

The perceptions of deaf youth about HIV/AIDS at two schools for the deaf
in the Eastern Cape Province

by

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DECLARATION

I declare that the work embodied in this dissertation is the result of my original research and has not been submitted before for a higher degree to this or any other university or institution of higher learning.

Lumka Nonkelela

DEDICATION

This dissertation is dedicated to my late grandfather who was a fountain of knowledge to me and who gave meaning to what is really meant by the saying, "Education is the key to success."

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One of the greatest pleasures in completing a work is to acknowledge people who have helped make the idea a reality. Many people have left their mark in one way or another in this study.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Treatment
ASL	American Sign Language
ASSA	Actuarial Society of South Africa
BHIVA	HIV Association
Deaf	A linguistic minority and cultural group who refer to 'Deaf' with a capital 'D' to denote their pride
deaf	A lower case 'd' refers to hearing impairment
DeafSA	Deaf Federation of South Africa
DBE	Department of Basic Education
FEDSAS	Federation of Associations of Governing Bodies of South African Schools
GALA	Gay and Lesbian Archives
HIV	Human Immune Virus
HRSA	Health Resources and Services Administration
HSRC	Human Science Research Council
IDUs	Injecting drug users
KAPB	Knowledge, Attitudes, Practices and Beliefs
NCS	National Curriculum Statement
NCV	National Curriculum Vocational
OSDP	Office on the Status of Disabled Persons
SASL	South African Sign Language
SLED	Sign Language Education and Development Programme
STI	Sexually Transmitted Infections
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations International Children's Emergency

WHO

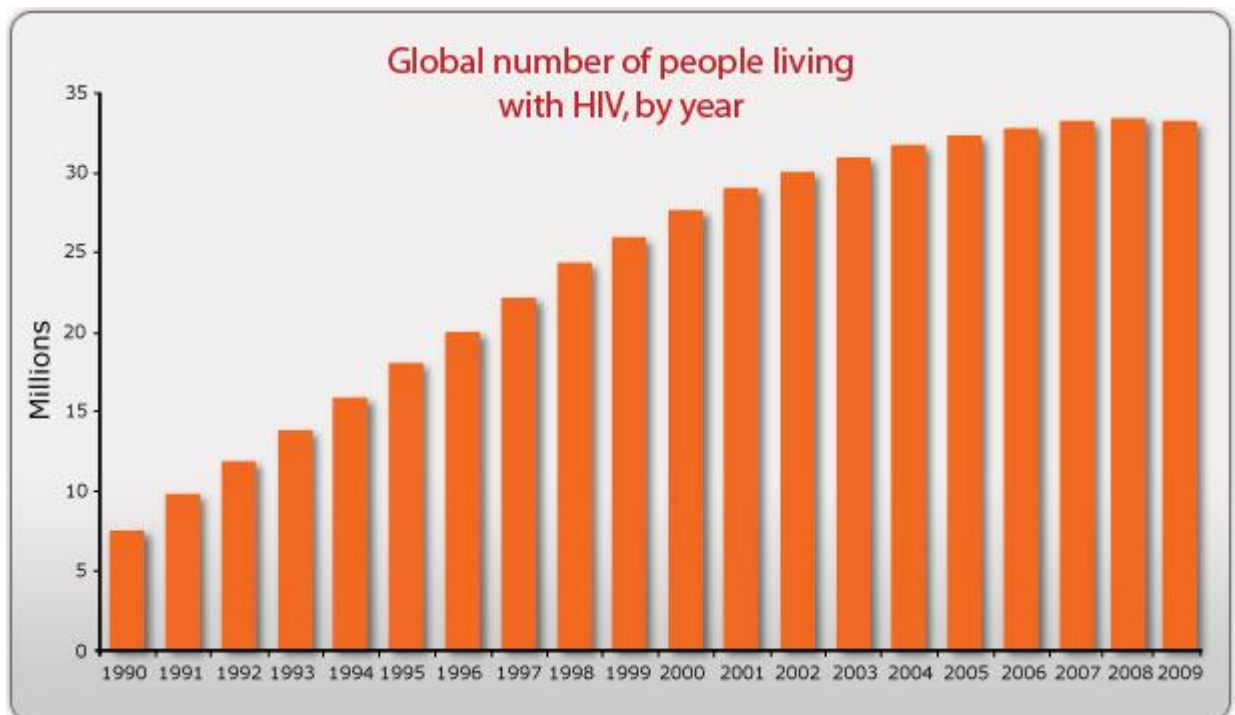
Fund
World Health Organisation

CHAPTER ONE

1.1. INTRODUCTION

Temmerman *et al.* (2005) define Acquired Immunodeficiency Syndrome (AIDS) as an incurable illness caused by the HIV virus. HIV stands for Human Immune-Deficiency Virus, and is sometimes also called the AIDS virus. The virus breaks down the immune system making the body more susceptible to all manner of infections and certain forms of cancer which it would otherwise be able to withstand. A person's immune system no longer functions as it should, thus allowing the virus to break down the immune system (Temmerman *et al.* 2005).

Figure 1: Global number of people living with HIV, by year (www.avert.org)

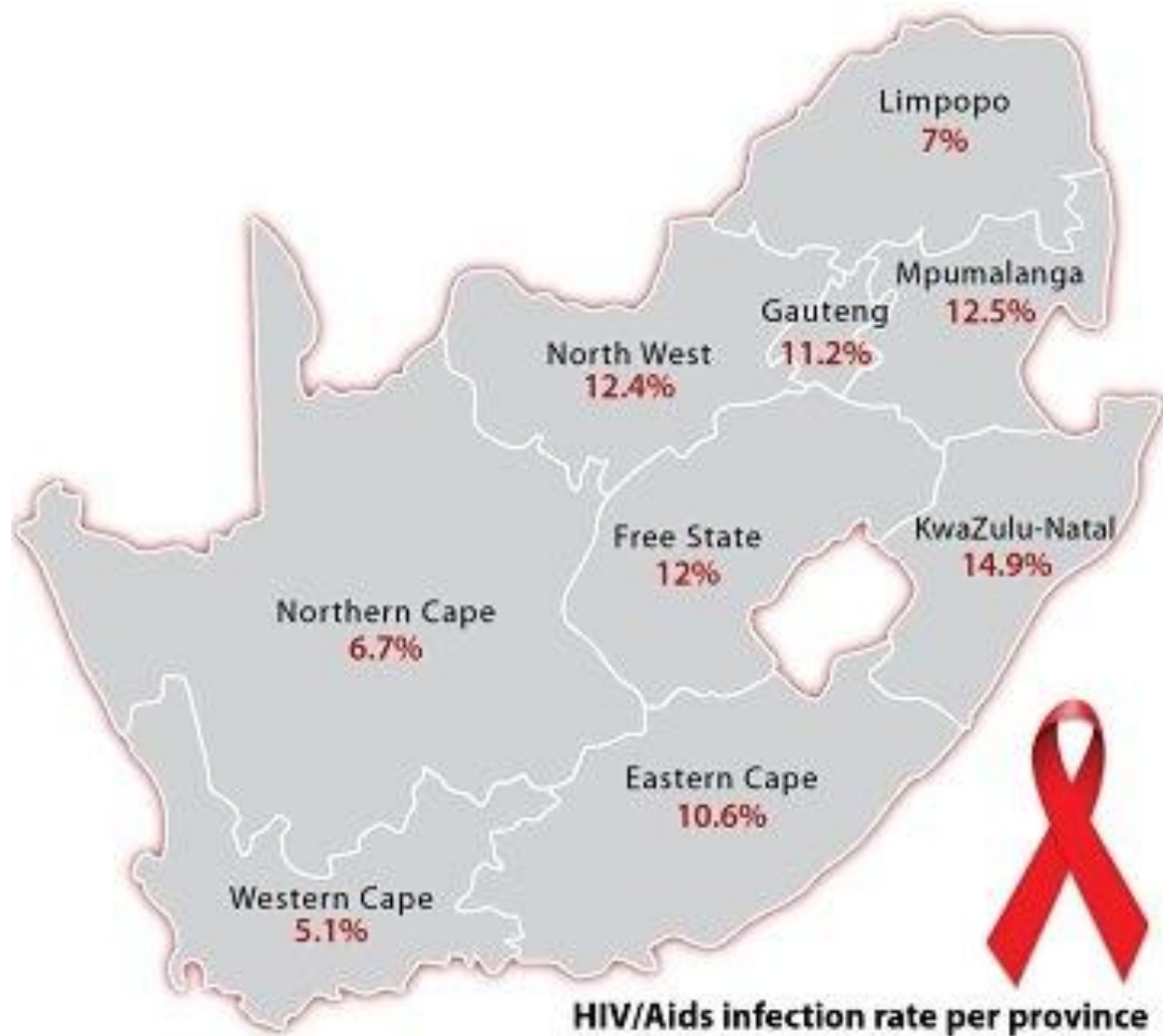


According to Joint United Nations Programme on HIV/AIDS (UNAIDS, 2010), the number of people living with HIV rose from around 8 million in 1990 to 34 million by the end of 2010. Collins (2007) argues that South Africa is one of the country's most severely affected by the AIDS epidemic, with the largest number of HIV infections in the world.

Human Immune Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) has been declared a pandemic in South Africa where it has changed the lives of individuals, ruined their health, caused deaths and left survivors mourning (Barnett & Whiteside, 2002). According to the UNAIDS report (2011), an estimated 5.6 million people were living with HIV and AIDS in South Africa in 2009, the highest number of people in any country. In the same year, it is estimated that 310,000 South Africans died of AIDS-related causes, reflecting the huge number of lives that the country has lost to AIDS over the last three decades.

Having looked at the state of the country, the following paragraph will focus on the state of the Eastern Cape Province. According to Hayward (2011), the Eastern Cape Province, where the research study is undertaken, is standing at 10, 6% in terms of HIV/AIDS infections (see Figure 2 below). However, as much as HIV/AIDS is a pandemic, it has been established that, due to the intensified campaigns of HIV/AIDS awareness, there is a slight decrease in the infections and the HIV/AIDS mortality rate (Khumalo, 2008) so this means HIV/AIDS education is one of the effective strategies to fight HIV/AIDS infections. A study conducted by the Eastern Cape Office of the Premier in 2008 revealed that students have a limited knowledge about HIV/AIDS (Phaswana-Mafuya *et al.*, 2009).

Figure 2: Prevalence of HIV/AIDS in South Africa (Breedt, 2012)



The preceding paragraphs have shown the extent to which HIV/AIDS has ravaged the country and the Eastern Cape Province. The figures are shocking but the picture becomes even scarier when one considers that the big part of the problem of HIV/AIDS is as a result of poor education and access to information. Chapter 2 (Section 29, 2) of the Constitution of the Republic of South Africa (1996) prescribes that, “Everyone has the right to receive education in the official language or languages of their choice in public educational institutions where that education is reasonably practicable.”

The Department of Education (DoE, 2010) thus further state that, in order to ensure effective access to and implementation of this right, the state must consider all reasonable educational alternatives, including single medium institutions, taking into account equity, practicability and the need to redress the results of past racially discriminatory laws and practices. In an attempt to redress the imbalances of the past and to ensure that all marginalised groups are afforded equal opportunities, in line with the South African government's commitment, the Eastern Cape Department of Education has undertaken to make HIV/AIDS education one of the key priorities and learners with disabilities are also included in the initiative (DoE, 2010).

Now that a brief introduction of the study has been articulated for the reader to know what to expect from the study, it is also critical to clearly present the statement of the problem.

1.2. STATEMENT OF THE PROBLEM

The White Paper 6 on Inclusive Education (2001) sees it as critical not only to identify and analyse the barriers to learning in the South African education system, but also to identify those mechanisms already in the system and those which need to be developed which will enable diversity to be accommodated in an integrated system of education.

Such mechanisms will include: initiatives aimed at providing for learners who have been excluded from the system by both the state and non-governmental organisations; innovative practices for recognising and accommodating diversity; activities that advocate against discrimination and challenge attitudes; processes towards the involvement of learners, parents, educators and community members in the governance of centres of learning; training programmes which equip educators to deal with diverse needs; curriculum restructuring; organisation and development of teaching and learning environments; and economic and political transformation supported by enabling and protective legislation and policy (The White Paper 6 on Inclusive Education, 2001).

Insufficient knowledge by deaf youth is not only a South African phenomena because international studies on differences in HIV/AIDS knowledge between deaf and hearing youth indicate that deaf youth are frequently unaware of or misinformed about HIV/AIDS and how it is transmitted and prevented (Heuttel & Rothstein, 2001). Furthermore, Job (2004) reveals that, in the United States, deaf adolescents have extremely limited core knowledge of HIV/AIDS. They also tend to be unaware of which behaviours place them at risk for infection, and they have limited knowledge of transmission prevention. Groce (2005) further states that deaf and hard of hearing people may also have limited access to mainstream information systems. He (2005) further states that television, radio, newspapers and magazines, as well as commercials and advertisements may not fully reach the Deaf community because such information is targeted at the general population who can hear. In addition to the latter statement, a South African scholar, Parkins-Maliko (2012), notes that most learners in Gauteng schools for the deaf between the ages of 15-19 years do not have a clear understanding of what HIV/AIDS is and how it is transmitted. Parkins-Maliko (2012) further states that learners in these schools for the deaf bully and tease learners who disclose their HIV status due to the fact that they are not adequately informed on HIV/AIDS. Such actions indicate that deaf learners lack information or education about pertinent HIV/AIDS issues, thus there was a need to undertake a study of this nature.

1.3. AIMS OF THE STUDY

A number of scholars, individuals and organisation advocating against the scourge of HIV/AIDS , that is, Chireshe, Rutondoki and Ojwang (2010); Eide, Otte, Van der Maas and De Boer (2008); Yousafzai, Dlamini, Groce, Wirz (2004); Mall (2012); Nyang'aya (1998); Meletse (GALA's deaf outreach coordinator); Peinkofer (1994); Barnett and Whiteside (2002); Heuttel and Rothstein (2001) and UNAID (2003) unanimously agree that in many countries including South Africa, the disabled, including deaf youth have limited knowledge or, are rather misinformed about issues related to HIV/AIDS. To understand the problem mentioned above this study was aimed at exploring

deaf youth's perceptions, the impact of HIV/AIDS on deaf youth's social life as well as the role that deaf youth play in the fight against HIV/AIDS in schools.

1.4. RESEARCH QUESTIONS

The main question in this study is, **“How do deaf youth perceive HIV/AIDS?”**

To unpack the main question, the following sub questions were asked:

- What are the perceptions of deaf youth about HIV/AIDS?
- How has HIV/AIDS affected deaf youths' social life?
- Why is it important that deaf youth be capacitated about HIV/AIDS issues?

1.5. OBJECTIVE OF THE STUDY

The objective of the study was to explore the perceptions that deaf youth have about HIV/AIDS by:

- exploring the perceptions of deaf youth about HIV/AIDS,
- determining the extent to which HIV/AIDS has affected deaf youth in their social life, and
- making recommendations to draw attention to and share with the Department of Education in order for them to investigate the impact of HIV/AIDS on the education of deaf learners.

1.6. SIGNIFICANCE OF THE STUDY

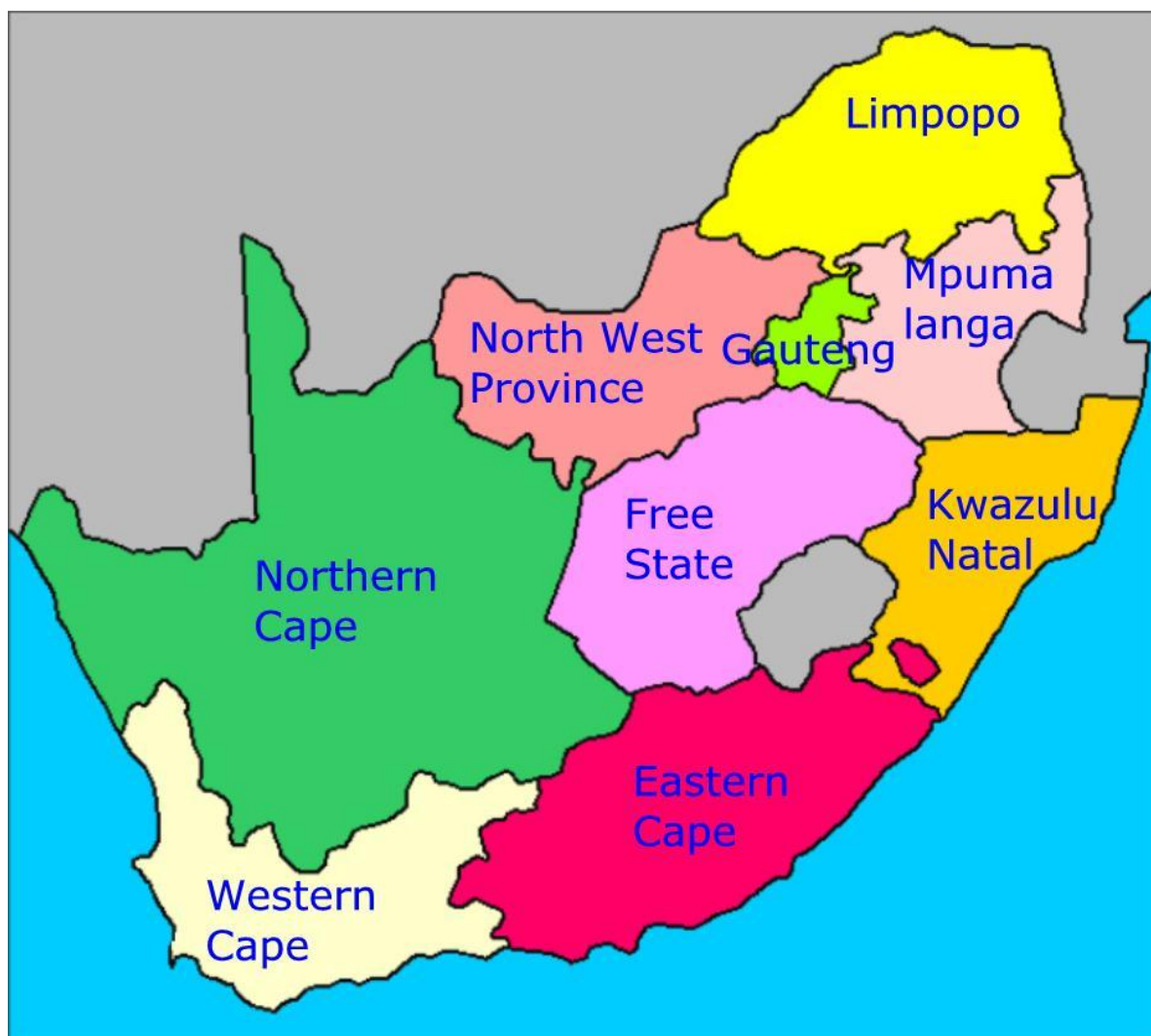
The Eastern Cape Department of Education (2008) states that HIV/AIDS is one of the top and critical challenges South Africa is facing today. In ascertaining that the rate of HIV/AIDS is decreasing and having effective HIV/AIDS on-going educational programmes could help address the problem. By so doing, people, including Deaf adults, will be more sensitised, thus taking precautionary measures. As aforementioned, these on-going education programmes will also assist Deaf adults, thus making it possible for the deaf youth to gain information and to have an opportunity of ask questions and get

first-hand information from their deaf instructors. Deaf community leaders must be given the resources and information to lead HIV/AIDS awareness campaigns in their communities. Trusted information sources can disseminate public health information in accessible ways. By involving the Deaf community in the campaign, accurate information will reach the community. As aforementioned in the problem statement, deaf youth have limited or wrong perceptions of HIV/AIDS, thus the study could highlight or identify some problematic perceptions, which could then be addressed through informed HIV/AIDS educational programmes. Knowledge gained from the HIV/AIDS educational programmes would also enable deaf youth to understand HIV/AIDS issues and, therefore, use it in their everyday lives. If perception-related challenges can be identified and addressed, then the envisaged objective of the Department of Education can be realised, that is, to ensure that effective HIV/AIDS educational programmes are accessible to deaf learners (DoE, 2010).

1.7. SCOPE OF THE STUDY

This study is undertaken in two schools for the deaf in the Eastern Cape Province, which is one of the nine provinces of South Africa (see Figure 3 below).

Figure 3: South African Provinces (South Africa Travel online, 2012)



The Eastern Cape came into being in 1994 and incorporated areas from the former Xhosa homelands of Transkei and Ciskei together with what was previously part of the Cape Province. Its capital town is Bhisho.

This research was undertaken in two schools for deaf learners, that is, School A for the deaf between King William's Town and Stutterheim in the Buffalo City Metropolitan Municipality, and School B for the deaf in Mthatha, in the O. R. Tambo District Municipality (see Figure 4). The Eastern Cape comprises six district municipalities and two metropolitan municipalities. There are four schools for the deaf in the Eastern Cape Province. The two schools under study cater for learners from Orientation class to Grade 12 and the focus of

this study is on learners between the ages of 14-21, who are mainly in Grades 7-12.

1.7.1. BACKGROUND OF THE STUDIED SCHOOLS FOR THE DEAF IN THE EASTERN CAPE

The following section will provide a description of both schools including the population and the curriculum offered.

(a) St Thomas School for the deaf

The school caters for deaf and hard-of hearing pupils from all over the Eastern Cape Province. The school is situated between King William's Town and Stutterheim. It was established by the Roman Catholic missionaries in 1962. It is currently a government-subsidised public school owned by the Roman Catholic Church. Ninety percent (90%) of the pupils at the school receive a government disability grant; this assists them in their day to day expenses which includes paying school fees. Not all learners pay school fees; learners who are from low socio-economic backgrounds do not pay. Social workers submit written reports to the Department of Education which state the financial status of parents.

All learners (100%) are from Xhosa-speaking and low socio-economic communities. The school also attracts learners from other provinces without prejudice. The school follows the National Curriculum Statement (NCS) and offers the following learning areas: Language, Literacy and Communication, Mathematical Literacy, Life Orientation, Technology, Business Studies, Tourism, Social Science, Arts and Culture, Natural Science, Economic and Management Science. This school has a Language policy which stipulates that the medium of instruction should be South African Sign Language (SASL). Some teachers use South African Sign Language to communicate with the learners in and outside the classroom, whereas some of the teachers use Total Communication and just talk sometimes when communicating and teaching the learners.

The school population is approximately three hundred (300) learners with thirty four (34) hearing teachers and four (4) teacher-aids who are deaf. The other staff members include six (6) administration staff, cooks, hostel staff, general assistants, cleaners and laundry assistants. Learners are also encouraged to perform their daily chores in the form of making their own beds, washing dishes, laying the tables and sweeping the floors.

The school is a boarding school and learners go home during school holidays which are in January, April, July and November annually. The school often holds meetings for parents and guardians of the learners. It is during these gatherings that parents get to understand about the progress of their children. They are given a chance to observe teaching and learning to get a deeper understanding of what is happening in the classrooms and how learners are taught. It is also at this time that parents are updated about the school and how it functions and the role that parents are expected to play in the education of their children. Parents are asked to help and support their children in their school work by listening to their children at home. They are also advised on how to sign to them as most of them do not understand Sign Language. They are advised to write down what they say, talk slowly and look at the child so that the child is able to lip read. The parents also get to share their experiences and challenges in catering for the needs of their deaf children. They are also given time to ask questions about whatever they don't understand about the school and the progress of their children as well.

(b) Efata School for blind and deaf learners

The school was established over five decades ago in 1958 on Melville Farm under the auspices of the Dutch Reformed Church as a school for the blind. It is situated eight (8) kilometres away from Mthatha along the R61 National Road in the Eastern Cape. School B is the only school in the Eastern Cape that caters for two kinds of disabilities, namely, blind and deaf, and also is the second oldest of the schools for the deaf in the province. There was an influx of parents coming to the school with deaf children from the surrounding areas, and, as the school only catered for blind learners initially, a recommendation

was, therefore, written by the then management of the school to the Department of Education, requesting that the school also accommodate deaf learners. The school aims to train and educate learners with special educational needs, specifically blind and deaf learners.

The enrolment of the school is one hundred and thirty two (132) blind learners and three hundred and thirty five (335) deaf learners, forty nine (49) educators employed by the Department of Education and one teacher aid who is a Deaf female. There is also support staff in the form of housekeepers, laundry workers, cleaners and cooks, including thirteen (13) Deaf adults. Comparable with the other school, learners are also encouraged to perform their daily chores in the form of making their own beds, washing dishes, laying the tables and sweeping the floors.

The school is a public school on private property. It is subsidised by the Department of Education to a certain percentage, which fluctuates between 75% and 89% depending on the budget allocation for that academic year. The principle is that the school covers the remaining percentage by donations and fundraising. There are written reports submitted by social workers to the Department of Education which state the financial status of parents. Some parents pay school fees whereas others do not because they are from low socio-economic backgrounds, according to the reports which are obtained from the social workers. Most learners receive a disability grant on which their families sometimes solely depend.

The school is divided into two sections, the section for blind learners which offers education from Grade R to 12 and follows the National Curriculum Statement (NCS). There is also the section for deaf learners which also follow the National Curriculum Statement and the National Curriculum Vocational (NCV). Learners who struggle academically and are more competent in skills are placed in NCV class. Teachers use their discretion when they see that a learner does not cope academically. Skills such as bricklaying, carpentry, cookery, needlework and welding are offered to deaf learners. From this point

the schools will be referred to as School A and B so as to protect the identities of the participants.

1.8. THEORETICAL FRAMEWORK

This qualitative research study made use of phenomenological theory. According to Brink (1996) phenomenological theory aims at describing what people experience in regard to some phenomena and how they interpret those experiences or what meaning the experiences hold for them. Haynes (2000) adds that phenomenology uncovers the things themselves by revealing the meaning of a thing as a showing of that meaning in the thing in question. Phenomenology looks at how people make sense of their experiences, how we build meaning from our experiences (Tuckett, 2012). In addition, Lester (1999) notes that the purpose of the phenomenological approach is to illuminate and to identify phenomena through how they are perceived by the actors in situations. Brian *et al.* (1996), further state that in phenomenology the researcher seeks a deeper and fuller meaning of the experience of the participants of a particular phenomenon.

In order to understand the phenomenon under study, which is the perceptions of deaf youth about HIV/AIDS, the learners were afforded an opportunity to share their experiences. Brink (1996) states that these experiences are lived experiences and, in this study, the participants shared their lived experience on how they perceive issues around HIV/AIDS. The phenomenological approach helps to develop a deeper understanding and meaning that the participants attach to their perceptions about HIV/AIDS. To ensure that the latter information is received; the research questions are shaped/structured in a way that will highlight the perceptions of the learners. In attempting to describe the lived experience, the researcher focused on what was happening in the life of the individual. In the light of the above, it was imperative that deaf youth share their experiences and meanings in relation to how they perceive HIV/AIDS.

1.9. CONCLUSION

This chapter has provided the reader with: an overview of the research study by discussing the background to the study, the statement of the problem, the research questions and objectives of the study, the significance of the study, a brief description of the scope of the work, and the theoretical framework.

The rest of the dissertation is structured in the following way:

- In chapter two, the relevant literature regarding HIV/AIDS, the background to deafness, and AIDS awareness are explored and discussed, and emphasis is also placed on South African and global approaches to HIV/AIDS education and the challenges thereof.
- In chapter three, the research methodology is outlined, that is, the research approach (qualitative), sampling, data collection and data analysis. Ethical considerations are also discussed in this chapter.
- In chapter four, data is presented and interpreted with the summary of findings at the end of each theme explained.
- In chapter five, findings in relation to the available literature are discussed.
- In chapter six, recommendations are outlined and a conclusion is drawn.

CHAPTER TWO

LITERATURE REVIEW

2.1. INTRODUCTION

The United Nations General Assembly Special Session (UNGASS) Country Progress Report (2010) stated that people are affected by HIV/AIDS in different ways in different countries of the world. In Hayward (2011, p. 56) it is noted that, “With 5.64 million residents living with HIV, South Africa is home to the highest number of HIV-positive people out of the global HIV-positive population of 34.6-million, according to UNAIDS, a United Nations HIV/AIDS watchdog.”

HIV/AIDS prevalence figures in the 15–19 year age group for 2005, 2006 and 2007 were 16%, 14% and 13% respectively (HSRC, 2011). According to the Human Sciences Research Council (2011), in 2007 only 28% of people in South Africa with advanced HIV/AIDS were receiving anti-retroviral treatment (ART). It is further stated by the Human Sciences Research Council (2011) that in 2004, 2005 and 2006 the figures were 4%, 15% and 21% respectively.

There is no disaggregated data on HIV/AIDS prevalence rates on the basis of deafness nationally and internationally. Blumberg *et al.* (2003) also reiterate that the prevalence of HIV/AIDS among the deaf population, and indeed among deaf youth, is not known. HIV/AIDS risk behaviour and prevalence remains critical health concerns in South Africa, particularly among youth, whose HIV prevalence is 10.2% (Pettifor *et al.*, 2004).

By 2009, nearly 1 million or about 2% of all adult South Africans were receiving ART, of which 38% were children. In 2010, some 280,000 South Africans died of HIV/AIDS; between 42% and 47% of all deaths among South Africans were HIV/AIDS deaths. Although new infections among mature age groups in South Africa remain high, new infections among teenagers seem to be on the decline.

Peinkofer (1994) states that deaf populations all over the world tend to have low levels of literacy, to be poorly educated and highly marginalized. Gaskin (1999) further argues that HIV/AIDS messages carried over the media globally often do not reach deaf individuals. Additionally, Peinkofer (1994) and Gaskins (1999) further state that confusion caused by the actual translation of HIV/AIDS messages into Sign Language without adequate understanding of the local Sign Language in Swaziland is also of concern because of potential inaccuracies. Kennedy *et al.* (1995) indicate that "HIV positive" is being misinterpreted by deaf individuals in a number of countries as a good (positive) diagnosis. Such misunderstandings underscore the importance of appropriate translation of ideas and not simply words.

In a study undertaken by the UNAIDS (2003) in rural Swaziland, a mountainous kingdom in southwest Africa with a population of 1 million, it is stated that the problem of HIV/AIDS has become prominent, fuelled by its central position between South Africa and Mozambique. In this study, deaf respondents listed an additional set of symptoms of HIV that are largely descriptive in nature, such as pimples, swelling, hot urine, penis falling off and liver rotting. By contrast, the hearing respondents listed specific clinical diagnoses like thrush, pneumonia and fluid loss. None of the hearing respondents reported the list of symptoms described by deaf respondents and this was a clear indication of the knowledge gap.

Deaf respondents also raised environmental risks of HIV transmission which included mosquito bites, germs in the air and dirty places. Beliefs about transmission through contact among deaf individuals is reflected in a significant difference in beliefs that HIV/AIDS can be prevented through avoidance of hugging and touching and avoidance of sharing bowls and utensils. Difference in perceptions of environmental risks was also evident in responses regarding the belief that HIV/AIDS can be prevented through hand washing and avoiding dirty places. Deaf respondents also regularly mentioned eating healthy foods as a preventative measure, which may represent misunderstanding of the health messages given to encourage HIV positive individuals to maintain healthy lifestyles.

To address the limited information available regarding HIV knowledge among Deaf adults, a computerized, self-administered HIV/AIDS knowledge survey in American Sign Language (ASL) for use with Deaf adults in America was developed (Eckhardt, 2005). Results indicated that the individuals have shortfalls in their HIV knowledge which may have critical implications for HIV prevention. From this study, the lack of knowledge about condoms as an effective HIV prevention mechanism among 30% of the sample (n=452), indicate that general HIV messages do not reach many deaf persons. Deaf people believe that “HIV is a hearing persons’ disease”, they believe themselves not to be susceptible to infection (Goldstein *et al*, 2006). This, therefore, makes it likely that a substantial portion of the deaf population may not take preventive action against HIV and this increase the rate of infection of the deaf youth. In support of the opinion above, emerging evidence shows that deaf people have amongst the highest rates of HIV infection in South Africa at 18%, according to Anthony Manion of Gay and Lesbian Archives (GALA, 2012). It is further stated in GALA (2012) that all official research only looks at HIV prevalence within disabled communities as a whole. Meletse, GALA's deaf outreach coordinator, in an article by Child (2012) indicates that deaf people are very vulnerable to HIV and AIDS in this country because there is very little information about the risks and the disease adapted to their needs. As a word of caution, Meletse further emphasises that the need to educate deaf people is quite rudimentary in many instances in South Africa. Deaf people, therefore, have great difficulties in accessing the preventive information that is out there.

There is simply too little information on HIV and AIDS in Sign Language as Meletse notes that lack of knowledge by deaf youth on how to protect themselves puts the lives of deaf people at risk. Meletse further notes that deaf youth do not have enough knowledge to recognize symptoms if they have been infected and they do not know their rights when confronted with a prejudiced health care system, for example, when the service they get is not pleasing. Schmaling *et al*. (2006) argue that there is still no widespread recognition of the fact that deaf people are living with and dying from AIDS at higher rates than hearing people. Taegtmeyer *et al*. (2008) state that statistics

from the Kenyan study show that Kenyan deaf people have a similar incidence of HIV (7%) as that of the hearing population, contrary to what was indicated by Schmaling *et al.* (2006).

Like all sicknesses, HIV/AIDS management requires support that is immediate to the sick person thus in this regard local clinics are providing essential services but most public health authorities do not recognize deaf people as an at risk population of HIV; therefore, they do not gather statistics. Although limited statistical information is available on the problem of HIV/AIDS in the deaf and hard of hearing population, studies suggest that HIV/AIDS affects deaf people at a higher rate than hearing people.

The Maryland Department of Health and Mental Hygiene in the USA collected data on HIV testing in 2003. During that time, 38,602 hearing people were tested in public facilities and 832 Deaf people were tested. Among those tested, 813 hearing people were HIV positive and 38 Deaf people were HIV positive (Monaghan, 2006). This data suggests that deaf people are two times more likely to be HIV positive. Monaghan (2006) further iterates that when one does allow for overall population estimates, this number rises to an estimate of deaf people being ten times more likely to be HIV positive. Below the background on HIV/AIDS is discussed to share light on what HIV/AIDS entails.

2.2. BACKGROUND ON HIV/AIDS

This section will define and discuss what HIV/AIDS is and its impact on the person's immune system.

2.2.1. What is HIV?

According to Barnett *et al.* (2002), HIV derives from a virus that crossed the species barrier from chimpanzees into humans. It is closely related to a number of Simian (monkey) Immunodeficiency Viruses (SIVs) found in Africa. In 1985 scientist Hahn from the University of Alabama and his colleagues

discovered the human immunodeficiency virus (HIV). McKenzie (1991) describes HIV as the Human Immunodeficiency Virus that is transmitted through body fluids such as blood, semen, breast milk and vaginal secretions from one person to another. Unprotected sex is the most common way to spread HIV, but it can also be transmitted by sharing needles when injecting drugs, or during childbirth and breastfeeding (Harper, 2010). As HIV reproduces, it damages the body's immune system and the body becomes susceptible to illness and infection (Barnett *et al*, 2002).

2.2.2. How HIV works?

The impact of the pandemic on youth generally is particularly severe as the rate of HIV is highest among young people between the ages of 15 and 24 years, and most new infections occur in adolescents or young adults (UNAIDS, 2009). Barnett *et al*. (2002) state that when a person gets infected with HIV, it starts destroying his or her immune system, which is responsible for protecting the body from infection. An HIV-infected person can carry the virus for many years, looking and feeling fine and not even knowing that he or she is infected. However, eventually the virus attacks so many of the immune system cells that whatever cells are left are incapable of effectively fighting off infection.

The blood contains white and red cells (Van Schaik, 1998), where the red cells transport oxygen and food to all parts of the body and the white cells fight and kill organisms which enter the body. The white cells are controlled by a cell called T4, which directs the other cells to destroy invading organisms, absorbing and destroying the macrophages and producing antibodies. The HIV virus, on entering the body, attaches itself to the T4 cell and enters the cell. The virus becomes part of the cell and uses it as a factory to reproduce itself. The cell eventually bursts, releasing more viruses which attach to other T4 cells. As the virus population increases, fewer T4 cells are able to direct and control the defence against invading organisms, and there is no coordination of the immune response.

A normal T-cell count ranges from 500-1400 cells (Eastern Cape Department of Education, 2008), and when a person has a T-cell count that is below 300, that individual is considered to have Aids. In that case, the B-cells that initially identify the virus as "foreign" and the macrophages consume the virus cells, as a result of which the immune system ultimately loses the battle. At this point, a person is incapable of fighting off a myriad of opportunistic infections that would not be a problem if encountered by a person with a normal immune system. Meanwhile, the AIDS virus is continuing to multiply.

Sometimes, some of the AIDS virus cells will refrain from reproducing. Barnett *et al.* (2002) state that, instead, they will enter T-cells and remain inactive for a while before choosing to multiply. They can remain in this dormant state for several years, during which they are not detected by B-cells or consumed by macrophages. This is another hindrance to eradicating the virus because though some of the virus cells may not be evolving, the fact that they remain inactive is an effective evolutionary strategy that allows them to concurrently stay alive and stay undetected (Barnett *et al.*, 2002).

Van Schaik (1998) further states that due to this process, the body becomes less able to fight off the many different illnesses and infections, such as tuberculosis, pneumonia, fever and vomiting which live in and around people all the time and, finally, people die from one or more of the diseases which the body cannot fight. When the virus enters the body, a person is referred to as HIV positive. He/she may feel and look healthy, but can pass the virus to others. People can remain carriers for many years. A person has AIDS only when the immune system does not function effectively, and by that time symptoms of different diseases start to show.

2.2.3. Modes of infection

Now that a comprehensive description of HIV/AIDS has been discussed, the modes of infection will be presented. Unlike many diseases, HIV can only be transmitted through contaminated body fluids (Barnett *et al.* 2002), which

means that a person can only be infected if the virus enters the body through mucous membranes into the bloodstream.

Infection via contaminated body fluids occurs through various ways; however the primary method of contamination is when one is having unprotected sex with someone infected with HIV. According to Harper (2010), any type of unprotected intercourse with someone who is infected with HIV can transmit the virus. HIV is also transmitted from infected mother to child, for example, through breastfeeding and being exposed to the virus as a foetus or infant before or during birth. Another mode is the use of or contact with infected blood or blood products, for example, receiving a transfusion of HIV infected blood and from bleeding wounds. Harper (2010) further states that intravenous drug use with contaminated needles is one of the modes of transmitting HIV. Needles come into direct contact with the veins and retain blood. Sharing needles with someone infected by HIV will put the infected blood directly into contact with the new vein. According to Gregson (2002) HIV is not spread through casual contact such as sharing food, utensils, towels, bedding, pools, telephones or toilet seats with HIV positive people. It is also not spread by insects such as mosquitoes.

2.2.4. Symptoms of HIV

According to the Centre for AIDS Research (2009), most people (up to 80%) who become infected with HIV develop some symptoms a few days or weeks after the infection occur. Some common symptoms of HIV, according to Mckenzie (1991), include diarrhoea that lasts for more than a week; a dry cough; pneumonia; profound unexplained fatigue; rapid weight loss; recurring fever or profuse night sweats; swollen lymph glands in the armpits, groin or neck; white spots or unusual blemishes on the tongue, in the mouth or in the throat; and short term memory loss. According to the Centre for AIDS Research (2009), it is further stated that some people who contract HIV experience very strong symptoms, but others experience no symptoms at all. The symptoms may last from a few days to several weeks.

2.2.5. Evolution of HIV/AIDS

According to Smith (2005) the HIV virus disrupts the immune system response by interfering with the T-cells. This allows the virus to replicate rapidly. It invades a T-cell and uses it as a place to reproduce. Ultimately, the cell becomes filled with HIV cells and it explodes, allowing the new virus cells to infect other cells. As discussed earlier, the HIV virus interferes with the T-cells which then make the immune system lose the battle against infection.

Smith (2005) further declares that though AIDS is incurable, it can be treated with drugs to boost the immune system and allow patients to live longer. This is evidenced by people who are managing it well but it is not known yet how long a person can live with treatment (Smith, 2005). As stated by the Department of Health (2009), currently there are four classes of drugs that can be used against AIDS and the most effective treatment uses multiple drug types. Charpentier *et al.* (2002) argues that over time, the virus evolves and in the process, develops drug resistance. This process is inevitable so it necessitates the use of different drugs for treatment as drug resistance occurs more quickly if a person neglects to take all doses of the drugs. This resistance is transmitted when new individuals are infected, meaning that as AIDS is spread, it becomes stronger and more resistant. Barnett *et al.* (2002) further state that an important starting point is that the spread of diseases from animals to humans is not unique to HIV, as is evidenced by the influenza virus which evolves in birds - waterfowl to be exact.

2.2.6. What is AIDS?

Smith (2005) defines Acquired Immune Deficiency Syndrome, or AIDS, as a condition that describes an advanced state of HIV infection. With AIDS, the virus has progressed over time destroying the immune system, causing significant loss of white blood cells (CD4 cells) or any of the cancers or infections that result from immune system damage. Those illnesses and infections are said to be "AIDS-defining" which means they mark the onset of AIDS, and due to the compromised immune system, people with AIDS have

difficulty fighting infections caused by viruses and often die from opportunistic infections, rather than AIDS itself. Like HIV, there is no known cure for AIDS. It is a collection of diseases that result when the immune system is broken down after it has been invaded and weakened by HIV.

Barnett *et al.* (2002) state that when a person is infected, the virus lowers the immune system. There is an initial burst of activity during which many cells are infected, but the immune system fights back, manufacturing immense numbers of antibodies. This period is marked by an unseen and unfelt war in a person's body. The viral load is high, the immune system is taking a knock and the person's HIV status cannot be detected using standard tests. This is commonly called the window period and lasts from several weeks to several months. At this stage, a person is highly infectious as his or her viral load is considerable. An infected person will usually experience an episode of illness at the end of the window period but this will often resemble flu and will not be seen as a marker for HIV. Doka (1997) argues that HIV is an exceedingly complex syndrome that directly infects certain cells including immune cells. By weakening the immune system, the virus indirectly allows other opportunistic infections such as flu, pneumonia and tuberculosis to attack the host.

2.2.7. Symptoms of opportunistic infections common with AIDS

According to the Eastern Cape Department of Education (2008), opportunistic infections are illnesses caused by various organisms that occur in people with weakened immune systems, including people with HIV and AIDS. Opportunistic infections common in people with Aids include tuberculosis, pneumonia, viral and fungal infections. When HIV infected people are in the advanced stages of HIV/AIDS, these are common symptoms which they experience.

The British HIV Association (2010) states that people with advanced HIV infection are vulnerable to infections that are called 'opportunistic infections' because they take advantage of the opportunity offered by a weakened immune system. The symptoms of opportunistic infections, according to the

Eastern Cape Department of Education (2008), include shortness of breath, difficulty or painful swallowing, extreme fatigue, fever, mental symptoms such as confusion and forgetfulness, nausea, severe persistent diarrhoea, severe headaches, vision loss, weight loss, and shingles, a painful nerve disease often accompanied by a rash or blisters.

Having discussed the background, evolution of HIV/AIDS, modes of infection and symptoms of HIV/AIDS, it is also important to discuss the background of deafness and the status of the world globally with regard to HIV/AIDS awareness and deaf education.

Although the research study focus is on deaf youth, it is important to give a background to what happens in broader deaf communities in relation to HIV/AIDS as this may shed light on some of the issues that may influence deaf youth's perceptions.

2.3. HIV/AIDS AND THE DEAF COMMUNITY

Mall (2012) reveals that a few studies have been conducted exploring HIV/AIDS issues in the deaf community. With regards to how disabled people know about HIV/AIDS, a number of studies have explored the knowledge of disabled people of transmission routes of HIV/AIDS, for example, (Chireshe, Rutondoki & Ojwang, 2010; Eide, Otte, Van der Maas & De Boer, 2008; Yousafzai, Dlamini, Groce & Wirz, 2004). The study findings revealed that disabled people do not have sufficient knowledge about HIV/AIDS and Mall (2012) confirms that by noting that, for example, deaf people cannot benefit from the services that are offered by some organizations such as telephone hotlines for counselling purposes, as well as for medical counselling services, unless there is an interpreter although the presence of an interpreter defeats the main purpose of these services, which is to offer anonymity and confidentiality. Nyang'aya (1998) advises that there are social and political obstacles that deaf people encounter when accessing HIV/AIDS prevention information. Information about HIV/AIDS is crucial as it has been established that deaf youth are sexually active and are also prone to sexual abuse.

Researchers found that both deaf and hearing girls were open about their sexuality and spoke freely while deaf and hearing boys adhered more to the questions posed to them in focus group discussion (Mall, 2012). Bisol *et al.* (2008) found that deaf youth were more at risk of sexual abuse than hearing youth of their age. Touko, Mboua, Tohmuntain and Perrot (2010) found in their study of the Deaf community in Cameroon that the HIV prevalence rate was 4%, comparable to that of the general population. This study found relatively high prevalence of high-risk sexual behaviour among the deaf. Among those participants who reported that they were sexually active, 53% of men and 54.3% of women reported that during the past 12 months (prior to recruitment) they had engaged in multiple concurrent partnerships and there were reports of transactional sexual activity.

Cambanis (2010) reported high rates of sexual abuse among deaf and hard of hearing children. Sullivan, Vernon and Scanlon (2000), as cited in Cambanis (2010), suggested that 54% of deaf and hard of hearing boys and 50% of deaf and hard of hearing girls had been sexually assaulted as children and the risk of sexual abuse was double for girls and five times as high for boys who are deaf or hard of hearing. Alriksson-Schmidt *et al.* (2010) also found that female students with a physical disability were more likely to report being forced into sexual intercourse than were their able bodied peers.

Groce (2005b) highlighted the practice of 'virgin rape' that has also targeted disabled people. Perpetrators may believe that disabled people are sexually inactive and, therefore, they could be victims of this practice. Disabled adolescents are often socially isolated and this limits their opportunities to learn to set boundaries and therefore they compromises their ability to refuse when pressured to have sex or drugs" (Groce, 2005, p. 217).

Similarly, Jenta *et al.* (2008) found in their study of 141 children and adolescents that 7% of disabled participants reported a history of sexual abuse. Hanass-Hancock (2009) explored the vulnerability of disabled women in South Africa to HIV/AIDS in a qualitative study of both disabled people and their care givers over a time span of 3 years. She found that the threat of

sexual abuse for disabled women is a major issue. She also explored myths about HIV and disability, finding that cultural representations were also contributing to the risk of HIV/AIDS for disabled people.

Other risk factors include: the societal view that disabled people are not sexually active, living conditions of extreme poverty, engagement in high risk sexual behaviour, sexually transmitted infections, poor knowledge of HIV prevention, and increased risk of sexual abuse, compared to able-bodied peers. Disabled people may live in institutions or be dependent on carers placing them at risk of sexual abuse. Perpetrators may believe that disabled people lack the skills to identify and report an attacker (Groce, 2003).

A number of studies have reported sexual risk activity in disabled people, for example, Choquet, Du Pasquier & Manfredi, 1997; Comulada et al., 2010; Maart & Jelsma, 2010; and Mustanski, Donenberg & Emerson, 2006). Maart and Jelsma (2010) compared the sexual behaviour of physically disabled adolescents and able-bodied adolescents in South Africa. They conducted a cross-sectional survey of risk behaviour patterns of adolescents with physical disabilities attending special schools in South Africa. This study found that adolescents with a physical disability are indeed sexually active with 27% of the sample reporting having had two or more sexual partners, and 12% of the sample believing that they were not at risk of contracting HIV/AIDS. Only 18% of the sample reported consistent condom usage. Perry and Wright (2006) explored sexual behaviour patterns in patients with mental illness and compared their findings to behaviour patterns in the general population. They found that, although patients with mental illness used condoms more consistently in their relationships than the general population, they were more likely to have sex sooner with a newer partner. This heightens the risk of HIV/AIDS.

They found that, as in the Hanass-Hancock study, disabled women may well engage in unstable relationships. If approached by a potential partner, they were unlikely to refuse a sexual relationship as they thought this would be their only opportunity for a relationship. Fellingner, Holzinger, Sattel, Laucht

and Goldberg (2009) found a relationship between the deaf child's inability to communicate with their family members and the frustration of being misunderstood, and psychiatric disorder.

In addition, Groce (2004) conducted a global survey sponsored by Yale University, USA and the World Bank. The survey aimed to explore risk factors for HIV/AIDS for disabled people all over the world. The survey found that poverty, lack of education, lack of sex education, and substance abuse were significant risk factors for disabled people for HIV infection. Drug abuse has been reported to be higher among disabled people than in the general population (Gaskins, 1999). According to Lowry *et al.*, substance abuse can be associated with sexual risk behaviour and could lead to the risk of sharing needles which also results in vulnerability to HIV infection (Hannass-Hancock & Nixon, 2009).

2.4. THE INTERVENTION STRATEGY: AIDS AWARENESS AND EDUCATION PROGRAMMES

Roberts (2006) argues that the main weapon to fight the spread of HIV/AIDS is information and education. Awareness campaigns both by the government and by non-governmental organisations are mainly through the mass media and through educational materials. Deaf people often have limited access to this information as it is presented either in spoken or written language with no Sign Language interpreter available to convey the message (Goldstein *et al.* 2006). This communication barrier is also present in medical settings as health care providers usually do not know Sign Language. The result is that the typical health education programmes as a means of combating the spread of HIV/AIDS do not reach the deaf communities. Goldstein *et al.* (2006) state that one survey with 450 Deaf adults in eight US states showed that, while most deaf participants had basic HIV knowledge, there were gaps in knowledge about transmission and protection.

Obstacles to implementing optimal HIV/AIDS and reproductive health education in schools for deaf and hard of hearing learners in South Africa include inadequate teacher proficiency in SASL as well as moral tension experienced by teachers when they are made to deliver reproductive health and HIV/AIDS education. In South African Country Progress (2011) it is stated that radio programmes, a common part of public awareness campaigns, completely exclude persons who are deaf or hard of hearing. Printed materials alone are clearly not sufficient (South African Country Progress, 2011). Sign Language interpretation and presentations are important but they are rare, especially in the developing world. According to the HSRC (2011) the four main HIV/AIDS awareness campaigns in South Africa are Khomanani (funded by the government), Love Life (primarily privately funded), Soul City (a television drama for adults) and Soul Buddyz (a television series for teenagers). The HSRC (2011) further states that Soul City and Soul Buddyz are the most successful campaigns although both campaigns experienced a slight loss of effectiveness between 2005 and 2008. Khomanani is the least successful campaign, although its effectiveness has increased by more than 50% between 2005 and 2008.

According to the National Department of Health (2011), Sexually Transmitted Infection (STI) prevention forms part of the government's HIV/AIDS programmes, as it is in most countries. In South Africa HIV/AIDS prevention is done in conjunction with TB prevention as TB also presents as one of the HIV symptoms. The National Department of Health (2011) further states that most patients who die from HIV related causes die from TB or similar illnesses. In fact, the Health Department's programme of prevention is called the "National HIV and AIDS and TB Programme." In line with United Nations requirements, South Africa has also drawn up an "HIV & AIDS and STI Strategic Plan" (National Department of Health, 2011). Quality media coverage of the HIV epidemic remains an essential component to increasing the public's awareness of the issue, and forms an integral part of any behaviour change drive (Roberts, 2006). It is, therefore, necessary that media practitioners are well informed of the technicalities, science and ethics of covering HIV, that

they have a good network of medical professionals and people living with HIV whom they can access, and that they are committed to ensuring that HIV remains on the public agenda.

Also as one of the public awareness programmes, Barriga (2010) argues that basic Sign Language and disability awareness training for health workers is absolutely fundamental to stopping the spread of HIV among people who are deaf. In addition, governments need to ensure that children who are deaf or hard of hearing are able to learn about health topics such as HIV. Barriga (2010) further mentions that without a concerted effort to reach out to the deaf population, they will continue to live in silence, and the HIV epidemic will quietly continue to spread.

Research conducted in the field of HIV/AIDS education for deaf learners has taken the form of a study by the Sign Language Education and Development Programme (SLED), a Deaf education materials organization promoting the use of SASL. This study aimed to determine the major problems facing the deaf community in terms of HIV/AIDS, sex and abuse. The research was conducted in collaboration with Love Life and it led to the development of core ideas for scripts, teacher manuals and learner activity books for the 'Life Skills HIV and AIDS Education for the South African Deaf Learner' programme (SLED, 2006). The programme was launched in 2004 by the South African Minister of Health, to create a comprehensive programme of SASL education materials designed to communicate key messages around HIV and AIDS to deaf pupils in their first 10 years of school.

Since 2005 SLED has reportedly hosted training workshops aimed at empowering educators, teaching assistants and caregivers of deaf learners with the necessary skills to be able to use the 'Life Skills HIV/AIDS Education for the Deaf Learner' programme effectively. One of the programme's aims is to teach educators who are not proficient in SASL the signs for sexual and

health-related terminology in an effort to enhance communication between educators and learners. They created and produced a series of videos suitable for different age groups of young deaf learners. The videos portray real-life scenarios acted out by young deaf people to communicate key messages around HIV and AIDS, sexual health, relationships and sexual violence. Different videos cater for different schooling age groups. The video for pre-school and primary school deaf learners focuses on basic health messages and the dangers of early sexual debut for pre-school and primary school children. The video for 17-25 year olds centers on harder issues such as living with HIV, peer pressure, date rape and drug abuse. The project also developed teachers' manuals to accompany the videos in classrooms.

These manuals are aligned with learner's activity books for deaf learners to use alongside the videos. The books rely on extensive artwork and illustration, which makes it easy for deaf learners to understand. According to SLED (2005), the teacher manuals and learner activity books are the first language appropriate materials of this kind to be developed for the deaf by the Deaf in Southern Africa.

The preliminary qualitative research conducted by SLED regarding this programme showed much positive feedback from both learners and teachers. However, the project which started so well has lost ground; SLED attributes this to a lack of support or follow-up from relevant national and provincial government departments. SLED argues that after initial pilot funding from the Department of Health ran out, no follow-up funding was assigned by either the Department of Health or the Department of Education (Maclons, n.d.).

However, research conducted by the Gay and Lesbian Archives (GALA) in 2005 has, in fact, revealed that deaf learners do not have critical information about HIV/AIDS and sexuality, even in schools that have the HIV/AIDS-related materials developed by SLED (Morgan, 2005).

DeafSA (2006) indicates that the majority of teachers in South African schools for the deaf are hearing and, as yet, no mandate has been set by the

Department of Education to enforce the training of these teachers in South African Sign Language (DeafSA, 2006). As a result, the majority of teachers have no proficiency in SASL. DeafSA (2010) further indicates that the philosophy of total communication is being used in schools and classes for deaf children. This encourages the combined use of whatever communication methods are appropriate to the deaf childlike speech, lip-reading, manually coded speech, finger spelling, mime, gestures, reading and writing. The majority of deaf learners, thus, leave school functionally illiterate and excluded both from tertiary education and from many employment opportunities (DeafSA, 2010).

According to PlusNews (2008), it is stated that the quality of the education is hindered due to a lack of training of teachers, and unwillingness on the part of teachers and schools to provide HIV and sex education. It further states that the shortage of trained teachers may result in just one teacher in a school being able to teach such classes. Teachers, therefore, need to be capacitated by the Department of Education so that when they face learners with such topics, they are in a better position to answer every question posed to them by the learners.

Groce (2003), Principal Investigator for the HIV/AIDS and Disability Survey, published by Yale University and the World Bank, said that one of the main reasons for this lack of outreach for deaf people has been that it was erroneously assumed that people with disabilities are not sexually active and therefore not at risk for AIDS. In an interview with Media Global, Groce stressed that not only is this untrue but also, in fact, people who are disabled are at significantly increased risk of sexual abuse, which then raises their risk of infection. Based on the above argument, men who tested HIV positive wanted to have sex with disabled women and children because they believed that they are virgins and will cure HIV if they sleep with them. This has been a serious myth in South Africa. In support of the latter statement, Madlala (2002) notes that, according to the virgin-cleansing myth in South Africa, a man can cleanse his blood of HIV/AIDS through intercourse with a virgin,

because sexual intercourse with a virgin is thought to provide vaccination against future HIV infection.

Madlala (2002) further states that, men who rape virgins believe that the vaginal passage is seen as being 'sealed off' by the intact hymen which is viewed as a barrier that prevents HIV from getting into the girl's womb and her blood. Additionally, the HIV/AIDS and Disability Global survey have identified numerous reports of rape of individuals who are blind, deaf, physically impaired, intellectually disabled or who have mental health disabilities. These rapes are being perpetrated in the belief that having sex with a disabled individual will transfer the virus from the infected person to the individual with disability. Earl-Taylor (2002) elaborates by stating that individuals with disability are apparently being targeted because they are often incorrectly assumed to be sexually inactive or virgins, hence men who are HIV positive target them to infect them with HIV/AIDS. With proper or adequate information about how HIV/AIDS is transmitted, when faced with the challenges mentioned above, deaf youth can know what to do when they are exposed to these latter dangers.

2.5. GLOBAL APPROACH TO HIV/AIDS EDUCATION AND DEAFNESS

Baker-Duncan *et al.* (1997) state that adolescents' knowledge of HIV/AIDS reveals that high school students who are deaf have extremely limited core knowledge of HIV/AIDS because in most cases when topics about HIV/AIDS are discussed, there are no Sign Language interpreters, whether it is on television or in our communities. This places them at risk of infection as they have limited knowledge about the transmission and prevention of HIV/AIDS.

Peinkofer (1994) conducted a study in New York on HIV education for the deaf. He states that schools for the deaf generally have no specific programmes on HIV/AIDS as part of their health curriculum, and general sex education is also under-emphasized at such schools. Knowledge about

sexuality, HIV/AIDS and methods to prevent HIV/AIDS are important in any community. As noted in a study published by the American Annals of the Deaf (2004), there is a lack of accurate sexual knowledge among youth who are deaf. More than 80% of the respondents in the study confirmed being sexually active (11% claimed to have had 10 or more sexual partners). Only one third of the participating college students reported using a condom during their most recent sexual encounter.

The majority of the students surveyed expressed the belief that having a regular sexual partner eliminated the need for birth control. Studies on adolescents' knowledge of HIV/AIDS further revealed that high school students who are deaf have extremely limited core knowledge of AIDS, tend to be unaware of which behaviours place them at risk for infection, and have limited knowledge of transmission prevention (Baker-Duncan *et al*, 1997). Within the Deaf community, there are numerous social and environmental factors that may influence lack of knowledge regarding sexuality and HIV/AIDS. Many youth who are deaf find few opportunities to acquire information, and encounter inadequate school-based instruction, misinformation from family members and peers, and parental reluctance to provide sexual education (Job, 2004).

Another challenge that these deaf learners are faced with is communication and Csoti (2001) emphasises that communication skills are about being able to pass on information without misunderstanding on either side. Children who do not develop good communication and social skills may have failed relationships that could leave them hurt, confused and feeling bad about themselves. Barriga (2010) argues that because of communication barriers, lack of education, ignorance and fear, deaf people around the world are overlooked by HIV services. Barriga (2010) further states that UNAIDS and the US State Department are taking a first step at addressing this gap by getting policymakers to think about how to make HIV strategic plans, programmes and services inclusive to people with all types of disabilities.

Groce *et al.* (2004) state that there are a number of interrelated reasons for lower levels of access to information and services, for example, deaf individuals who rely on Sign Language as their primary means of communication often face substantial communication barriers. The mass media is largely inaccessible to them; much AIDS information is simply inaccessible because radio campaigns and non-captioned television campaigns rarely reach the deaf and lower literacy results in less recourse to magazines and newspapers. Groce *et al.* (2004) further argue that deaf populations, on the whole, tend to have less access to education than the surrounding hearing population. Even when educated, individuals who are deaf have significantly lower levels of literacy, a circumstance which interferes with their ability to understand AIDS information. Sign Language is rarely used by AIDS outreach workers in the dissemination of AIDS messages and Sign Language interpreters are rarely available in HIV public clinics or testing centers.

Groce *et al.* (2004) further affirm that the information that deaf individuals rely on is often received through an active collection of stories, folklore and rumours commonly found within the deaf population. The deaf grapevine routinely carries and reinforces information - and all too often, misinformation - about HIV/AIDS that is difficult for AIDS experts not fluent in Sign Language to monitor or correct. The issue of knowledge and attitudes towards HIV/AIDS within disabled populations in general and among deaf populations in particular, has not been extensively studied, but it is clear that they are no less at risk for HIV infection than the rest of the population. Yousafzai *et al.* (2004) indicate that findings from qualitative studies in Uganda and Rwanda show that adolescents with disabilities are highly vulnerable to HIV and sexually transmitted infections due to sexual abuse, misconceptions about sexuality and rights and issues of self-efficacy affecting control in relationships.

In summary, sexuality education, when done in schools and taught properly, reflects the needs of the community and acknowledges the value of both abstinence and safer sex as tools to prevent HIV infection. Successful

prevention activities focus on providing access to accurate information and personalizing this information to motivate change and provide training in behavioural skills to build competence, communication and self-esteem.

The UNGASS Country Progress Report (2010) states that although HIV prevalence is much lower in Nigeria than in other African countries such as South Africa and Zambia, the size of Nigeria's population (around 149 million) meant that by the end of 2009, there were almost 3 million people living with HIV. This Report (2010) further states that approximately 192,000 people died from AIDS in 2009. With AIDS claiming so many lives, Nigeria's life expectancy has declined significantly. In 1991 the average life expectancy was 54 years for women and 53 years for men; in 2009 these figures had fallen to 48 for women and 46 for men.

India has a population of one billion, around half of whom are adults in the sexually active age group. In 2008 the figure of the sexually active group was confirmed to be 2.31 million, which equates to an HIV/AIDS prevalence of 0.3%. While this may seem a low rate, because India's population is so large, it is third in the world in terms of greatest number of people living with HIV (UNAIDS, 2008). With a population of around a billion, a mere 0.1% increase in HIV prevalence would increase the estimated number of people living with HIV by over half a million.

With regard to HIV/AIDS prevalence, according to the Mozambique National Strategic Plan (2004), the first case of HIV/AIDS in Mozambique was diagnosed in 1986 in Mozambique. This was followed by a steady increase in the prevalence rate up to an estimated 16.2% among the population aged 15 to 49 years in 2004. In July 2004, the Mozambique Government declared HIV/AIDS a national emergency.

Tanzania, Mainland and Zanzibar reported that the first cases of AIDS were reported in the Kagera region in 1983 and by 1987 every region in the country had reported AIDS cases. It is not clear as to who reported the cases. The HIV epidemic on Tanzania mainland is described as generalised, meaning it affects all sectors of the population. On the semi-autonomous island of Zanzibar the HIV prevalence is far lower among the general population (0.6 percent) and the epidemic is more concentrated, primarily affecting female sex workers, men who have sex with men and injecting drug users (IDUs). The latter statement is based on the fact that, the tendency to have multiple partners, share needles, engage in 'flash-blood' practices, and have unprotected sex place drug users in Zanzibar at high risk of HIV infection (UNGASS/TACAIDS, 2010).

In summary, research is needed to understand the reasons why HIV/AIDS education in schools for the deaf is still not adequate, despite the creation of materials for deaf learners. This necessarily involves understanding the teacher and school related variables that may be hindering the optimal education of deaf learners. It is thus imperative that more research is conducted to determine the extent to which these SLED materials are being put to use by the HIV/AIDS teachers of deaf learners.

2.6. HIV/AIDS EDUCATION AND DEAF EDUCATION IN SOUTH AFRICA

South Africa is a signatory to a number of Human Rights international treaties and conventions. South Africa signed the United Nations Convention on the Rights of Persons with Disabilities in 2006. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (UN Convention on the Rights of Persons with Disabilities, 2006).

Education can play an important role in the global challenge to HIV simply by doing more of what it is doing already and doing it better, and ensuring that all children have access to good quality learning. This is a key conclusion

emerging from a new publication by the UNAIDS Inter-Agency Task Team IATT (2008), that is, the need for one education which explores what is already known and what needs to be learned about expanding the education sector's response to the epidemic.

The IRIN/PlusNews (2008) states that HIV and sex education exist in South African schools as part of the wider Life Orientation curriculum which was implemented in 2002 and also covers subjects such as nutrition and careers guidance. The quality of the education, however, is hindered due to a lack of training of teachers, and unwillingness on the part of teachers and schools to provide this education. Training for Life Orientation for teachers often takes place outside of school hours, which acts as a disincentive to training. The shortage of trained teachers may result in just one teacher in a school being able to teach such classes, and school management could be resistant to what is being taught. This has led teaching unions to call for a Life Orientation module to be included in all teachers' training.

Ahmed *et al.* (2009), states that in one survey, some teachers reported feeling uncomfortable about teaching a curriculum that contradicted their own values and beliefs. Another problem was believed to be the disadvantaged home life of the students, with some teachers believing poor role models at home did not help to reinforce HIV prevention messages received in the classroom. The high dropout rate in South African schools could also compromise effective HIV and sex education; therefore, this could mean it is more necessary to direct prevention programmes towards younger children while more of them are in education and before most are sexually active.

In addition to teachers thinking that HIV/AIDS education is a taboo, in an article by Van Rooyen (2009), it is stated that deaf education in South Africa is failing miserably. Although there are about four million deaf or hard-of-hearing people in the country, Van Rooyen (2009) further states that the

overwhelming majority never make it to matric and only a handful reach university. Storbeck and Henning (2004) reiterate the above statement by stating that the education of deaf people in South Africa has failed to produce pathologists, audiologists, teachers, and parents of the deaf with a clear and cohesive direction for practice. Fitz Gerald *et al.* (2004) highlight that generally sex education is under-emphasized in schools for the deaf.

Poor schooling and a shortage of teachers who can use Sign Language mean that many deaf people have inadequate literacy, according to Manion of Gay and Lesbian Archives (GALA) in an article, Impassioned fighter for 'the devil's people' by Katharine Child (2012). In South Africa a new comic book on HIV/AIDS was launched for the Deaf community in 2006. John Meletse, GALA's deaf outreach coordinator, states that deaf youth are dying and they don't know why. Meletse further said,

“We have realised that the Department of Health doesn't have programmes specifically targeting deaf people with HIV messages, so we started going into communities and doing education. From our conversations with young deaf people, we learned that what little education they had received about HIV and AIDS had not been developed with deaf people in mind and they (deaf people) had difficulty relating to it. A lot of them think of HIV as a death sentence - they don't understand the difference between HIV and AIDS.”

DeafSA in 2007 in a joint monitoring committee meeting on the improvement of quality of life and status of children, youth and disabled persons said that the medical approach used to educate deaf learners in South Africa focuses on speech training and this results in many deaf persons being functionally illiterate; nonetheless, the Department fails to consult and engage sufficiently with the Deaf community. Deaf people are not provided with sufficient opportunities to speak for themselves. Instead they are too often reliant on others who interpret on their behalf. The Federation of Associations of Governing Bodies of South African Schools (FEDSAS) said that the White Paper is being interpreted and applied differently throughout the country and

that educators do not always have the necessary knowledge to teach children with disabilities effectively. This results in social exclusion rather than inclusion of learners with disabilities within the classroom.

The exclusion of learners becomes worrying when one considers that according to Mont (2007) in a document (Policy Brief on HIV and Disability, 2009) produced by UNAIDS working with WHO and the Office of the UN High Commissioner for Human Rights, an estimated 650 million people or 10% of the world's population, have a disability. The relationship between HIV and disability has not received due attention, although people with disabilities are found among all key populations at higher risk of exposure to HIV. According to the UNAIDS, It is further stated that people with disabilities experience all of the risk factors associated with HIV, and are often at increased risk because of poverty, severely limited access to education and health care, lack of information and resources, lack of legal protection, increased risk of violence and rape, vulnerability to substance abuse and stigma.

2.7. COMMUNICATION WITH DEAF YOUTH

There are four communication systems that can be used to communicate with deaf people, like manualism in which Sign Language is used, oralism which uses speech and sound, total communication which uses speech, sound, lip-reading, gestures and manually coded speech and, lastly, there is bilingualism which uses both languages, which are Sign Language and any spoken language, preferably one used at home by a deaf child and his or her family because of the fact that 90% of deaf children are born into hearing families (Storbeck, 2004).

Storbeck (2004) states that total communication reaches the learner through any means or method that is available be it through oral or manual modes, and it improves communication between deaf and hearing people. The issue

of communication is still the challenge deaf youth face when interacting with hearing youth. This becomes a barrier in communication especially for the deaf who depend on appropriate Sign Language to understand what is being communicated. Camm *et al.* (1990) highlight that news broadcasts on television sometimes attempt to teach attitudes and set values by informing youth and the general public about dangerous practices. It is, however, questionable how much of this information reaches deaf people as there is no Sign Language on television for the majority of the broadcasts.

According to Peinkofer (1994), the resources and information about any medical topic can be accessed with ease by the nation's hearing population. Television, books and other mediums bring HIV/AIDS to society's attention, yet many barriers prevent even basic information from reaching the deaf community. Peinkofer (1994) further states that limited access to accurate information about sexuality also puts a deaf adolescent at a disadvantage and, therefore, educators need to explore concepts of sexuality more thoroughly and parents need to foster such discussion at home using the language which can be easily understood by their children. Bares in Gaskins (1999) notes that, as early as 1992, experts estimated that the deaf population was about eight years behind the hearing population in HIV knowledge and awareness, based on the fact that in a risk assessment that was conducted only 15 percent of deaf respondents from the community demonstrated knowledge of HIV transmission facts and also because of lack of communication strategies between the deaf and the hearing population.

Groce (2003) states that sex education programmes for people with disability are rare, and there are almost no general campaigns about HIV and AIDS targeting or including people with disabilities and where AIDS campaigns are on radio or television, groups such as Deaf people and blind people are at a distinct disadvantage. Most of the time there are no Sign Language interpreters for Deaf people to understand and follow what is said. Groce (2003) further stated that currently little is known about HIV/AIDS and disability and very little data on prevalence exists for any disabled population globally. Major gaps in the national HIV/AIDS prevention campaigns and

treatment programmes as indicated by Groce (2003) have made disabled populations more vulnerable to HIV infection than their non-disabled counterparts.

Centre for AIDS Development (2002) attest that exposure to the risks of HIV infection and opportunities for responding effectively to HIV/AIDS have been shown to differ by: locality (rural/urban, urban/peri-urban); socio-economic status; educational level; age; gender; and physical capacities (able-bodied/disabled) amongst other characteristics. In spite of whatever homogenising forces may impact on young people, the mediators which underlie these differences continue to impact in a major way on HIV vulnerability and response.

According to Mancoske *et al.* (2004), the youth can protect themselves from HIV if they are given appropriate information and then helped to develop the skills to use the information. On the other hand, Heutell *et al.* (2001) note that there is apparent lack of accurate knowledge of sexuality among deaf students and they are frequently unaware of or misinformed about HIV/AIDS and how it is transmitted and prevented.

In conclusion, from what has been discussed in this chapter, it can be realised that Deaf people may have misconceptions about any information they receive because of the different language, Sign Language, that they use, which is not generally understood in society. This may be particularly so when they try to get clarity on issues under general discussion like those around HIV/AIDS. Misconceptions may be exacerbated by little or no knowledge of Sign Language by health care professionals who have a responsibility to give health education to patients/clients.

As much as the deaf youth report to be accessing information in different ways, as highlighted by Baker-Duncan *et al.* (1997), which is through conversations and television, there is a risk or a chance that due to language barriers, the deaf youth can be misinformed by the hearing youth. Bat-Chava *et al.* (2005) confirms that there are large disparities between deaf and

hearing individuals' reading and writing levels which can hamper communication. In addition to the possible lack of accurate knowledge, Heutell and Rothstein (2001) state that deaf youth are frequently unaware or misinformed about HIV/AIDS, how it is transmitted and prevented than their hearing counterparts. Based on the large disparities between deaf and hearing youth on accessing information, it is therefore vital to also look at lessons taught at schools in relation to HIV/AIDS.

2.8. CONCLUSION

This chapter presented a background about deafness, HIV/AIDS and how it emanates in the lives of deaf youth and how it impacts on the outlook and perceptions of deaf youth. It is clear from the literature that globally and locally, there is still much that need to be done to ensure that enough information and skills are transferred to the disability sector in general, although for the purpose of the study, with specific reference to deaf youth. Information dissemination and the transference of skills to all role players in schools will ensure that deaf youth are able to respond appropriately when dealing with a number of risks that deaf youth are exposed to, for example, sexual abuse, risky behaviours, etc.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1. INTRODUCTION

This section focuses on research method and design as applied in this study. It also explains the methods used to choose the sample from the target population, data collection methods and the methods used for data analysis. Ethical considerations are also addressed in this chapter, which will include what is right with regard to the participants. Research methodology is concerned with the researcher's goals and general plan to achieve these goals (Burns *et al.*, 2004 & Polit *et al.*, 2001). On that note, the study under investigation seeks to explore the perceptions that deaf youth have about HIV/AIDS.

3.2. RESEARCH METHOD

A qualitative research approach was followed in this study. This approach was relevant for this type of study as it involves the study of phenomena in their natural setting (De Vos *et al.*, 2002). The study took place in a setting known by the participants so nothing was intimidating and participants were familiar and comfortable in the research environment. In addition, a qualitative approach was the most appropriate because it helps to interpret issues and realities linked to the phenomenon as experienced by the individuals under study (De Vos *et al.*, 2002). Therefore, in this study the qualitative approach assisted the researcher in the understanding of a social situation as experienced by the deaf population. Coombes (2001) and Rossman and Rallis (2003) also confirm that the qualitative approach to research aims at getting an in-depth study of the phenomenon under study. Furthermore, Creswell (2003) emphasises that it is important for qualitative research to take place in a natural setting, that is, the researcher needs to go to a site so as to develop the level of detail about the individual or a place and to be involved in actual experiences of the participants.

According to Patton (2002), qualitative research has the following characteristics:

- Qualitative research is concerned with understanding the social phenomenon from the participants' perspectives; in this case the opinions of the deaf youth with regard to their perceptions about HIV/AIDS needed to be understood.
- In qualitative research human actions are strongly influenced by the setting in which they occur; therefore, it is critical to investigate how being deaf youth studying in a Deaf community influences their perceptions of HIV/AIDS.
- Qualitative research has great flexibility in the research process; for example, in this study the researcher had the flexibility to probe by rephrasing questions in order to get a deeper understanding of an issue under discussion.

The qualitative research method involves the study of occurrences in their natural setting, which means it attempts to make sense of or interpret issues or realities linked to such phenomena experienced by individuals in society, and how these shape their existence and outlook on life (Polit & Beck, 2008:17). Accordingly, Denzin & Lincoln (1998) state that qualitative researchers employ a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand. Researchers could blend their observations with the observations provided by participants through interviews and life stories, personal experiences, case studies and other documents (Leedy & Ormrod, 2005). In this study, a qualitative research method was used to investigate the perceptions of deaf youth at two schools for the deaf in the Eastern Cape.

3.3. RESEARCH DESIGN

According to De Vos *et al.* (2003), research design refers to a logical strategy to collect evidence about desired knowledge. A research design involves a clear focus on the following: the research question, the purpose of the study,

deciding on the appropriate information to answer specific research questions, and strategies most effective for obtaining the information (Willis, 2007). Research design situates researchers in the empirical world and connects them to specific sites, persons, groups, institutions and bodies of relevant interpretive material (Denzin & Lincoln, 1998). A research design also specifies how the investigator will address the two critical issues of representation and legitimation (Denzin & Lincoln, 1998, p. 28).

A case study approach is a perfect methodology for this kind of study because, when a holistic, in-depth investigation is needed, case studies give a picture that illustrates relationships and patterns of interaction between variables (Feagin, Orum, and Sjoberg, 1991). Gregan and Kaylor (1999, p. 103) define this approach as taking an in-depth look at an individual in context, in a situation or an intervention, but each case also has a number of elements within it which make up a total picture or a vignette which 'says it all'. Multiple-case studies follow replication logic and therefore serve to strengthen the results by replicating the pattern matching, thus increasing the level of confidence in the robustness of the theory, and each individual case study consists of a "whole" study, in which facts are gathered from various sources and conclusions are drawn based on these facts (Bell, 1992).

Case studies can satisfy the three tenets of the qualitative method: describing, understanding and explaining, and case studies have been used to develop critical thinking (Hesse-Biber, 2004). The quintessential characteristic of case studies is that they strive towards a holistic understanding of cultural systems of actions (Campbell & Groundwater-Smith, 2007). The cultural systems of action refer to sets of interrelated activities engaged in by the actors in a social situation. The case studies must always have boundaries (Cohen & Manion, 2003; Hesse-Biber, 2004). Furthermore, Dawson (2002, p. 139) notes that each case should have enough information in it that the reader can understand what the problem is and, after thinking about it and analyzing the information, the reader should be able to come up with a proposed solution. The multi-site case study was undertaken in two schools for the deaf in the Eastern Cape Province. The determining sampling criterion was to source

deaf youth's perceptions from two different schools in two municipalities in the Eastern Cape Province. Based on the above information, a multi-site case study was more suitable to use in this study as the researcher was studying two cases, looking at a specific school and a specific group of participants, focusing on deaf youth's perceptions with regard to HIV/AIDS. A case study assisted the researcher to explore and develop a rich description of how deaf youth perceive HIV/AIDS.

Case studies are multi-perspective analyses; this means that the researcher considers not just the voice and perspective of the actors, but also of the relevant groups of actors and the interaction between them. This one aspect is a salient point in the characteristic that case studies possess. They give voice to the powerless and voiceless (Cohen, Manion & Morrison, 2003; Davies, 2007). Each individual case study consists of a "whole" study, in which facts are gathered from various sources and conclusions drawn from these facts (Davies, 2007).

3.4. SAMPLING

Trochim (2006) describes sampling as the process of selecting units such as people or organisations from a population of interest so that by studying the sample one may fairly generalize the results back to the population from which they were chosen, while Denzin *et al.* (2000, p. 11) state that sampling is stated as "... selecting a portion of the population in a research area which will be a representation of the whole population." Convenient and purposive samplings were used to select the two schools. Wellman (2005) and Swann & Pratt (2003) define convenience sampling as involving selecting haphazardly those cases that are the easiest to obtain for the sample, for example, geographically or on the basis of accessibility. Denscombe (1998), Bernard (2002) and Given (2008) define purposive sampling as 'hand-picked' for the research and the term is applied to those situations where the researcher already knows something about the specific place or people. Discussions with focus groups were held in both schools and on these two occasions participants were encouraged to interact with one another. Group interaction

enabled participants to share experiences and ideas and allowed their knowledge, perceptions and attitudes to be explored. In addition Smith (2005) cautions that focus groups may be more useful for participants that would be intimidated by a one-to-one interview as some participants feel that they have nothing useful to say.

The Office of the Premier's (OTP) preliminary research study that was aimed at informing the content of the capacitation programmes was undertaken in 2008, and it was found that the deaf learners' perceptions of HIV/AIDS in School B are in conflict with HIV/AIDS facts, for example, it was established in the preliminary research that there were learners who believed that HIV can be transmitted through a mosquito bite (OTP OSDP Research Results, 2008).

The study on perceptions of deaf youth about HIV/AIDS consisted of forty (40) participants who are deaf, twenty (20) from each of the two Municipality districts, namely Amathole and O.R. Tambo district Municipalities. Ten (10) boys and ten (10) girls were randomly selected from each of the districts, ranging from 14-21 years of age. The age of the participants was very important to ensure that participants were able to comprehend the issue under study and be able to respond to the questions. In both schools, participants are accommodated in hostels, where they are under the supervision of housemothers. Before the final selection was done, housemothers were asked to assist in the selection process because they knew the ages of the learners. They were also asked to randomly select the participants without any favouritism. After the housemothers had selected thirty learners from each school, the researcher also confirmed the ages of the participants and also noted that the actual number that was required was twenty. Therefore, learners who were reluctant/didn't want to participate were allowed to withdraw. Ten from each group willingly excused themselves and the required number remained. In line with ethical prescripts all the learners willingly participated and no learner was coerced; as a result the researcher hoped to get rich data from willing participants.

3.5. DATA COLLECTION

For data gathering, focus groups were used in the study. The researcher selected the focus group approach because in trying to collect data that will answer the research questions the researcher aimed to collect rich data from a substantive number of people. The other advantage of focus groups is that it makes participants less anxious as they will not be expected to give answers for every question that is asked. Smith (2005) confirms that focus groups may be more useful for participants who would be intimidated by a one-to-one interview as some participants feel that they have nothing useful to say.

An interview schedule with seven questions was designed. Although there was a list of questions, as aforementioned the questions were open-ended and the advantages, as Ohio Reference Excellence (2000, p. 8) notes, are that "... open-ended questions developed trust, are perceived as less threatening, allow an unrestrained or free response, and may be more useful with articulate participants." Although open-ended questions have advantages, according to Kumar (2011) the disadvantage is that they are time-consuming as the participants also share unnecessary information, for example, in this case, when they were talking about what they do in the hostels.

Gall *et al.* (2003) describe interviews as a way of identifying how people think more openly and accurately than is possible with a questionnaire. Gall *et al.* (2003) further state that interviews allow the researcher to further probe the ways in which people make meaning of things, why they think the way they do and allow them to clarify their meaning. Focus group interviews were, therefore, used as a data collection method as it is the best method when interviewing deaf learners because they will be able to articulate clearly how they feel in their first language, that is, the South African Sign Language (SASL). It can be problematic at times to expect deaf youth to communicate in written language as what they write is not always easily comprehended.

Using SASL, I interviewed the participants personally. While interviewing them, I took notes as they clearly articulated their facts in South African Sign Language. It is much better to use a first language when expressing yourself as opposed to the second language that deaf learners might not understand. I recorded the responses by note taking, writing down each response as given by the participants. While taking notes, I would ask each participant to pause and quickly take notes and continue again. This was done after every response, so as a researcher I could control the process. Due to financial constraints, I could not afford either the video or a person that was going to operate it for me; hence the responses were not video-recorded.

As a trained Sign Language interpreter, I trusted my capacity to interview the participants in South African Sign Language thus I didn't foresee any challenge that could impede the proceedings. All the participants were deaf and felt comfortable in being addressed in their first language.

3.5.1 FOCUS GROUP INTERVIEWS

Morse (2002) defines focus groups as a special type of group interview where, rather than the researcher asking each person a question in turn, the group members are encouraged to interact with one another, with the researcher simply acting as the facilitator. This group interaction enables participants to share experiences and ideas and allows their knowledge, attitudes and behaviour to be explored; the resulting data may be more useful than that collected through one-to-one interviews (Bowling, 2002).

Before the focus group discussions/interviews the researcher emphasised that it was important for the participants to present their true opinions and not to conform to what they think is perceived as normal/acceptable by other participants and by the researcher. The researcher also ensured that all the participants in the group were participating and no participants were allowed to dominate the discussion so the researcher ensured that quieter members were encouraged to participate.

As suggested by Mudhara (2004), focus group interviews entail the researcher introducing the subject, guiding the discussion, cross-checking comments and encouraging all members to participate. The researcher also described the outline of the study and the concept of a focus group, encouraging participants to speak to one another rather than the researcher. Then, the researcher introduced the questions to the group and ensured that the conversation was balanced and the participants stayed focussed on the topic at hand and did not spend too long on any particular point. The topic was so interesting to the participants that they went as far as diverting from the point under discussion and the researcher had to continuously remind them about the point of focus. As much as the researcher would have been tempted to participate, the researcher was conscious that her main role was the one of presenting questions, probing for further clarity and for challenging what was being said and to encourage further debate. Denscombe (1998) suggests that probe follow-ups be used for the purpose of encouraging the participants to elaborate more so as to enable the researcher to understand the participants' feelings, thoughts, intentions, meanings and recollection of past experiences. The questions posed were open-ended and all the questions posed were directed to all the participants, that is, a question would be asked and a discussion around that question would ensue.

Wisker (2001) encourages the use of open-ended questions and notes that these questions manage to address the need for comparable responses, that is, there are the same questions being asked of all the participants. The same interview schedule was used in both schools (refer to Appendix E). Morse *et al.* (2002) outline the following advantages of open-ended questions: help obtain relevant information of the subject under study, give the freedom to explore general views or opinions in more detail, can use an external organisation so as to retain independence, and can be used for sensitive topics. Additionally, McNamara (2007) states that open-ended questions tend to achieve greater response from the participants. Open-ended questions, according to Compton (2005) & Lichtman (2006), allow participants to introduce unique thoughts and encourage elaboration, as a result of which participants were free to come up with their thoughts without fear, considering

that HIV/AIDS is a sensitive topic. The researcher was, therefore, able to collect subjective information from the participants by using the knowledge gained through personal involvement and interaction with the participants.

This study made use of a semi-structured interview as Smith (2005) states that an unstructured interview is concerned with the way people think and feel about the research topic in question. Morse *et al.* (2002) note that semi-structured interviews are used when the researcher knows most of the questions to ask but cannot predict the answers. They ensure that the researcher will obtain all the information required without forgetting a question; at the same time, it gives participants freedom to respond. The semi-structured interview allowed the researcher to further explore issues raised by the participants without losing sight of the study purpose which is to explore the perceptions that deaf youth have about HIV/AIDS. Participants are also allowed to answer the question in any way and Kumar (1999, p. 48) attests this by saying, "... open ended questions are good for obtaining opinions, attitudes and perceptions, they provide a more holistic, in depth view of a situation." The participants were, therefore, allowed to express their views freely without limiting them in what they had to say and that provided a lot of information. In cases where participants deviated from what was asked, I ensured that I brought them to the key question by rephrasing the question.

During the focus groups discussions participants did not give one answer. At times and to regulate the debate/discussion the researcher encouraged the participants not to speak, however, there were times when the participants would have a heated debate but the researcher regulated the discussions. It was also evident that some of the opinions shared were mainly influenced by gender, as boys would hold different opinions to girls and vice versa.

As the responses were recorded through note taking, before the data was analysed the researcher wrote down (transcribed) the participants' responses and called a meeting with all the deaf youth that participated in the focus group interviews and presented their responses to check if the responses

were captured correctly. The participants confirmed that those responses were a true reflection of their responses.

3.6. DATA ANALYSIS

A number of authors define data analysis as making sense of accumulated facts or information the researcher has collected from the field (Merriam, 2001; Vithal & Jansen, 1997, p. 27). The researcher analyzed the data according to Babbie & Mouton's technique, which is conducted as follows:

- firstly, the details of the data are organized in a logical order according to the research questions,
- secondly, specific meanings of the data collected are examined and categorised as related to the research questions,
- thirdly, in search of patterns that the data reflected, the data is scrutinized and grouped into themes, and
- fourthly, as patterns are identified, the conclusions from the emerging themes are drawn (Babbie & Mouton, 2004, p. 178)

Cresswell (2003) notes that the data analysis technique mentioned above constitutes content analysis and entails developing some manageable classification. Merriam (2001, p. 145) further defines data analysis as a complex process that involves moving back and forth between concrete data and abstract concepts, between inductive and deductive reasoning, between description and interpretation. Patton (2002, p. 463) maintains that raw data in the form of field notes and verbatim transcripts constitutes the undigested complexity of reality.

Based on the above evidence, first the researcher familiarised herself with the data and then picked up words that the respondents frequently used, also looking for similarities and differences. The researcher looked for nouns that were repeatedly used and that seemed to express an idea or feeling. The researcher used colour-coding to identify themes. After coding, the researcher

grouped the participants' responses under each interview question. After grouping them, the researcher was able to put them into categories, which developed into themes, that is, knowledge about HIV/AIDS; access to information; lessons taught at school; peer views in relation to HIV/AIDS; social impact; ways to prevent infection and use of condoms. The mentioned themes informed the flow of discussion in Chapter 5.

3.7. ETHICAL CONSIDERATION

After the research proposal was approved by the ethics committee (2010ECE190C), the process of requesting access to use the schools as research sites began. To access the schools to do research, the researcher wrote a letter to both the Provincial Education Department and the District Director's office to gain approval (refer to Appendix F), thus ensuring that all protocols were observed. Only after their permission was granted did the fieldwork ensue (refer to Appendix G and H). Letters requesting permission to do research in the schools were sent to the school principals giving full details of the purpose, methodology, significance of the study and an estimated time of completion (refer to Appendix A and B). Principals in both schools gave consent as the participants are entrusted to them by their parents, since both schools are boarding schools.

The researcher visited each research site twice; the first visit was for the introduction of the study to the participants, and the clarification of the purpose of the study, the format in which the data will be published and the administration of the actual focus group interviews. The second visit was for the confirmation of the transcribed notes.

Issues of anonymity and confidentiality were also discussed with them. Because the study was used for academic purposes only, the confidentiality of participants was ensured. I informed the participants that their names would not be mentioned, their consent forms were not going to be published and pseudonyms would be used when transcribing the data. The researcher informed the participants that participation was voluntary and they had a right

to withdraw at any time without the fear of being penalized. As a result, by show of hands, some of the learners withdrew (n=10) and the rest remained (n=20). In addition, the researcher informed all participants that the transcribed information from the focus group interviews would be returned to them for verification.

To ensure that the ethical requirements were met, after the group selected by the housemothers was informed about all the ethical rights and those not interested in participating were released, the researcher gave the participants consent forms to complete. The researcher was well aware that, ideally, the forms were supposed to be signed by the parent; however, in the case of the sampled schools, learners stay in a boarding school and go home during school holidays. This was discussed with the school principals as the trustees of the learners during their stay in the boarding schools and the principal gave permission that learners could complete the forms.

Lastly, letters of consent (see Appendix C) were given to the participants to give consent to all ethical issues, such as anonymity and confidentiality that may be relevant (Henning *et al.*, 2005). Cresswell (2003) states that informed consent is a mechanism for ensuring that people understand what it means to participate in a particular research study so they can decide in a conscious, deliberate way whether they want to participate or not. Informed consent is one of the most important tools for ensuring respect for persons during research. Anonymity and confidentiality were guaranteed by ascertaining that the signed consent forms were treated with the utmost discretion. The researcher remains accountable for the ethical quality and should take great care and when in doubt seek advice (Henning, 2004).

In this chapter the research method used in the research design, the sampling process and data collection were discussed and justified. The results of the data collected through the interviews will be analyzed and interpreted in Chapter 4.

CHAPTER FOUR

DATA PRESENTATION

4. 1. INTRODUCTION

This chapter presents and analyses the data of this research study. The chapter is divided into seven main sections which are divided according to themes. The themes are: biographical data; knowledge about HIV/AIDS; access to information; lessons taught at school; peer views in relation to HIV/AIDS; social impact; ways to prevent infection and use of condoms.

4. 2. PROFILE OF RESEARCH PARTICIPANTS

From the 60 learners that were selected by housemothers (30 from each school), 10 from each school withdrew and a number of 40 learners (20 learners from each school) agreed to participate. The profile of participants is as follows, from:

School A: From a rural area, four boys and three girls participated, from a farm area (land/area owned by one person) two boys and four girls participated and from urban areas three boys and four girls participated.

School B: From a rural area, five boys and two girls participated, from a farm area two boys and four girls participated and from urban areas two boys and five girls participated (See Figure 5 below).

Figure 5: Profile of Research Participants

BUFFALO CITY METRO MUNICIPALITY	SCHOOL A		SCHOOL B		TOTAL
	BOYS	GIRLS	BOYS	GIRLS	
RURAL	4	3	5	2	14
AGES	14-19	16-18	15-19	18-21	
FARM	2	4	2	4	12
AGES	16-17	15-20	17-18	19-21	
URBAN	3	4	2	5	14
AGES	19-21	16-20	14-16	15-20	
TOTAL	9	11	9	11	40
GRAND TOTAL	20		20		40

Out of forty participants interviewed, thirty five were deaf and five were hard of hearing. All participants use South African Sign Language when communicating with one another at school. Some of the participants use Total Communication at home when communicating with their siblings as their siblings are hearing, with the exception of only three participants who also use Sign Language at home because their parents are also deaf.

4.3. DATA PRESENTATION

To understand the perceptions of deaf youth in relation to HIV/AIDS, issues related to level of knowledge about HIV/AIDS (general and school taught), access to information and peer views with relation to HIV/AIDS, the questions and responses below share a light.

4.3.1. LEVEL OF KNOWLEDGE ABOUT HIV/AIDS

In order to get the deaf youth's level of knowledge about HIV/AIDS, questions asked were meant to understand the participants' general knowledge and the knowledge that was gained from school.

4.3.1.1. Participants' general knowledge

To be able to understand the learners' perceptions it was critical for the researcher to first establish the deaf youth's level of knowledge in relation to HIV/AIDS issues, thus the participants were asked to share what they know about HIV/AIDS. To establish their general knowledge, the following question was asked: **What do you know about HIV/AIDS?** The participants gave the following responses:

Bonga said, "One gets infected by using one's toothbrush or sharing spoons."

Winiwe said, "One also gets infected if she used the same toilet used by an HIV positive person."

Ziyanda supported the latter participants by saying, "I also know that."

Some participants shared that the first thing that comes to their minds when asked about HIV/AIDS transmission is sex. In verbalising that, the participants' responses were as follows:

Bongiwe said, "People always get HIV from sex."

Lindiwe supported Bongiwe's perception by saying, "Yes, that's true."

Zandile further added, "Sex is dangerous."

Buntu said, "One gets infected when he/she is having multiple partners."

Thando emphasised the latter point by saying, "There is no other way you can get AIDS unless you have sex."

Other participants argued that HIV is not only transmitted through sex and mentioned various ways in which it can be transmitted.

Monwabisi said, “I heard that AIDS comes from monkeys.”

Samora said, “I don’t know that a person like me can get HIV.” I asked her what she meant, she replied, “I am beautiful and I am deaf. I have only seen ugly people infected with HIV.”

Hlomla argued that AIDS is not only transmitted through sex. He further said, “I know that if you touch another person’s blood you can be infected.” In addition, Nwabisa shared that, “People get HIV from unprotected sex and it makes them lose weight, lose their hair, become weak and lose appetite, at the same time.”

It is clear that most participants who responded to the questions have little or incorrect knowledge about HIV/AIDS, that is, statements like people can be infected by sharing toothpaste, toothbrushes, spoons and toilets are incorrect as far as HIV transmission is concerned. The emphasis that HIV can only be transmitted through sex shows that the participants have a slight understanding of HIV transmission because there is evidence that people can get infected through other ways, e.g. through breastfeeding; being exposed to the virus as a foetus or infant before or during birth; use of or contact with infected blood or blood products, etc. Harper (2010). Although not all the opinions shared above are true in terms of HIV transmission, for example, getting HIV/AIDS from monkeys and only ugly people get HIV/AIDS, it is evident that some participants have correct information with regard to HIV transmission, that is, HIV can be transmitted through unprotected sex and through contact with blood.

4.3.1.2. Knowledge gained from school

In order to understand the extent to which HIV/AIDS issues are taught at school, I asked the participants about the lessons that are taught at school in relation to HIV/AIDS. The question was also asked in order to establish if lessons taught at school have an impact on the participants’ perceptions. The question was: **At school, what have you been taught, if anything, about HIV/AIDS and sexually transmitted diseases?** The participants gave the following responses:

Siphokazi said, “We are not taught in depth about HIV and sexually transmitted diseases.”

Bayanda said, “In class we are not taught about HIV/AIDS.”

Mongezi and Nozipho concurred with the latter participant while Sabelo and Zukiswa said they are not taught at all. In explaining this Nozipho said, “We are not taught at all about HIV and sexually transmitted diseases at school.”

Inathi reported that, “Mam Daweti* said one can be infected with HIV if bitten by a mosquito.”

Siyabulela and Nomsa confirmed what Inathi had reported about the teacher (Mam Daweti*).

Participants also stated that more emphasis is on religion in their school, HIV/AIDS is not prioritised. To explain this, Phakama said, “We are taught Christianity in depth not HIV.”

Isivile added that, “HIV is just mentioned in passing, but if you can ask me about Christianity and being the child of God, I can clearly tell you.”

In explaining the extent in which religious education was prioritised over HIV/AIDS education, Isivile said, “We are taught Religious Education more than Life Orientation.”

I further probed the participants on what could be the reason why teachers emphasised religious education more than HIV/AIDS education, Bulelwa said “We think they are afraid that if they talk about HIV/AIDS, it would mean that they are encouraging us to have sex.” Inam also supported what Phakama was stating by saying, “They think we will practise it.”

The responses above indicate that HIV/AIDS education is not taught/not taught in depth in the schools. It is notable that teachers can also share incorrect information with learners with regard to HIV/AIDS, for example, HIV being transmitted through mosquito bites. Furthermore, it was also clear that religious education was given priority over HIV/AIDS education or rather Life Orientation. Participants also noted that the reason for the over-emphasis of religious education over HIV/AIDS education could emanate from fear that

learners might misinterpret such lessons as giving an impression that learners can have sex.

4.3.2. ACCESS TO INFORMATION

In order to understand if participants had access to information with regard to HIV/AIDS, the question posed to participants was: **How do you access information about HIV/AIDS?** The participants noted the following:

Isive said, "I only get HIV/AIDS information from friends and family members."

Inam said, "I only get information when we talk amongst each other, I mean hearing friends, who can use sign language to explain things."

Phakama said, "I only learn from TV, TV tells us a lot."

Bulelwa said, "I get HIV/AIDS knowledge from television and adverts, although at times we don't understand what they are saying."

Sisipho confirms the latter response by saying, "Sometimes we see pictures of sick people and condoms."

Hlomla said, "Stories like Soul City and Dynamite Diepkloof Dudes teach us about AIDS but I sometimes I do not understand what they say on TV."

Abongwe said, "I just see words written HIV/AIDS and do not follow at times."

In the course of the discussions, condom usage kept on coming up many times. The researcher noted that although not directly linked to the study, these issues raised could possibly reveal issues related to access to information. In addition, although not directly said in words, choosing to use a condom could imply that a person knows something (has information) about HIV/AIDS. Amongst the probing questions that were asked are the following: **What are the preventive measures you would choose? How accessible are condoms to you as the youth?** Amongst many things that participants said about condoms with regard to the above questions are the following:

Zikhona mentioned that, "Condoms supplied by the government break."

Noncedo said, "Condoms supplied by the government are not of good quality, they break."

Malakhiwe stated that “In our school, condoms are not easily accessible.”

Mcebisi further stated that, “Condoms are not easily accessible in our school because we have to go to the nurse’s room to take condoms, even though we don’t ask for them from her. The nurse can see you when you take the condoms and one prefers not to take them. They are not put in bathrooms, for example, where no adult would see who takes how many, when, and comes back again for more.”

However, Songezo noted that in their school condoms are easily accessible and there is privacy. He said, “Condoms are put in a shelf in the passage and so no one sees us when we take them.”

It is clear from the participants’ responses that friends, family and the media (television through short stories) are the main sources of information although what is communicated in the media is not always comprehensive. The critique on the quality of condoms supplied by government could mean that participants have some kind of information with regard to the role of condoms in HIV prevention; therefore, the condoms that break could expose them to HIV infection, thus the critique. The argument around accessibility of condoms in the schools and the learners’ willingness to take them when they are not seen by teachers could mean that participants have information about how condoms can prevent HIV transmission.

4.3.2 PEER VIEWS IN RELATION TO HIV/AIDS

It was also important to investigate how peer views influence the participants’ perceptions and to establish that the following questions were asked: **Why do you think it is important for you and your friends to talk about the topic of HIV, AIDS or STD in your conversations? If you adopt preventive measures, how would your partner or your friends react?** In answering such questions, the participants gave the following responses:

Nomsa said, “We talk about sex not HIV/AIDS,” while Abongwe said, “We avoid talking about HIV/AIDS.”

Inathi said, “Sometimes when it comes up, when I talk about it, some of my friends think I am infected or they think a member of my family is infected and they gossip about me, thus causing tensions amongst us, so I choose to avoid the topic.”

Siyabulela said, “When the topic about HIV/AIDS comes up, I don’t want to express how I feel in front of my friends and, as such, I don’t engage in discussion when the topic comes up.”

Unam, one of the participants, relayed a story about a classmate who once attempted to commit suicide in the school hostel because other learners were making a mockery of her being HIV positive as she was losing weight. In narrating the story, Unam further said, “I reported that to the principal and the hostel matron.”

The responses listed above indicate that participants are afraid of being ostracised/socially isolated by other learners if they choose to disclose their HIV status, thus in avoiding talks about HIV/AIDS they rather settle on talking about sex in general. Participants also revealed that exposure to stigmatisation can also lead to prevalence of suicide.

4.4. CONCLUSION

The above mentioned findings reveal the following perceptions:

- Participants have little and incorrect knowledge about HIV/AIDS.
- HIV/AIDS education is not taught in depth in schools.
- Some teachers share incorrect information with regards to HIV/AIDS.
- Religious education is given priority over HIV/AIDS education for fear that learners might misinterpret HIV/AIDS education as a licence to be sexually active.
- Friends, family and the media are the main sources of information dissemination with regard to HIV/AIDS.
- Participants seem to have some kind of information with regard to the necessity of using condoms for HIV/AIDS prevention.

- Participants are reluctant to talk openly about HIV/AIDS to their peers for fear of being ostracised.
- Being stigmatised or ostracised can result in people committing suicide.

It is clear from the above mentioned findings that the participants have limited or insufficient insight or awareness with regard to HIV/AIDS. It could also be deduced that the sampled schools and the media are not making much impact as far as teaching the deaf youth about HIV/AIDS. Lastly, the fear of being stigmatised or ostracised is causing the deaf youth not to talk openly about HIV/AIDS and exposure to stigmatisation can also lead to suicide.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.1. INTRODUCTION

This chapter presents a discussion of the main findings of the study and the findings will be discussed under the following topics: knowledge levels about HIV/AIDS; the role of the schools in teaching about HIV/AIDS; access to information and the social impact of HIV/AIDS on deaf youth.

5.2. DISCUSSION OF MAIN FINDINGS

5.2.1. KNOWLEDGE LEVELS ABOUT HIV/AIDS

According to the research findings the participants have little and incorrect knowledge about HIV/AIDS. Heutell and Rothstein (2001) confirm that there is an apparent lack of accurate HIV/AIDS knowledge among deaf students and, furthermore, that it is not only a South African problem but is an international challenge. Heutell and Rothstein (2001) also note that this chronic lack of information has to do especially with how HIV/AIDS is transmitted and prevented.

As uttered by the participants, statements like HIV is only transmitted through sex and mosquitoes and that it only affects ugly people confirms what Heutell and Rothstein (2001) say that deaf youth have wrong or limited knowledge about HIV/AIDS. These unfounded opinions about HIV/AIDS (mosquitoes being transmitters of HIV and HIV infecting only ugly people) are called myths and Theron (2005) and Leopeng (2004) note that due to inadequate information people tend to believe in a number of myths in relation to HIV/AIDS, for example, the belief that being HIV positive is a judgment on immoral behaviour; HIV comes from baboons; HIV is developed by whites to kill blacks or sex with a virgin will cure them.

The revelation that there is little and incorrect knowledge about HIV/AIDS exposes a need directed to both schools and broader communities to close the knowledge gap.

5.2.2. THE ROLE OF THE SCHOOLS IN TEACHING ABOUT HIV/AIDS

The study findings revealed that HIV/AIDS education is not taught in depth in schools. Morgan (2005) cautions that, even in schools that have HIV/AIDS related material developed by a curriculum development organization specializing in Sign Language Education, deaf learners in such schools also do not have critical information about HIV/AIDS and sexuality. To remedy the above mentioned problem (teachers not offering in-depth HIV/AIDS education) Corbett (2007) states that it is important to ensure that HIV/AIDS issues are incorporated in the curriculum.

In addition to not offering in-depth HIV/AIDS education, participants also reported that some teachers share incorrect information with regard to HIV/AIDS. The learners report that a teacher once said, "HIV could be transmitted through a mosquito bite." This is also confirmed by Rauf's (2010) research study that discovered that 74% of Rauf's participants feared that they could acquire HIV if a mosquito bit them after biting an HIV-positive patient. If teachers as transmitters of knowledge are also not well capacitated with HIV/AIDS related issues, there is a risk that, instead of empowering learners about HIV/AIDS, they can instead be the ones sharing wrong information with learners. Because teachers are seen as authority figures by learners, learners can end up believing what teachers are saying without question.

The participants revealed that religious education is given priority over HIV/AIDS education for fear that learners might misinterpret HIV/AIDS education as a licence to be sexually active. Sipalan and Majawat (2009) confirm that the issue of sexual education is seen as a taboo in schools and that is not only evident in Christian schools but also in other religious sectors

too, for example, in the Muslim schools, Malaysia and North Western communities. Mahabeer (2008) also notes that stigmatization and secrecy around HIV/AIDS issues is not only a taboo to teachers but to parents too. Job (2004) highlights that parents of deaf children are also often of the belief that the responsibility for sex education lies with the school, as a result of which they are reluctant to talk about it. Skuy *et al.* (1995) explain that this reluctance stems from a number of issues, which include that discussions around sex have to be graphic and explicit considering the fact that 90% of deaf children are born to hearing parents. Delius *et al.* (2001) also confirms that the majority of hearing parents cannot communicate with their deaf children and, like parents of hearing children; they also believe that talking about sex with their children will lead to sexual experimentation. Campbell *et al.* (2005) cautions that the secrecy about sexual issues and HIV/AIDS often encourages children to seek information about sex from less informed friends and people within their community, who could often then share incorrect information.

From the discussion above it is clear that non-prioritisation of HIV/AIDS education by teachers, teachers' negative attitude towards HIV/AIDS education and their inadequate knowledge with regard to HIV/AIDS are the challenges that are causing HIV/AIDS education not to be offered the way it should be. This shows that there is a need to change the teachers' attitudes, to revisit the curriculum and to capacitate teachers.

5.2.3. ACCESS TO INFORMATION

Research findings revealed that friends, family and the media are the main sources of information dissemination with regard to HIV/AIDS. With regard to the media, that is, short TV stories about HIV/AIDS, the challenge is that some of these stories do not have subtitles; as a result deaf learners only see pictures and may not understand what is being said. The advantage is that these stories are shown at 7pm when participants are already in the hostels where they are able to watch them.

With regard to friends and hearing siblings communicating HIV/AIDS information with deaf youth, it is important to note that that can also pose a risk because Dolnick (1993) says that there are large disparities between deaf and hearing individuals' reading and writing levels which can hamper communication. There is a potential risk when non-disabled people who are not competent in using Sign Language communicate issues around HIV/AIDS because there is a chance that distorted messages can be conveyed. The National Department of Health Report (17 January 2011) further confirms that disabled people are more likely to be illiterate than non-disabled people and are often denied access to education and discriminated against so the chance of them relying on non-disabled people for information is increased. As much as it is not totally wrong for non-disabled people who are not competent in using Sign Language to share opinions about HIV/AIDS information with deaf youth, such engagements cannot always be encouraged, more especially if there is a high risk that information can be distorted.

Although research findings revealed that deaf youth rely mostly on friends, family and the media for HIV/AIDS, it was also evident that participants had some kind of information with regard to the necessity of using condoms for HIV/AIDS prevention. Although participants noted that their schools make condoms available to learners, they did not openly take them but they were taking them in secret to protect themselves against HIV. Although the participants have some kind of information about the importance of condom usage, the data also reveals that deaf youth do not have deeper knowledge about HIV/AIDS related issues and the importance of having protected sex as certain participants noted that they will use condoms if the government provides them with Lovers Plus condoms as they don't feel the enjoyment with Choice condoms, the ones that are currently provided by the government. A number of writers also confirm a number of misconceptions about free/cheap products (Muheua, 2007, p. 51, Rigillo, 2009 & Goraseb, 2006). It is clear that although that are channels on which deaf youth rely for information, that is, hearing friends and siblings and the media (television), it is evident that such sources of information are not met without challenges as a number of communication barriers could be experienced. Although one

cannot discourage deaf youth from using the latter information channels, it is critical to be reminded that such channels are not always reliable; therefore, there is a need for more effective communication channels and programmes to ensure that deaf youth receive appropriate and reliable information.

5.2.4. THE SOCIAL IMPACT OF HIV/AIDS

According to Aronson (2010) social impact defines a result of an activity on the composite demographics of a defined area of the community and the well-being of the individuals and families. Furthermore, Aronson (2010) also notes that it is equally important to explain the social meanings that people attach to those results. In the case of the social impact of HIV/AIDS on deaf youth, the participants revealed that deaf youth are reluctant to openly talk about HIV/AIDS to their peers for fear of being ostracized, stigmatized or isolated by their communities. Peers play a critical role in the lives of learners, thus in certain schools the concept of peer educators is encouraged. In support of the above, Kempe (2003) notes that it is necessary to have such programmes in schools so that deaf youth can be positive role models for one another and they are also more likely to change their behaviour if they observe peers whom they like and trust to change their behaviour.

Campbell *et al.* (2002) define a peer educator as a student who is a leader and role model to fellow students regarding living responsible, healthy lifestyles. Furthermore, a peer educator is a student who other students can feel comfortable talking to about personal issues in order to get the help/services that they need (Mukoma, 2001). A number of scholars (Dube and Wilson, 1999; Kaya and Mabetoa, 1997 & Mukoma, 2001) believe that peer education and support can be especially effective among adolescents because friends are their main sources of information about sexual practices, and peer influence often motivates their behaviour. The studies above note that the underlying messages of peer education built into the activities were to postpone sexual involvement, to use condoms if sexually active, and to

promote respectful relationships and communication about sex and HIV. Another message was that sex was not the only way to show love and caring (Borgia, Marinacci, Schifano & Perucci, 2005; Cartagena, Veugelers, Kipp, Khishgee & Laing, 2006; UNICEF, 2002). The other positive thing about peer educators is that young people feel free to ask questions on taboo subjects, such as sex, and are able to discuss without the fear of being judged and labelled and can discuss issues that are difficult to discuss with adults and they gain insights through mutual sharing of experiences, knowledge and information.

Visser *et al.* (2004) summarized the advantages of peer education and support as follows:

- Adolescents are more likely to discuss openly sexual practices with their peers than with adults whom they regard as authority figures.
- Knowledge and experiences can be shared in a language understandable and accessible to young people.
- Adolescents identify with and can be positive role models for one another. They are also more likely to change their behaviour if they observe liked and trusted peers changing their behaviour.
- Group discussions and debate can contribute to the development of new collective norms of behaviour and relationships
- Young people are recognised as partners in solving problems. Increased youth participation in decision-making contributes to their taking ownership of their own health and taking the initiative to address some of the problems they experience. This contributes to higher levels of empowerment.
- Peer education and support can improve relationships and the climate in a school.

Kirby *et al.* (2006) note that the effectiveness of peer education programmes and support in an HIV context was illustrated in a variety of studies and proved to contribute to higher levels of knowledge, change attitudes and self-efficacy.

In the two schools under study, the data indicates that discussions about HIV/AIDS are seldom held because participants stated that they don't want their peers think that they are affected by or infected with HIV/AIDS. Anthony (1992) affirms the above statement by saying that misinformation, gossip and hearsay travels quickly within the Deaf community and those who are anxious about topics such as HIV transmission will tend towards rumour promulgation. Rumour promulgation does not happen only among the Deaf community. Aggleton *et al.* (2005) in their study on HIV Related Stigma and Human Rights Violations state that participants mentioned gossip, verbal harassment or ridicule, and ostracism as frequent community responses to HIV. People used the words "scorned" and "shunned" to describe community responses, and described HIV as a "taboo" (Aggleton *et al.*, 2005). A participant in Aggleton's (2005) study discussed what happens when a person's HIV status is disclosed noting that: "they talk down", "the talk goes around the community". As a result, people living with HIV have particular fears about disclosure and knowing whom to trust. Gossip enforces a silence around HIV. Aggleton *et al.* (2005) further state that one Ethiopian man explained how gossip creates a situation in which people will not disclose their status to anyone, thus HIV remains invisible.

The study findings also revealed that being stigmatised, ostracised or isolated by his/her society can result in people committing suicide. Although the study participants didn't report that they were HIV positive, the UNAIDS (2000) study reports that HIV positive learners are also ostracised or stigmatised to an extent that some learners decide to commit suicide. Khumalo (2008) confirms that a hearing woman in the Gauteng province killed her four children before committing suicide because a rumor that she was HIV-positive led to her being abused and isolated by her society. This confirms the notion mentioned in 5.2.2 that HIV/AIDS is a taboo and communities are not supportive to people infected and affected by HIV virus. The National Department of Health report (2011) stated that by virtue of being people with disabilities, stigma expose them to suffer from all kinds of victimization, that is, for being disabled and for being HIV positive.

UN Secretary-General Ban Ki Moon (2008) says stigma remains the single most important barrier to public action and that is a main reason why too many people, including people with disabilities, are afraid to see a doctor to determine whether they have the disease, or to seek treatment. Brady *et al.* (2011) explained that a stigma helps make AIDS the silent killer because people fear the social disgrace of speaking about it or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world and in pursuit of the latter, stigma not only makes it more difficult for people trying to come to terms with HIV/AIDS and manage their illness on a personal level (Burki, 2011). In the light of the above, the stigma associated with HIV can also make deaf youth reluctant to access HIV testing, treatment and care.

The research finding is that deaf youth are reluctant to talk about HIV/AIDS as talking is viewed as a social taboo and therefore could possibly expose them to stigmatization/social isolation and self-harm (suicide). The above mentioned finding indicates that there is an urgent need to open platforms for debate about HIV/AIDS for deaf youth, their communities and the country at large.

5.3. CONCLUSION

The findings reveal that deaf youth perceptions around HIV/AIDS reflect misinformation around HIV/AIDS. This chapter argued that there is an urgent need for HIV/AIDS education programmes to be appropriately incorporated in the school curriculum, and the people responsible for these programmes, that is, teachers, must have adequate knowledge and capacity to teach deaf youth in ways that will not distort the information given to them.

In as much as no interviews were made with educators because the main focus was on the learners, it is also evident from what has been said by participants that it is likely that teachers from the two participating schools have inadequate knowledge about HIV/AIDS education, thus participants do not have proper information in relation to HIV/AIDS. As previously mentioned,

DeafSA (2006) also confirmed that one of the reasons deaf children do not have proper information about HIV/AIDS is because the majority of teachers in South African schools for the deaf are hearing and are not proficient in South African Sign Language. That is also caused by the fact that they are sent to schools for the deaf if there are vacant posts without being trained in Sign Language, and when they are already in schools no formal training takes place. Educators end up teaching learners using Signed English/isiXhosa which confuses or which does not add any meaning to deaf learners in terms of accessing relevant information about HIV/AIDS.

CHAPTER SIX

RECOMMENDATIONS AND CONCLUSION

6.1. INTRODUCTION

This chapter summaries the recommendations that could assist in changing the perceptions of deaf youth with regard to HIV/AIDS and in ensuring that the information given to them is reliable and adequate as that could assist them to conduct themselves in ways that could save them from the scourge of HIV/AIDS.

The recommendations pull together the study as a whole, with the aim of giving practical ways in which the Deaf Education community can tackle this large challenge. The recommendations are also aimed at drawing the attention of the Eastern Cape Department of Education and the Department of Health to the importance of taking cognisance of the education of deaf learners and in order for them to investigate the impact of HIV/AIDS on the education of deaf learners. The recommendations will be classified in term of crucial issues that were picked up as the discussion unfolded.

6.2. RECOMMENDATIONS

6.2.1. Recommendations for knowledge improvement

As it became obvious during the course of the research study that there is a serious lack of adequate and reliable knowledge about HIV/AIDS by deaf youth, it is clear that that there is an urgent need to intensify capacitation of deaf youth about HIV/AIDS by both schools and communities. This capacitation process demands that the DoE, schools, teachers, deaf youth and parents must actively participate. With regard to what DoE can do to improve the deaf youth perceptions about HIV/AIDS, it is important for the DoE to consider that Sign Language should be introduced in mainstream schools so that friends and hearing siblings are able to communicate with

their deaf friends, sisters and brothers. It is notable that this study is not focusing on the mainstream; however, it is also important to highlight the importance of introducing Sign Language in mainstream schools. If Sign Language is introduced in mainstream schools, that will make it possible for hearing siblings to communicate properly with their deaf siblings. This will also enable the deaf siblings to access information with regard to HIV/AIDS from the hearing sibling in a language that they understand, without assuming what is being said. The onus is, therefore, on the Department of Education to infuse Sign Language as one of the languages taught in mainstream schools. It is also very important for deaf people who have undergone training and who have specialised in deaf Education and DeafSA to play a major role in the development of the education material, by so doing assisting the Department of Education in understanding the adaptations needed in the day to day teaching and assessment of deaf learners.

The study findings reveal that there is also a need to capacitate teachers on HIV/AIDS related issues. Compulsory training on HIV/AIDS issues and new developments in deaf Education should be given to all teachers by the Department of Education, which will enable teachers to be fully informed and confident about the subject they offer. The role of the teacher is critical for the success and effect of HIV/AIDS education for a programme to be faithfully implemented; teachers must be properly trained for, and committed to, the programme (Gallant & Maticka-Tyndale, 2003).

The 'Life Skills HIV and AIDS Education for the South African Deaf Learner' programme was launched by SLED in 2004 by the Minister of Health, and since 2005 SLED has reportedly hosted training workshops aimed at empowering educators of deaf learners with the necessary skills to be able to use the programme (SLED, 2006). It is also evident from the findings that educators need to go to HIV/AIDS empowerment workshops. This is based on what was said by the participants on how one gets infected with HIV/AIDS as taught by one of the educators. It is also evident that this particular teacher does not implement or rather did not understand the information gained from the SLED programme. Life Orientation as a learning area, through

programmes such as Life Skills, Religious Education and Social Responsibility, is also well positioned to be used as a programme to teach deaf youth about HIV/AIDS.

It has also been observed in the findings that there is a lack of understanding and knowledge among some participants, which could be linked to a lack of HIV/AIDS education. The seriousness of the abovementioned misconceptions around condom usage around the world re-emphasizes the need for intensive HIV/AIDS programmes that will help deaf youth in correcting their perceptions around HIV/AIDS. Intensified campaigns will, therefore, play a major role in assisting deaf youth to be on the same level of understanding with their hearing counterparts. HIV/AIDS education programmes in schools for deaf learners should, therefore, be introduced accurately and be taught in depth just like other programmes. It is thus important that the SLED programme is investigated and that any pitfalls in the programme are resolved so that this programme can be effectively implemented as Trafton (2006) states that visual materials constitute an extremely important teaching mode. Getch *et al.*, (2001) note that when visual resources such as films are used they should rightly feature deaf persons so that an increased understanding of the HIV risk by deaf youth is achieved.

Parental awareness workshops on sexual issues and HIV/AIDS should be organised by the Department of Education whereby parents will also be encouraged to learn Sign Language and talk freely to their children so that what the learner has been taught at school is also reiterated at home. Indeed, the training of the parents of deaf learners is particularly pertinent due to the communication barriers that hinder deaf learners from gaining important information from parents and other spheres (Getch *et al*, 2001).

6.2.2. Recommendations for improvement of access to information

From the findings, it is evident that HIV/AIDS education is implemented at both schools A and B but the information given to learners is limited, thus leaving deaf youth not accessing sufficient information in relation to HIV/AIDS.

Outreach and peer education programmes among deaf youth should be encouraged and should include steps to improve access to information as well as HIV/AIDS prevention.

In addition to that there is a need for well-planned peer HIV/AIDS education programmes because, when peers share information amongst themselves, knowledge and experiences can be shared in a language understandable and accessible to them. Peer educators can also present a platform where unclear issues picked up from media can be discussed. Media companies must also take into consideration that the needs of the previously marginalized groups, e.g. the disabled, need to be prioritized. In a country like South Africa it becomes worrying if such issues are ignored. Campbell and Foulis (2002) advise that HIV/AIDS-related peer education in school contexts often aims at postponing sexual involvement and promoting condom use and this is done through sharing information about HIV/AIDS, providing role models that promote healthy behaviour, demonstrating negotiation skills and providing individual support.

6.2.3. Recommendations for addressing social stigma against HIV/AIDS

Deaf youth also need to know that HIV/AIDS is also manageable if handled well and that it does not mean that people are promiscuous; anybody can be infected. If people are taught well, there should be no stigma. It is important to open platforms for talks such as group discussions and debates so as to contribute to the development of new collective norms of behaviour and relationships (Campbell & MacPhail, 2002), thus peer education is also relevant when one is aiming to eradicate social stereotypes. The necessary peer education related support involves the training and use of individuals from deaf youth to educate and support their peers. Campbell and MacPhail (2002) and Sikkema *et al.* (2000) note that peer-led interventions are based on the assumption that behaviour is socially influenced and that behavioural norms are developed through interaction.

To highlight the negative impact that limited information can have with relation to HIV/AIDS, one of the participants also cited a story about her friend who tried to commit suicide in the hostel because of gossip spread about her. Educators of deaf learners need to explore with deaf youth the social, psychological and economic implications of being infected with and affected by HIV/AIDS. By letting the youth know how the disease has affected individuals and families, they may be more empathic to the needs and rights of persons infected with HIV. There is a need for more awareness campaigns for deaf youth about HIV/AIDS and the value of condom usage.

6.2.4. Recommendations for further research

Although it was not the intention of the study to explore the areas mentioned below, in order to create effective intervention programmes to improve the perceptions of deaf youth, it is important to investigate the following areas:

- As teachers (both in mainstream and schools for the deaf) are expected to incorporate HIV/AIDS in all the learning areas, the research findings highlight that this is not happening; therefore, the reason for that need to be investigated.
- Although there is a lack of adequate HIV/AIDS information and sex education is seen as a taboo by some teachers, it is important to investigate other factors, besides curriculum issues, that may be causing teachers not to be able to offer in-depth HIV/AIDS education to deaf youth.
- There is also a need to determine the extent to which these SLED materials are being put to use by the HIV/AIDS teachers of deaf learners.

6.3. CONCLUSION

In summary, it is imperative that deaf youth have the right knowledge and skills that reduce their vulnerability and enable them to protect themselves and each other against the international epidemic of HIV/AIDS.

The intention of this study was not to apportion blame or give praise to anyone but was solely to establish how deaf youth perceive HIV/AIDS and this was done in order to generate a body of knowledge that could contribute to the on-going endeavours to inform society, with more focus on deaf youth, on the workings of the pandemic. Once an understanding is developed of how these young people understand the pandemic, it becomes that much more possible to design effective programmes that will succeed in empowering them with knowledge.

As has been shown in Chapters 4 and 5, current communication media have not been optimally used to reach out to deaf youth. Having shown, as this study has, how limited knowledge appears to reach deaf youth on HIV/AIDS, educators in schools for the deaf will need to change the way they teach. They will need to adopt a positive attitude as far as taking part in sexual education and HIV/AIDS lessons is concerned. By so doing, deaf youth will be enlightened and, when taught about these issues, will be in a better position to make informed decisions, thus reducing the chances of being infected with HIV/AIDS.

The gap in knowledge among deaf youth highlights a need for collaborative efforts by all who work with these young people. For example, the Department of Education, the Department of Health and the Department of Social Development from the Social Needs Cluster in the Eastern Cape Province need to strengthen and create new strategic partnerships in order to deal with HIV/AIDS issues. The collaboration will assist both the learners and the educators in areas that they are not clear about; trained officials from the three Departments will, therefore, be in a better position to answer any question posed to them by deaf youth. This collaboration will also assist the

deaf youth in getting equal access to resources and information just like their hearing counterparts. It is also important that schools for the deaf take cognisance of the fact that deaf learners will be able to access any kind of information in the language of their choice, namely South African Sign Language. If Sign Language is used eloquently, no information will be misinterpreted.

The gaps in knowledge among deaf learners that have been highlighted clearly show that deaf youth need to know that no one is invincible and they also need to defuse the stigma and discrimination associated with HIV/AIDS. Therefore, outreach and peer education programmes among deaf youth should be encouraged and introduced by the Department of Education and those should include steps to improve access to information as well as HIV/AIDS prevention.

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APPENDIX A

P.O. Box 635
King William's
Town
5600
29 January 2010

The Principal
St Thomas School for the Deaf
King William's Town
5600

Dear Madam

REQUEST TO CONDUCT RESEARCH

My name is Lumka Nonkelela and I am currently registered for the degree of Master of Education in Deaf Education at the University of the Witwatersrand in Johannesburg. This research will focus specifically on **The perceptions of deaf youth about HIV/AIDS**, and I propose that it takes place at two schools for the Deaf in the Eastern Cape. Therefore, I humbly request permission to conduct this Master's research in your school.

The topic of the study is **The perceptions of deaf youth about HIV/AIDS** with the following objectives:

- to establish the extent to which deaf youth would be concerned about being infected with HIV,
- to determine the extent to which HIV/AIDS has affected deaf youth in their social life, and

- to establish the role of deaf youth, as identified by them, in the fight against HIV at school.

If I am granted permission, I propose that the study will be undertaken from February 2010 and will spread over a period of approximately three months. Twenty learners from each school will be invited to participate in the research and there will be no financial implications on the part of the school or the learners. All attempts will be made not to interfere with the normal functioning of the school, and confidentiality will be maintained at all times.

A separate letter of application has been submitted to the EC Department of Education to secure permission to do research with learners in the Eastern Cape, and once approval is received from the two schools, letters of invitation will be sent to the learners and the school.

For further information or clarity please do not hesitate to contact me at the following contact numbers:

Cell : 0829712971

Fax : 0865857091

Email: nonkelela@gmail.com

Your cooperation in this regard will be highly appreciated

Yours truly

.....

Lumka Nonkelela

Researcher

APPENDIX B

P.O. Box 635
King William's
Town
5600
29 January 2010

The Principal
Efata School for the Deaf
Umthatha

Dear Madam

REQUEST TO CONDUCT RESEARCH

My name is Lumka Nonkelela and I am currently registered for the degree of Master of Education in Deaf Education at the University of the Witwatersrand in Johannesburg. This research will focus specifically on **The perceptions of deaf youth about HIV/AIDS**, and I propose that it takes place at two schools for the Deaf in the Eastern Cape. Therefore, I humbly request permission to conduct this Master's research in your school.

The topic of the study is **The perceptions of deaf youth about HIV/AIDS** with the following objectives:

- to establish the extent to which deaf youth would be concerned about being infected with HIV,
- to determine the extent to which HIV/AIDS has affected deaf youth in their social life, and
- to establish the role of deaf youth, as identified by them, in the fight against HIV at school.

If I am granted permission, I propose that the study will be undertaken from February 2010 and will spread over a period of approximately three months. Twenty learners from each school will be invited to participate in the research and there will be no financial implications on the part of the school or the learners. All attempts will be made not to interfere with the normal functioning of the school, and confidentiality will be maintained at all times.

A separate letter of application has been submitted to the EC Department of Education to secure permission to do research with learners in the Eastern Cape, and once approval is received from the two schools, letters of invitation will be sent to the learners and the school.

For further information or clarity please do not hesitate to contact me at the following contact numbers:

Cell : 0829712971

Fax : 0865857091

Email: nonkelela@gmail.com

Your cooperation in this regard will be highly appreciated

Yours truly

.....

Lumka Nonkelela
Researcher

APPENDIX C

PARTICIPANTS' INFORMED CONSENT

I agree to participate in the research study entitled **The perceptions of deaf youth about HIV/AIDS**. I realize that whether or not I decide to participate, my decision will not affect me in any way. I also realize that I can withdraw from the study at any given time for any reason and will not be penalized in any way.

I am aware that pseudonyms will be used in order to maintain anonymity and confidentiality in publication and that there will be no payment made for participating in the research study.

I have had all questions answered to my satisfaction.

.....
Participant

.....
Date

.....
Lumka Nonkelela
Researcher

.....
Date

APPENDIX D

INFORMATION LETTER TO THE PARTICIPANTS

Study Title :The perceptions of deaf youth about HIV/AIDS

Researcher :Lumka Nonkelela

Supervisors : Dr Claudine Storbeck

Mr Lucas Magongwa

The objectives of the study will be to:

- understand the perceptions of deaf youth about HIV/AIDS and to establish the extent to which deaf youth would be concerned about being infected with HIV,
- to determine the extent to which HIV/AIDS has affected deaf youth in their social life, and
- to establish the role of the deaf youth, as identified by them, in their endeavour in decreasing the spread of HIV at school.

Forty learners in the Eastern Cape will be interviewed from two schools for Deaf learners, ten girls and ten boys from each school, ranging from fourteen to twenty one years old.

The place and time of the interviews will be suggested by the participants. Questions will be related to the perceptions of deaf youth about HIV/AIDS. Any questions that the participants feel uncomfortable with will not be asked.

Pseudonyms will be used in order to maintain anonymity in publication. Your cooperation in maintenance of confidentiality and anonymity is of utmost importance.

Please feel free to ask any questions of concern before signing the consent form and these questions will be answered as completely as possible.

Your participation will be highly appreciated

.....

Lumka Nonkelela
Researcher

.....

Date

APPENDIX E

INTERVIEW SCHEDULE

1. What do you know about HIV/AIDS?
2. How do you access information about HIV/AIDS?
3. Why do you think it is important for you and your friends to talk about the topic of HIV, AIDS, or STD in your conversations?
What do your friends say about HIV/AIDS?
4. What do deaf youth think condoms are for: preventing pregnancy or preventing HIV and STD's?
5. How accessible are condoms to you as the youth?
6. At school, what have you been taught, if anything about HIV and sexually transmitted diseases?
7. If you adopt preventive measures, how would your partner or your friends react?
8. What are the preventive measures you would choose?
9. Why would you adopt these preventive measures over others?
10. How would you react if your partner does not accept your adopted preventive measures?

APPENDIX F

P.O. Box 635
King William's
Town
5600
29 January 2010

The District Manager
Department of Education
King William's Town
5600

Dear Sir

REQUEST TO CONDUCT RESEARCH

My name is Lumka Nonkelela and I am currently registered for the degree of Master of Education in Deaf Education, at the University of the Witwatersrand in Johannesburg. This research will focus specifically on **The perceptions of deaf youth about HIV/AIDS**, and I propose that it takes place at two schools for the deaf in the Eastern Cape. Therefore, I humbly request permission to conduct this Master's research in your district at St Thomas School for the Deaf and at Efata School for the Deaf.

The topic of the study is **The perceptions of deaf youth about HIV/AIDS** with the following objectives:

- to establish the extent to which deaf youth would be concerned about being infected with HIV,
- to determine the extent to which HIV/AIDS has affected deaf youth in their social life, and

- to establish the role of deaf youth, as identified by them, in the fight against HIV at school.

If I am granted permission, I propose that the study will be undertaken from February 2010 and will spread over a period of approximately three months. Twenty learners from each school will be invited to participate in the research and there will be no financial implications on the part of the school or the learners. All attempts will be made not to interfere with the normal functioning of the school, and confidentiality will be maintained at all times.

For further information or clarity, please do not hesitate to contact me at the following contact numbers:

Cell : 0829712971

Fax : 0865857091

Email: nonkelela@gmail.com

Your cooperation in this regard will be highly appreciated

Yours truly

.....

Lumka Nonkelela

Researcher

.....

Date

APPENDIX G



Province of the
EASTERN CAPE
DEPARTMENT OF EDUCATION
EDUCATION SUPPORT PROGRAMME
KING WILLIAM'S TOWN EDUCATION DISTRICT

19 BUFFALO ROAD, KING WILLIAM'S TOWN, 5800
REPUBLIC OF SOUTH AFRICA * Tel: 043 6425923 Fax: 043 6425937
ENG: S P MUDAU

TO : LUMKA NONKELELA
FROM : DISTRICT DIRECTOR
SUBJECT : REQUEST TO CONDUCT RESEARCH: YOURSELF
DATE : 10 FEBRUARY 2010

You are hereby informed that permission to conduct research as indicated above has been granted. It is hoped that you will furnish the office of the district direct with the research results of your study.

Good luck with your research


F C SOKUTU
DISTRICT DIRECTOR


DATE

