speech and language development). A child that has congenital deafness is disadvantaged from the start as they will have more language and communication issues to contend with than a child who, for example, developed acquired hearing loss at the age of 10 years after an adverse reaction to a drug treatment. The reason is that a child of 10 would have grown and been raised in an environment where they develop a spoken language before their hearing loss.

Sign Language

KSL is the official language of the Deaf community in Kenya. The Kenyan Constitution recognizes KSL as an official language, promoting and protecting its use in Articles 7 and 20 (Government of Kenya, 2010). In doing so, the Government and people of Kenya, not only recognize and acknowledge the significance of KSL, but are also creating a conducive structural environment for the promotion of KSL and Deaf culture. Kennedy & Buchholz (1995) explain that language is one of the basic elements of culture – therefore recognition of KSL in the Constitution would appear to respect deaf Kenyans' human rights. However, in practice this is debatable. Haualand & Allen (2009) suggest that the human rights are guaranteed when that language enables someone to participate and contribute to the communities and societies they live in. Analysis of the data generated in this study suggests that there could be a significant number of deaf Kenyans who are not using their official language, KSL, and are therefore having one of their most basic human rights denied.

Homesign[7]

Evidence from the literature informs us that deaf children who are not exposed to a formal sign language are likely to adopt a system of gesturing and homesigning to communicate (Botha, 2007; de Garcia, 2012; Morford, 1996; Morford & Hänel-Faulhaber, 2011; Russell, Yang & Coppola, 1014; Senghas & Coppola 2001).

There is a body of literature that explores the potential of homesigning children to learn a sign language later in life. De Garcia (2012) poses the critical question as to whether or not homesigns and gestures that homesigners use provide an adequate foundation for later acquisition of sign language and a written language. She argues that homesign children should be viewed as language users who are capable of learning. However, Morford & Hänel-Faulhaber (2011) explore the fact that use of a homesign system during childhood does not support sign language acquisition in adulthood in the way that a first language supports second language acquisition. The key conclusion from these studies is that time is of the essence as it seems that sign vocabulary can be learned at any age; however, isolates cannot master a sign language (eg, grammar) as a first language if not exposed until adulthood.

During the literature review for this study, I identified 12 themes from which to develop the study. These themes explored why deaf people might be at risk from HIV infection, and included: poverty; language; self-esteem; lack of education; lack of HIV information; deaf sexuality; sexual abuse; substance abuse; stigma; health care; Deaf culture; and criminal justice. After observations from the field that there was evidence of a wide range of communication potential in the deaf population, coupled with the findings presented in chapter 5 that 20% of the deaf respondents in this study did not have enough language to engage in a conversation about HIV/AIDS, I have decided to explore the

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[7] The terms 'homesign' and 'village sign' are often used interchangeably in Kenya to refer to the way a non-KSL signing deaf person gestures. Essentially 'village signer' is used for those deaf people who reside in rural areas, typically in villages; and 'homesigner' for those deaf people who reside in urban areas. In this thesis, I shall use the term 'homesign' and 'homesigner'.

research question with a specific focus upon two of the identified themes from the literature: language and Deaf culture.

Table 6.1 presents the framework (category, concept and code) from the qualitative analysis of language and Deaf culture.

Table 6.1:   Qualitative analysis framework

Category	Concept	Code
Language	KSL (signing)	Usage (urban – rural – Rongo), deaf - deaf, deaf - hearing
	Homesigns/Isolates (non-signing)	Who (gender), family, where (urban – rural), how to communicate, lexicon, potential to learn KSL, human rights
	Speaking	Age of deafness, which language (vernacular), migration
	Writing things down	Education, where (urban – rural), usage
	Access	Health service, training, relationships, friendships, HIV information (sources, opportunities, barriers)
Deaf Culture	Deaf Grapevine	HIV/AIDS information (opportunities, barriers)
	Opportunities	Support, Language, Information, where (clubs, church, schools)
	Barriers	Competition, gossip, fear church, Deaf schools

6.3   Deaf people and language in Western Region, Kenya

This part of the chapter will consider and explore some of the language and communication issues that confront deaf people in Western Region. A Deaf man in Kisumu summed it up for people in this region: 'Communication is the biggest problem for us' (Deaf male, urban, 17 August 2013).

It was very clear during this study that there are a number of different options that deaf people use to communicate in the hearing world around them. The options, choice and level of communication will depend upon a number of different factors – for example, the age at which the person became deaf (pre-lingually or post-lingually); level of education; and knowledge of signing (homesign or KSL).

Signing and non-signing

Evidence from presentation of the findings in the previous chapter informs us that approximately 20% of the deaf respondents (*n*=82) in this study did not have enough language (sign language) to be able to engage in conversations about HIV/AIDS. However, to establish a better understanding of levels of KSL knowledge in this study, deaf participants were asked if they used KSL. I did not however test the extent of their knowledge but simply asked them if they used it or not. The findings are presented in the graphs below.

Figure 6.1:   Do you use KSL? Deaf participants by urban - rural geographical area
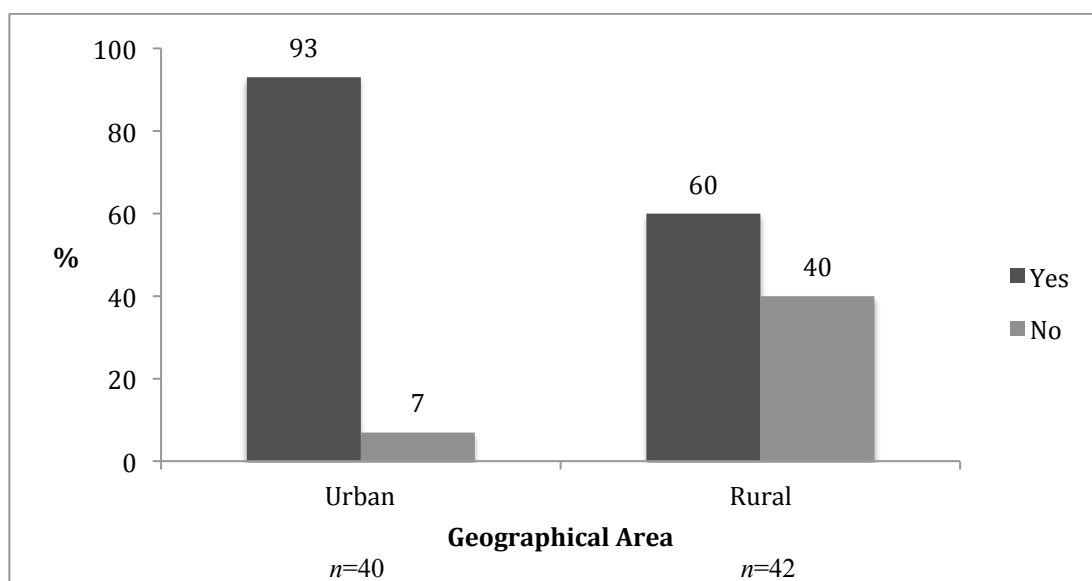
There was a statistically significant association (X^2 = 12.08, p<0.001) between using KSL and geographical area (urban-rural) with urban deaf participants (93%, *n*=40) more likely to report using KSL than rural deaf participants (60%, *n*=42) (Figure 6.1). In order to explore the data more, the groupings of urban – rural (no Deaf school) – Rongo (with Deaf school) are considered.

Table 6.2:   Do you use KSL? Deaf participants by urban – rural (no Deaf school) – Rongo (with Deaf school) geographical area

	Yes	**No**	**Total**
Urban	37	3	**40**
Rural (no Deaf school)	13	13	**26**
Rongo (with Deaf school)	12	4	**16**
Total	**62**	**20**	**82**

A statistically significant association between knowing KSL by geographical area urban – rural (no Deaf school) – Rongo (with Deaf school) in the deaf population in this study was found (Fisher's Exact 15.2(df=2), p<0.001). This may help

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explain that one of the reasons for differences in awareness and knowledge levels of HIV in the deaf population in this study may be related to proficiency in sign language. From the above findings (Table 6.2), there are clearly different types of rural area to consider as 50%, or 13 out of 26, of the deaf people in a rural area without a Deaf school did not know KSL, as compared to only 25%, or 4 out of 16, of the deaf people in a rural area with a Deaf school. Since there was statistical significance, exploration of the data by gender using the same geographical groupings urban – rural (no Deaf school) – Rongo (with Deaf school) is given.

Table 6.3: **Do you use KSL? Deaf participants by gender & urban – rural (no Deaf school) – Rongo (with Deaf school) geographical area**

		Male	**Female**	**Total**
Urban	Yes	23	14	37
	No	2	1	3
	TOTAL	**25**	**15**	**40**
Rural (no Deaf school)	Yes	10	5	15
	No	8	3	11
	TOTAL	**18**	**8**	**26**
Rongo (with Deaf school)	Yes	7	5	12
	No	1	3	4
	TOTAL	**8**	**8**	**16**
Total		**51**	**31**	**82**

Table 6.3 shows that the highest levels of KSL use for both Deaf men and women were in urban areas (Deaf men: 92%, or 23 out of 25; Deaf women: 93%, 14 out of 15). Whilst there was no statistical association for the deaf women and knowing KSL by this geographical grouping (urban – rural - Rongo), there was an association for deaf men (Fisher's Exact 8.47(df=2), p<0.001). Posthoc testing revealed that whilst there was no difference between knowing KSL and

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the grouping urban - Rongo group of deaf men, there was a significant difference between urban – rural (p<0.001) and Rongo – rural (p=0.035).

The implication from the above analysis therefore is that the key issue regarding knowledge and language seems not to be as simple as geographical location (urban versus rural), but rather community and interaction with other deaf people. There is a body of literature that includes work by Senghas & Coppola (2001) that supports the finding that for deaf people to communicate and become proficient in sign language, they must be exposed to other deaf people and Deaf culture. Essentially, this means that deaf children need to meet and interact with other deaf people.

Given the constraints of this study, I was unable to pursue an in-depth assessment of levels of sign communication. I assumed that a negative response to 'do you know KSL?' in whatever modality included any regional varieties of KSL since locally a distinction is not usually made. Consequently those people who answered 'no' in the previous section – and to which the focus of this part of the discussion is centred - are either assumed to know homesign or to be isolates. Therefore, from evidence in this study where half of the rural deaf respondents (13 out of 26) did not know KSL, it would therefore be expected that some of them would use homesigns to communicate with the hearing people around them; and others, not.

A Deaf woman in the city acknowledged differences in sign language, 'Deaf here in town are different from the deaf in the village. Their signing is different. In the village, they don't understand the same signs as in town'. She continued, 'There are language problems. Sometimes the deaf in villages don't understand the same signs as the Deaf in towns' (Deaf female, urban, 26 October 2012). In this dialogue, she is acknowledging the difference between KSL and homesigns. An example of the difference in signs was illustrated when one deaf woman's gesture for 'condom' was the same as the KSL sign BALLOON.

In this study, the deaf participants were asked if they knew any other form of sign communication other than KSL. They were essentially being asked to assess themselves in terms of their knowledge of sign systems other than KSL because it was beyond the scope of this study to test it.

Figure 6.2:   Do you use any other sign communication? (deaf participants)
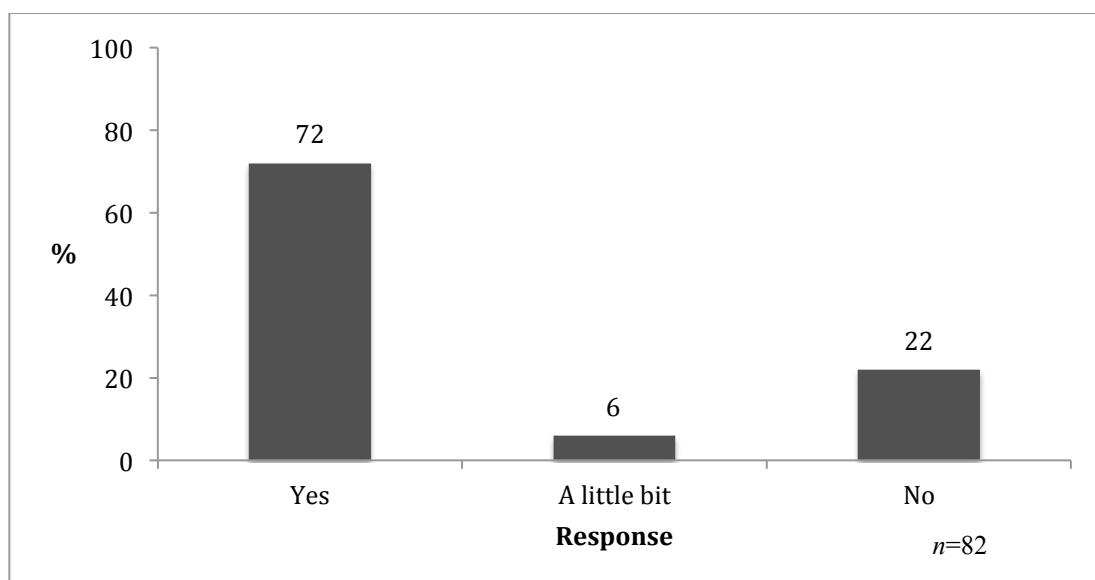
72% (59 out of 82) of the study's deaf population (n=82) reported using some other form of sign (homesign) communication (Figure 6.2).

Whilst testing showed that there was no significant difference of knowing another form of sign communication and the geographical location of urban - rural (no Deaf school) - Rongo (with Deaf school) when grouping the deaf participants as a whole, there was a sign of difference in the proportion of women knowing another form of sign communication (Fisher's Exact 8.9 (df=4), p=0.023). However, it was not possible from the data where exactly this difference lies, although one gets the impression that rural women are disadvantaged (Table 6.4).

Table 6.4: Do you use any other sign communication? Deaf participants by urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area

		Male	**Female**	**Total**
Urban	Yes	19	10	29
	A little bit	1	0	1
	No	5	5	10
	TOTAL	**25**	**15**	**40**
Rural (no Deaf school)	Yes	13	3	16
	A little bit	2	2	4
	No	3	3	6
	TOTAL	**18**	**8**	**26**
Rongo (with Deaf school)	Yes	6	8	14
	A little bit	0	0	0
	No	2	0	2
	TOTAL	**8**	**8**	**16**
Total		**51**	**31**	**82**

Analysis of the signing knowledge of the non-KSL users was done. It showed that 5 deaf individuals in this group of 20 non-KSL users do not appear to know any signs (Table 6.5). This suggests that they are unable to communicate except for the use of very basic gestures.

Table 6.5: Do you use any other sign communication? By non-KSL user deaf participants, gender & urban – rural (no Deaf school) – Rongo (with Deaf school) geographical area

		Male	Female	Total
Urban	Yes	2	0	2
	A little bit	0	0	0
	No	0	1	1
	TOTAL	**2**	**1**	**3**
Rural (no Deaf school)	Yes	5	1	6
	A little bit	2	1	3
	No	3	1	4
	TOTAL	**10**	**3**	**13**
Rongo (with Deaf school)	Yes	1	3	4
	A little bit	0	0	0
	No	0	0	0
	TOTAL	**1**	**3**	**4**
Total		**13**	**7**	**20**

There was no statistical association between knowing another form of sign communication and the geographical areas of urban – rural (no Deaf school) – Rongo (with Deaf school).

There were 5 deaf people (6%) of this study sample population of 82 deaf people who showed having no form of sign communication (KSL or homesigns) (Table 6.5). Four out of 5 of the twenty non-KSL using deaf participants in this study were from rural areas (Table 6.5). Only 1 of the non-KSL users was living in an urban area.

The implication from this finding is that these 5 people would probably be using very basic gestures or some other rudimentary form of communication,

effectively having no language to communicate. This situation of not having language appears to be in direct contravention of the Kenyan Constitution that stipulates in Article 54(1) 'A person with any disability is entitled–– (d) to use Sign language, Braille or other appropriate means of communication' (Government of Kenya, 2010, p.37). In the literature, this is the group of people that are termed 'isolates'.

During this investigation, there were some important issues mentioned regarding isolates that need further exploration.

The Deaf community is very aware that there are deaf people in remoter rural areas who have no language. This fact was expressed throughout the study. For example, during a conversation about communication challenges, one Deaf man in Kisumu diverted the conversation and said, 'There are some deaf people in the village who can't sign. For some, it's impossible to communicate' (Deaf male, urban, 29 October 2012). Another Deaf man stressed the fact that all forms of communication were restricted, 'Some deaf, they can't sign or even write. There is a very big problem here' (Deaf male, urban, 17 August 2013).

In discussing the issue of isolates with one of the leaders in the Deaf community, it became clear that there may be a gender dimension to consider. This community elder explained that he believed there were a greater number of female than male isolates. In exploring possible reasons for this, he explained that deaf boys – like hearing boys – venture out from home more than girls. Girls are more restricted in having to stay home and do chores around the house. However, the boys have the possibility to interact with other children when they are away from home. In interacting with other children, they are more likely to develop a system of gesturing that could develop a more extensive lexicon, and therefore communication system, similar to homesigning.

Whilst this study did not seek to explore the gender dimension to isolates sufficiently to comment on the above opinion, some observations can be made from the data. During administration of the semi-structured questionnaire,

participants were all asked the two factual questions about HIV transmission and prevention. Of the 82 deaf people who participated in the study, there were 15 deaf participants (12 male and 3 female) who were unable to engage in the question about HIV transmission; and 19 deaf participants (12 male and 7 female) on the other about HIV prevention. It is interesting that the findings from this analysis do not support the observations of the Deaf elder above who suggested that deaf girls were more likely to be isolates than deaf boys. The implication is that this whilst this analysis does not support his opinion, it is inconclusive and probably suggests that further investigation is needed to determine the exact situation.

The Deaf community convenes trainings in rural areas around a number of issues including SRH and HIV/AIDS. During one of these trainings in which I attended in August 2013, I noticed that approximately 10%, or 3 out of 30, of the deaf participants did not seem to have enough signs to participate in the training. In exploring how the facilitators handle participants who effectively do not have enough language to contribute or learn, one facilitator explained:

> 'I have to get local people to teach them very basic village signs and then the language can develop. Before you can teach about AIDS, you must teach sign language. At seminars, if isolates come, I will try and encourage deaf people who live nearby to interact and visit the isolate. In this way, social skills and language can develop' (Deaf male, urban, 31 August 2013).

During one interview in this study, it became clear that sign language is something that can be learned; and if not used, lost. One female participant who lived in a rural area had gone to a Deaf school for early primary education. However, something had happened and she had dropped out of school and moved back home where she was the only deaf child and isolated from the Deaf community. Whilst she had been proficient in sign language as a child in a Deaf school, when I met her in her late teens, she was re-learning KSL as she had recently come into contact with Deaf people again. This reinforces the finding that for deaf people to communicate, they must be linked into the Deaf community where they are exposed and use sign.

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Homesigns

For most deaf people in this study, homesigns are principally used to communicate with hearing family and community members around them. In this enquiry, one deaf participant was asked to illustrate how he would communicate using homesigns at home. He shared the following example, 'They [his family] know some signs [KSL] but we use local signs [homesigns]. But you must point at something for hearing people to understand. For example, if you want shoes, you point at them for someone to understand that you want them' (Deaf male, urban, 26 October 2012).

One Deaf man who is very conversant with KSL explained, 'With the Deaf I am using KSL; but with the hearing, I am using homesigns' (Deaf male, urban, 29 October 2014). From this comment, it is possible to deduce that the skill of communicating with hearing people using simple signs and gestures is a skill that will always be useful and needed. A participant in one rural area who did not interact with many deaf people said that he found it easier and more comfortable to connect and socialise with hearing people with whom he could communicate using homesigns than with the more linguistically competent Deaf people who used KSL. The work of Marie Coppola in Nicaragua could help explain why this non-signing proficient deaf man found social interaction with non-signing hearing people easier. Marie Coppola found that the hearing culture in Nicaragua had a lot of conventional gestures that everyone knows and understands. For example, one of them is hand flapping at the mouth that means 'eat'. Everyone in Nicaragua knows this gesture and uses it. They have another one that means drink, which is your thumb pointed up towards your mouth with the other fingers curled into the palm (Senghas & Coppola, 2001). Therefore, if you are a non- proficient signing deaf person and you are able to communicate wanting food or drink through conventional gestures, it might be more familiar and a less intimidating experience to do so with a group of gesturing hearing people than with a group of signing proficient Deaf people.

Once non-KSL signing deaf people meet and interact with other deaf people – for example, upon entry into a Deaf school or migration to an area where there

are other Deaf people - the opportunity to learn sign language arises, assuming entry is before adulthood.

Spoken communication & lip reading

> 'With us Deaf, we communicate with signs but the hearing, they communicate with their mouths. The Deaf who speak have an easier interaction with the hearing and they will understand one another quicker' (Deaf male, urban, 29 October 2012).

For deaf people who are post-lingually deaf, there are more communication options available. Once this fact became evident, I tried to ask the deaf participants the age at which they became deaf to see how age of deafness related to communication options. However, it was obvious that I would not be able to explore the data from this angle because many deaf respondents were unsure and not able to confidently say the age at which they became deaf. Nevertheless, I present the findings in this section from the evidence and observations that I made during the data collection phase of the project.

In homes in Western Region of Kenya, the first language learned is most likely a vernacular language (for example Dholuo or Maragoli, amongst others) or Kiswahili. Some other children are likely to also be exposed to English, especially those in the more urban-based areas. Whatever the language used at home, the deaf child is likely to use that language as the basis for spoken communication with the family. For example, one Deaf man explained, 'There is nobody else in my family who knows KSL. We use lip reading/speaking' (Deaf male, urban, 25 October 2012). A female participant explained how she copes at home, 'If I want to communicate with my family, I only look at their mouth' (Deaf female, urban, 26 October 2012).

During this study, many participants appeared to be post-lingually deaf which meant that they are likely to have some lip-reading and spoken language potential for communication. Clearly, for those deaf people who can speak with hearing people, there are some obvious communication barriers that come down – namely, that the hearing person - assuming they know that language -

will understand them. The barrier will come up again if, in the absence of any signs, the deaf person cannot capture or understand the response from lip reading.

Spoken communication is used by deaf people, both in the home and outside in the community. One participant explained how he widely uses this communication technique, 'I speak with the hearing. And we communicate there at the Municipal council using spoken language. Same with the neighbours, I speak. I use spoken communication with my workmates and neighbours' (Deaf male, urban, 25 October 2012).

One interview revealed how deaf people can use the lip reading skills to their advantage. The interviewee informed the study, 'Many deaf people lip read when you are communicating with them'. He continued to illustrate how the skill has helped him:

> 'Hearing people always cheat deaf people. I can lip read and there are so many times when hearing people communicate with each other and I understand what they are saying and they turn to me and tell me something very different. Or they say to each other "Don't tell him what we are talking"' (Deaf male, urban, 29 October 2012).

Vernacular communication

Spoken communication is made more complicated by the number of vernacular languages in Kenya. As explained above, deaf children who are post-lingually deaf will have been exposed to one – or possibly more - of a number of languages. Whilst some of these vernacular languages may be similar, it cannot be assumed that if you know one, you will automatically understand another. For example, one Deaf man said, 'Hearing people always speak their vernacular and I don't understand' (Deaf male, urban, 17 August 2013). The reason that he does not understand is because he will probably be from a different ethnic community and not familiar with that particular vernacular language.

A Deaf woman explained her situation at home, 'My husband is a Luo and myself I am a Luhya so when we are communicating, he needs to talk carefully so that I can understand' (Deaf female, urban, 2 November 2012).

Deaf people – like hearing people - are often very mobile, moving from one place to another in search of work and a better life. In this study, I met a Deaf couple in Kakamega who had travelled from their rural home over 400km away to secure employment. In moving around in this way, deaf people face even more communication challenges. As was described earlier in this section, some post-lingually deaf people can lip read and speak in their vernacular language. However, in migrating to other areas in the country, the possibility to communicate using spoken language is lost once someone moves into an area where the local people are not communicating in their vernacular mother tongue.

Writing things down

The link between education and communication options is appreciated in the Deaf community as illustrated by the following comment, 'You know with the deaf, they have low education. Sometimes it is hard to communicate' (Deaf male, urban, 26 October 2012). One Deaf woman said, 'I write things down with hearing people' (Deaf female, urban, 29 October 2012). Another Deaf woman explained the significance of being able to write things down, 'I don't have language problems if I can write' (Deaf female, urban, 29 October 2013). One Deaf man even explained why he preferred to communicate with hearing people, 'When you sign, you get tired. When you write, you don't' (Deaf male, urban, 29 October 2012). This man had become deaf at an older age and therefore found communication in sign more problematic and slower than some of the other alternatives – for example, writing in this instance.

One Deaf man explained how communication is made easier at home because he can read and write, 'Even my parents don't know homesigns. They just point at things. If I want to communicate with them, I have to write things down'. It is clear from this example that communication at home is only made possible for

this man because he can write (Deaf male, urban, 17 August 2013). Groce (2005) suggests the literacy rates for adults with disability could be as low as 3% for men, and 1% for women. Cognizant of these estimates, I decided that it was important to see how many of the participants in this study could read and write. Given the constraints of study, I was unable to pursue an in-depth assessment of levels of literacy. Instead, participants were asked to assess themselves. The findings are presented here and help us understand the potential of this means of communication for the deaf respondents in this study.

Figure 6.3:   Can you read and write? by hearing status
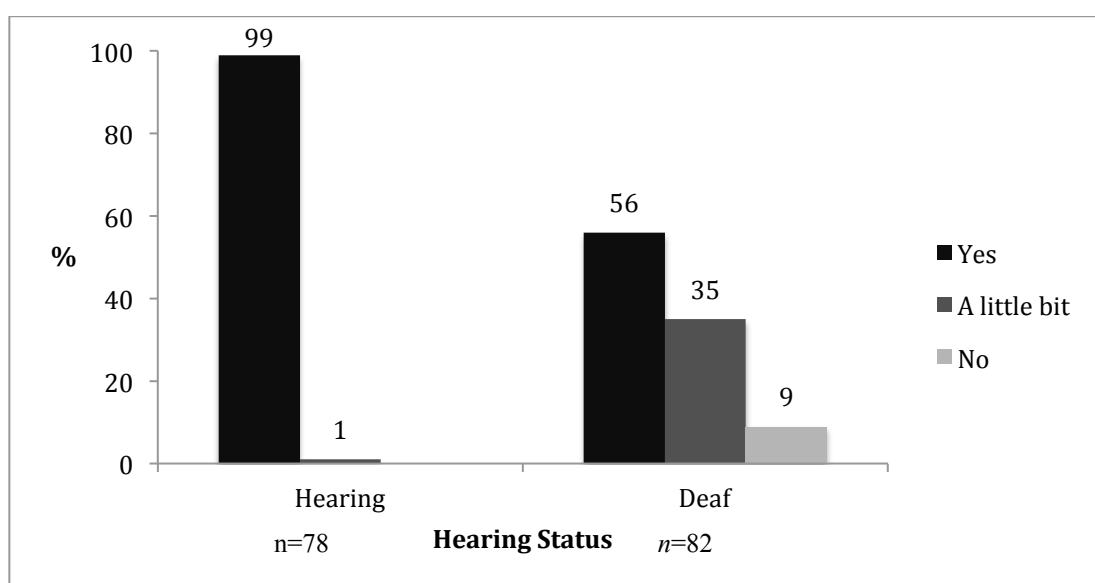
There was a statistically significant difference   (X^2 = 41, p<0.001) between hearing status and being able to read and write: 99% of the hearing respondents (*n*=78) compared to 56% of the deaf respondents (*n*=82) reported being able to read and write (Figure 6.3).

It is also important to remember that if someone cannot read and write, they will not be able to understand and use the fingerspelling alphabet to expand the potential for communication.

Since there was a significant association by hearing status, the data was analysed by the urban - rural geographical area to consider any association.

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Figure 6.4:   Can you read and write? Deaf participants by urban - rural geographical area
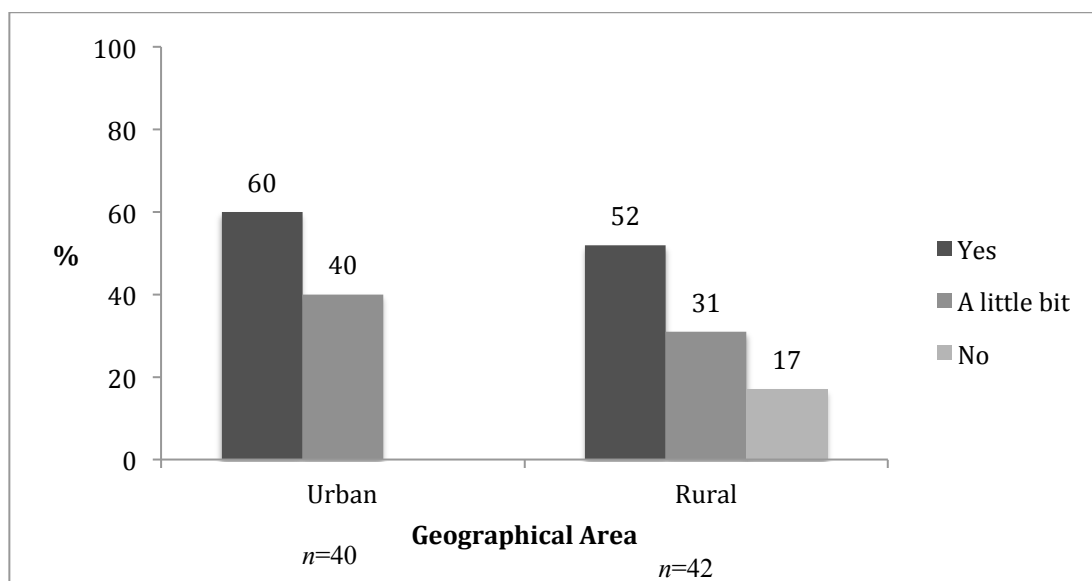
A statistically significant association was found (X^2 = 7.53, p=0.03) for deaf people being able to read and write and living in an urban or rural location for deaf participants in this study: 17% of the rural deaf respondents (*n*=42) reported not being able to read and write compared to no one in the urban community (Figure 6.4). In order to get a greater understanding, the test was run again by the groupings of urban - rural (no Deaf school) - Rongo (with a Deaf school) to determine if there was any difference from being in a Deaf community.

Table 6.6:   Can you read and write? Deaf participants & urban – rural (no Deaf school) – Rongo (with Deaf school) geographical area

	Yes	A little bit	No	Total
Urban	24	16	0	**40**
Rural (no Deaf school)	8	12	6	**26**
Rongo (with Deaf school)	14	1	1	**16**
Total	**46**	**29**	**7**	**82**

There was a significant association (Fisher's Exact 20.8 (df=4), p<0.001) between being able to read and write and geographical area as defined by urban - rural (no Deaf school) - Rongo (with Deaf school) for the deaf participants in this study (Table 6.6).

The findings from the analysis in this study are very informative and show the impact of living in a Deaf community near a Deaf school (Rongo). Literacy levels for the deaf respondents in this study appear highest at 88% (14 out of 16) in Rongo; then 60% (24 out of 40) in urban; and finally 31% (8 out of 26) in rural areas. Obviously given the small sample size, further research is needed to clarify this link. It was also beyond the scope of this study to confirm whether the increased reporting of being able to read and write in Rongo was because of living in a Deaf community near a Deaf school, or because the deaf participants in this study attended that school.

Table 6.7: **Can you read and write? Deaf participants by gender & urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area**

		Male	Female	Total
Urban	**Yes**	12	12	24
	A little bit	13	3	16
	No	0	0	0
	TOTAL	**25**	**15**	**40**
Rural (no Deaf school)	**Yes**	5	3	8
	A little bit	7	5	12
	No	6	0	6
	TOTAL	**18**	**8**	**26**
Rongo (with Deaf school)	**Yes**	8	6	14
	A little bit	0	1	1
	No	0	1	1
	TOTAL	**8**	**8**	**16**
Total		**51**	**31**	**82**

Deaf men and women had the lowest literacy rates in rural areas (deaf men: 28%, or 5 out of 18; deaf women: 37%, 3 out of 8) (Table 6.7). The interesting finding is that deaf men in Rongo reported 100% literacy (8 out of 8), and deaf women, 75% (6 out of 8). These rates are higher than those reported in urban areas for deaf men (48%, 12 out of 25), and slightly lower for deaf women (80%, 12 out of 15). For the deaf men, there was a significant association between being able to read and write, and geographical location urban – rural (no Deaf school) - Rongo (with Deaf school): Fisher's Exact 18.8 (df=4), p<0.001. However, the findings for deaf women did not have any significant association.

For children who are post-lingually deaf and lose their hearing at an older age, they will have an increasing number of communication options. Once they have entered school, children will start to learn Kiswahili and English from early primary school so the language options for spoken communication expand and grow. Furthermore, literacy skills will develop once in school - for those that are able to read and write, they will always be able to write things down when communicating with hearing people, even if it is – as was suggested by two Deaf women – the less preferred communication option. One Deaf woman in Kisumu described how she communicates with her neighbours, 'We try to communicate with spoken communication. If that fails, we must write' (Deaf male, urban, 2 November 2012). Another woman shared the same approach, 'Sometimes when it is hard to communicate with lip reading, we write things down' (Deaf female, urban, 26 October 2013).

It does appear that the potential for written and spoken communication could be decided by the experience and exposure of each individual person before they became deaf. 'What I can read and write is only English and not Kiswahili but I am not that perfect' (Deaf female, urban, 2 November 2012). The reason for this lack of proficiency in reading and writing Kiswahili is because English is the language in which lessons are taught in Kenya from Class 4. Kiswahili is a language class within the school curriculum. Therefore, for those children who do not use Kiswahili at home, they can become proficient in English at an earlier age than they can Kiswahili.

The deciding factor in the use of whatever means of communication is adopted seems to be – for post-lingually deaf people – the level of education attained. One Deaf man was very clear about the importance of education, 'The Deaf lack education and information. This is what is creating all their problems' (Deaf male, urban, 13 September 2013). Since public health messages regarding HIV/AIDS for deaf people will have to be visual, a lack of literacy could severely impede access to much published and produced material.

After meeting a number of deaf participants in this study, I became aware that whilst some might claim to know KSL or be able to read and write, I could not assume that they had reached the levels requited to participate fully in society. Since I did not test their KSL proficiency or literacy levels, I am unable to establish precise levels of attainment. However, there is a considerable body of literature that suggests that deaf children's reading achievements lag significantly behind those of their hearing peers resulting in the average deaf student leaving school with a reading age approximately equivalent to that of a 8- to 9-year old (4-5 grade) hearing child (Kyle, 2010; Paul, 2003; Pollard et al, 2009; Traxler, 2000).

I was aware of some deaf people in this study who had very low levels of awareness or understanding of how the human body functioned. Whilst I had no way to assess levels of health literacy, there was evidence – for example, I am reminded of one Deaf woman who shared her perception and understanding, 'I was told by a deaf person that hearing and deaf are equal [the same] and I was very much surprised. I was told they can all be positive [HIV-positive]. I didn't know that deaf and hearing lives can be the same: both can be positive' (Deaf female, urban, 11 November 2012). Upon reflection, it appears that this woman thinks that HIV/AIDS – and perhaps other diseases and health conditions – are not things that are shared by both hearing and deaf people.

6.4   Sources of HIV/AIDS information

In this study, participants were asked where they sourced HIV/AIDS information. The graph below shows us the range of different avenues from which deaf people accessed information about HIV/AIDS.

Figure 6.5:   Sources of HIV Information (deaf participants[8])
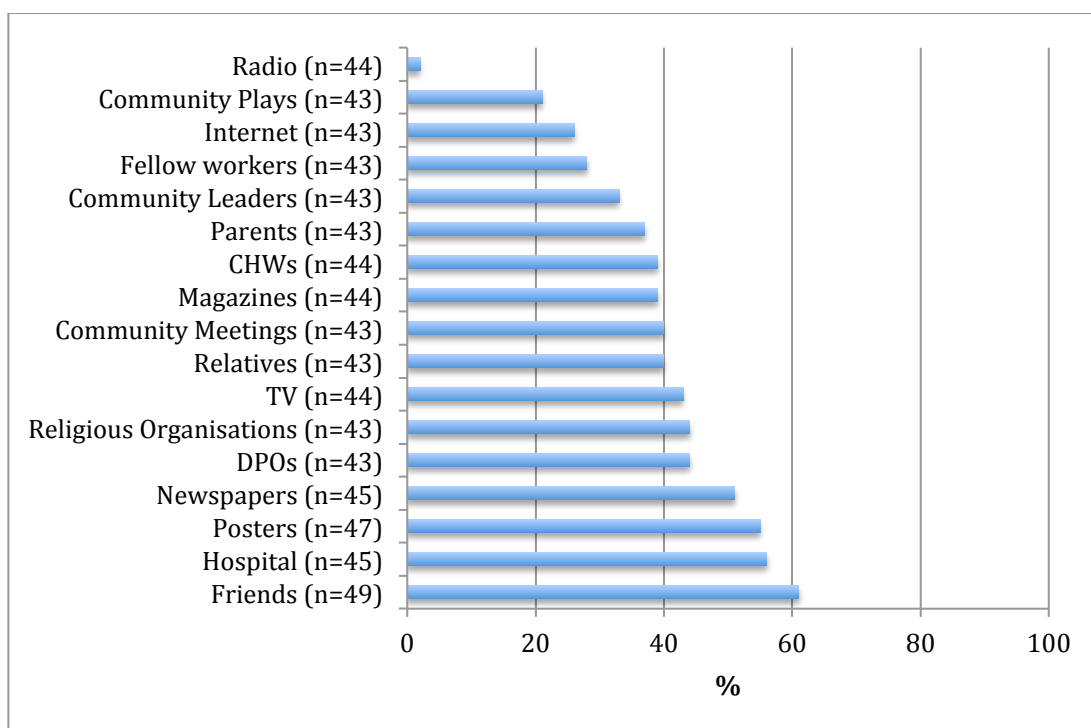
The top sources of information for the deaf respondents in terms of where they access HIV/AIDS information were friends (61%, or 30 out of 49), hospitals (56%, or 25 out of 45), posters (55%, or 26 out of 47) and newspapers (51%, or 23 out of 45) (Figure 6.5). Other avenues included institutions (religious and DPO), family and friends.

Whilst it is not possible to make a comparison between of the sources of information between the deaf and hearing respondents in this study because most of the hearing respondents said that nowadays they could access HIV/AIDS information everywhere, comparison can be made with two other

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[8] Participants could answer positively to more than one source.

Deaf studies from Africa. The sources identified in this study are consistent with results presented in two published studies from Africa that explored where deaf people sourced information related to HIV/AIDS. The first, in Swaziland, 191 deaf people were asked where they got their HIV/AIDS information, and results showed that the top three sources of information were: posters (70%); DPOs (69%); and TV (66%). Interestingly, health facilities only received 24%, and newspapers 54% (Groce et al., 2006). The second study, in Nigeria, found that clinics were accessible to (46%), newspapers (20%), and posters (17%) of deaf participants (*n*=50) (Groce, Yousafzai & Van Der Maas 2007).

Since deaf people are falling short in terms of comprehensive knowledge about HIV/AIDS, the implication is that there are some limitations in each of these communication channels. For the purposes of this investigation, discussion in the next section will focus on the experiences of these sources of information (friends, family, DPOs, hospitals, posters and newspapers) and why they might be failing to meet the HIV/AIDS information needs of deaf people.

6.5   DPOs and religious institutions: Training

Participants were asked about whether they had ever participated in an HIV/AIDS education class or programme. Community level HIV/AIDS education programmes are often convened by NGOs, CBOs, DPOs and religious organisations for hearing and deaf people. In addition, KNAD and other Deaf organisations convene training programmes exclusively for deaf people. In this question, AIDS education classes or programmes were not restricted to classes in the formal education system but could include instruction through any avenue that might include more informal gatherings, in clubs for example.

The aim of this question was to determine if everyone in this study population had been reached by some form of structured HIV/AIDS education programme and had not simply relied upon their knowledge of HIV/AIDS being established by *adhoc* information gathered through various other informal channels that might include friends, family or media.

There was no difference between the percentages of hearing and deaf respondents having participated in an AIDS education class or programme (hearing: 85% (*n*=78); deaf 85% (*n*=75)). Furthermore, within the deaf sample in this study, no significant differences were found by either gender or geographical location and having participated in an AIDS education class or programme.

One Deaf participant explained why he thought rural deaf people may be disadvantaged, 'The problem is you don't have access in the remoter rural areas of the region to seminars and trainings' (Deaf male, urban, 31 October 2012). In exploring why this may be the case, he continued to suggest that for those deaf people who were very isolated living in the more remoter rural areas of the region, it could be very hard for them to get invitations to trainings and seminars because of the way of identifying and inviting participants to trainings. He explained that often the practice was for the conveners of trainings to approach local NGOs, and particularly Deaf Associations, for them to identify potential deaf participants for inclusion in trainings, and therefore, if a deaf person lived in an inaccessible place, far removed from other deaf people, they may not be known or remembered for inclusion in training programmes. The inference therefore in this comment is that it is not only lack of access to information but also the isolation from being away from other deaf people that may be a cause for lack of knowledge.

In spite of these findings, it is important to note that the deaf respondents in this study were consistently less accurate than the hearing respondents in their answers to the questions to test their knowledge about HIV/AIDS. The implication is therefore that there are some communication issues to explore further.

There was some evidence from information shared during discussions of this question that some people, notably from rural areas and who were not very confident in KSL, did not enjoy attending HIV/AIDS trainings and seminars. They spoke of their discomfort and inability to communicate well. One even

spoke of his fear of going to trainings and seminars because even if there were interpreters available to translate the sessions, he would not be sure that he would be able to understand the information; and he was afraid of being made to look foolish by not understanding any questions that were put to him. Another Deaf participant offered her explanation, 'With the hearing, they get a lot of information, but with the deaf, they are very slow to get it' (Deaf female, urban, 17 August 2013). It could be that educators may not allow sufficient time to ensure that the deaf participants have achieved the learning aims of each session. In failing to ensure that all participants are keeping up, some deaf participants may get frustrated with the consequence that the trainings fail to meet their objectives and they do not like them.

One Deaf man shared his frustration of attending an HIV/AIDS seminar, 'I don't know how someone can get HIV/AIDS and I just went for a training!' (Deaf male, urban, 17 August 2013). A Deaf woman spoke about the content of the course that she had attended, 'They only taught us about VCT and people who were positive' (Deaf female, urban, 11 November 2012). Whilst verification of the content or programme is outside the scope of this study, the fact is that even if these training programmes did include other topics, these deaf participants did not get the information they needed. In discussing this situation with a KSL interpreter who has interpreted at some AIDS education trainings in the region, she offered two possible insights. The first was that some training programmes do not have sufficiently qualified or experienced interpreters to facilitate. The second was that some deaf participants might not have enough language to understand and this made them frustrated and angry. She gave an example of her experience in one training where some deaf participants had confronted her and challenged her interpretation skills by saying that she must be signing the wrong things because they did not understand. She continued to explain that she had been giving them the right signs and correct information and suggested that they did not have the signing proficiency to keep up.

The second point the interpreter makes in the above situation raises a potentially more complicated issue. It is possible that some deaf individuals,

particularly those who have had limited educational opportunities, do not have a vocabulary that includes specific signs for some of the issues covered in these medically focused trainings (infection, blood count, etc.). In 2013, WHO produced a report, 'Health Literacy: The solid facts'. Whilst acknowledging that health literacy is an evolving concept, the report clearly acknowledges that education is vital to health:

> 'An individual's level of literacy directly affects their ability to access health information, learn about disease prevention and health promotion, follow health care regimens and communicate about health messages with other people' (WHO, 2013,p.35).

The situation therefore where some deaf individuals are getting angry and frustrated in HIV training programmes may reflect the fact that they may have had limited education and lack not only a broader knowledge of health related signs but also potentially enough educational background (i.e. 4th grade or above) to allow them a conceptual framework within which to interpret the medical and public health information they are receiving.

6.6   Family and communication

A CODA noted that deaf children are no different to any other children in that, 'The family is the core foundation for a deaf child' (CODA, 2 September 2013).

'Learning about one's sexuality does not take place in six 1-hour sessions nor is it restricted to one period in one's life. It is a life-long process'. (Griffiths, quoted in Watson, 2002, p.36). The implication from these words is that education about sexuality and SRH matters generally should be something that is imparted in different places, in different ways, throughout someone's life, including at home. Before exploring SRH communication and education in this study, I have decided to present some findings from published literature to establish global findings on these issues.

Mall & Swartz (2012b) undertook a qualitative study with 9 parents of Deaf adolescents in South Africa. They found that the parents were aware of the need

to address healthy relationship choices with their children. Further studies involving educators and PWD show a general consensus that young people with disabilities need some sexuality education; however, there was some debate about where best to deliver the information. Love (1983) undertook a study to determine parental and staff attitudes towards the subject of human sexuality instruction for sensorially impaired students at the Alabama Institute for Deaf and Blind. A questionnaire was developed and shared with 603 parents/guardians and 265 staff, with a 32% return from parents/guardians and 41% from staff. The responses showed – like with the parents and educators of PWD – a strong agreement between parents and staff about the need for instruction in human sexuality. Contrary to the notion that parents of children with sensory impairments are resistant to the subject of sexuality instruction for their children, this survey confirmed the idea that parents and staff are not only supportive but are in fact eager for instruction in this area. When asked where they felt the best place for sexuality education, 75% of the parents responded that the best place was the home.

It is interesting to note that in the Love study presented above, the majority (75% of respondents, *n*=301) said that the best place for sexuality education for deaf and hard-of-hearing young people was in the home, whilst some other studies have found that parents are reluctant to educate their deaf children on matters related to their SRH (Ajzenstat, Gentles & Human Life Research Institute, 1988; Schirmer, 2001). Shirmer (2001) notes that parents often defer, or shirk their responsibility to educate their deaf children about sexuality, and lists 7 reasons: (i) embarrassment because of the issue itself, as well as the graphic nature of sexual signs and discomfort; (ii) lack of knowledge; (iii) uncertainty about personal values and sentiments concerning sexuality issues; (iv) an underlying fear that discussion would encourage experimentation; (v) uncertainty about how to initiate discussion; (vi) the belief that it was the school's job; and (vii) the belief that the child already knew the material.

In this study, many deaf people spoke of their childhoods and memories. A constant theme was about the lack of communication that deaf people

experienced growing up within hearing families. The following comment by one Deaf man sums up the common experience that many expressed, 'It was so hard to grow up in a hearing home. No one knew sign language at home' (Deaf male, urban, 31 October 2012). It should be noted that whilst hearing parents of deaf children in western industrialized countries are often actively discouraged from signing or even gesturing to their deaf children, this is unlikely to be the case in developing countries like Kenya.

There is an acceptance in the literature that 5-10% of deaf children have deaf parents (Schein, 1989, Shirmer, 2001). This means that the majority (90-95%) of deaf children have hearing parents who most likely neither know nor use sign language when their child develops deafness. The key point is that hearing parents are unable to communicate with a deaf child in the language that is most easily accessible (sign). Communication between them will be dependent upon the parents learning sign, but first they have to know that their child is deaf.

Diagnosis of deafness is the first barrier that children with congenital deafness will have to contend. Hospitals in Kenya's major towns are equipped with audiological testing facilities, and mobile MoH workers assist with the identification of deaf children in the community. However, as highlighted earlier in this thesis, confirmation of hearing impairment – especially in resource-challenged countries in the developing world – can take years in some countries (Olusanya, Luxon & Wirz, 2005). Once deafness has been confirmed, the aim of hearing parents of deaf children should be to improve sign language communication at home (Yousafzai et al., 2005). As already described, this will mean enrolment in sign language classes. However, in many countries, particularly – but not exclusively – the countries of the developing world, the opportunities to learn sign language can be very scarce. Even when classes are available, there can often be other barriers – for example, Mall & Swartz (2012b) found that one parent in their South African study explained that it was hard for her to learn South African sign language at her child's Deaf school because of the financial and transport barriers to attending classes held at the

school. It therefore follows that in most developing countries, the majority of deaf children grow up in homes where they are unable to communicate because there are simply not the facilities available for sign language instruction, especially in the areas outside of the main cities. Unfortunately, with late diagnosis of deafness and inadequate support and slow intervention after diagnosis, many parents experience difficulties and lack of confidence in learning and using sign language with their children (Young, 1995).

Since the main aim of this study is to explore the awareness and knowledge of HIV/AIDS of different groups of deaf people, it was important to explore whether lack of communication was something that the deaf participants in this study still experienced in adult life. Initially, participants were asked if they lived with anyone else who was deaf.

Twenty-three deaf respondents (28%, *n*=82) in this study reported that they were living with someone else who was deaf (Table 6.8).

Table 6.8:   Who else is deaf?

Person	Number
Parent	1
Child	2
Sibling	2
Friend	5
Partner	13
Total	**23**

Only 1 deaf person was living with a deaf parent and 2 deaf people were living with a deaf sibling. These are life-long relationships and so it is possible to suggest that 3 people had definitely grown up with other deaf people in their childhood homes where there would have been some form of sign communication. Whilst this figure may not capture the exact number of

participants whose childhood home environment included another deaf person, we can see that the number of deaf participants who live with other deaf people does increase in adulthood in this sample. For the majority of these people who reported that they were currently living with a deaf person, 18 out of 23 reported living with an adult partner or friend who was also deaf. A key finding from this question though is that 59 deaf people, or 72% of the deaf respondents, in the study reported not living with anyone else who was deaf in adulthood.

In this study, during an interview I had with a Deaf woman who was still living with her family in an urban area, I became aware that lack of communication and feelings of isolation could extend beyond childhood, and at worst could even be lifelong issues for some deaf people. She said, 'My family members are always quiet. We don't communicate. I am just bored there at home. Even with the neighbours, I don't communicate' (Deaf female, urban, 17 August 2013).

The following discussion presents some of the literature that suggests that a child's sexual behaviour might be influenced by the family culture in which that child was raised. Findings from available literature indicate that open communication between parents and children can have a positive impact upon the children's sexual behaviour (Commendador, 2010; Deptula et al., 2010; Doswell et al., 2003; Mall & Swartz, 2012b).

One study suggests that open communication can result in a delay in sexual debut. Fasula & Miller (2006) undertook a study with 530 non-sexually active high school students to examine the effects of mother-adolescent sex discussions and peer norms on intentions to delay or initiate intercourse within the next year. They found that although sexually active peers have a negative effect on adolescent sexual delay, responsive parent and sex discussions can buffer these effects. The findings for this study will be encouraging for those parents who are afraid that their children may engage in early sexual relations and perhaps motivate them to open dialogue channels with their children. However, for parents of deaf children – and especially those parents of deaf

children who cannot communicate in spoken and/or written language - the challenge of communicating (in sign) about these matters presents an additional barrier that they must overcome if they are going to feel comfortable in granting their children the independence to interact and socialize with their peers.

Research shows that the parents of hearing children need support, and perhaps training, to best prepare for dialogue with their children on matters related to SRH. In one study, Campero et al (2010) investigated changes in parent-adolescent sexual health communication following an intervention for parents of 10th graders in Mexico. The intervention was aimed to sensitize and develop skills of appropriate parent-child communication about prevention of STIs, unplanned pregnancy, birth control, encouraging condom use and emergency contraception back up. In total, 66 in-depth interviews with parents and children were undertaken after the intervention. They found that when parents are sensitized to the risks their adolescent children face, it is easier to initiate communication about prevention. The Fasula & Miller (2006) study above also concluded that intervention efforts can help parents develop the knowledge and communication skills they need to discuss sexual topics with their children effectively. It is interesting to note that the authors acknowledge that parents need to have not only the knowledge, but also the communication skills for dialogue with hearing children. Unfortunately, the communication skills for addressing the same issues with deaf children - and particularly prelingually (congenital or early-onset) deaf children - are much more complex because the parents will have to do it in a learned language and not their mother tongue. From this literature, it would seem that the barriers to open communication between parents and deaf children are stacked up against them and they will need much more support if they are going to address these obstacles.

Another study informs us that it is not only communication between the generations but also involvement in everyday activities that is important. Pearson and colleagues (2006) explored data from the National Longitudinal Study of Adolescent Health in North Carolina in the United States to determine

what aspects of parental involvement are related to sexual initiation. Results indicated that when young women have positive relationships with their parents, share mealtimes and participate in shared activities, they are less likely to initiate sex. The suggestion from this study is that young women gain confidence and control of their lives if they have been raised in homes where they participate and engage with other family members. Once again, deaf children could be disadvantaged and denied this opportunity. Involvement is very challenging for many parents of deaf children because they are unable to communicate confidently with their deaf children in sign.

The potential for parents to develop a family environment that is founded upon open communication and involvement with their children will be impossible for parents of deaf children unless they can sign. Unfortunately there is a lack of opportunity for parents to learn sign to make this possible. The result for deaf children is that not only is the potential for communication with their parents made impossible, but they are also denied the additional benefits that relate to their SRH that come from being raised in home environment that is open and fosters communication between the parents and their children.

In order to gain an insight in to the potential for communication at home, participants were asked if they were living with someone who knows KSL. Twenty-four deaf people, or 29% of the deaf respondents (*n*=82) reported living with someone who knows KSL. This figure is comparable to the number of deaf people in this study who said they were living with someone else who is deaf (*n*=23), and presumably using KSL to communicate. There are two implications from this finding. The first is that it is highly likely there is a link between living with another deaf person and use of KSL in the home environment; and the second is that the lack of communication that deaf people spoke of in childhood is an issue that extends into adulthood home environments for many deaf people as 71% of the deaf respondents (*n*=82) were not living with anyone with whom they could communicate in KSL.

All children point and gesture before learning language, either spoken or signed. Goldin-Meadow et al (2007) express this fact well when they say that 'children enter language hands first!' (p.778). The key point is that all language (spoken and signed) is accompanied by gesture. However, one participant suggested that there needed to be a greater awareness about signing and its potential for communication, 'Some hearing fear signing. They don't know that signing is just normal. They need to be aware that signing and gesturing is normal and not to be afraid of it' (Deaf female, rural, 10 October 2013). It is interesting that the perception is that it is not merely the language and lexicon of signs that need to be learned but also the fact that it is even possible to communicate using signs. This context contrasts the situation that existed in nineteenth century Martha's Vineyard, and was described by Groce (1985). A result of the high numbers of deaf people on the island meant that hearing islanders were all exposed to and learned sign because it was one of the mainstream languages in that environment.

One Deaf participant spoke of how, in the absence of anyone who knew KSL, his older brother had built up some signs to become his 'interpreter' at home. He explained how life was made much easier and more inclusive when his brother was there. However, when his brother left home to study and work away, he spoke of the isolation and loneliness he experienced at home. In this situation where only one family member was able to communicate in any form of signs, the result was that this Deaf person became dependent on that one person being around to help them. If they were not around, they suffered.

Whilst this study cannot confirm the communication environments of deaf participants during their childhoods, it can shed light on participants' current living circumstances. Evidence from the study does suggest that parents or families may lack the KSL communication skills to consider discussing SRH matters as only 29% of the deaf respondents in this study (n=82) lived with someone who knows KSL.

Guided by the literature and the importance of family in the education of its members on matters related to SRH, and specifically about HIV/AIDS, in this study, I felt that it was important to explore whether there was any evidence of deaf people discussing and learning about HIV/AIDS with their family members.

In hindsight, it is interesting that this question was only one of two that triggered a negative reaction from any deaf participant in this study. One Deaf woman clearly did not like my asking this question. She responded, 'THAT is a bad question. No, I don't feel free to discuss with my family!' (Deaf female, urban, 24 October 2012). In exploring her reaction to the question with her, it seemed like she felt in some way challenged by my asking about communication with her family. Without knowing it, I was confronting her with the reality that she did not discuss such issues with her family, and all her attempts to try and do so had been unsuccessful and had clearly left her frustrated.

There were some conversations in the study that did reveal some levels of communication that deaf people had had with their families around SRH, including HIV/AIDS. One deaf woman who had moved to Kisumu to live with her hearing sister informed the study of the advice that she had received from her, 'We keep quiet about sex but my sister explained and warned me to protect my vagina. I should not be giving out my body. I shouldn't sleep with anyone. She tells me it is better for me to understand this' (Deaf female, urban, 11 November 2012). During the conversation it became clear that whilst this participant had been told not to engage in vaginal sex with anyone, she did not know why or have any clear facts about HIV/AIDS.

Figure 6.6:   Do you discuss SRH with your family? by hearing status
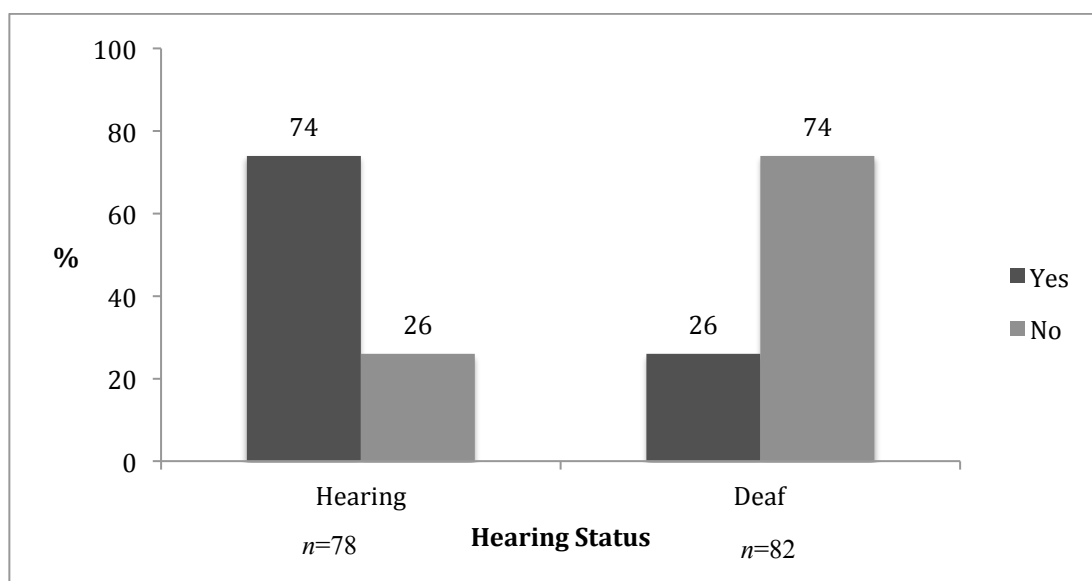
In this study, a significant association was found between hearing status and whether someone discusses SRH matters with their family ($X^2 = 34.2$, p<0.001): 74% of the hearing (*n*=78) and 26% of the deaf (*n*=82) reported discussing SRH with their families (Figure 6.6).

According to the Schlesinger and Meadow's 1972 finding (cited in Job, 2004) that parents and deaf children tend to communicate about things that are in the here and now with 95% limiting communication to topics with a visual reference, it is clear that discussing information and behavioural topics related to health and sexuality would not be something that could be discussed easily in families. Whilst this could be an important factor, one Deaf man I spoke with in this study offered an alternative perspective when he suggested there could in fact be two barriers that hinder deaf people, and particularly deaf children, from communicating about SRH matters in their families. The first was indeed the inability of family members to communicate in sign. The second being the cultural barriers that prevent parents from easily discussing SRH with their children. However, it was also suggested in another conversation in this study that in today's environment where HIV/AIDS has devastated communities, families had been forced to confront traditionally taboo subjects because the risks of not doing so were so high. In order to explore this suggestion with

reference to the responses from the hearing sample in this study, it can be seen that 74% of the hearing respondents (*n*=78) do in fact discuss SRH issues with their families. The conclusion from evidence in this study must therefore be that it is the communication barriers rather than any cultural influence that is hindering discussion and dialogue in families.

Some other deaf participants mentioned the family culture of silence on matters of SRH; however, there was an inference that things could change and that this situation was not necessarily fixed – for example, one Deaf man explained, 'We don't talk in the family, not yet' (Deaf male, urban, 17 August 2013). Another Deaf man spoke of the potential, 'I don't but I will go and try and talk to them about SRH' (Deaf male, urban, 29 October 2012).

There was no association confirmed between either gender or the urban – rural geographical location, and discussing SRH with families in this study. However, the situation changes a little when the data is explored according to the geographical groupings of urban – rural (no Deaf school) – Rongo (with Deaf school). In this instance, there is approaching significance: Fisher's Exact 5.6 (df = 2), p=0.057 (Table 6.9).

Table 6.9: Do you discuss SRH with your family? Deaf participants by gender & urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area

		Male	**Female**	**Total**
Urban	Yes	8	3	11
	No	17	12	29
	TOTAL	**25**	**15**	**40**
Rural (no Deaf school)	Yes	4	0	4
	No	14	8	22
	TOTAL	**18**	**8**	**26**
Rongo (with Deaf school)	Yes	4	4	8
	No	4	4	8
	TOTAL	**8**	**8**	**16**
Total		**51**	**31**	**82**

The highest level of communication of SRH between deaf people and their families appears to be in Rongo, at 50% (8 out of 16), and least in rural areas for both deaf men (22%; 4 out of 18) and deaf women (0%, 8 our of 8). A significant association was confirmed for deaf women in rural areas, Fisher's Exact 5.8 (df = 2), p=0.041.

One deaf participant shared his views as to why the level of communication of SRH between deaf people and their families might be highest in Rongo. The main reason, he suggested, was because communication in families would most likely be easier in Rongo. He thought there were likely to be more deaf-deaf marriages; or if there were deaf-hearing marriages, the hearing partner would probably be KSL competent because of the increased exposure and opportunities to learn the language. In addition, he explained that in Rongo, there is a Deaf primary and secondary school, a Deaf association branch office, and a Deaf church. All of these things, he believed, helped to create a strong Deaf

community and an environment that fosters positive communication and interaction.

For participants who said that they did not discuss SRH with their families, there were a number of reasons expressed to explain why.

One Deaf man explained, 'I don't discuss because I don't know anything about SRH from which to start talking about it. I cannot discuss SRH with my family because I am afraid to do so' (Deaf male, urban, 25 October 2012). The interesting thing to consider here is whether his fear stems from the reluctance he feels due to his lack of knowledge or his discomfort of it perhaps being a taboo or sensitive subject. Some participants suggested SRH may be a taboo subject as they expressed being able to talk about 'safe' issues as opposed to more intimate or personal subjects – for example, 'It is possible to discuss testing but not sex or AIDS' (Deaf male, urban, 25 October 2012) or, 'I discuss ARVs and testing with my aunt. We can't talk about boyfriends' (Deaf female, urban, 29 October 2012).

The value attributed to open communication was often expressed in this study. However, usually within certain boundaries or limitations – for example, one Deaf man in Kisumu summed things up, 'I think parents should always advise their children to focus on their work, both boys and girls' (Deaf male, urban, 17 August 2013). For this man, he felt that any discussion between parents and their children should be on their education and advancement in life and not touch upon more intimate or personal matters like perhaps SRH.

Siblings seemed to be an important source of information – for example, one Deaf man came from a home where communication appeared, at the first instance, to be open between family members. However, he emphasised his preference, 'I can talk to all of them but I always talk with my brother' (Deaf male, urban, 29 October 2012).

One female participant explained, 'I don't fear to discuss with them [her family] but we don't. I am not comfortable and free with my family' (Deaf female, urban, 26 October 2012). It is interesting to note that she does not mention the language or communication barriers but rather the family dynamics. During a conversation with another Deaf woman, she also raised the issue of family dynamics. She highlighted the kinds of conversations she could have with her parents. She explained:

> 'I fear my parents. I can't tell them anything. I am not free to complain because they will kick me out of the house. I am only free with my parents to tell them I want a job and share ideas or I want to go and interact with Deaf people to make my mind strong' (Deaf female, urban, 31 August 2013).

Whilst it cannot be concluded that since this is the experience of one or two participants, that it must hold true for others, it raises the issue of fear. In this instance, this participant expresses her fear of challenging her parents on anything because of the potential negative reaction she may experience.

6.7   Health service and communication

In this study, hospitals were clearly an important source for deaf people to get information about HIV/AIDS: 25 out of 45 deaf people said that they had heard about HIV/AIDS at the hospital. In this section, the discussion will explore some of the issues that deaf people contend with when trying to access the health service in environments where the system is typically ill-prepared to meet their communication needs.

Another popular source of information about HIV/AIDS, posters, is very closely related to hospitals. In this study, 26 deaf people out of 47 asked (or, 55%, n=47), reported having got HIV/AIDS information from posters. Some people might suggest that the two sources almost go hand-in-hand because of the poster and information displays in waiting areas in health centres, hospitals and VCT clinics. In this study, it is also interesting to note that the percentage of deaf participants who spoke of receiving information from posters was also almost

exactly the same as the number who said they could read and write, 56% (*n*=82) (Figure 6.3).

Mallinson (2004) discovered that deaf people in the US often resorted to accessing health information by reading pamphlets and other published material because the health professionals were unable to communicate with them. This seems to confirm Nyang'aya's claim that deaf Kenyans were excluded from much of the public health, and particularly HIV/AIDS, materials because they were produced in English (Nyang'aya, 1998). However, some deaf people in this study spoke of looking at posters in waiting rooms at health facilities and having family and friends explain diagrams and drawings when they did not understand the messages. This is an example of how some deaf people are adapting to overcome some of the barriers that they face in accessing information. It is worth noting however that to access information in this way in hospital waiting rooms - either from reading from posters or through sign interpretation with family - both are inaccessible for deaf isolates who are functionally unable to communicate and therefore access such information.

Mallinson's (2004) study in North America highlights one of the ways that deaf people have to adapt to the failure of health systems to offer services that meet their language and communication needs. In this study, Mallinson found that in order for deaf and hard-of-hearing men in the United States to obtain access to HIV prevention services, they were sometimes expected to read information that was usually disseminated orally or discussed with the health care provider. Mallinson considered this strategy ill-advised because deaf and hard-of–hearing people in the United States often find reading difficult. Traxler (2000) suggest that the English reading level of the average deaf adult at the completion of formal education in America is usually placed somewhere between the fourth to fifth grade in achievement. In relying on the correct dissemination of HIV-related information through this way could therefore be risky because inaccurate information could be transmitted.

The language barrier is only the first obstacle to understanding HIV/AIDS printed material. Many deaf people also have only a rudimentary understanding of anatomy, disease and medicine. To confidently comprehend the pathology and disease process of HIV/AIDS requires some considerable understanding and comprehension of the human body, its defence system and function. A system which therefore relies on deaf people accessing health information and services through printed material would therefore seem very likely to fail, especially in countries where many deaf people are illiterate or marginally literate because they have been denied an education.

UNAIDS, in collaboration with WHO and the Office of the United Nations High Commissioner for Human Rights (2009), issued a policy brief that highlights 3 possible barriers that may exist for PWDs in accessing quality care in health centres. These barriers are supported by other literature.

- Service providers may lack knowledge about disability issues, or have misinformed or stigmatizing attitudes towards PWD

- Locations may be physically inaccessible, lack sign language facilities or fail to provide information in alternative formats such as Braille, audio or plain language

- Confidentiality – or perceptions of confidentiality - for PWD in HIV testing and counselling may be compromised – for example, the need for a sign language interpreter to be present

For the purposes of this discussion in this section about the language and communication challenges facing deaf people, I would like to focus on (2) and (3) above.

Whilst the health services sought at hospitals and VCT centres are often very different, the barriers to accessing these facilities for deaf people in this study are often very similar, as the following two participants' comments illustrate: for hospitals, 'When you go to hospital it is hard because of the communication

barrier' (Deaf male, urban, 29 October 2012); and VCT centres, 'The problem is in the VCTs are not friendly with the deaf. In most of the village areas, we have VCTs but the problem is that they are not friendly to the deaf. When the deaf go there, no person will communicate with them in sign language - so there are big challenges there' (Deaf male, urban, 31 August 2013).

The consequences of the communication barriers at health centres were explored with deaf participants. One Deaf woman said, 'The Deaf fear going to the hospitals. They say, "When I go to the hospitals, whom will I communicate with? So let me give birth at home"' (Deaf female, urban, 7 October 2013). This comment affirms a recommendation from Groce and colleagues' study in Swaziland where they suggested that the result of a situation where there are barriers between health service professionals and deaf clients could mean that less deaf people will utilize HIV VCT services (Groce et al., 2006).

Research shows that whilst some deaf people may not be able to communicate with health professionals because of a lack of sign language interpreters or literacy, for others (homesigners & isolates) it will be because they do not have the language to communicate. From available literature, it seems universal for deaf people to struggle to communicate with health professionals. I reference three studies here, from the United States, Swaziland and Kenya that illustrate the issues and experiences of deaf people.

The first, a study by Bat-Chava, Martin & Kosciw (2005) found that all 134 deaf participants in their study in New York State reported difficulties in communication with medical providers, limiting their access to health information and proper medical care. Two deaf participants illustrated the interaction that deaf people encounter in trying to access health care in an environment that is ill-equipped to meet their needs. In the first example, a deaf patient who had sought medical support believed that he could stop taking his ARV medication once his seropositive status had changed to negative:

'The doctor said if I take my medicine it may, the medicine may [be able] to stop because it may be negative. I don't know; it's the doctor's decision. He's the one who checks me out and I've been taking my medicine regularly and the perfect timing and everything, and it may turn into negative later on'. (p.628)

The information relayed in this communication is wrong on two counts. Firstly, once someone starts ARV therapy, they stay on medication for the rest of their lives; and secondly, it is not possible for an adult to seroconvert to negative status once they have had a positive HIV test result. Clearly there had been a breakdown in communication between the health service provider and deaf patient.

The second study that illustrates the experiences of deaf people was undertaken by Groce and colleagues (2006), when they found that almost all of the deaf respondents (99%) in their study involving 191 hearing and deaf individuals in urban and rural areas of Swaziland reported difficulties in communicating with health care facility staff. The study recommended addressing the accessibility issues in healthcare facilities for deaf sign language users.

Finally, the African Union of the Blind's (AUB) 2007 report on the state of disabled people rights in Kenya explored the issue of access to health facilities. The report illustrates the barriers that deaf people face in accessing health services by sharing one deaf woman's experience:

'One time I was very sick and went to the hospital to consult the doctor and explain to him about my problem. I couldn't get an interpreter and yet I was seriously sick and needed a doctor very urgently, of course... it was not explained to me properly how I was supposed to take the medication. I was so confused. I scarcely understood what was said due to inadequate communication' (African Union of the Blind 2007, p.53).

Helander (1998) and Ludders (1987) inform us that most health professionals are not confident users of sign language. However, it would seem to be unreasonable to lay the blame for this situation with the health service provider or doctor. From the discussion so far, the conclusion seems to be that it is a

failure of the system, compounded by a situation where there is a dearth of certified and available sign language interpreters; however, a study by Atkinson & Woll (2012) in the UK suggests that the situation may be more complex. In this study of 6-8,000 Deaf signers with neurological disorders, they found that the Deaf signers experienced under-representation in clinical referrals and inappropriate assessment. They argue that even the use of highly experienced interpreters can be inappropriate, unreliable, and error-prone, since, in this instance psychological validity was lost in translation.

Another example from the Bat-Chava, Martin & Kosciw (2005) study in New York exemplifies a typical experience that a Deaf person can experience in accessing medical services that are not supported by professionally qualified and certified interpreters. In this instance, a Deaf man went for an HIV test in New York City. At the start of his appointment, he asked for an interpreter. The hospital responded by calling a nurse with limited signing skills who was trying to finger spell everything and was obviously not signing proficient. He felt frustrated because he wanted to sign and discuss the test and some post-test issues but was unable to do so. As a result of this limited communication, the patient understood very little of what occurred during his medical appointment.

Yarger (2001) looked at interpreter training in the US and found that the practice of relying on untrained interpreters is more common than might be expected. Yarger undertook a study with 63 educational interpreters employed in two rural states in the America, and found that only 10 of the 63 interpreters had completed Interpreter Preparation Programmes, with 5 of these having no coursework related to the education.

With reference to Yarger (2001) and the finding that service delivery is often dependent upon untrained interpreters, I sought to establish how many KSL trained and certified interpreters were operating in Kenya at the start of my fieldwork data collection. The University of Nairobi has a KSL Research Project that offers KSL instruction, and as of 2012, the Co-ordinator of the Project estimated that were less than 50 trained KSL interpreters for the whole country.

Taking the National Survey for PWD estimate of 216,000 deaf and hard-of-hearing people in Kenya, this would mean that there is only 1 KSL-trained and certified interpreter per 4,320 deaf or hard-of-hearing people in Kenya. Clearly this dearth of qualified interpreters makes implementation of Article 54 of the Constitution in which it states that a person with any disability is entitled to reasonable access to all places, public transport and information, almost impossible for the majority of deaf people.

Whilst this study did not attempt to calculate the number or percentage of deaf people who had experienced problems at health centres, there was certainly evidence that this was a common issue for many deaf participants in the study. However, the following comment sums up the feeling of many deaf participants in this study: 'Few deaf people would go to hospital for HIV services because of communication problems' (Deaf male, urban, 26 October 2012). The implication therefore is that the health service is not meeting the access commitments set out in the Constitution.

There are also a number of other studies undertaken over the last decade from eastern and southern Africa that show a similar situation is also shared by deaf people from across the region. One study explored the barriers to accessing health services among PWD in rural northern Namibia, and found that a lack of sign language interpreters was a key issue for the Deaf community (Van Rooy et al, 2012). Yousafzai et al (2005) undertook two studies in Rwanda and Uganda in 2003 involving 123 adolescents with disability aged between 11 – 18 years old. One of the conclusions of the study was health workers were unable to communicate with deaf adolescents using sign language.

Kritzinger and colleagues undertook a qualitative study in Worcester, South Africa involving 16 deaf participants that confirmed that communication difficulties were a prominent barrier to accessing health care services. However, in addition to sign language interpretation, they also found that interpersonal factors including lack of independent thought, overprotectedness, non-questioning attitudes and lack of familial communication interact with

communication difficulties in a way that hampers access to health care services. This study recommended that health care services need to take cognizance of the fact that providing sign language interpreters in the health care setting will not make access more equitable for deaf patients as they have additional barriers besides communication to overcome before successfully accessing health care services (Kritzinger et al., 2014). The implication from this study is therefore that the communication challenges for deaf people are more complex than simply providing sign language interpreters.

One Deaf woman in this study referred to two kinds of pain, the 'inside' and 'outside' pain that deaf people experience. The 'inside' refers to the physical pain that is in her body because of her medical condition; and the 'outside' is the emotional hurt that originates from the communication barriers out there in society. She said, 'It is painful for the deaf because they wont get an interpreter. They will die feeling the pain. Some deaf people can write and so they can communicate so they only die with their inside pain' (Hearing female, urban, 7 September 2013). It is notable here that she groups post-lingually and literate deaf people in the same bracket as hearing people, presumably because of their increased communication options. This comment echoes the finding from the Mallinson (2004) study in which it was discovered that some deaf people are forced to get health information from published materials. In this instance though, deaf individuals rely on their literacy to be able to communicate with the health professionals and not simply to get information. Another Deaf participant spoke of the consequence of being illiterate, 'If a deaf person goes to the hospital, the doctor can chase them from the room if they cant write because of communication problems' (Deaf male, urban, 29 October 2012). This situation must be frustrating for everyone. For the deaf person they are unable to receive the attention they require; and for the medical personnel, they cannot offer the medical treatment that they are trained to do.

In order to appreciate the experience that deaf people can face at health facilities, I have decided to share three real-life experiences given to me in this

study that illustrate some of the frustrations caused by the communication barriers that deaf people can face in trying to access health services.

6.7.1 Case studies

Case Study 1: Trying to see a health professional

During one discussion, it became clear that some barriers that obstruct a deaf person from getting medical treatment relate to avoidable procedures implemented at the health centre.

A Deaf participant explained the usual process in Kenyan health facilities of registering your name and handing your medical records to a receptionist who will then call you when it is your turn to see the doctor. The patients then sit and wait for their names to be called whilst in a waiting area. Deaf people will obviously not hear their names being called for their appointment by the receptionist. When there is no response to their names being called, their appointment slot to see the doctor is passed to someone else, usually the next person registered on the list. The result of this procedure in busy health centres can be that deaf people are left in the waiting rooms for hours and go home at the end of the day not having seen any medical professional.

When I asked the participant about how he felt about this situation, he replied, 'If I am waiting for a long time, I will feel bad. I get annoyed'. He continued, 'I will go direct to the medical staff and complain about waiting all day and we end up quarrelling or even fighting'. In exploring other solutions to this situation, he said, 'Without an interpreter at the hospital, it forces deaf people to write things down and communicate that way. If I can't read and write, I can take a member of my family to try and communicate with local signs' (Deaf male, urban, 29 October 2012).

This situation is similar to one that was found in a study by Harris & Bamford (2001) in the UK where they found that the NHS routinely operated systems that relied upon shouting patients' names and this practice led to frustration

among deaf patients. Clearly this is an unacceptable situation as either one's right to accessing health care; or, if someone is forced to take a family member to interpret, one's right to privacy, could be compromised.

The Kenya Health Policy 2014 – 2030 seems to address this issue through a system of digitalizing all health records and systems on an architectural platform with emphasis on interoperability (Government of Kenya/Ministry of Health, 2014). In this way, if a person were deaf, a note would presumably be made on their electronic records and so the system would then be in place for all the staff to be ready to respond to their needs.

Cast Study 2: Contraceptives

The second case study concerns accessing contraceptives, and particularly condoms. During this investigation, participants were asked about where they would get condoms. It was found that 37 out of the 45 (or, 84%) deaf respondents who responded to this question said that they get condoms at the hospital. There was no statistically significant difference between urban and rural deaf inhabitants and getting condoms at hospital.

One deaf man in Kisumu explained that he had found that he had much more choice about where to get condoms in town than his rural neighbours. Another Deaf participant explained his reluctance to pick condoms at hospital, 'When you go to a hospital and ask for condoms, it is hard for them to understand your communication' (Deaf male, urban, 29 October 2012). The communication barriers were also noted at VCT centres, as one Deaf man explained: 'It is easy to get condoms for the hearing community but not for the Deaf community because those who work there are not people who are friendly to the Deaf community because there is a communication barrier in the VCTs' (Deaf male, urban, 31 August 2013). It therefore stands to reason that deaf people would be more likely to source condoms from places where the condoms are openly available to pick without having to ask anyone for them – for example, public toilets.

The reluctance to utilize HIV VCT services was a warning that emerged from Groce and colleagues' study in Swaziland (Groce et al., 2006). They found that the difficulties that deaf people face in communicating with health professionals might deter them from using them. In response to the situation where it is hard to source condoms, I was given an example of the strength, resilience and creativity of the Deaf community, and how it is constantly changing and adapting to meet the challenges it faces. In this instance, to address this situation, one of the local Deaf community leaders takes it upon himself to regularly go and collect condoms from health centres and then travel around the community to distribute them to deaf people. In this way, he is sure that deaf people under his jurisdiction are not denied contraceptives because of the awkwardness and embarrassment caused by the communication barriers between deaf people and health sector staff.

Case Study 3: Male circumcision

During a conversation with a public health officer who was interviewed during the data collection phase of the project, another preventive measure was discussed: male circumcision.

Traditionally, the Luo community does not circumcise men. However, research has shown that male circumcision reduces the transmission of HIV/AIDS (Cohen, 2005). In response to this – and other studies - there has been a rollout of a voluntary programme on male circumcision in this region where there are high concentrations of Luo people.

Initially, I noted that there could have been some confusion and misinterpretation in the public health campaign that could be putting some deaf people at risk of HIV infection. From a comment that a Deaf man made, it appears that some people may believe that it is impossible for men who are circumcised to get HIV whereas evidence from the research studies actually suggest that male circumcision could help prevent transmission, but not eliminate it.

'They [deaf men] believe - many men - believe that if you are already circumcised, they think they cannot be able to get HIV positive but they believe like those who like the Luo community who are not circumcised, they have higher rates of HIV because they are not circumcised' (Deaf male, urban, 31 August 2013).

The public health officer I met continued to explain how at one mobile male circumcision campaign in a rural area in the research study region, a deaf man presented to be cut. She explained that they could not do the procedure because they were not confident that the man had enough language to understand the after care instructions that they were required to give. She noted the man's frustration but said they did not feel able to proceed because of the communication barrier. This was the first example I was aware of where a deaf person was denied a health intervention because of the language barriers. In none of the literature reviewed in preparation for this study did I find an example of exclusion on the grounds of hearing impairment in this way.

Denying this deaf man from undergoing this procedure would, in the first instance, appear to be in conflict with the Persons with Disability Act 2003 (Government of Kenya, 2003). Article 25(1) clearly states that no person shall, on the ground of disability alone, deny a person with disability the provision of any service or amenities to which members of the public are entitled. However, the Act continues to qualify this provision by stating, unless such denial is motivated by a genuine concern for the safety of such person. Furthermore, there is provision for prosecution of medical personnel in Article 46 if they negligently cause a disability to a patient. Therefore, if there were medical complications that resulted in some form of impairment or disability as a result of doing the procedure, there may be grounds for prosecution. Therefore, in the absence of signed interpreters to support communication between this public health officer and the deaf man, she decided to err on the side of caution and deny him this service.

6.7.2 Solutions

The opportunity was taken during this study to explore some of the solutions to address the communication barriers that deaf people contend with when trying to access HIV/AIDS information and related-services in health facilities.

From the literature review, the solution was clear: for people who are deaf and can sign, the use of qualified sign language interpreters is virtually the only means through which effective communication with the health service can occur (Lotke, 1995; Chilton, 1996). However, the communication issue is compounded in resource poor settings of the developing world, like Kenya, by a lack of trained and available sign language interpreters (Napier, 2004; Yarger, 2001).

The literature review findings are supported by evidence from this study. For example, a Deaf woman in Kisumu acknowledged the central role that interpreters have in communication when she said, 'There is no language problem because we have an interpreter at the VCT here' (Deaf female, urban, 29 October 2012). Another Deaf person in this study explained how he had successfully got information about HIV/AIDS through signed communication, 'I heard that AIDS was there from the 1980s up until now. I heard about it in Kuja school. Our teacher, who was an interpreter, taught us (Deaf male, urban, 31 October 2012).

70% of the deaf respondents (*n*=42) in this study said that they would access HIV/AIDS information and services at hospital. Since there is a lack of qualified KSL interpreters in Kenya, and most - if not all - public health centres and hospitals do not routinely provide interpreter facilities, deaf people are adapting to find solutions to the barriers they face. There were a number of ways shared that illustrate how deaf people are responding to this situation.

One deaf participant from an urban area said his answer to ensuring getting a good service at hospital was to pay for a KSL interpreter to go with him. He did however have two reservations about this strategy: the first, the expense could

make it unaffordable for some deaf people; and second, the concern about privacy issues since the interpreter could gossip about his medical issues. The implication from this reasoning could be that either he was uninformed or not aware of the ethical standards to which certified sign language interpreters must adhere, or he was engaging unqualified or non-certified interpreters to go to medical appointments with him.

For other deaf participants, some take a family member with them to act as an interpreter. Rohleder et al (2010) found that this situation exists in South Africa where family members act as interpreters with health professionals with the result that confidentiality was often compromised. In exploring the data in this study, this could also be applicable to this study population as findings from the data inform us that on the one hand, 72% of the deaf people in this study (n=82) do not discuss SRH with their families; however, on the other hand, to access SRH services - including HIV/AIDS services – deaf people may have to rely upon family members to interpret for them because of the scarcity of KSL interpreters at health facilities. There therefore appears to be a conflict in this situation with deaf people appearing to either suffer from the discomfort of having family members present and interpreting personal and private health matters with the health professionals or not being able to access the services at all.

One deaf participant told me that in the past he has asked another deaf person to accompany him to a medical appointment. His deaf friend can speak and is therefore able to facilitate communication with the health professional by interpreting his signs.

Article 31 of the Constitution provides that every person has the right to privacy, which includes the right not to have information relating to their family or private affairs unnecessarily revealed; or the privacy of their communications infringed. Therefore, the situation in which a deaf person may be required to access health services with a family member or another deaf person interpreting for them, or communicating with the health professionals

directly, could be in contradiction to this Article if the deaf person does not have a choice regarding this arrangement.

There was one Deaf participant in this study who appeared to challenge the suggestion that his privacy was compromised because of communication barriers, 'When you go to hospital, there IS privacy' (Deaf male, urban, 2 November 2012). Whilst it was encouraging to note his interactions with medical personnel had been private and confidential, we need to explore his situation to see if it could be applicable to other deaf people. After exploration of his circumstances, I discovered that he was a man who was post-lingually deaf and had graduated from primary school. He was currently employed and living with his family. From the discovery that he was post-lingually deaf and had had 8 years of primary school education, we can assume that he was literate and able to speak. The experience for other deaf people who do not have as many communication options may therefore not be the same. It is clear that his privacy and confidentiality was linked to his ability to communicate – through speaking or writing down - in a hearing world.

The Persons with Disability Act (2003) offers some hope to the Deaf community to addressing these barriers to accessing health services. Within Articles 24 and 25 of the Act, access and adjustment are addressed. The Act sets out a process where the National Council can serve an adjustment order upon the owner of the premises or the provider of any service or amenity requiring them to address any structural, physical, administrative or other impediment to access within a stipulated period of time. It may therefore be possible for the Council to serve an adjustment order on the MoH to address the communication barriers that face the Deaf community in health centres that operate without the provision of sign language interpreters. However, there are limitations and not all the needs of all deaf people would appear to be addressed under Articles 24 and 25. The right to health could still be denied some deaf people - for example, barriers created by a lack of language on the part of a deaf isolate to communicate with a medical professional. The point being that certain barriers are almost beyond the scope of the Act and require different attention.

Another Deaf man suggested that the solution lay with the medical staff themselves: 'We need to train the health workers and the public health personnel so that they can be able to understand the sign language. Then they will know how to communicate with the Deaf community' (Deaf male, urban, 31 October 2013). I met one post-lingually Deaf man who lives close to a Government hospital and regularly hosts KSL training lessons in the evenings for medical staff. These training sessions are often well attended and this shows a willingness of the health staff to respond to the situation. In addition, some NGOs and DPOs, including the Disability Programme at LVCT Health, have programmes where they train health practitioners throughout the country in basic KSL. Whilst these interventions may alleviate some of the communication challenges, their effectiveness and sustainability is questionable as the real impact of the training on the deaf person's experience at the health institution will be dependent upon a KSL-trained person staying in work, being on duty, and practicing and using the language to retain those signing skills when they are needed.

Another possible solution would be the expansion of the Deaf-staffed VCT centres. Taegtmeyer et al (2009) found from evidence at the 3 VCT centres that were run by deaf Kenyans in Nairobi, Mombasa and Kisumu that deaf people are better able to deliver HIV/AIDS services, like VCT, to other deaf people.

In this study, in an attempt to best understand how and where to provide HIV counselling and testing services, participants were asked a number of different venue options. In this study, Deaf VCT services seemed to have the support of deaf people, as evidenced by the fact that 29 out of 41 deaf respondents (or, 71%) said they would access HIV testing services that were offered by other deaf people. In exploring reasons for the 'no' responses, it appears that there were anxieties regarding confidentiality of results.

In 2007, HI in Kenya discovered that 44% of deaf clients at VCT centres found communication a major problem (Handicap International, 2007). This was an interesting finding as some VCT centres offered services in sign. There are two

ways that this statistic could be interpreted. The first is that the programme is probably only reaching a small percentage of all the deaf people who need it so the majority of deaf Kenyans still have to struggle with the communication barriers at VCT centres geared towards the majority hearing population. The second interpretation is that the issue could be that communication around issues of HIV could be complicated by the nature of the subject itself and a lack of signs or vocabulary to discuss the subject and not simply a lack of signing or interpretation services. In 2007, in response to this situation, the Kenyan Deaf Community produced a SRH dictionary by standardizing some SRH signs and creating others, in order to support communication at VCT centres and health facilities. Whilst this was an important step, the challenge is to rollout this information so that all deaf people in the country are aware of the signs and proficient in KSL.

One Deaf man said, 'You can't be deaf-friendly with a communication barrier' (Deaf male, urban, 1 September 2013). I have pondered these words during the analysis and write up of this study. Initially, I understood his comment to refer to the communication barriers that exist between hearing and deaf people as a result of the hearing world's failure to provide KSL interpretation services. However, after reflecting upon some of the findings from this study, there is scope for a broader interpretation. As 7% of the deaf respondents in urban areas (*n*=40) and 40% in rural (*n*=42) do not know KSL, I can now see that for societies to be truly deaf-friendly, there must be the scope to manage the communication needs of all deaf people, including both signing-KSL and non-signing deaf people. With an understanding that non-signing deaf people includes both homesigners and isolates, the challenge becomes much greater and more complex.

The next section explores issues related to isolation and loneliness that result from the exclusion that many deaf people experience, and how this could increase risk to HIV infection.

6.8   Isolation, mental health and HIV/AIDS

One consequence that many deaf children face born to hearing families where parents cannot sign is that they grow up feeling isolated and lonely.

To explore isolation and feelings of loneliness from the perspective and experiences of the participants in this study, they were asked 3 questions: (1) Do you live alone? (2) Do you have friends outside of the family? and (3) How often do you feel lonely?

A Deaf woman in this study shared her experience and understanding, 'Deaf children are never free at home. They will only feel free when they are in a Deaf community' (Deaf female, urban, 31 August 2013). Being 'in' a Deaf community only happens when deaf people meet and link-up with other deaf people. For those deaf children who go to Deaf schools, it happens at school. However, WHO (2011) inform us that most deaf children in developing countries never go to school with other deaf children. For these deaf children who do not access special schools for the Deaf, feeling 'free' or entry into the Deaf community will only happen at the time when they meet and interact with other deaf people. This typically happens as adults after moving to areas where they can interact with other deaf people.

A Deaf man talked about the impact and how this experience of isolation can make deaf children feel, 'We always feel lonely in the home because we are never involved. We are stigmatized in our families. We don't grow in our families' (Deaf male, urban, 29 October 2012). Some deaf people in this study said that their experience of living in a world where there was a lack of communication was oppressive. One Deaf woman suggested this situation needs attention, 'We must look for a way to communicate with parents to stop them oppressing their deaf children so that the children can feel free' (Deaf female, urban, 31 August 2013). Another participant echoed similar sentiments, 'Deaf children need protection and support from their parents. Some parents ignore their children. It is hard for them to support us' (Deaf male, urban, 17

August 2013). In exploring why it might be difficult for hearing people, and particularly parents, to 'support' deaf people and children, one Deaf man summed it up very succinctly, 'It is hard to support the Deaf community when you can't communicate with them' (Deaf male, urban, 31 August 2013). The point being that you cannot begin to meet the needs of someone – even raising a child - if you cannot communicate with them.

Parents can be over-protective of their deaf children. McCracken & Sutherland (1991) quote one deaf man who referred to his over-protective parents and his 'cotton wool existence' (p.147). In segregating him from opportunities to interact with his peers, he was denied the opportunity to develop confidence, self-esteem, friendships, peer learning and support networks. As a consequence of these family restrictions, many are subjected to further loneliness and isolation: they are, as Ree (1999) acknowledged, 'shut out from the human world' (p.85). As outlined in the previous section, published literature shows how a home environment that fosters openness and dialogue can have a positive impact upon a child's mental health and behaviour, including sexual behaviour later in life. Many of these benefits are denied to deaf children because they live in homes where their family members are unable to communicate with them in sign.

One deaf participant in an interview said he was still feeling the impact of a lack of communication within his family, 'how can I know who I am when I don't know my father or his language?' (Deaf male, urban, 29 October 2012). This lack of really knowing someone because of an inability to communicate was clearly evident from an interview in this study in a rural area of Nyanza. It became obvious that some families can be very disconnected from the reality of their deaf children's lives. An interview with a Deaf teenage girl and her principal caregiver, her aunt, illustrates this point well. The Deaf girl I was interviewing had lived with her aunt for many years. Before starting the interview with the Deaf participant, the aunt explained how their communication was always about things in the present – for example, "I want… I need" and that she could 'send her [her niece]', meaning she could send her to the kiosk for provisions.

The reason for communication on this level was that her niece 'was unable to focus out of the here and now'. However, during the interview, it became clear that the niece was able to communicate very comfortably in KSL about many things. She knew all the facts about HIV and spoke of discussing SRH matters, including condom use, with her Deaf friends. The aunt who was present for this interview was very surprised with the answers that her niece was giving. In being present at the discussion, she came to an understanding of the situation. After the interview, it was a very humbling moment when the aunt commented on her realisation that it was in fact she, herself, that did not have language, and not her niece. I discussed this situation with a hearing professional that works closely with deaf children and their families. She explained that this lack of parental awareness was not an uncommon situation for deaf children who are pre-lingually deaf. For children who become deaf later in life, since they are usually able to speak some words or write things down, family members realise they are able to communicate with them. However, for children who sign without the support of speaking or writing backup, many families may assume there is no potential for communication. She told me that one important part of her work was to encourage family members to come to the meetings when deaf children get together so that they can see how deaf people communicate and interact.

6.8.1 Young and lonely

71% (*n*=17) of the hearing and 42% (*n*=24) of the deaf respondents in this study believed that being young and lonely increases someone's risk of getting HIV. The two themes in much of the discourse about risk centred around, firstly, the human need for love, contact and support on the one hand; and secondly, the predatory nature of men.

Initially, discussions tended to focus on someone's mental health and self esteem. For example, one participant explained, 'A person who doesn't get friendship, love or counselling gets depressed because of the same things that keep happening in her life. They are at risk of bad seduction' (Hearing female,

urban, 7 September 2013). It was interesting to note that at this stage, in referring to someone who was young and lonely, the automatic assumption reflected in this person's comment was that that person would be female. Nobody specifically mentioned or singled out that that a deaf person may feel young and lonely. The assumption therefore in the early discourse was that a young and lonely person was hearing and female.

Another participant explained that feelings of loneliness and depression would most likely not be transient and short-lived like a mood, but rather something established like a condition, 'If you study her, you'll see, loneliness is not something that comes and disappears' (Hearing female, urban, 7 September 2013). The point being made was that the person's vulnerability and mental state would be something that could be seen and picked up from her physical appearance; and this was the key thing that would put them at risk of male advances.

Most women in this study framed the discussion about risk around male behaviour and their predatory nature or 'instinct'. The general consensus of opinion throughout the study was 'the one who is lonely is desperate. Men take advantage of ladies who are desperate' (Hearing female, urban, 11 September 2013). There were two approaches to 'taking advantage' identified. The first was that young and lonely women could be easily seduced; and the second that they could be targeted for crimes of sexual violence, including rape.

Discussions considered what might make the young people, and particularly young women, at risk of these seductions by men. This conversation with young hearing women in Kisumu was very insightful. One woman suggested:

> 'It is a risk. When you don't get someone to communicate to, how will you feel, and the desires to have sex are natural. God created us with them so if you don't have someone to communicate to, how you feel, you are lonely, you are at risk. You will try to get that comfort zone from somewhere else' (Hearing female, urban, 20 August 2013).

This comment echoes a finding from a study by Becker, Stuifbergen & Tinkle. They found that women with disabilities may become promiscuous as they become appreciative of any sexual attention they may receive (Becker, Stuifbergen & Tinkle, 1997). The point being that the loneliness and isolation they know and experience in life is alleviated in sexual contact with other people.

In the developing conversation, another woman continued:

> 'When you are lonely, you are vulnerable to those men who seduce you. You fear asking a man to test [for HIV] because he might leave and you'll be lonely again. The love you receive when you're lonely is like a drug. It heals. It takes the pain of loneliness away. Some men are predatory. They can sense if she is lonely' (Hearing female, urban, 7 September 2013).

This point was supported by another woman who added, 'Yes, she is at risk because she will need companionship and if she falls into the wrong hands she will do anything for this person just for the companionship' (Hearing female, urban, 1 September 2013).

For these women, there seemed to be an emerging understanding of conflict of desires, 'Shall I be lonely or risk going there [engaging with the man]?' (Hearing female, urban, 11 September 2013). Essentially the dilemma or decision to be made for these women was therefore whether the pain of loneliness or the risk of engagement was more damaging or painful.

The negative result of 'taking advantage' could also end up being a crime of sexual violence. For example, one Deaf woman expressed her observations, 'If you are young and alone, men out there will see you and come and rape you sometimes' (Deaf female, urban, 1 November 2012). The impression was that perpetrators of these attacks would be older and richer men. There were numerous references to support this opinion, as typically expressed by one Deaf participant, 'The big people can use you and they can rape you. Being young and lonely makes you a target for older people' (Deaf male, urban, 31 October 2012).

Some participants spoke of the emotional impact of being isolated, having nothing to do and lacking guidance, support and love. One hearing participant suggested hope was the essential thing that people needed:

> 'If you are isolated, you become careless because you have no hope…No hope like a woman who reaches an age that she knows she will never get married… If you have no hope, you don't have anything. You lose everything – direction, focus, everything. When you lose everything, you are careless, you are drunkard' (Hearing male, urban, 8 October 2013).

Towards the end of discussions on this issue, I asked participants to consider if they felt that deaf people may be particularly lonely or at risk. A study in South Africa showed that educators of deaf and hard-of-hearing adolescents believed that deaf and hard-of-hearing adolescents were more at risk of HIV/AIDS than their hearing peers because they may be vulnerable to having a premature sexual relationship if they felt lonely or socially isolated (Mall & Swartz, 2012a). In this study, the group of hearing young women agreed with the South African study finding that the loneliness and exclusion that deaf people, particularly women, feel would make it much harder for them to resist the attentions of men. Whilst this may be true, the irony is that in this study, as shall be explored later in this chapter is that it is in fact the deaf men who reported feeling more lonely 'a lot' than the women (34% of deaf men [n=50] compared to 10% of deaf women [n=31]) (Figure 6.9). The question therefore becomes, what is the impact of the men's feeling lonely and how do they deal with it.

6.8.2 Living alone

The rationale for asking if someone lived alone was that they would obviously be more likely to spend a greater part of their lives without the support of having others around them.

There was no statistically significant difference between the hearing and deaf participants in this study and living alone (X^2 = 1.57, p=0.211). In addition, there was no statistically significant difference between the geographical location

groupings of urban - rural (X^2 = 1.63, p=0.202), or urban – rural (no Deaf school) - Rongo (with Deaf school) (X^2 = 2.48, p=0.289), and deaf participants and living alone. Furthermore, no significant difference was found between deaf men and deaf women; or within each gender by the geographical location groupings of urban - rural (no Deaf school) and Rongo (with Deaf school).

A number of deaf participants in this study spoke of the fact that many deaf people migrate from their rural family homes to urban areas, or other areas where there are concentrations of other deaf people in the hope of a better life with more opportunities. However, from evidence in this study, it seems that in the process of moving and settling down in other areas, deaf people can find themselves living alone. A deaf man in this study suggested a couple of reasons to explain why 12 out of 51 (24%) deaf men, and 2 out of 31 (7%) of deaf women might live alone. He suggested that families of deaf children might be more at ease in letting their deaf male rather than deaf female family members move out of the home alone. The first is that families may be more protective of deaf girls and less likely to let them more out of the home alone; or secondly, that deaf girls and women may be living or move with their children.

To try and explore the issue of migration from rural to urban areas, I decided to look at the statistics from available literature on migration in Kenya. UNDP (2013) states that the proportion of the Kenyan population aged 15-18 years that lives in rural areas is close to 90%, while that of those aged 30-34 years is only 70%. This shows the extent of rural to urban migration in the country. Whilst there are no statistics to inform us about the migration of deaf people, there were a couple of conversations that I had during this investigation that suggest that deaf people also migrate. During a conversation with one deaf man, he informed me that he had noted in his interaction with deaf children at Deaf schools that they often dream and talk about leaving school and their homes to migrate to Kenya's towns and cities for a better life where they are close to other deaf people and in employment. In another conversation with a deaf elder, he explained that migration had often been tabled as an agenda item for attention and discussion when KNAD had met with donor agencies in recent

years. However, from the analysis in this section, it can be seen that this dream of migrating to a better life – for many young people – does not always come true as approximately 1 in 4 deaf people in this study who lives in urban areas, lives alone.

From the analysis and discussion about KSL in an earlier section in this thesis, it was concluded that the majority – approximately 70% of the deaf population in this study (*n*=82) are living with people who do not know KSL. The association between loneliness and communication was made by one Deaf participant, 'If a deaf person is with a hearing group, they feel lonely because the hearing group will not consider their inability to communicate. It makes us feel very lonely when the group has to change from talking to writing things down to include us' (Deaf male, urban, 29 October 2012). Essentially, he is suggesting that loneliness is an emotion that he feels when he is with other people with whom he cannot communicate. In fact, there can be no greater loneliness than living in an environment in which you cannot participate because you do not share the language of the people around you. For hearing people, however, the primary cause of loneliness would presumably be at times when they are not around other people.

The point is that whilst living alone may be a good indicator for the hearing population because in living alone, they clearly will not have anyone they are living with to talk to. It may not be a good indicator for a deaf person because the feelings of loneliness will not be determined by living alone but by communication. The implication that even though, for example, 23% of deaf people in urban areas (*n*=40) reported living alone, the actual number who actually feel lonely may in fact be much higher when we consider language and communication as approximately 20% of the deaf participants (*n*=82) did not know KSL; and only 29% (n=82) reported living with someone who knows KSL. The suggestion from this analysis therefore appears to be that whilst living alone may be a good indicator for determining if a hearing person is lonely, the issue is much more complicated for deaf individuals and there are therefore other factors to consider, including language and communication.

6.8.3 Friends

Many participants in this study considered having friends as being something positive – perhaps even life saving, as one deaf woman suggested, 'Having many friends protects you from HIV/AIDS' (Deaf female, urban, 1 November 2012). In exploring this comment with her, she explained that friends could act like a protective shield as not only were they an important source of information, but they could also guide and counsel you through difficult times or situations. However, not everyone considered friends in such a positive light. One deaf man expressed an alternative opinion, 'Being young and lonely is a lower risk because the number of friends is small' (Deaf male, urban, 25 October 2012). His point being that if you had a lot of friends you would have more opportunities to hook up with and establish sexual relationships with people and therefore if someone were young and lonely, they would be less at risk because of the lack of opportunities.

In this study, 30 out of 49 deaf people, or 61%, reported having heard of HIV/AIDS from their friends. Friends are therefore clearly a very important source of information within the deaf population in this study. This fact is supported in the literature. Doyle (1995) undertook a study at Gallaudet University in 1993 that involved 84 Deaf undergraduates. Findings in this study found that students had a relatively high level of knowledge about HIV/AIDS with 82% (n=68) reporting getting information about sex and HIV/AIDS from friends. Bat-Chava, Martin & Kosciw (2005) also found in their study that deaf people living in urban areas and in sizable Deaf communities were more exposed to information about HIV/AIDS than others.

Clearly the foundation for bonding and support with friends or families – whether hearing or deaf - must be communication. Without language with which to communicate, people will struggle to form attachments and develop intimacy with others. The significance of language and communication was constantly expressed throughout this study. One Deaf woman acknowledged, 'I have different friends, many friends, but communication is the problem' (Deaf

female, urban, 2 November 2012); another Deaf man explained, 'I always communicate so I don't ever feel lonely' (Deaf male, urban, 31 October 2012). The suggestion from these comments is that the focus to address issues of loneliness and boredom should again be on language and communication.

Since one of the findings in this study was that approximately 70% of the deaf respondents (n=82) reported not living with someone who knows KSL, the implication is that loneliness may be a feeling with which many are very familiar. A Deaf elder in a rural area explained the consequence of such conditions at home, 'Deaf people don't want to stay at home because when they stay at home, they feel lonely. They have no person they can communicate to so that is the big problem' (Deaf male, urban, 31 August 2013). 'For many deaf children', he continued, 'the consequence of these conditions is that they decide – if they haven't been forced out earlier – to leave their homes in search of a better environment' (Deaf male, urban, 31 August 2013).

Only when language has been established can friendships and connections really develop. The point being that deaf people need the opportunity to interact, meet and make friends with other deaf people - or hearing people who can sign - and with whom they can communicate. As one hearing participant shared, 'Many deaf – I have a neighbour who is deaf – don't socialise with people. They feel lonely. I always pity them. The deaf are at risk because they don't have a person who can guide them on how to protect themselves' (Hearing female, urban, 7 September 2013).

In this study, I asked participants if they had friends outside of the family to explore the possible extent to which deaf people in Western Region may find themselves isolated and alone and therefore, according to the literature and opinions of the participants above, at risk of HIV infection.

Figure 6.7:   Do you have friends outside the family? by hearing status
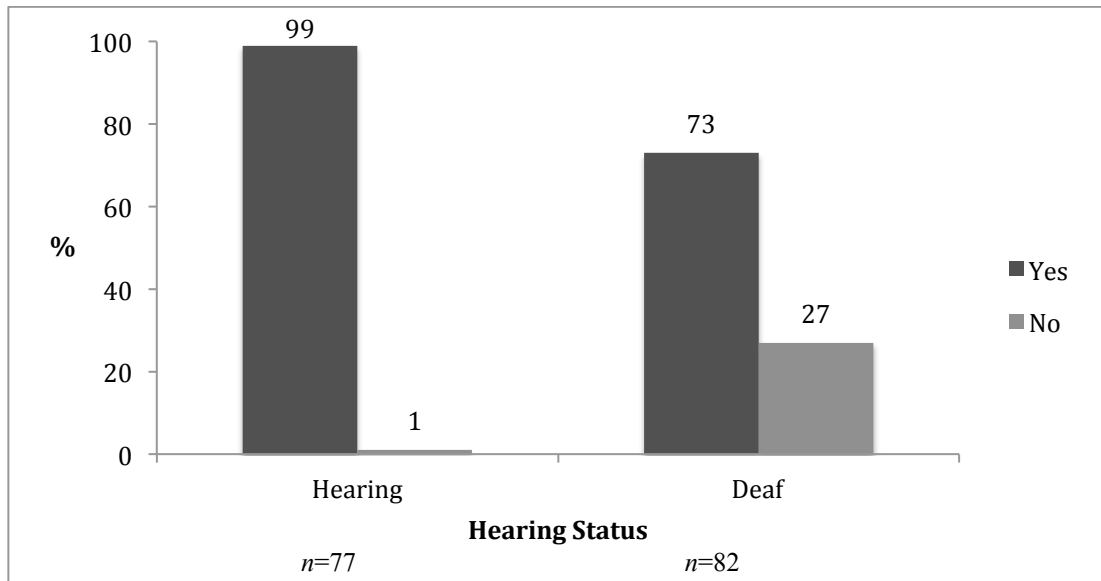
Fewer deaf participants (73%) than hearing (99%) reported having friends outside the family (X^2 = 20.9, p<0.001) (Figure 6.7). Within the deaf population in this study, there was approaching significance (X^2 = 3.462, p=0.053) with deaf respondents in urban areas (83%) reporting having more friends outside of the family than the deaf respondents in rural areas (64%) (Figure 6.8).

Figure 6.8:   Do you have friends outside the family? Deaf participants by urban - rural geographical area
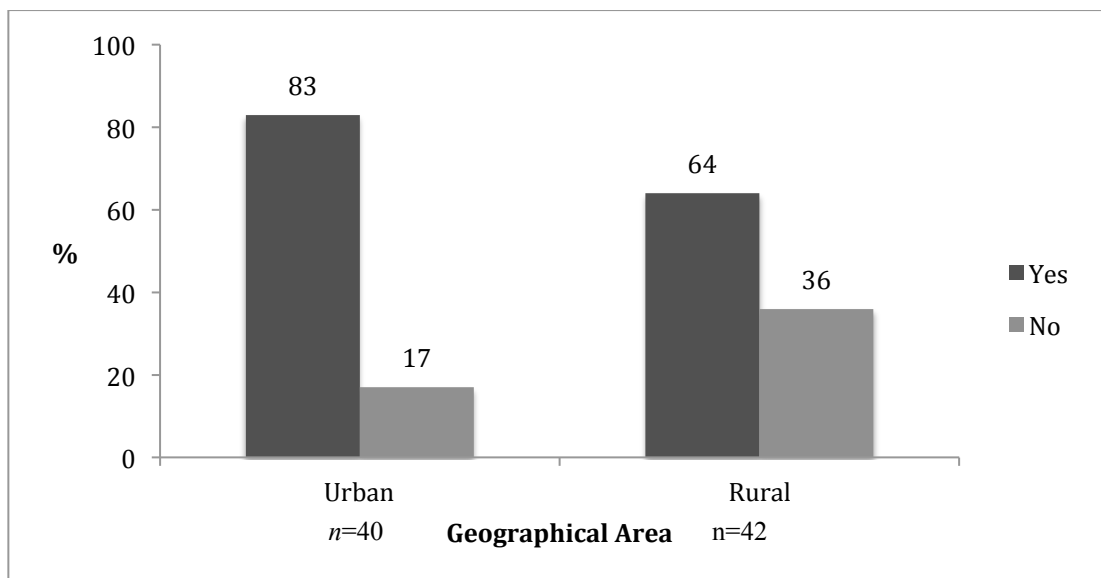
The analysis regarding friendships outside the family did not consider the hearing status of the friends or whether they could sign. The question simply focused on whether the participants had contact and support from people outside of the home. During discussions held with some deaf participants, it appeared that some deaf people, particularly in rural areas, found it hard to meet and interact with other deaf people. As a consequence, friendships and support are often developed with hearing people. In fact, when asked to compare life in urban and rural areas, one Deaf man explained, 'It is better to be in town because you will meet deaf people' (Deaf male, urban, 13 September 2013). However, a comment by another Deaf man revealed that the Deaf Community in the city was not always so easily accessible, 'I have hearing friends. I have a few deaf friends. You know where I am living, it is hard to meet deaf people' (Deaf male, urban, 31 October 2012). Another deaf person in the city expressed a similar situation, 'Most of my friends are hearing as I only meet hearing people. I have one deaf friend who is a neighbour' (Deaf female, urban, 29 October 2012). It is important to acknowledge that whilst I heard that many deaf people are motivated to migrate to urban areas to get away from home and seek employment and introduction to the Deaf community, the experience can still be a lonely one.

Table 6.10: Do you have friends outside the family? Deaf participants by urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area

	Yes	**No**	**Total**
Urban	33	7	40
Rural (no Deaf school)	12	14	26
Rongo (with Deaf school)	15	1	16
Total	**60**	**22**	**82**

There was a significant association (X^2 = 13.8, p<0.001) between region of residence (urban – rural - Rongo) and having friends outside the family. In this study, 15 out of 16 deaf people in Rongo, and 33 of the 40 urban deaf respondents, report having friends outside the family (Table 6.10). In addition, approximately half of the rural respondents (14 out of 26) reported not having friends outside the family.

Table 6.11: **Do you have friends outside the family? Deaf participants by gender & urban - rural (no Deaf school) - Rongo (with Deaf school) geographical area**

		Male	Female	Total
Urban	Yes	20	13	33
	No	5	2	7
	TOTAL	**25**	**15**	**40**
Rural (no Deaf school)	Yes	9	3	12
	No	9	5	14
	TOTAL	**18**	**8**	**26**
Rongo (with Deaf school)	Yes	8	7	15
	No	0	1	1
	TOTAL	**8**	**8**	**16**
Total		**51**	**31**	**82**

There was a significant association for both deaf men (Fisher's Exact 7.72 (df = 2), p=0.017) and deaf women (Fisher's Exact 13.8 (df=2), p=0.028) between region of residence (urban – rural - Rongo) and having friends outside the home (Table 6.11). For deaf men, the significant difference was found between rural and Rongo (p=0.022); and for deaf women, urban and rural (p=0.027), and rural and Rongo (p=0.056, approaching significance).

6.8.4   Feelings of loneliness

I became aware during the fieldwork that no common understanding or definition of a friend was established for all participants. Therefore, a contact which one person may have defined as a friend, another may have called an acquaintance or just someone they knew. My point being that if a deaf person had called a hearing person who was a non-signer, a friend, it may be somewhat questionable when in asking this question, I was trying to establish the potential for emotional support and guidance from their friends. To provide this kind of support, some degree of proficiency in KSL would therefore be necessary. I decided that a better indicator would be to ask participants directly about how often they felt lonely. The premise being that someone who reports having friends could still feel lonely 'a lot' and, according to the opinions outlined so far in this discussion, at risk of HIV infection. Participants in this study were therefore asked to say whether they felt lonely, 'a lot', 'sometimes' or 'never'.

There was no significant association between hearing status and feeling lonely. However, there were differences within the deaf population in this study. Deaf men were significantly more likely to report feeling lonely 'a lot' compared to deaf women (X^2 = 9.56, p=0.008). In exploring this finding to see whether there were any significant differences between hearing men and deaf men in this sample, no association by hearing status was confirmed.

Figure 6.9:   Do you ever feel lonely? Deaf participants by gender
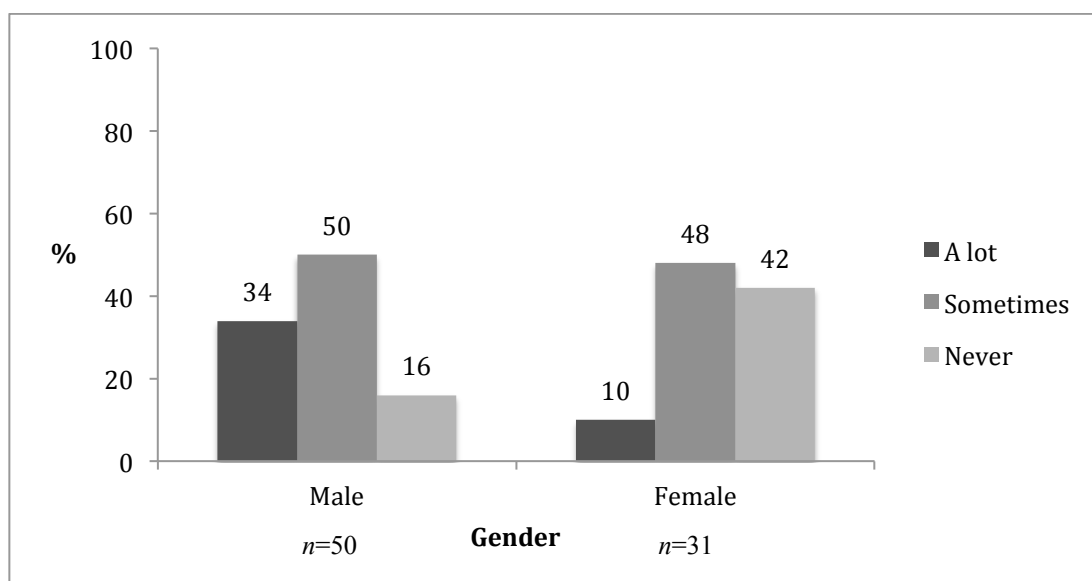
34% of Deaf men (*n*=50) and 10% of Deaf women (*n*=31) report feeling lonely 'a lot' (Figure 6.9).

There was no statistical difference between the percentages of urban and rural deaf participants feeling lonely. There was, however, evidence from conversations with deaf participants in this study that people in rural areas feel that life is better in towns. One Deaf man explained, 'It is better to be in the town because you will meet deaf people' (Deaf male, urban, 13 September 2013). Whilst many deaf people spoke of meeting other deaf people, often for the first time, on coming to town, there is still the issue of language to consider. When one Deaf man said, 'When they [deaf people] get to town, they will get to deaf people with whom they can talk to' (Deaf male, urban, 31 August 2013), I realised that this would not be the case for all deaf people on arrival in towns. For many, this indeed may be true; however, for others, the first thing they will have to do before really making friends and establishing a support network is to simply interact with other deaf people so that they can expand their lexicon of signs to enable them to communicate. This fact may help explain the finding from this study that informs us that while the feelings of isolation and lack of communication are prevalent for deaf people in rural areas, it is important not

to forget that some deaf people in urban areas, particularly men, find themselves just as lonely and isolated in towns.

Some deaf participants spoke of how they found that isolation and loneliness were feelings that they still had to deal with in urban areas. As one participant explained, 'You feel more isolated in the town than in the village' (Deaf male, urban, 29 October 2012). Another participant explained that in rural areas, deaf people tend to live with their families; however, in moving to towns, they often find themselves living on their own for the first time in their lives. In exploring these feelings of isolation, one participant explained that in rural areas, people in the community - whilst acknowledging the communication barriers – were more willing to help out in times of need. Clearly, not everyone in town is linked in to a community. I can remember one deaf man I met who said that deaf people in Kisumu needed to form a group. This was an interesting suggestion because there are already a number of different deaf groups operational in Kisumu that meet around different issues - for example, sports, HIV/AIDS support groups, amongst many others; and this man did not appear to know that deaf people in his area had already established groups.

As has been discussed many deaf people leave home to escape their situation in rural areas to search for a better life. However, some participants in this study spoke of being faced with renewed stigma and oppression once in urban areas. One Deaf man compared the two environments, 'Deaf people are always oppressed in town. They are not oppressed in the village' (Deaf male, urban, 13 September 2013). Another Deaf man shared his experience, 'It is better to be in the village than in the town. In the town people fear to come near if you are deaf. It is better in the village' (Deaf male, urban, 29 October 2012). He continued to express the dilemma that deaf people face, 'Yes, in the town there are more deaf people than in the village but we are more oppressed in town than in the village' (Deaf male, urban, 29 October 2012).

Some deaf women spoke about the need to create opportunities to meet and interact with one another. It appears that this process of meeting other deaf

people is not something that just happens but it needs some form of coordination or setting up. As one Deaf woman explained, 'Most of my friends are hearing as I only meet hearing people. I have one Deaf friend who is a neighbour' (Deaf female, urban, 29 October 2012). Another Deaf woman suggested, 'We need community activities' (Deaf female, urban, 24 October 2012), presumably to create such opportunities for deaf people to meet.

There was a call that the focus of attention should be on rural areas, 'We need these key people in rural areas who can support the deaf population in their communities' (Deaf female, urban, 26 October 2012). I think the point that this participant was making is that deaf people should not feel that they have to travel to urban areas to live full and better lives. There should be the option for them to live in rural areas and that society needs to provide that support for them to have that choice. After all, for the majority of hearing people, very few would ever say that they have to travel to an urban area in order to learn a language or to make friends.

During discussions with both hearing and deaf participants in this study, both groups referred to loneliness as being times when they did not have friends around them. One deaf man explained, 'When I am with my friends, I am ok; but when they are away and I am alone, I think a lot' (Deaf male, urban, 17 August 2013). A Deaf woman shared similar feelings of discomfort when she was alone, 'When I am with my friends, I feel happy. When I am alone, I feel lonely' (Deaf female, urban, 2 November 2012).

To explore this further, I decided to regroup the locations by urban – rural – Rongo to see if this would confirm this proposition. If loneliness were simply determined by friends, I would expect urban and Rongo to have a significant lower number of 'a lot' responses. However, the results from this study challenge this premise as there was no association between feelings of loneliness and geographical location (urban – rural - Rongo) found within the deaf respondents – either for deaf men or deaf women - in this study. The implication is that feelings of loneliness are likely to be the result of a more

complex set of circumstances rather than just being around other deaf people or engaged in Deaf culture.

This result could help us understand the linkage between activity and loneliness. It seems that once friendships and a network have been made, it is important for people to have some kind of employment or activity to keep them busy. In the rural areas, everyone in the homestead will have their assigned tasks to do in the home throughout the day – for example, boys and young men are often responsible for looking after the animals and taking them out to graze, whereas the girls are more engaged in group activities around the home. In urban areas, however, young people will have more time because there will be less of these traditional tasks to do around the home.

A Deaf woman suggested that employment was something that can protect someone from feeling lonely or bored when she said, 'I am always happy for myself - and you know I am Deaf - why should I feel lonely?' (Deaf female, urban, 26 October 2012). Responding to me with a question prompted me to explore why she had appeared somewhat defensive with this line of questioning. My aim was to explore exactly what she meant by saying 'I am Deaf – why should I feel lonely?' It became clear that in her mind there was a stereotype in the hearing community that deaf people were cast as inactive, lonely and bored and that in saying this she was challenging any association that I may have had about this association. I was reminded of findings from two studies that helped me understand her viewpoint. The first was from a study in the UK by Kyle & Pullen (1988) in which they found that 63% of profoundly deaf people viewed their social life as better than hearing people because of the closeness of the Deaf community; and the second from work undertaken by the African Union of the Blind (2007) in which they found that Kenyan society often portrays PWD as burdens and useless.

Another Deaf woman made the connection between loneliness and unemployment, 'Sometimes I feel lonely, like when I am looking for a job' (Deaf female, urban, 24 October 2012). A Deaf man shared his understanding, 'It is

hard for deaf people to get jobs because communication is hard' (Deaf male, urban, 29 October 2012). One Deaf woman in the same town shared her opinion, 'There should be interpreters in all organisations. We should not have to go and look for interpreters all the time. Even if I am going to hand in a CV in an office, I should be able to communicate with them freely but I can't' (Deaf female, urban, 24 October 2012). In considering these comments and following the line of thought, it can be seen that the root cause of all these issues is grounded in communication barriers and the inability to communicate freely with people.

Another Deaf man in town shared his views of loneliness being associated with times of trouble, particularly financial hardship:

> 'It depends, like, sometimes when there are some challenges you are facing, maybe like you need something and you have no solution. Like sometimes in the month of January, when the children are about to go to school, and you have no place where you can get a person to help. That is, where sometimes you can feel like you have no other and you get stuck. Those are the challenges that are there sometimes. Maybe you have some problem you are facing and the way and what next so we have different circumstances that can make a person feel lonely sometimes' (Deaf male, urban, 31 August 2013).

The association between loneliness and lack of support in facing problems or challenging times was one that was echoed by a number of deaf people in this study, both men and women. For example, one Deaf woman explained, "I don't feel lonely. Maybe if I have any problem is when I feel lonely' (Deaf female, urban, 1 November 2012). Another Deaf woman shared her coping strategy, 'Yes, myself I do worry. But when my husband comes, all the worries disappear. My worries finish' (Deaf female, urban, 2 November 2012). The implication from this statement is that the solution could lie in the support from people – in having company or in and being part of a community.

A Deaf man spoke of the implications for deaf people in having nothing to do: 'Many Deaf people feel bored and that is a risk' (Deaf male, urban, 31 October 2012). In reviewing the data in this chapter together with evidence from the

literature, the aim is to try and consider what some of these possible risks might be. One woman in this study explained, 'And mostly in the village, you are just idle so the only thing you can do is just that, just having sex with anyone who is willing' (Hearing female, urban, 1 September 2013). The concern must be that if young people are engaging in unprotected casual sex because of boredom, they will be putting themselves at risk of infection.

There is a body of literature that suggests that people who are bored could also be at risk of getting involved in drug and alcohol abuse. Dow & Kelly (2013) undertook a study to examine the primary reason for alcohol and other drug use in adolescents. They found that the reasons for use fell into 2 broad domains: using to enhance a positive state (47% of youth) and using to cope with a negative state (53% of youth).

Kathungu, Mwaura & Wambugu (2013) found that 20% of the 486 PWD in their Kenyan study who reported using drugs said that they did so to cope with stress. At worst, they reported that some PWD at the point of committing suicide turn to drugs as the better option. They quote one participant who said, '*Kupunguza stress…. Wacha tukunywe dawa tufe* (To reduce stress… let's take drugs to hasten our death)'. Whilst suicide was never mentioned in this study, the recurrent themes of boredom, especially in rural areas, were issues that were often talked about frequently. During one interview, a Deaf man spoke of a Deaf friend of his who is regularly smoking *bhangi* (marijuana). When he spoke to his friend about his *bhangi* use, he says:

> 'My friend told me, "It is time wasting for me to go to school. What I love is bhangi and staying with the cows. I'm not at risk of HIV. The only thing I am interested in in bhangi. I am not interested in women"' (Deaf male, urban, 7 October 2013).

There is a body of literature that confirms that substance abuse is associated with greater sexual risk taking. It may also lead to sharing injecting drug equipment with increased risk to HIV infection (Blanchett, 2000; Goodwin et al., 2004; Groce, 2004; Ostrow et al., 1990). Kalichman et al (2007) confirm a link

between alcohol use and sexual risks of HIV. In light of the above literature, participants in this study were asked about their views and opinions on substance abuse and risks of HIV infection. The results are presented below.

Figure 6.10: Does drinking alcohol increase someone's risk of getting HIV? by hearing status
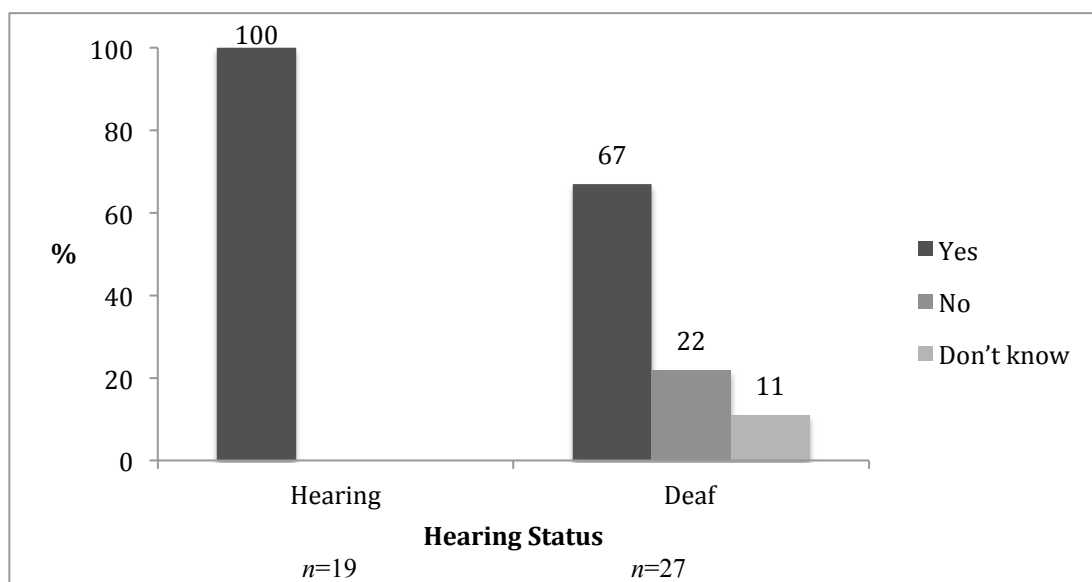
There was a significant association between hearing status and believing that drinking alcohol increases someone's risk of getting HIV (X^2 = 7.87, p=0.02) (Figure 6.10).

6.9   Deaf culture and grapevine

Kennedy & Buchholz (1995) state that to appreciate the magnitude of HIV-related problems facing the Deaf community, one needs to gain insights into the Deaf community and Deaf culture.

In order to understand Deaf culture and its impact upon deaf people, we need to remember the memories and experiences deaf participants shared about their early family life. The sense of isolation and loneliness that many deaf people spoke of is very significant because it could explain the overwhelming feelings and awareness of 'the Community' (Deaf Community) that was often expressed by deaf people who had been exposed to the Deaf community and culture in this

study. The strength and force of feeling part of a community, often for the first time, must contrast completely with the isolation and loneliness that deaf children must have felt growing up in hearing homes without communication.

As is true of any culture, there are features of Deaf culture that can both challenge and support the implementation of HIV programme interventions (Gaskins, 1999). Peinkofer (1994) describes how the Deaf community is closely knit with the great majority of deaf people interacting socially with other deaf people. In such a tight community, should HIV enter the group, the infection rate can spread at an accelerated speed. However, on the upside, successful education and public health campaigns can have a greater impact in a smaller amount of time.

There are however some concerns regarding HIV/AIDS information being shared throughout the Community if, as some studies have shown, the information is incorrect. Gaskins (1999) studied the Deaf community and made some observations on the networking or Deaf grapevine that is used to share information among the Deaf community. The Deaf grapevine can bring deaf people closer together. Gaskins observed that deaf people learn from each other, freely passing on information. In this way, deaf people are more likely to receive HIV/AIDS information and gain knowledge about the disease from each other via this informal communication route rather than from formal information sources like education programmes that have been convened especially for the Deaf community. The issue remains, however, that the HIV/AIDS information that is passed through the Deaf community must be reliable and accurate for it to be useful.

From the literature review, there are a couple of examples of how HIV awareness and education have been successfully introduced and rolled out through the Deaf community. It is important to note at this stage that these programmes are controlled in the sense that the Deaf educators have been trained and equipped with the right information and skills for successful rollout. In this sense, the information is accurate and there is no concern of inaccurate

information about the disease being shared. The first example is provided by a peer education programme at Gallaudet University. Joseph (1993) investigated Gallaudet's peer education programme after it had been operational for a decade and concluded that peer education may be the answer for how best to deliver HIV/AIDS information to deaf people. The second example is from Kenya where Taegtmeyer et al (2009) found that the majority of deaf clients in their sample from 3 VCT sites indicated that they had learned of existence of HIV services from other deaf people through the peer education programme.

The operation of the Deaf grapevine may hinder successful implementation of HIV/AIDS programmes for two reasons. Kennedy & Buchholz (1995) go as far as to suggest that one factor putting deaf individuals actually at risk of HIV/AIDS is the Grapevine itself. The first reason, some researchers have observed, is that relying on information exchange within the Deaf community alone, via the Grapevine, risks misinformation about the disease being shared as truth and facts (Gaskins, 1999; Groce et al., 2005). The second reason is that some individuals might be reluctant to access needed services because of the fear of having their confidentiality compromised (Kennedy and Buchholz, 1995). One CODA in this study explained, 'The Deaf world is small. They don't keep secrets. If I say something now, they will have heard in Mombasa by lunchtime ... the Deaf love gossip' (Hearing female, urban, 4 September 2013). This participant is referring to the operation of the Deaf Grapevine. It should, however, be noted that evidence from a couple comments that people made in this study – and presented later in this section - suggest that fear of having one's confidentiality compromised is not particular to individuals in the Deaf community, but is also applicable to people in the hearing community.

This fear of exposure through the Grapevine is further compounded by the fact that Deaf people often rely upon the support of interpreters to use services. Steinberg, Loew & Sulliven (1999) found that Deaf people often do not trust professional interpreters because they may provide services to one's acquaintances or be seen again on other occasions. Kennedy & Buchholz (1995) explain this from a deaf person's perspective, 'Because of the pervasiveness of

this grapevine, deaf people usually don't understand or don't trust the concept of the confidentiality ethic as observed by interpreters and other pertinent professionals' (p.155). Clearly the nature of confidentiality of health matters, and anonymity associated with HIV testing for example, go against the norm of openness associated with the Deaf grapevine and Deaf culture.

Job (2004) poses that the informal or incidental learning from day-to-day living, including over-hearing conversations, is often denied to deaf people. This is clearly true if we refer to information sources being non-signing hearing people. Deaf people, however, as has been shown from the literature review have an efficient grapevine through which information is passed, often very quickly. By-chance meetings are an important source of information, as one Deaf man explained, 'Maybe sometimes I'm walking along and I will get information from deaf people I meet along the way' (Deaf male, urban, 26 October 2012). The point is that there are opportunities for sharing information between deaf people in areas where there are concentrations or communities of deaf people – either by off-chance meetings or indeed by incidental learning by observing other deaf people signing in open areas. A CODA gave the insight, 'In signing, there is no secret. If I see a couple at the bus stop and they are communicating in sign, I will know what they are saying, even if I am on a bus and out of earshot' (Hearing female, urban, 4 September 2013).

Clearly there are some advantages to having a system in which information can pass quickly and effectively. Gaskins (1999) spoke about how the Deaf Grapevine can bring people together. In this sense, the Deaf grapevine can be viewed as a double-edged sword with both advantages and disadvantages in terms of sensitive issues like HIV/AIDS.

A consequence of the potential negative impact of the Deaf grapevine has led to fear and concern within the Community with some deaf people in this study expressing reluctance to interact with other deaf people. Some participants in this study - notably urban deaf people - made rather harsh condemnations of the Deaf community. For example, in exploring friendships and support in

people's lives, one man who had recently migrated to an urban area explained his preference to mix with hearing people, 'With hearing we make good stories and enjoy a lot; but the Deaf: they are my enemies' (Deaf male, urban, 17 August 2013); a woman, who was staying with her sister, shared her views, 'Deaf girls ignore me and they always cheat me. They go hide and make stories and gossip me' (Deaf female, urban, 11 November 2012).

Gossip within the community was often mentioned in this study. A Deaf man summed it up, 'There are 2 types of thinking: simple thinking and great thinking. Simple thinking is when you discuss people. Great thinking is bringing ideas to people. The Deaf have simple thinking' (Deaf male, urban, 13 September 2013). Others also shared their observations and opinions - for example, one Deaf man said, 'the activity of the Deaf is only to discuss other people. This is wrong' (Deaf male, urban, 19 August 2013). Another Deaf man noted, 'gossip wastes my time' (Deaf male, urban, 7 September 2013). The harm caused was expressed by a Deaf man who said, 'gossiping, gossiping – destroying other people's name for nothing' (Deaf male, urban, 20 August 2013). One KSL interpreter who was sometimes present at the Deaf church had observed this behaviour and had seen that when she goes to the Church, people accumulate outside and all you see is groups of people signing, 'this one bad; that one bad' (Hearing female, urban, 4 September 2013).

Some deaf women in this study spoke about the need for positive interaction with other people. For example, one deaf woman informed the study, 'We need to make friends and communicate well' (Deaf female, urban, 24 October 2012). The interpretation of this comment could either mean that the person needs enough language to communicate well, or, in view of the discussion in this section, might mean that the interaction and exchange must be positive and affirming rather than negative and destructive.

Some deaf people had developed a defence and were not bothered by the operation of the Deaf grapevine. As one participant shared, 'if you want to gossip about me: welcome to gossip about me!' (Deaf male, urban, 7 September

2013). Another participant, upon reflection of the Grapevine, explained that gossip and scandal were not particular to the Deaf community. He remembered being a hearing-teenager, and therefore confidently said with first-hand knowledge and experience, 'hearing people gossip the same as us!' (Deaf male, urban, 13 September 2013).

A Deaf man expressed his awareness that gossip in the Deaf Community was not only contained within one geographical community but could reach beyond the perimeter of the city, 'Not only Kisumu but all over I hear deaf people talk about the HIV status of deaf people, how someone's health has changed or they have died' (Deaf male, urban, 29 October 2013). Another man who was 30 years old and became deaf at the age of 12, made a comparison between the Deaf and hearing community with regards disclosure:

> 'If you are Deaf and positive, everybody will know. There is more secrecy in the hearing community. There are no secrets in the Deaf community. The Deaf don't hide things. If they suspect you are positive, they must ask openly "you positive, true?"' (Deaf male, urban, 29 October 2013)

Fear of one's status being revealed was expressed by one Deaf man in Kisumu who said, 'I would not test at Nyaweri [Deaf VCT] because of the gossip' (Deaf male, urban, 25 October 2012) Whilst many Deaf people in urban areas seem very conscious and aware of the Deaf Grapevine and the speed with which scandal and rumours can spread, this concern is also evident in the hearing community. One hearing man told me that he didn't like to drink or 'play away from home' too much in Kisumu because it is a small place and he would be seen' (Hearing male, urban, 5 August 2013). Kennedy & Buchholz (1995) found that the fear of confidentiality being compromised made some deaf people reluctant to access services in their study. However, this is not only something that affects the Deaf community as a hearing woman informed this investigation that she would not be comfortable doing an HIV test in Kisumu for fear that if she got a positive result, the information would 'leak' (Hearing female, urban, 1 September 2013). She said that she would travel to Ahero (20km from Kisumu)

to do a test because it was a 'safe' distance away for her not to be known or seen going in to a VCT centre.

6.10 Conclusion

From the discussion of the findings in this chapter, it can be seen that deaf people find themselves in many different environments with varying degrees of communication and participation in society. Essentially, there is a range of communication options available to deaf people, from very basic gesturing through homesigning to using KSL. Ultimately, the mode of communication will be determined by the age of deafness, level of education and amount of interaction with other deaf people. However, the one constant factor that links the experience of all deaf people is the challenge of communicating in a hearing world that is ill-prepared to accommodate them. A consequence of these barriers is that the deaf participants in this study had less awareness and knowledge of HIV/AIDS than hearing people in all communities investigated.

One important finding from this analysis is that deaf people who are isolated from other deaf people are the most disadvantaged in that they have less language and consequently less awareness and knowledge about HIV/AIDS. In exploring the data by the geographical grouping of urban – rural – Rongo, it can clearly be seen that in living as part of a Deaf community, there are clearly some benefits. The first benefit is in the development and use of language; the second is the exposure to Deaf culture and potential to make friends. Within the context of HIV/AIDS, Woodroffe et al (1998) found that deaf people are 7 times more likely to receive HIV/AIDS information from another deaf person than a hearing one. Therefore, an additional benefit from being linked in to the Deaf community is that someone is more likely to have awareness and knowledge about HIV/AIDS. This fact was borne out in this study with deaf people in Rongo obtaining a higher mean test score on awareness and knowledge about HIV/AIDS (transmission and prevention) than their deaf neighbours in urban or rural areas. This fact underlines the importance of social contact for deaf people in helping them to remain safe from infection from HIV/AIDS.

To sum up this chapter, I would like to repeat the words said by one deaf participant in Kisumu because I think his comment captures the essence of what is important and links everything that has emerged from this discussion. He said, 'I always communicate so I don't ever feel lonely' (Deaf male, urban, 31 October 2012). The suggestion from this comment is that the focus to address issues of loneliness and boredom should be on the development of language and communication as clearly the foundation for bonding and support with friends or families must be communication - without language with which to communicate, people will struggle to form attachments and develop intimacy with others. Furthermore, without language proficiency, people will not get the information, develop the skills or be able to access the services required to protect themselves from HIV infection.

Chapter 7 Discussion

7.1 Introduction

The chapter opens with a summary of the findings from this study by responding to the research question. Once the limitations of the study have been set out, an exploration of the policy and programme implications, as well as suggested areas for further research are explored. The chapter ends with some final concluding remarks setting out how the study has contributed to knowledge.

7.2 Summary of findings

Awareness and knowledge of HIV/AIDS

The research question to be explored in this study was how much deaf Kenyans in Western region know about HIV/AIDS compared to their hearing compatriots. In order to address this research question, participants answered 3 questions to determine their levels of awareness and knowledge of HIV/AIDS, and specifically about transmission and prevention. The results were presented in chapter 5.

There is an important initial observation from the findings from this study: some deaf people in this region did not have sufficient signing skills to communicate about HIV/AIDS. Approximately 20% of the deaf people (n=82) recruited to this study did not have enough language (KSL) to engage in the questions about HIV/AIDS transmission and prevention. This fact must be putting them at risk of HIV infection because they do not have the language proficiency to engage in conversations about HIV/AIDS or receive public health messages about it. In this investigation, it has therefore clearly been shown that language is a SDH for deaf people. Furthermore, 20% of the deaf respondents (n=82) in this study reported not having heard of HIV/AIDS. This means that in spite of the billions of shillings that have been spent on HIV/AIDS awareness

and education programmes in Kenya over the last 3 decades, there are still some Kenyans who have not heard of the disease.

Evidence from the results in this study suggests that deaf Kenyans in Western region have less awareness and knowledge than their hearing compatriots as the deaf participants scored lower on all 3 questions to establish awareness and knowledge levels of the disease (Table 7.1).

Table 7.1:   Summary of HIV/AIDS awareness and knowledge by hearing status

	Hearing	**Deaf**
Awareness (%) $X^2=7.175$, p=0.007	100	80
Transmission Mean (/12), SD Variance, Range t(106)=3.86, p<0.001	9.73, (1.99) 3.96, 12	8.04, (3.25) 10.56, 12
Prevention Mean (/9), SD Variance, Range t(7.47)=138, p<0.001	7.79, (2.2) 4.84, 10	4.56, (2.91) 8.47, 11

The results for HIV/AIDS knowledge (transmission and prevention) above are presented for those deaf respondents who answered the questions (Table 7.1). However, it could be argued that if the non-respondent deaf group has no HIV/AIDS knowledge (transmission and prevention), the discrepancy in HIV/AIDS knowledge between the hearing and deaf populations would be even more marked.

This conclusion is consistent with findings from seven American studies (Bat-Chava, Martin & Kosciw, 2005; Bisol et al., 2008; Luckner & Gonzales, 1993; Peinkofer, 1994; Swartz, 1993; Tripp & Khan, 1986; Woodroffe et al., 1998), and 4 from Africa (De Andrade & Baloyi, 2010; Enwereji & Enwereji, 2008; Groce et

al., 2006; Groce, Yousafzai & Van Der Maas, 2007). All of these studies that were presented in Chapter 3 of this thesis confirmed that deaf young people have less awareness and knowledge about HIV/AIDS than their hearing compatriots.

The finding in this study is also consistent with the conclusion from the Girois study with the Deaf community in Kenya (Hanass-Hancock & Satande, 2010). Whilst the Girois study included different samples of people, in different areas of Kenya and separated by 10 years in time, it is interesting to note that the level of HIV/AIDS awareness in the deaf population appears to have not changed in this time.

The findings in this study are also consistent with the general opinion expressed by many participants in this study. One Deaf man summed it up, 'the awareness of HIV/AIDS in the Deaf community is very low. If you compare a deaf person and a hearing, there is a very big difference in knowledge (Deaf male, urban, 29 October 2012).

It is interesting to note that the conclusion from analysis of results to this question about awareness of HIV/AIDS in the study challenges the claim in the DHS that there is near universal awareness in the adult population (aged 15-49) of HIV/AIDS in Kenya (Government of Kenya/Kenya National Bureau of Statistics & ICF Macro, 2010) as this study found only 80% of deaf respondents (n=82) had heard of HIV/AIDS.

From a historical perspective, awareness levels of HIV/AIDS in the deaf population appear to have plateaued over the last 10 years as the 2004 Girois study also found an 80% awareness level. This situation can be contrasted with the improvement in awareness levels of the disease in the hearing community. The 2003 DHS found that 99% of men and 98% of women had heard of HIV/AIDS (CBS, MoH & ORC Macro, 2004). These awareness rates rose to 100% for men, and 99% for women in the 2008-09 DHS (Government of Kenya/Kenya National Bureau of Statistics & ICF Macro, 2010).

According to the 2008-09 DHS, rural inhabitants in Kenya have less knowledge about HIV/AIDS than their urban counterparts. The DHS found that 62% of urban compared to 44% of rural women (n=6,296); and 70% of urban men compared to 51% of rural men (n=2,392) had comprehensive knowledge of HIV/AIDS (Government of Kenya/Kenya National Bureau of Statistics & ICF Macro, 2010).

The DHS finding led me to consider whether urban or rural location has the same impact upon deaf people in Western Region. Evidence from the literature suggests that geographical location can have an impact upon a deaf person's awareness and knowledge of HIV/AIDS – for example, in America, Peinkofer (1994) noted a difference in knowledge levels about the disease between those deaf people who live in urban and rural areas, with rural inhabitants disadvantaged.

From initial analysis, and the evidence presented below, the suggestion is that rural deaf people – like the 2008-09 DHS finding - have less knowledge about HIV/AIDS than urban deaf people is true for this group of people in Western Region, Kenya. In this sample, there is less awareness of the disease in the rural population: 70% in the rural deaf (n=42) population compared to 93% in the urban (n=40) (X^2 =7.175, p=0.007).

A number of deaf people in this study believed that rural deaf people would have less awareness and knowledge than urban inhabitants. One Deaf man summed up the situation, 'People in the village don't know much about HIV' (Deaf male, urban, 25 October 2012). Another Deaf man shared his observation, 'Some deaf girls in the village have never even heard of HIV' (Deaf male, urban, 29 October 2012). Some deaf participants who had migrated from rural areas to the towns in Western Region, and therefore clearly understood the challenges of getting information about HIV/AIDS in rural areas, made an appeal on behalf of their rural deaf neighbours: 'We need to go deeply in the villages [with education interventions] because deaf people don't know about AIDS' (Deaf female, urban, 25 October 2012).

Some deaf participants in this study were very open and honest about proclaiming that they were not well informed about matters relating to HIV/AIDS. For example, in a fishing village on Lake Victoria, one participant shared his situation, 'I only hear people talking about HIV/AIDS but I don't know anything about it' (Deaf female, rural, 3 August 2013). Not knowing about the disease could either be the result of never having been given the information; or, alternatively, the information could have been passed to them and the person had either not understood, had forgotten or could not express their knowledge. In this study, there was evidence to suggest the former –some deaf people had never received comprehensive information about the disease. A Deaf participant in Kisumu said, 'I have never gotten information about HIV/AIDS' (Deaf male, urban, 2 November 2012). For example, in one village, a post-lingually deaf man explained how he had first heard of HIV at the time he was a hearing child but he has never got all the information about the disease. He continued to explain, that even today - as a deaf adult - he was still not very confident about the facts of HIV/AIDS because he had never had all his questions about the disease answered.

Some deaf participants, whilst clearly showing awareness and some knowledge about the disease, also revealed their lack of comprehensive knowledge. This was evident because they seemed to have a black-and-white view of the disease. On the one hand, whilst an expression like, 'HIV/AIDS is a killer disease' can be argued to be true, it is not always the only conclusion considering the potential of treatment and support programmes. There seemed to be evidence of a fatalistic view of the disease – for example, 'it [the prevalence rate] is impossible to come down' (Deaf male, urban, 25 October 2012) reflects a resigned acceptance of the situation.

The above situation where some deaf participants spoke of an all-or-nothing view of the disease can be contrasted with the depth of understanding shared by some members of the hearing community. For example, one hearing woman was able to discuss the disease history and progression in the area. She had noticed how things were changing in her community, 'HIV kills slowly now. It's

not like before when you got thin and it dried you quickly' (Hearing female, urban, 7 September 2013). Clearly the impact of the disease has been devastating to many communities in the region but there are signs that the epidemic is changing – for example with the rollout of the treatment programmes in the last 5-10 years. It is important that people, both hearing and deaf, can see and acknowledge this change because in doing so, their response can adapt also. One Deaf man said, 'With myself, I know the HIV/AIDS risks and so I just focus on my life' (Deaf male, urban, 26 October 2012). This man's response and reaction to the situation has been to find his own personal solution to deal with the issue – for him, his solution lay in controlling his sexual behaviour. Whilst this is responsible and could ensure his protection, a community response from the Deaf community would produce the best, sustainable solution. However, to achieve this outcome, deaf people must have a broader and deeper understanding of not only the disease and its pathology, but also some of the factors that are driving its spread.

Peinkofer (1994) suggests that deaf people living in rural areas are less likely to be engaged and linked-in to a Deaf community and culture and therefore have less opportunities to get information about HIV/AIDS. This finding is consistent with a study undertaken by Bat-Chava and colleagues in New York state (Bat-Chava, Martin & Kosciw, 2005). In the Bat-Chava study, one deaf participant suggested that the presence of the National Technical Institute for the Deaf in Rochester may have contributed to the greater knowledge levels of HIV in that local community. He proposed firstly that the presence of the college meant that the local deaf population was better educated and therefore able to comprehend written information about HIV/AIDS; and secondly, the greater understanding of the significance of HIV/AIDS would have triggered local Deaf groups to initiate community HIV/AIDS education programmes targeting local non-college community Deaf groups.

Guided by the suggestion that engagement in Deaf culture and community is an important factor to consider, it was decided to regroup the urban - rural categories to explore the data using a different location criteria, namely, urban –

rural (no Deaf school) – and Rongo (with Deaf school). Since Rongo has a Deaf school with a sizeable deaf population nearby, the aim was to see if there was any impact of 'community' as opposed to simply the urban - rural geographical groupings.

Table 7.2: **Summary of HIV/AIDS awareness and knowledge, deaf participants by urban – rural (no Deaf school) –Rongo (with Deaf school) geographical area**

	Urban	Rural (no Deaf school)	Rongo (with Deaf school)
Awareness (%) X^2=22.942, p<0.001	93	50	100
Transmission Mean (/12), SD Variance, Range Fisher's Exact 1.407 (df=2), p=0.252	8.10, (3.26) 10.63, 12	6.92, (3.42) 11.70, 10	8.93, (2.93) 8.58, 10
Prevention Mean (/9), SD Variance, Range Fisher's Exact 3.74 (df=2), p=0.03	3.83, (2.69) 7.24, 11	4.83, (3.63) 13.18, 11	6.21, (2.11) 4.48, 10

100% of the deaf participants in Rongo had heard of HIV/AIDS (Table 7.2). They scored higher on the awareness tests than either of the other deaf participant groups (urban or rural) in the study. The implication from this finding is that the initial analysis of data using the urban and rural locations presented a statistic that was distorted as once analysis is explored by the urban - rural (no Deaf school) - Rongo (with Deaf school) geographical groupings, it can be seen that the level of awareness of HIV/AIDS in the deaf population in rural areas

drops from 70% to 50%. The situation, however, appears to be more nuanced regarding knowledge levels of HIV/AIDS transmission and prevention.

In discussing this finding of greater HIV awareness in Rongo, one Deaf elder explained to me:

> 'There are a number of reasons why deaf people in Rongo may have more awareness or knowledge about HIV/AIDS. The first is that there are often HIV workshops, trainings and seminars held specifically for deaf residents in Rongo. It is very easy for them to attend. Secondly, the Deaf school in Rongo has a lot of information about HIV/AIDS that it shares with the deaf organization and groups in the area. And finally, there are 3 Deaf teachers in Rongo who are very knowledgeable about HIV/AIDS and used to teaching about SRH. All of these factors can contribute to the deaf residents of Rongo having more awareness and knowledge about HIV/AIDS than their counterparts in urban or rural areas' (Deaf male, urban, 10 October 2013).

Language, Community & HIV/AIDS

From this analysis, there are two key findings: the first is that some deaf people in the region lack the language proficiency to discuss HIV/AIDS, and this fact must put them at increased risk for infection; and the second, that deaf people who are linked-in to a Deaf community have increased levels of awareness about HIV than their more isolated deaf compatriots who typically live in rural areas. It can therefore been argued that engagement in the Deaf community is also a SDH for deaf people.

Evidence from the literature review presented in chapter 3 of this thesis clearly illustrates that one of the principal reasons that deaf individuals have less awareness and knowledge about HIV/AIDS is because of the language and communication barriers they have to contend in societies that are not responsive to their particular needs. This was confirmed in this study by the fact that approximately 20% of the deaf participants (n=82) did not have enough language to engage in a conversation about HIV/AIDS.

To better understand the language and communication issues facing deaf people in this study, deaf participants were initially asked if they knew KSL. It was found that 93% of urban (n=40), 75% of Rongo (n=26), and 50% of rural (n=16) deaf people used KSL (Fisher's Exact 15.2, (df=2), $p<0.001$). Rural deaf men were found to be the most deficient in terms of KSL knowledge (Fisher's Exact 8.47 (df=2), $p<0.001$; and urban – rural ($p<0.001$), Rongo – rural ($p=0.035$)) with 8 out of 18 reporting not knowing KSL. It is unclear why the Rongo KSL levels appear lower than those recorded for urban areas, however it could be because deaf people who reside in Rongo, like urban areas, will most likely have migrated there. If the rates are lower, it could be because the respondents may have migrated in the recent past and had not yet had time to develop competency in KSL.

For deaf people that are not exposed to deaf culture and sign language, the literature informs us that they use homesigns to communicate with hearing people around them (Botha, 2007; de Garcia, 2012; Morford, 1996; Morford & Hänel-Faulhaber, 2011; Russell, Yang & Coppola, 1014; Senghas & Coppola 2001). In this study, 72% of the deaf participants (*n*=82) reported knowing homesigns. Whilst knowledge of homesigns will enable someone to communicate with a restricted lexicon of perhaps 200-300 signs, it is highly unlikely that it will empower someone enough to get all the information they need to protect themselves from HIV infection. The conclusion is that those isolated, non-signing deaf people in the region are very disadvantaged in terms of language and communication and this fact must be putting them at risk of HIV infection.

There is wide agreement in the literature that individuals with later-onset deafness differ from those with congenital or early onset deafness. Experience of deafness can therefore vary widely. The reason is that those deaf individuals with acquired hearing loss have more communication options like lip reading or writing things down; and these options will be determined by a number of factors that include age of deafness (pre- or post- lingual), education and language use history. To illustrate this point, participants were asked if they

could read and write: 99% of the hearing (n=78), and 56% of the deaf (n=82) populations reported being able to read and write (X^2=41, p<0.001). Within the deaf population, literacy rates were highest in Rongo, 88% (n=16); then urban, 60% (n=40); and finally, rural, 28% (n=18) (Fisher's Exact 20.8 (df=4), p<0.001). It therefore seems that the rural deaf inhabitants are the most disadvantaged in terms of literacy. It should be noted that in this study posters (55%) and newspapers (51%) were the third and fourth most popular ways through which deaf people obtained information about HIV/AIDS. The success of these however will be dependent upon the deaf person being literate or having someone to interpret the text for them.

Low literacy rates may also explain why the HIV/AIDS education classes and programmes seem to be failing in their objective to educate deaf people about HIV/AIDS. Whilst 85% of the hearing (n=78), and 85% of the deaf (n=75) participants in this study reported having attended an HIV/AIDS class or programme, the deaf respondents scored less than the hearing in all the HIV/AIDS knowledge assessment questions.

The family and health service, two important sources of HIV information, were explored in this study. 56% of the deaf respondents (n=45) reported that they did get HIV/AIDS information at the hospital. However lack of literacy, health literacy and interpreters are clearly hindering the effectiveness of hospitals to disperse information about HIV/AIDS. The potential for the family to be a source of information about SRH is undoubtedly restricted because most family members do not know KSL. This was evident when participants were asked whether they discuss SRH with their families as 74% of the hearing (n=78), and only 26% of the deaf respondents (n=82) reported doing so (X^2 = 34.2, p<0.001). In fact, only 29% of the deaf participants (n=82) reported living with someone who knows KSL. Engagement and discussion about SRH matters will only be possible if both the deaf individual and family members are proficient in sign. Evidence from this study clearly shows that there is not universal awareness of KSL in the deaf population, and the rates of knowledge are marginal in the hearing community.

In this study, friends were found to be an important source of HIV/AIDS information for deaf people: 30 out of 49 deaf respondents, or 61%, reported having heard of HIV/AIDS from their friends. However, not everyone reported having friends outside home: 99% of the hearing (n=77) and 73% of the deaf (n=82) respondents reported having friends outside the family (X^2 = 20.9, p<0.001). Within the deaf population, rural inhabitants were the most disadvantaged with 46% (n=26) reporting having friends outside the home as compared to 83% of urban (n=40), and 94% of Rongo (n=16) (X^2 = 13.8, p<0.001). Rural deaf women (n=8) were found to be the most disadvantaged in terms of friends outside the home with 5 out of 8 (or, 63%) reporting having no friends (Fisher's Exact 13.8 (df=2), p=0.028, and urban –rural (p=0.027) and rural – Rongo (p=0.056)).

Kelly et al (2002) found that many HIV/AIDS intervention strategies in South Africa have been designed on the assumption that all young people have the same SRH needs. This was also echoed by Winningham et al (2008) who claimed that one of the key lessons learned from more than two decades of HIV/AIDS prevention efforts is that, where HIV prevention interventions are concerned, is that 'one size does not fit all' (p.51). Evidence from this study show that these words are also applicable to deaf people in this region of Kenya, and one, all encompassing programme response to reach all deaf people is unlikely to work because of their varying and complex needs.

The conclusion from the discussion in this thesis is that there are subgroups in the deaf population in this study, each with differing needs. The discovery of subgroups in this region echoes findings from two earlier North American Deaf studies. The first, Kenny & Buchholz (1995), discovered subgroups existed based upon educational approaches, communication modes and linguistic ability. The second, Bat-Chava, Martin & Kosciw (2005) found grouping by language use (sign users, oral deaf and hard-of-hearing) and age. This is the first study that confirms the existence of subgroups in East Africa, with clear groupings being signing and non-signing deaf people. Deaf individuals who are proficient in a language or linked-in to a Deaf community show more awareness

and knowledge of HIV/AIDS than their isolated, non-KSL proficient compatriots. It did not matter whether the non-signers live in urban or rural areas – the key determinants were language proficiency or engagement in Deaf culture.

7.3   Limitations of the study

This study was conducted between 2011 and 2014. This was a time when there were a number of safety and security concerns in Kenya, notably following the Westgate shopping mall attack in Nairobi on 24 September 2013, and in which 67 people were killed and 175 wounded. Whilst no major security incidents directly influenced the outcomes of this research, I was in that shopping mall the morning of the attack and I felt that the data collection had to be accelerated because my own safety and security concerns of being in the country at this time.

With regard to selecting participants, my original plan was to randomly select from a list of deaf people provided for by KNAD. However, since no up-to-date register was available, I had to rely on the Deaf Grapevine to recruit participants for this study. Whilst there was no shortage of participants in any geographical area that I visited, there was no way of confirming how truly representative they were of deaf people in this region.

The ratio of men to women in the hearing group is approximately 3:5, but the ratio of men to women in the deaf group is approximately reversed, 5:3. This may be a possible confounder. There are various indications that if the sample size were greater, gender could be an important factor in HIV knowledge, especially in rural areas not associated with Rongo. However, given the time constraints and recruitment process, more in depth analysis was not possible.

Sometimes, it was impossible to confirm a person's age because they did not know. In these instances, if there was no one around to confirm which age bracket the participant fell in to, they were grouped in to the 'other' section for analysis. This was most likely to be the older deaf participants in rural areas.

After reviewing Campbell's 'how to write good multiple choice questions', it could be argued that the research instrument had some limitations that should be mentioned. The first is that the hearing participants may have been at an advantageous position as compared to the deaf participants because they were more 'test wise', being more familiar with multiple-choice questions and how the test process works (Campbell 2011). Furthermore, there was no grading of questions according to difficulty so that answering harder questions right did not impact upon a participant's performance or score.

A detailed presentation of the responses to the two questions on HIV/AIDS knowledge (transmission and prevention) is contained in appendices 9 and 10. Some people might argue that there is little difference between the hearing and deaf respondents in this study and the correct responses to the modes of HIV transmission (Table 7.3), especially the most common mode in this region: unprotected heterosexual sex. Furthermore, where differences have been found – for example, with razor blades, it could be argued that evidence for HIV transmission in this manner is very small. Similarly, the testing of blood prior to transfusion is out of the control of the participants – this is the responsibility of health facilities, and the difference in knowledge between the groups is unlikely to have any effect on the practices of such facilities. Guided by the findings that a lack of information about HIV puts someone at risk of HIV exposure (Baker-Duncan et al, 1997), and that partial knowledge is not good enough (Strunin & Hingson, 1987), any differences could be important. It can be further argued that, if for example, someone incorrectly believes that mosquitos transmit HIV, should they be bitten by a mosquito, they may think they have contracted the virus and have nothing to lose and engage in high risk behaviours that might have been avoided had they had the right information.

Table 7.3:   Knowledge of modes of transmission by hearing status

	Hearing (%)	Deaf (%)	X², p-value
Sex (man – woman)	100	97	2.397, p=0.122
Sex (woman – man)	100	97	2.361, p=0.124
Unsterilized needles	97	92	2.003,p=0.157
Unsterilized razors	99	91	4.812, p=0.028
HIV+ mother to baby	94	81	5.871, p=0.053
Blood transfusion	96	84	6.8, p=0.03

Due to the social and cultural climate in Kenya, questions about HIV transmission through sex (man – woman, and woman – man) was assumed to mean penetrative vaginal sex. After discussion with the study advisory team, it was decided that the investigation would not explore other sexual practices like heterosexual or homosexual anal sex, oral sex, mutual masturbation or any other sexual practices.

The use of KSL and Kiswahili in data collection made the translation and data analysis in English into a complex task due to the fact that these 2 languages are structurally different and neither are my mother tongue. Ladd (2003) notes that there are cultural features of sign languages that make it challenging to render them in written languages. He lists, for examples, the importance of storytelling, 'theatrical re-enactment', repetition, poetics, and the tendency for creation of new-signed lexical items as a matter of course, which may be for one-off usage. I, as the researcher, had to be aware of this whilst translating and recording the participants' perspectives. Temple (1997, 2002) argues that researchers who use translators need to acknowledge their dependence on them, not just for words, but to a certain extent for perspective. Whilst, I am confident in KSL and Kiswahili, I must say that I was to some extent dependent upon my interpreter/research assistant in this process.

Furthermore, although the use of a KSL interpreter meant that the participants' comments were more-or-less accurately expressed, it must be acknowledged that because the interpreter was a CODA and must have been known to some of them, some of the participants may not have disclosed some personal information; thus influence or bias may have influenced the responses due to the role of the interpreter and the fact that she was CODA and local.

In spite of these limitations, a number of recommendations can be made from this study. Evidence clearly shows that the current public health education response to HIV/AIDS is not successfully reaching everyone. Deaf people are a group that is persistently failing to get the message. The situation is therefore much more nuanced with certain groups requiring specifically targeted and focused interventions. The next section explores some suggested interventions.

7.4   Policy recommendations

The new policy recommendations that emerge from this discussion are presented according to (1) language and (2) HIV/AIDS awareness and knowledge.

7.4.1   Language

Article 56(d) of the Constitution commits the state to put in place affirmative action programmes to 'develop cultural values, languages and practices' (p.38). There are therefore grounds for the Deaf community, including KNAD, to lobby the Government to meet the cultural, including language, needs of all deaf individuals. In this regard, there were two key subgroups identified in this study:

Non-signers (isolates)

Evidence from this research shows that deaf people who are not linked in to a Deaf community firstly need the opportunity to meet other deaf people, and support with sign language development. Deaf individuals and their families

need to be able to access sign language instruction to facilitate the development of language; and the earlier, the better.

Signers

Deaf people who are part of a Deaf community will find that their language and signing skills will naturally develop and expand as they interact and meet with other deaf people. However, to engage with the hearing community, access to interpreter services is very important. There should be opportunities therefore for hearing people to take sign language classes to develop the proficiency and skill to reach an interpreter level of competency.

7.4.2   HIV/AIDS awareness & knowledge

Deaf people need the information to stay safe from HIV infection. During this study, deaf participants were asked how to increase awareness and knowledge about the disease. A three-pronged approach emerged from the discussions and included:

- General sensitization and awareness raising

- Information and knowledge sharing

- Discussion and dialogue for understanding

General sensitization & awareness raising

'We need to have and create awareness' (Deaf male, urban, 31 August 2013).

HIV/AIDS campaigns need to be designed and created to ensure that hearing and deaf populations are able to capture advocacy campaign meanings and messages at the same time. No community should be left behind. A successful campaign will therefore be one that is inclusive of everyone. In order to achieve this, it was recommended that prior to delivery, any HIV/AIDS campaign should be part of a communication strategy that is planned, developed, implemented,

monitored and evaluated by a core team of represented members of the society. In this way, it will be inclusive and consider the particular needs of all members of society, including deaf people. It was said that deaf people are reliant upon visual material and special consideration should be given to facilitate this requirement.

Information & knowledge sharing

One deaf participant suggested that organizers of training programmes should ask deaf participants prior to training if any special arrangements could be made to facilitate their participation. During this study, participants recommended the following considerations: transport refunds to the venue, interpreter and child care facilities. Furthermore, it was suggested that during the evaluation and feedback from trainings, deaf participants should be asked specifically about support so that a wish list could be compiled and consequently shared with GoK county training coordinators. In this way, a standardized support list for future training programmes could be prepared and budgeted in the most effective way.

In addition, organisations that host training programmes need to ensure that an assessment component is included in their training plan to confirm that the objectives of the exercise have been met by all participants. If evaluation of training programmes could be shared with other interested agencies, possibly through a GoK focal point, the experience and learning from hosting training programmes could be shared so that everyone interested in delivering programmes could benefit from other's experiences.

Discussion & dialogue for understanding

One Deaf woman said, 'Deaf people need more discussion about HIV/AIDS' (Deaf female, urban, 24 October 2012). Her point was that whilst increased information and knowledge about the disease were important, deaf people needed dialogue and discussion to fully appreciate and understand their situation to develop coping strategies. Furthermore, she suggested that deaf

people needed the skills to use the information and knowledge to lead healthy and protected lives. To do this, the recommendation is that training programmes should include a life skills component to addresses broader issues like assertiveness, negotiation and stress management.

7.5 Implications

The findings of this study show us that the GoK claim in the 2008-09 DHS (Government of Kenya/Kenya National Bureau of Statistics & ICF, 2010) that there is universal awareness of HIV/AIDS is unfounded. Deaf people are falling behind in terms of awareness and knowledge of HIV/AIDS with non-signing deaf isolates the most at risk.

Article 21(3) of the Kenyan Constitution bestows on all State organs and public officers the duty to address the needs of vulnerable groups within society. There is therefore a national commitment in the Constitution to address this situation. This commitment is also factored into the KASF 2014/15 – 2018/19 as there is an in-built flexibility for County Governments to identify and address emerging marginalized and vulnerable groups in their local response to HIV/AIDS. The narrative in the Framework emphasizes that the nature of the epidemic never stays the same and forever changes with the challenge being to identify and respond to these changes as soon as possible: 'Surveillance should focus on tracking emerging hotspots (NACC, 2014b, p16)…. detect emerging trends in the epidemic' (NACC, 2014b, p.45). Essentially, 'The success of the HIV response is dependent on protecting and promoting the rights of those who are socially excluded, marginalized and vulnerable' (NACC, 2014b, p.4). The findings from this study inform us that the deaf people have been left behind the hearing population in terms of awareness and knowledge of the disease.

There is however some concern regarding the future as funding levels for HIV may be decreasing. In 2012, NACC & NASCOP announced that recent funding for HIV was down by 10% as a result of the global economic recession (NACC & NASCOP, 2012). Whilst expenditure levels are planned to remain high with the

implementation of KASF 2014/15 - 2018/19, there are some planned changes to funding sources that could impact the response. Whilst KNASP III, 2009 – 2013 was largely resourced from external donor funding, at over 70% (NACC, 2014a); KASF 2014/15 – 2018/19, is estimated to require US$ 5,486 million for 5 years, with 50% of this budget to be sourced from the national budget (NACC, 2014b).

Clearly if Kenya's national AIDS response is dependent upon external funding, there is some concern in the assumption that donor funds will remain at a constant level as there are suggestions that external funding levels could in fact drop in future.

Currently, Kenya is a low-middle income country. Vision 2030, Kenya's long-term planning strategy, sets out plans for transformation to a successful middle-income country by 2030. The premise is that in this process of greater domestic wealth, it is possible that donor resources may decline. The possibility of this happening compounds the argument to develop domestic mechanisms to fund public health interventions to ensure their sustainability.

The global recession and financial insecurity of the last decade shows that it would be unwise to assume that international funds for HIV/AIDS will forever remain at the high levels of recent years. Whilst some donor country governments have ring-fenced their overseas development aid budgets - notably the British Government at 0.7% of GDP - others are facing increasing pressures to cut their international aid budgets due to competing domestic priorities. Should some of these cuts be made, there will inevitably be an impact upon development programmes, including HIV/AIDS, if recipient countries cannot meet the shortfalls with their domestic budget.

There has clearly been a historic dependency on external resources to fund HIV programmes in Kenya. Whilst there is a national commitment to address this dependency, there is cause for concern. The first is that Kenya's national budget might not be able to resource the targeted 50% of the KASF 2014/15 –

2018/19. The worry is that should external funding levels fall short, programmes may need to be cut back if internal sources cannot meet the funding shortfall. At a time when evidence shows that there may neither be universal awareness nor comprehensive knowledge about the disease, and should cuts be made, this poses the question as to where the savings will be made and who will they most impact. In such a situation, if there is evidence to confirm that deaf people do lack HIV awareness and knowledge, there will be a strong case for prioritization of their needs using available resources.

Article 19 of the UNCPRD sets out the situation where the State claims insufficient resources to implement a right – for example, in this instance, a person's right to access SRH information and services. In such a situation, in allocating resources, 'the State should give priority to ensuring the widest possible enjoyment of the right or fundamental freedom having regard to the prevailing circumstances, including the vulnerability of particular groups of individuals' (United Nations, 2006, p.14). Therefore, in this environment, where there is clear evidence to show the existence of marginalized deaf Kenyans whose lack of awareness and knowledge is putting them at risk of a disease that if contracted, is at best, life changing and at worst, life threatening, the GoK needs to make a commitment to meet their needs.

7.6 Suggestions for future research

This study can inform academic and programme research investigations.

Findings from this investigation could lead to research that will inform a programme response to the meet the needs of deaf people. One participant shared his vision: 'My dream is to see a life in which they [deaf people] are living a life they are enjoying, and not one where they are unhappy and suffering' (Deaf male, urban 31 August 2013). A research programme could help steer a response. However, there are a couple of considerations: the first is that deaf people should be engaged, and have a key voice in the development and implementation of a research programme so that their needs and priorities are

addressed. Secondly, whilst a research programme has the potential to increase knowledge and understanding of issues related to deaf people, it is important that a system is established to ensure that information is accessible and useful to them.

As a result of this research project, there are five key areas that remain unexplained and need further investigation. These areas include: language and communication; HIV/AIDS training; family; health service and the Deaf community.

There were a number of language and communication issues that were revealed during this study. Given the responses to knowledge of other sign systems and being able to read and write, clearly these are areas that deserve further investigation in future, with particular attention to more in-depth study of not just presence/absence of knowledge but the degree to which informants are able to communicate in other sign systems and their level of literacy that can be determined by more standardized means of testing. To address the language and communication barriers in society, it will be essential to roll out a KSL training programme for deaf individuals, their families and the wider society. Experiences and evidence on how best to do this could help inform a programme response. There were also a number of concerns regarding KSL interpreters that need to be better understood. Whilst these issues were not discussed in this thesis, key concerns that were raised included: certification; shortage; ethics; maintenance of competency and skills; and appropriate skill level for assignments.

Whilst 85% of the deaf (*n=75*) and 85% of the hearing (*n=78*) respondents in this study reported having participated in an HIV/AIDS class or training programme, there are evidently some concerns regarding the effectiveness of the current delivery of training programmes as the deaf participants scored lower than hearing ones on questions to establish awareness and knowledge levels about HIV/AIDS. Future research could help establish components of a

successful training programme for deaf people as well as opportunities for reaching and training them.

The family has been shown to be a significant influence in deaf people's lives. Many participants spoke of their isolation and loneliness growing up in homes where they struggled to communicate with their families. There is a need for further exploration of deaf people's experiences in families and evidence of how they have dealt with the barriers they have faced.

Many deaf people in this study spoke of their experiences in accessing health services. Most found that the health service was ill-equipped to deal with their particular language and communication needs. Future studies could explore what would comprise a 'Deaf-friendly' health service that is accessible and prepared for the needs of deaf people.

The fifth area for further investigation concerns the Deaf community. There are clearly some challenges for deaf isolates to meet and engage with other deaf people. Future studies could explore opportunities for deaf people to meet in isolated rural areas. This could include an exploration of how KNAD can best support deaf people with views and experiences from the community itself.

7.7   Conclusion

The main conclusion from this study is that deaf people have less awareness and knowledge about HIV/AIDS than the hearing western region, Kenya. This is not the sole finding: Kenny & Buchholz (1995) suggest that there is a common misconception that all deaf people are alike. There is diversity and complexity within Deaf communities and among deaf people that should be recognized (Myers & Fernandes, 2010; Obasi, 2008). Kelly (2008), for example, notes the long-standing oversight of the Deaf female experience, subsumed – she argues – subsumed under the universal 'Deaf'. Bienvenu (2008) writes that the term 'Deaf' has been defined using normative baselines of sexuality. Myers & Fernandes (2010) argue that Deaf culture has come to be largely defined according to a white Deaf ASL perspective. De Clerck (2010) reminds us of the

significance of generational differences among those who describe themselves as 'Deaf'. This study confirms the existence of subgroups in the deaf population in this region, and includes a very marginalized group of deaf isolates that neither use KSL nor are engaged in Deaf culture. This very marginalized group of deaf isolates, or non-signers, is at increased risk of exposure to HIV/AIDS compared to the larger signing deaf population. Public health professionals have argued that the more education someone has, the greater health status or benefits people will enjoy. I believe a corollary argument could be made in terms of language. That is to say, the less language you have, the more likely you are to have less information, knowledge and access to health services, including SRH and HIV/AIDS services. Therefore, by suggestion, when someone has very limited language they are at a greater risk of ill-health, including HIV infection. Language therefore becomes a SDH for deaf people. I suggest that isolated deaf people have less language development than their more proficient signing deaf counterparts and this fact is putting them at greater risk of HIV infection. One of the solutions to help alleviate this situation is to assist deaf people – as early as possible - to interact and socialize with other deaf people to develop sign language skills and engage in Deaf culture.

7.8   Final comments

The findings in this study have implications for the broader disabled community. The results from this study in Western Kenya clearly show that there are different groups in the deaf population with varying levels of HIV/AIDS awareness and knowledge. To ensure that all deaf individuals have access to the information, skills and services to protect themselves from HIV infection, a range of targeted responses will have to be initiated to meet the specific needs of each group. The implication from this finding is that the situation for the wider disabled community may also be more nuanced than is currently being discussed. Too often, HIV/AIDS outreach programmes are designed to reach 'all people with disabilities' while, as has been shown here, targeted programmes that are not only disability-specific, but in some cases – as with the deaf population – consider subgroups within disability-specific

outreach efforts, are needed. With awareness and understanding of the findings from this study, it is clear that any programme response to an all-encompassing group of disabled persons will not meet the needs of everyone that it is intended to reach. It is therefore hoped that this study will encourage those people who want to improve the lives of disabled people in general, and deaf individuals in particular, will consider the existence of different groups that have varying and unique needs – and plan HIV/AIDS outreach efforts accordingly. For the Deaf community in Kenya – and other developing countries that share similar challenges to Kenya – I suggest the specific response for deaf people could be developed according to the subgroups discussed in this thesis.

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Appendices

Appendix 1: Map of Kenya

(Google Maps, 2016)

Appendix 2: Types of researchers with deaf communities

In exploring the literature, I came across a journal article in which the authors attempt to set out the types of researchers who typically work with deaf communities. Baker-Shenk & Kyle (1990) warn that a failure to consider these points will undermine the validity of supposedly objective results or findings. In order to strengthen this study, and as part of the on-going exploration of my position, I often went back to it. I have decided to include it here because it helped me reflect on what I was doing and why I was doing it.

The Types

The Directors
We hold the knowledge and the power. We may hire and use deaf people to get the information we want. However, we do not make more than minor efforts to share our knowledge with them because we do not expect them to be able to understand or take the initiative.

The Aloof
We are not involved or particularly interested in the problems of deaf people.

The Semi-Aloof
We are trained professionals, we focus on our work and we do our job well. But we do see some of the injustices done to deaf people and do think this should stop, and we do not mind saying so on occasion.

The Hurt and Frustrated
We have really tried to be understanding and caring while doing our jobs. But they (the deaf people) misunderstand us and do not appreciate all that we have done for them. Their demands are unreasonable, and they will just have to grow up and accept life as it is.

The Involved
It has been quite an internal and outward struggle but, thanks to the extreme patience and encouragement of deaf friends, we have developed sign skills which are accepted by deaf people. We feel guilty and angry about the historical and on-going oppression of deaf people by hearing people.

The Aficionados
Deaf people are our friends. They are marvelous people with a wonderfully honest view of the world.

The Experts
We have lived with deaf people all our lives.

(Taken from Baker-Shenk & Kyle, 1990)

Appendix 3: HIV/AIDS checklist questionnaire

Date:_____   Reference:_____   Location:_____

1.   Are you?

☐   (a) Male   ☐   (b) Female

2.   How old are you? (in years)

☐   (a) 18-20   ☐   (b) 21-24   ☐   (c) 25-30

☐   (d) 31-35   ☐   (e) Other

3.   Where do you live?

☐   (a) Urban   ☐   (b) Rural

4.   Are you Deaf?

☐   (a) Yes   ☐   (b) No

5.   Who lives in this homestead?

☐   (a) Mother   ☐   (b) Father   ☐   (c) Sister(s)

☐   (d) Brother(s)   ☐   (e) Children   ☐   (f) Grandparent

☐   (g) Spouse   ☐   (h) Partner   ☐   (i) Cousin(s)

☐   (j) Uncle(s)   ☐   (k) Aunt(s)   ☐   (l) Friend(s)

☐   (m) Orphan(s)   ☐   (n) Nephew   ☐   (o) Niece(s)

☐   (p) Alone   ☐   (i) Other(s)

i) Please specify:

6. Is anybody (else) in this homestead deaf?

☐ (a) Yes   ☐ (b) No

7. If Question 6 is yes, who else is deaf in this homestead? If the answer to Question 6 is no, please proceed to Question 8.

(a) _____

8. Do you use Kenyan Sign Language?

☐ (a) Yes   ☐ (b) No

9. Does anybody (else) in this homestead use Kenyan Sign Language?

☐ (a) Yes   ☐ (b) No

(c) Please specify who

10. Do you use any other kind of sign communication?

☐ (a) Yes   ☐ (b) No   ☐ (c) A little bit

(d) Please specify what and with who

11. Can you read/write?

☐ (a) Yes   ☐ (b) No   ☐ (c) A little bit

12. What is your highest level of education? (Some and/or completed)

☐ (a) Primary   ☐ (b) Secondary   ☐ (c) Vocational

☐ (d) College   ☐ (e) University   ☐ (f) None

13. Are you still in school?

☐ (a) Yes   ☐ (b) No

(c) Please elaborate

14. Do you have a job?

☐ (a) Yes   ☐ (b) No

15. Are you employed?

☐ (a) Yes   ☐ (b) No

16. Are you self-employed?

☐ (a) Yes   ☐ (b) No

17. What do you do?

(a)_____

18. How much do you earn a month?

(a)_____

19. Is your income enough to pay for your daily living expenses?

☐ (a) Yes   ☐ (b) No

(c) Please explain

20. Do you have friendships outside the family?

☐ (a) Yes   ☐ (b) No

(c) If yes, please describe

21. Do you ever feel lonely?

☐ (a) A lot   ☐ (b) Sometimes ☐ (c) Rarely/Never

22. Do you discuss sexual and reproductive health with your friends?

☐ (a) Yes   ☐ (b) No

(c) Can you give an example

23. Do you discuss your sexual and reproductive health with your family?

☐ (a) Yes   ☐ (b) No

(c) If yes, who? Please elaborate

24. Have you heard of HIV/AIDS?

☐ (a) Yes   ☐ (b) No

25. Where have you heard about HIV/AIDS?

(a) Television	☐	(b) Radio	☐	(c) Newspapers	☐
(d) Magazines	☐	(e) Friends	☐	(f) Internet	☐
(g) Parents	☐	(h) Relatives	☐	(i) Disability Organisations	☐
(j) Hospitals	☐	(k) Community Health Workers	☐	(l) Posters	☐
(m) Community Plays	☐	(n) Community Meetings	☐	(o) Religious Organisations (Deaf church, mosque etc.)	☐
(p) Fellow Workers	☐	(q) Community Leaders	☐	(r) Other	☐

(s) Please Specify:

26. Have you ever participated in an AIDS education class or programme?

☐ (a) Yes   ☐ (b) No

(c) Please explain:

27. Which of the following are ways somebody can get AIDS?

	True	False	Don't Know
(a) Mosquito bites			
(b) Kissing			
(c) Sex (man to woman)			
(d) Sex (woman to man)			
(e) Sharing bowls/utensils			
(f) Touching or hugging			
(g) Needles (unsterilized)			
(h) Razors (unsterilized)			
(i) HIV+ mother to baby			
(j) Germs in the air			
(k) Dirty places			
(l) Witchcraft			

(m) Any other? Please specify:

28. Which of the following can increase someone's risk of getting AIDS?

	Yes	No	Don't Know
(a) Using male condoms			
(b) Using female condoms			
(c) Being male			
(d) Being female			
(e) Being rich			
(f) Being poor			
(g) Rape/sexual abuse			
(h) Taking alcohol			
(i) Living in town			
(j) Living in a rural area			
(k) Being young & lonely			
(l) Having many sexual partners			
(m)Having a disability			
(n) Being Deaf			
(o) Having unprotected sex			

(p) Any other? Please specify:

29. How can HIV infection be prevented?

	True	False	Don't Know
(a) Sterilization of needles, razors			
(b) Avoiding places that are dirty			
(c) Testing blood before transfusion			
(d) Not sharing bowls or utensils			
(e) Using condoms			
(f) Not hugging			
(g) Abstinence (no sex with anyone)			
(h) Eating healthy foods			
(i) Washing hands			

30. Where would a person go for HIV/AIDS services (information, testing)?

(a) Hospital ☐   (b) Door-to-Door ☐   (c) Deaf VCT ☐

(d) Clinic ☐   (e) Ante-Natal Clinic ☐   (f) Mobile VCT ☐

(g) Traditional ☐   (h) VCT ☐   (i) Other
Healer

(j) Any other? Please specify:

31. Select why you think someone might have difficulties in getting tested

	Yes	No	Don't Know
(a) No one willing to test me			
(b) VCT too far away			
(c) I'm too busy			
(d) Can't afford the transport			
(e) Lack of privacy			
(f) Language problems			
(g) Other			

(h) Any other? Please specify:

32. Do you think it is difficult for people to get condoms in this community?

☐ (a) Yes   ☐ (b) No

33. If Question 32 is yes, please tick which of the following could explain why it is difficult for people to get condoms. If the answer to question 32 is no, please proceed to Question 34.

(a) Cost ☐   (b) I don't know where to pick them ☐

(b) Supplies run out ☐   (d) Embarrassed to pick them ☐

(e) Other ☐

(f) Any other? Please specify:

34. Where would you go to get condoms?

(a) Hospital ☐   (b) Youth Club ☐   (c) Deaf VCT ☐

(d) Clinic ☐   (e) Friend ☐   (f) Shop/Kiosk ☐

(g) Bar ☐   (h) Public Toilet ☐   (i) VCT ☐

(j) Other ☐

(k) Any other? Please specify:

35. What needs to change to decrease the risk of AIDS in this community?

(a)   Please specify:

36. Is there anything you would like to say or comment upon about HIV/AIDS or being deaf in your community that we have not asked?

(a)   Please specify:

Appendix 4: Extra questions added during data collection

1. How old were you when you became deaf? (in years)

   (a) From birth ☐   (b) 1-4 years ☐   (c) 5-10 ☐

   (d) 11-14 ☐   (e) 15+ ☐

2. How long have you lived here?

   (a) Less than 6 months ☐   (b) 6 months – 1 Year ☐

   (c) 1-2 Years ☐   (d) 2+ years ☐

3. Are you married?

   (a) Yes ☐   (b) No ☐

4. If Question 3 is yes, how old were you when you married?

   _____ (years)

Appendix 5: Topic guide

Key objectives

- To explore deaf young people's access to information and services related to SRH (including HIV/AIDS) in Western Region, and to compare findings with the knowledge base of their hearing peers.

- To investigate the role of language, communication, isolation and deaf culture, as well geographical location and gender upon the risk of HIV infection.

- To establish baseline data from which future studies on SRH information and services (including HIV/AIDS) for deaf young people in Western Region can be compared.

1.   Introduction

Introduction to the study/purpose of the interview

Confidentiality/don't have to answer all questions

Explain the Information Sheet

Video recording/data kept anonymous and then destroyed after translating

Participation is voluntary

Leave interview anytime/length of interview

Explain feedback process

If everything is agreed, have the participant sign the Consent form.

Leave the Information Sheet with the participant.

2.   Background details (Questionnaire numbers 1-23)

Gender & age

Household composition & family

Communication & literacy

Education, employment & financial status

Friendships – whether they have friendships outside their family/household

Probe hint: (i) extent of language/signing for deaf participants (ii) level of and support/participation in home/community

3.   HIV/AIDS knowledge & risks (Questionnaire numbers 24-35)

General background knowledge, information about HIV/AIDS

Where do they get the information about HIV/AIDS?

Explore issues around HIV/AIDS, testing, condoms, risks

Probe hint: (i) extent of participation in HIV education programmes and explore reasons for/against their participation (# 26)

4.   Last question (Questionnaire number 36)

This is an open question for participants to raise any issues that they feel are important in their community.

Probe hint: Encourage any response to this question.

5.   To finish

Thank the respondent.

If appropriate, acknowledge any difficulties or distress experienced during the interview. If necessary, suggest the respondent contact someone from the list below to discuss their difficulties/distresses further. Give contacts for the following:

- KU (Department of Special Needs Education)

- KSL interpreters in the area

- VCT services for deaf people (LVCT Health)

- Counselling services (Kenya Association of Professional Counsellors)

- Kenya National Association for the Deaf (Kisumu & Kakamega Offices)

- University of Nairobi Kenya Sign Language Programme

Appendix 6: Information sheet

Information sheet for *Deaf/Hearing Young People (aged 18-35)* in Research Studies

You will be given a copy of this information sheet.

Title of Project: **A comparative study of the HIV knowledge, attitude and practices within the Deaf community in Western Region, Kenya**

This study has been approved by the UCL Research Ethics Committee (Project ID Number): **3600/001;** and the Kenyatta University Ethics Review Committee (Application Number): **PKU/046/E06**

Name Robert Keatley

Work Address Leonard Cheshire Disability & Inclusive Development Centre

Contact Details University College London
1-19 Torrington Place
London WC1E 6BT
Tel: (+44) 07753 242717
Fax: (+44) 020 7388 2291
Email: r.keatley.11@ucl.ac.uk

Name
Work Address
Contact Details Nickson Kakiri
Kenya National Association of the Deaf
P.O. Box 28507-00100,
Nairobi
Tel: (+254) 020 2636832
Fax: (+254) 020 2636832
Email: nickson.kakiri@knad.org

We would like to invite you to participate in this research project.

You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read/understand the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Details of Study: This research project is looking at the HIV knowledge, attitude and practices of young deaf and hearing Kenyans (aged 18-35) in Western Region. The findings from this study will help us to better understand the sexual and reproductive health needs of young Deaf Kenyans with a particular focus on HIV and AIDS. The study aims to identify young deaf and hearing people in the community and to explore their needs. The information gathered will be made available to Deaf associations, Disabled People Organisations (DPOs), Government Ministries and other development partners who are willing to improve the sexual and reproductive health of Deaf Kenyans with regard to accessing HIV information, prevention, care and support.

This is a letter from our office to certify the study is in progress. Mr. Robert Keatley is the contact person from UCL for any questions you might have. Mr. Nickson Kakiri, Chairperson for the Kenya Association of the Deaf is also a contact person for any questions you might have.

You are invited to participate to the study along with 150 respondents. We will be working with 80 deaf young people and 80 hearing young people. There is no immediate benefit (including financial incentive) for you, but your answers will help us and other partners or stakeholders to better address the sexual and reproductive health (including HIV/AIDS) needs of young Deaf people in the community. Should you agree to participate in the study, we would like to spend about an hour talking to you about matters related to HIV/AIDS and complete a short questionnaire with you. The interview will be filmed/recorded. Once the interview has been translated and written up, the tape will be wiped clear.

Your answers are confidential and will not be shared with any other people. The records of this study will be private. Only the people who are doing this study will be able to look at the answers that you give to the questions.

Whether you choose to be in the study is up to you. There will be no effect on your family. Only those people who are doing the study will know whether you are in the study. They will not tell any other people in the community. You have the right not to be in the study or to stop at any time. If you do not understand a question, please ask me to explain it to you. You are free to stop at any time during the interview. If a question makes you uncomfortable, we will skip the question and go to the next question.

The researcher working with you today is a qualified Kenyan Sign Language interpreter and has counselled and tested Deaf Kenyans for HIV. Today, he is here to interview you and work through a questionnaire with you. Whilst this entails some discussions around issues related to HIV/AIDS, this is not a counselling or testing session. Our team will happily share the contact details of professionally trained people who can offer guidance, counselling, testing and support services to you should you wish to discuss anything in a confidential and safe environment after the study. Do you have any questions before we start? It is important to say that there are no right or wrong answers for these questions, just tell us what you think or feel.

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you be given this information sheet to keep and be asked to sign a consent form.

A summary report of the research findings will be available from Mr. Kakiri on completion of the interviews with all the respondents. Once an in-depth analysis of the data has been made, a more comprehensive report will be available also.

Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information.

Kenyatta University Ethics Review Committee, P.O. Box 43844-00100, Nairobi

Tel: 8710901/12; Fax: 8711242/8711575; Email: kuerc.chairman@ku.ac.ke; kuerc.secretary@ku.ac.ke

Nickson Kakiri, National Chairman, Kenya National Association of the Deaf, P.O. Box 28507-00100, Nairobi

Tel/Fax (+254) 020 2636832; Email: nickson.kakiri@knad.org

Liverpool VCT Health Nyanza Regional Office, Tivoli Centre, P.O. Box 3294-40100, Kisumu

Tel: (+254) 057 20209061/20209046/2025945

The Kenya Association of Professional Counsellors, P.O. Box 2973, Kisumu

Tel: (+254) 057 2027091/2027959, 0727 232452

The Kenya Sign Language Research Project, University of Nairobi, P.O. Box 22024-00400, Nairobi

Tel: (+254) 0722 358088, 0713 730313

All data will be collected and stored in accordance with the UK Data Protection Act 1998.

Appendix 7: Consent form

Informed Consent Form for *Deaf/Hearing Young People* in Research Studies

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: **A comparative study of the HIV knowledge, attitude and practices within the Deaf community in Western Region, Kenya**

This study has been approved by the UCL Research Ethics Committee (Project ID Number): **3600/001** and the Kenyatta University Ethics Review Committee (Application Number): **PKU/046/E06**

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I

- have read the notes written above and the Information Sheet, and understand what the study involves.

- understand that my participation in the study is voluntary and there is no financial remuneration

- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.

- I understand that my participation will be taped/video recorded and I consent to use of this material as part of the project.

- consent to the processing of my personal information for the purposes of this research study.

- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the UK Data Protection Act 1998.

- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Signed: Date:

Contacts: Mr. Robert Keatley, UCL, 1-19 Torrington Place, London WC1E 6BT. Email: r.keatley.11@ucl.ac.uk; Mr. Nickson Kakiri, P.O. Box 28507-00100, Nairobi. Tel/Fax (+254) 020 2636832, Email: nickson.kakiri@knad.org; Kenyatta University Ethics Review Committee, P.O. 43844- 00100, Nairobi. Tel, 020 8703312, Fax 020 8711575, Email: kuerc.chairman@ku.ac.ke; kuerc.secretary@ku.ac.ke

Appendix 8: Research licence

CONDITIONS

1. You must report to the District Commissioner and the District Education Officer of the area before embarking on your research. Failure to do that may lead to the cancellation of your permit
2. Government Officers will not be interviewed with-out prior appointment.
3. No questionnaire will be used unless it has been approved.
4. Excavation, filming and collection of biological specimens are subject to further permission from the relevant Government Ministries.
5. You are required to submit at least two(2)/four(4) bound copies of your final report for Kenyans and non-Kenyans respectively.
6. The Government of Kenya reserves the right to modify the conditions of this permit including its cancellation without notice

GPK6055t3mt10/2011

REPUBLIC OF KENYA

RESEARCH CLEARANCE PERMIT

CONDITIONS - see back page)

PAGE

THIS IS TO CERTIFY THAT
Prof./Dr./Mr./Mrs./Miss/Institution
Robert Keatley
of (Address) University College, London
1-19 Torrington Place London WC1E 6BT
has been permitted to conduct research in

Location
District
Nyanza & Western

on the topic: A comparative study of HIV knowledge, attitude and practices within the deaf community in Nyanza and Western Provinces in Kenya.

for a period ending: 31st March, 2015

PAGE 3

Research Permit No. NCST/RCD/12A/012/67
Date of Issue 1st October, 2012
Fee received USD. 400

Applicant
Signature

Secretary
National Council for Science & Technology

Appendix 9: Analysis of HIV transmission responses

Table A9.1: The modes of HIV transmission believed to be true by hearing status.

	Hearing % (N of total =78)	Deaf % (N of total = 67)	X^2, P–value	Earlier studies
True statements				
Sex (man-woman)	100 (78)[a]	97 (64)[m]	2.397, 0.122	
Sex (woman-man)	100 (78)[b]	97 (65)[n]	2.361, 0.124	
Unsterilized needles	97 (76)[c]	92 (60)[o]	2.003, 0.157	
Unsterilized razors	99 (77)[d]	91 (59)[p]	4.812, 0.028	
HIV + mother to baby	94 (73)[e]	81 (52)[q]	5.871, 0.053	
False statements				
Germs in the air	8 (6)[f]	22 (14)[r]	7.127, 0.028*	
Dirty places	3 (2)[g]	22 (14)[s]	12.88, 0.002*	
Kissing	68 (53)[i]	49 (33)[u]	8.348, 0.015*	39.6% in the 2004 Girois study (cited by Hanass-Hancock & Satande, 2010).

	Hearing % (N of total =78)	Deaf % (N of total = 67)	X^2, P–value	Earlier studies
Mosquito bites	14 (10)[h]	27 (18)[t]	5.606, 0.061	In 2008/09, a Pathfinder study found that 20% in the general population believed mosquitoes could transmit HIV (NACC & NASCOP, 2012). 41% in the 2004 Girois study (cited by Hanass-Hancock & Satande, 2010).
Sharing bowls, utensils	5 (3)[j]	11 (7)[v]	2.248, 0.325	26% in the 2004 Girois study (cited by Hanass-Hancock & Satande, 2010).
Touching or hugging	3 (2)[k]	14 (9)[w]	6.358, 0.042*	
Witchcraft	3 (2)[l]	14 (9)[x]	6.83, 0.033*	

- Categories which are significantly different by X^2 (p<0.05).

The following total N was used to calculate the percentage: [a], N=78; [b], N=78; [c], N=78; [d], N=78; [e], N=78; [f], N=78; [g], N=77; [h], N=78; [i], N=78; [j], N=78; [k], N=78; [l], N=78; [m], N=66; [n], N=67; [o], N=65; [p], N=65; [q], N=64; [r], N=64; [s], N=64; [t], N=64; [u], N=67; [v], N=64; [w], N=66; [x], N=64.

Appendix 10: Analysis of HIV prevention responses

Table A10.1: The modes of HIV prevention believed to be true by hearing status.

	Hearing % (N of total = 78)	Deaf % (N of total = 63)	X^2, P–value
True statements			
Sterilization of needles, razors	94 (72)[a]	93 (52)[j]	0.54, 1.0
Testing blood before transfusion	96 (74)[b]	84 (47)[k]	6.8, 0.03
Using condoms	98 (76)[c]	97(60)[l]	1.41, 0.769
Abstinence (no sex with anyone)	99 (77)[d]	90 (53)[m]	5.7, 0.041*
False statements			
Avoiding dirty places	6 (4)[e]	43 (24)[n]	25.4, 0.00*
Not sharing bowls, utensils	10 (7)[f]	20 (11)[o]	2.64, 0.222
Not hugging	3 (2)[g]	14 (8)[p]	6.74, 0.03*
Eating healthy foods	21 (16)[h]	58 (34)[q]	19.9, 0.00*
Washing hands	8 (6)[i]	53 (31)[r]	34.5, 0.00*

- Categories which are significantly different by X^2 (p<0.05).

The following total N was used to calculate the percentage: [a], N=77; [b], N=78; [c], N=78; [d], N=78; [e], N=77; [f], N=78; [g], N=77; [h], N=78; [i], N=78; [j], N=56; [k], N=57; [l], N=62; [m], N=59; [n], N=56; [o], N=56; [p], N=58; [q], N=59; [r], N=59.