

TITLE PAGE

**The perceptions and experiences of people with physical disabilities about
HIV/AIDS in the urban university environment in Johannesburg**

South Africa

**A Study presented to the Department of Social Work, School of Human and
Community Development, Faculty of Humanities, University of the
Witwatersrand**

**In partial fulfilment of the Requirements for the Degree of Master of Arts
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Abstract

It is important to capture perceptions and experiences of people with physical disabilities about HIV/AIDS, because it may help service providers to understand the effects of HIV/AIDS on individuals with physical disabilities, their households and communities. People with physical disabilities may be a strategic group to engage in HIV/AIDS prevention strategies, lobbying and advocacy. The researcher conducted semi-structured interviews with 15 participants including students and staff with physical disabilities with the Disability Unit of the University of Witwatersrand.

The results of the study show that people with physical disabilities have the perception that they are among the worst hit groups of people and who have received less focus for awareness, protection and prevention programmes. They believe that this adds to the already harrowing problems of discrimination and vulnerability that exacerbate the risk of contracting HIV/ AIDS. The stigmatization and discrimination have impacted negatively on their self confidence and personal pride, which in turn has an effect on their interpersonal relationships. They perceive services relating to HIV/AIDS as being not easily accessible to them, due to distance from lecture halls and students hostels, infrastructural barriers as well as lack of skills by service providers to specifically handle people with physical disabilities.

Recommendations include improving capacity of service delivery by providing adaptable infrastructure, additional structured services for people with disabilities, awareness campaigns, in-house or additional training specifically on handling people with physical disabilities for Campus Health and Wellness Clinics, other services providers and staff members.

Declaration

I declare that the research report “The Perceptions and Experiences of People with Physical Disabilities about HIV/AIDS in the Urban University Environment in Johannesburg, South Africa” is my work and has not been submitted previously for a degree at another University.

Dolu Johnson Ashani

Candidate

Date

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CHAPTER ONE: INTRODUCTION

1.1 General introduction, rationale and statement of the problem

The impact of the HIV/AIDS epidemic on people with physical disabilities is clearly substantial and unique. In many African societies, the general attitudes towards disability are likely to compound this impact on people with physical disabilities, who are also likely to be particularly affected by the HIV/AIDS epidemic (Ozaji, 1992). HIV/AIDS is one of the most serious health threats in the world today, with the burden of the infection being felt most acutely in Africa (Swartz et al, 2006). Consequently, HIV/AIDS is perceived to have attained epidemic proportions in sub-Saharan Africa over the past ten years with particularly high prevalence rates in Southern Africa. It is not just the epidemic proportion that makes HIV/AIDS different from other diseases. The age, and gender of those infected and the structure of the illness, as well as the stigma attached to it make the effects of HIV/AIDS on individuals, families and communities different from other diseases commonly found in Africa (Schatz & Ogunmefun, 2004).

The impact of the protracted morbidity and mortality of HIV/AIDS on people with physical disabilities is multi-faceted. Despite the fact that the risk factors associated with disability – extreme poverty, social stigma and marginalization, strikingly high rates of unemployment and lack of access to education and health care - are similar to those for HIV/AIDS, there has been almost no attention to the impact of the AIDS epidemic on this large and largely overlooked population (Groce, 2003). They are already constructed as social outcasts. In this respect, HIV/AIDS and disability share common characteristics of stigmatization (Groce, Trasi & Yousafzai, 2006).

Although AIDS researchers have studied the disabling effects of HIV/AIDS on previously healthy people, little attention has been given to the risk of HIV/AIDS for individuals who have physical disabilities (Groce, 2003). It is commonly assumed that people with physical disabilities are not at risk because they are perceived to be asexual (Milligan & Neufeldt, 2001). They are incorrectly thought to be sexually inactive, unlikely to use drugs, and at less risk for violence or rape than their non-disabled peers. Yet a growing body of research indicates that people with physical disabilities are actually at increased risk for every known risk factor for HIV/AIDS (World Bank, 2004). Groce (2003, p.215) reported the findings of Blumberg and Dickey (1999)

which showed that adults in the United States of America with physical disabilities are more likely to report a medium or high chance of becoming infected with HIV, are more likely to be tested for HIV infection, and are more likely to expect to be tested within the next 12 months than are members of the general population.

Despite the assumption that disabled people are considered sexually inactive, those with physical disabilities and women with disabilities in particular are likely to have more sexual partners than their non-disabled peers (Nelson, 2003; Mulindwa, 2003). Therefore, people with physical disabilities are in all probability more vulnerable to HIV/AIDS infection than many other sectors of the population. Nevertheless, the area remains largely unexplored systematically (Rohleder & Swartz, 2005).

Although, HIV/AIDS is likely to have important consequences on people with disabilities in Africa, very little empirical work has focused directly on this issue (Groce & Trasi, 2004). Although researchers have studied the disabling effects of HIV/AIDS on previously healthy people, little attention has been given to the risk of HIV/AIDS for individuals who have physical disabilities (Groce, 2003). It is commonly assumed that people with physical disabilities are not at risk because they are perceived to be asexual (Milligan & Neufeldt, 2001). They are similarly incorrectly thought to be unlikely to use drugs, and at less risk for violence or rape than their non-disabled peers. Yet a growing body of research indicates that people with disabilities are actually at increased risk of every known risk factor for HIV/AIDS (World Bank, 2004).

Researchers have found that people with physical disabilities are routinely left out of HIV/AIDS prevention efforts and service delivery system in spite of the wealth of work in South Africa on HIV/AIDS (Elwan, 1999; Swartz, Schneider & Rohleder, 2006). Although people with physical disabilities are in all probability more vulnerable to infection than many other sectors of the population, the area remains largely unexplored systematically. HIV/AIDS intervention programs have done little to ensure that individuals with physical disabilities are included. This is of particular concern for individuals whose specific disability may decrease or block access to general HIV/AIDS education and outreach efforts (Swartz, Schneider & Rohleder, 2006).

It is commonly observed that awareness programme campaigns are often held where there is no accessibility for people using wheel chairs. Many clinics and hospitals do not have ramps. Where

such exist, little specific information is offered to people with physical disabilities. This continuous circle of exclusion is mostly exacerbated by the incorrect impression that people with disability are not sexually active hence, not at the risk of contracting HIV/AIDS.

HIV/AIDS is a major development concern in the developing world. Recent studies by development Non Governmental Organisation (NGOs) have indicated that the millennium goals may not be achieved if HIV/AIDS is not addressed (World Bank, 2008). Major interventions around HIV/AIDS prevention, care, support and mitigation have been done, but little or none has targeted people with physical disabilities as a special category. For example, awareness based interventions that have strong component of information, education and communication have not looked at the needs of the people with disability (Groce, 2006).

Even when AIDS service organizations promote safer sex life styles like the use of condoms, people with disabilities are often unable to use them. According to the HIV/AIDS and Disability Conference Report (2003, p. 10) disabled people are quoted as saying that, “Policy makers and development agencies continue to talk about us without us”.

Groce & Trasi (2004), stress that the HIV/AIDS epidemic had and would continue to have great impact on people with physical disabilities but that very little research has explored the impact. In South Africa, ‘the few studies conducted have been done mostly in rural communities’ (Swartz, Schneider & Rohleder, 2006, p.108). A study in an urban university community would therefore be useful. There is thus a need for research that explores the perceptions of people with physical disabilities in the urban university environment about HIV/AIDS.

1.2 Research questions

- i. What are the perceptions of people with physical disabilities in an urban university community about their risk exposure and vulnerability to HIV/AIDS?
- ii. What are the myths and misconceptions that surround people with disabilities regarding HIV/AIDS?

- iii. What are the relevant and specific educational and awareness programmes, prevention and protection services available for people with physical disabilities in an urban university community?

1.3 Research design and methodology

1.3.1 Research design

The study used a qualitative approach and made use of an exploratory descriptive design to gain insight and understanding about the experience and perceptions of people with physical disabilities in an urban university community about HIV/AIDS.

The objective of qualitative research is to describe and understand social issues and phenomena (De Vos, 1998). Exploratory research as a form of qualitative research is conducted to gain insight into an unexplored situation, phenomenon, community or individual so as to formulate a problem or develop a hypothesis. This approach has been selected in order to gain a first hand and holistic understanding of the issues by means of a flexible strategy of problem formulation and data collection.

1.3.2 Sampling procedure

A non - probability sampling method was used for this study. This is a sampling method where the chance of selecting a particular individual is not known (De Vos, 1998). Non-probability purposeful sampling therefore 'is based entirely on the judgement of the researcher in that a sample is purposeful and composed of elements that contain the most characteristics, representative of typical attributes of the population' (Rubin & Babbie, 2005, p. 247). The sample consisted of 12 students with physical disabilities, two staff members with physical disabilities and one non-disabled staff member from the university's Disability Unit. A total of 15 participants were therefore included. The participants' ages were 18 years and upward. Prospective participants were invited to participate by the Director of the Unit. An appeal letter was distributed among staff members and students in the Unit. The first 15 participants that responded were included.

1.3.3 Research instrument

The instrument used for collecting data was a semi structured interview schedule (Appendix A). This consists of 18 questions directed to exploring the knowledge, experiences and perceptions of people with physical disabilities about HIV/AIDS. Other questions related to exploring the services relating to HIV/AIDS for people with physical disabilities in the university community.

1.3.4 Data collection

Semi-structured face-to-face interviews were used to collect data. The questions were asked verbally and the participants' responses were tape recorded. Open ended questions were used to encourage participants to express themselves freely and impose no restriction on responses.

The researcher secured permission for audio taping the responses of the participants which was later transcribed by the researcher. Transcribing soon after an interview allowed the researcher to add in comments about what was happening during the interview, and make notes about non-verbal communication and other cues that added to the meaning of the respondents' words.

1.3.5 Data analysis

Data analysis is the process of bringing order, structure and meaning to the mass of collected data (De Vos et al, 2005). In qualitative research, data analysis has been described to be very challenging and involving a highly creative process starting from the data that it generates. 'The process involves data management which consists of activities aimed at achieving a systematic manner of data collection, storage and retrieval' (De Vos 1998, p. 90). Thus the researcher made notes about the recorded data. Interview transcripts were prepared and information was classified into categories, themes and patterns. These were used to interpret the results of the findings.

1.4 Research limitations

The study was limited to participants from one specific university community. Consequently, the results cannot be generalized to other institutions of higher learning. However, as this was a qualitative study, the interest was in the specific responses of the participants.

It is also possible that the presence of the researcher may have lead to the participants providing what they saw as desirable responses to some of the questions. However, the researcher ensured

that questions were asked in such a way that participants felt comfortable and he assured them that their honest responses were important.

A further limitation related to the open ended nature of the responses and their interpretation. The researcher had to ensure that he continuously reflected on his own ideas and thoughts and their contribution or influence on the process of analysis.

1.5 Ethical considerations

The field of social and human sciences focuses on human beings as the object of research. This brings unique ethical problems and researchers have the responsibility of respecting the rights, privacy and dignity of persons who participate in research projects. This ethical consideration also requires that the researcher ensure that there is accuracy and honesty in the report of their research (Ross, 2009).

In view of the above, application was made and approval was received from the Humanities Ethics Committee of the University of the Witwatersrand (See Appendix B clearance certificate).

Avoidance of harm (maleficence): Respondents were informed beforehand about the potential impact of the study, its aims and objectives and that participants have the opportunity to continue or withdraw from the study if they so wish. Questions were asked in a sensitive way that participants' emotional distress was limited. Consequently, counselling was arranged and offered to participants if they felt emotionally unsettled in any way.

Informed consent: All relevant information on the aims and objectives of the study, the research procedures, duration of participation and the advantages and disadvantages and the fact that there were no rewards (financial or other) or negative consequences for participating were explained to the participants before commencement of interviews. Written permission was obtained from all the participants as well as from the institution (See Appendix C & D).

Coercion and perverse incentives or deception: The researcher did not coerce participants into giving consent and participating through fear of victimisation, withholding of benefits or undue incentives. No form of deception was deliberately inflicted on the participants and the researcher was honest and did not mislead them in anyway.

Confidentiality: Participants were assured that their information would be kept confidential as data would only be used for the stated purposes of the research and that only the researcher and supervisor would have access to it. It was explained that data would be kept safe and that it would be destroyed after six years if no publication arises from the study and after two years if any publication was made.

Action and competence of researcher: No value judgements were made about the participants' behaviour, action and opinions even when they conflict directly or indirectly with those of the researcher. The researcher is adequately skilled, qualified and competent for investigation and is trained not to impose his own personal value system on the participants

Publication of findings and feedback given to participants: The participants will be informed of the main findings that emerged from the study to show recognition and gratitude to them. All sources used were acknowledged.

1.6 Terms and definitions

For the purpose of this study, various terms are used in tandem with social science and disabilities studies so as to convey the scientific meaning of those terms.

Physical disabilities: The term 'physical' and 'orthopaedic' disability will be used interchangeably throughout this report. This refers to impairments affecting ambulation and coordination, cerebral palsy, speech and language disorders, Down syndrome, etc. Essentially, 'the physically disabled are those individuals with functional limitations relating to physical ability. Examples of these are hand use; trunk use; and movement' (Abang, 1992, p. 247).

Human Immunodeficiency Virus (HIV): This is a virus that is transmitted from person to person through the exchange of body fluids such as blood, semen, vaginal secretions. In addition, infected pregnant women can pass HIV to their babies during pregnancy or delivery, as well as through breast-feeding. This is the virus that causes acquired immune deficiency syndrome (AIDS)" (Cichocki, 2009).

Acquired Immune Deficiency Syndrome (AIDS): AIDS is a medical syndrome which occurs because HIV has damaged body's natural defenses against disease (Janson, 2004; AVERT.org.

2009; Cichocki, 2009). AIDS is the final stage of HIV infection. When the immune system's CD4 cells drop to a very low level, a person's ability to fight infection is lost. In addition, there are several conditions that occur in people with HIV infection with this degree of immune system failure—these are called AIDS defining illnesses (UNAIDS, 2008; Medicine net .com 2009).

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Understanding the experiences and perceptions of people with physical disabilities about HIV/AIDS requires a compendium of information that has been documented by experts and professionals on the topic. The impact of the protracted morbidity and mortality of HIV/AIDS on people with physical disabilities is multi-faceted. Despite the fact that the risk factors associated with disability – extreme poverty, social stigma and marginalization, strikingly high rates of unemployment and lack of access to education and health care - are similar to those for HIV/AIDS, there has been almost no attention to the impact of the AIDS epidemic on this large and largely overlooked population (Groce, 2003). Consequently, this study reviews the prevalence of physical disabilities, various views on the construction of disabilities, social economic impact of HIV/AIDS, the sexuality and the reproductive health of people with physical disabilities to gain a wide breath of knowledge about the impact of HIV/AIDS on people with physical disabilities. The predisposing factors and issues that exacerbate the perpetuation of the disease among people with physical disabilities must be understood in order to contextualise the scourge of the epidemic among this vulnerable group in society.

2.2 Prevalence of physical disabilities in South Africa

Very little data exists on disability trends in developing countries. The evidence is for the most part, fragmented and often anecdotal (Emmett, 2006, p. 207). Existing information does however suggest that, in general, the trends in developing countries are similar to those in industrialized countries, except that conditions in the developing countries are likely to be worse and considerably more prejudicial to disabled people and especially disabled women (ibid: 218). However one person in ten of the world population amounting to 600 million individuals, live with a disability significant enough to make a difference in their daily lives; eighty percent of these live in developing countries (Groce, 2003; World Bank, 2003; Helander, 1999).

Useful statistics from the United Nations Development Programme (UNDP) and the Central Statistical Service (CSS) provide insights into the problem of HIV/AIDS and disability. While

the UNDP estimated that in 1990, slightly above five percent of the world's population was experiencing moderate to severe disability, for South Africa the figure stood at approximately five percent in 1995 (Stats SA, 2001).

During the Census of 2001, a total of 2, 255 982 persons reported that they had some kind of disability that prevented them from full participation in life activities. This number constituted five percent of the total population 44, 819 778 enumerated in the census (Stats SA, 2003).

Table 1: Number of disabled persons by gender and population group

Population Group	N	N	N	%	%	%
	Male	Female	Total	Male	Female	Total % of population group
African	879 680	974 696	1 854 376	5.2	5.3	5.2
Coloured	88 583	80 095	168 678	4.6	3.9	4.2
Indian/Asian	21 550	19 685	41 235	4.0	3.5	3.7
White	92 230	99 463	191 693	4.4	4.5	4.5
Total	1 082 043	1 173 939	2 255 982	5.1	5.0	5.0

Source: Prevalence of Disabilities in South Africa, Census 2001.

According to the figure above the highest number of people with disabilities were recorded among the black population with disabilities at 1 854 376 or 5. 2%, followed by white at 191 693 or 4. 5%, coloured at 168 678 or 4. 2% and Indian at 41 235 or 3.7% (Stats SA, 2003). These percentage differences are probably due to a variety of socio-economic and demographic factors, as well as unique social cultural perceptions and inhibitions with regard to reporting on disability (Disability population in SA cited in Stats SA 2005, p. 11).

It is also important to recognize that even within the disabled community; there are sectors that experience discrimination and exclusion more acutely than others. According to Nelson (2003), “Women with disabilities bear the brunt of discrimination and exclusion more acutely than men and tend to have a higher rate of disability than men, due primarily to women's higher average longevity”. The information collected in the 2001 census followed this trend with 1 173 939 females affected compared to 1 082 043 males. The percentage of females affected was slightly

higher than for males in the African and white population groups and slightly lower in the Coloured and Indian/Asian population groups (Stats SA, 2003).

Similarly, each type of disability has a unique impact on an individual's ability to perform certain activities. The table below presents the profile of disabled persons by specific disabilities including those with multiple disabilities:

Table 2: Percentage of disabled persons by type of disability

Type of disability	Male	Female	Total
Sight	28.3	35.6	32.1
Hearing	19.4	20.7	20.1
Communication	7.2	5.8	6.5
Physical	30.7	28.6	29.6
Intellectual	13.5	11.3	12.4
Emotional	17.3	14.3	15.7

Source: Prevalence of Disabilities in South Africa, Census 2001.

The prevalence of physical disabilities in South Africa according to the above table shows that approximately 30%, of the disabled population are people with physical disability.

2.3 HIV/AIDS

The history of attention to HIV began early in July 1981, when the New York Times reported an outbreak of a rare form of cancer among gay men in New York and California. The disease was initially called "GRID" (gay-related immune deficiency), stigmatizing the gay community as carriers of this deadly disease (About.com., 2009). However, when cases started to be seen in heterosexuals, drug addicts, and people who received blood transfusions, it showed that the syndrome knew no boundaries (Cichocki, 2006). This "gay cancer" as it was called at the time was later identified as kaposi's sarcoma (About.com., 2009). The symptoms were presented with flu-like fevers and a rare pneumonia. Two years later, an international committee of scientists renames the virus HIV (Human Immunodeficiency Virus).

Abundant scientific evidence has proven that AIDS is caused by the human immunodeficiency virus (HIV) (Cichocki, 2007). AIDS is the advanced form of infection with the HIV virus, which may not cause recognizable disease for a long period after the initial exposure (Medical dictionary, 2008). No vaccine is currently available to prevent HIV infection. At present, all forms of AIDS therapy are focused on improving the quality and length of life for AIDS patients by slowing or halting the replication of the virus and treating or preventing infections and cancers that take advantage of a person's weakened immune system (Boschert, 2004).

2.3.1 Prevalence of HIV/AIDS in South Africa

South Africa is currently experiencing one of the most severe AIDS epidemics in the world (RSA National AIDS council, 2008). At the end of 2007, there were approximately 5.7 million people living with HIV in South Africa, and almost 1,000 AIDS deaths occurring every day (UNAID, 2008). Statistics are showing that almost one in five adults is infected (AVERT.org, 2009).

With antiretroviral drug treatment, HIV-positive people can maintain their health and often lead relatively normal lives. However, few people in South Africa have access to this treatment. This means that AIDS deaths are alarmingly common throughout the country. It is thought that almost half of all deaths in South Africa, and a staggering 71% of deaths among those aged between 15 and 49, are caused by AIDS (Dorrington, Johnson, Bradshaw & Daniel, 2006). So many people are dying from AIDS that in some parts of the country, cemeteries are running out of space for the dead (The New York Times, June 2004). A recent survey found that South Africans spent more time at funerals than they did having their hair cut, shopping or having barbecues. It was also reported that more than twice as many people had been to a funeral in the previous month than had been to a wedding (SAARF, 2004).

The effect of HIV/AIDS pandemic has been recorded to have adverse effect on the longevity of South Africans with life expectancy now at 54 years. However, without AIDS, it is estimated that it would be 64 (CARSA & MRCASSA, 2006). Between 1990 and 2003, a period during which HIV prevalence in South Africa increased dramatically, the country fell by 35 places in

the Human Development Index, a global directory that ranks countries by how developed they are (UNAIDS/WHO, 2006). The present situation shows that hospitals are struggling to cope with the number of HIV related patients that they have to care for. In 2006 the estimate was made that HIV-positive patients would soon account for 60-70% of the medical expenditure in South African hospitals (Inter Press Service News Agency, 2006).

HIV/AIDS is also beginning to have serious effect on the educational institutions with schools having fewer teachers because of the AIDS epidemic. In 2006, it was estimated that 21% of teachers in South Africa were living with HIV (UNAIDS/WHO, 2006). It is clear that AIDS is having a devastating impact on South Africa. There are many possible reasons why South Africa has been so badly affected by AIDS, including poverty, social instability and a lack of government action (AVERT.org, 2009). A hallmark of the HIV/AIDS epidemic has been its impact on vulnerable populations.

2.3.2 HIV/AIDS and physical disabilities

Individuals with disabilities are among the most stigmatized, poorest, and least educated of all the world's citizens. Yet they have been almost entirely overlooked despite the fact that they are at equal or increased risk of exposure to all known risk factors for HIV (Groce, 2003). The extent of HIV infection specifically among disabled people in South Africa is not known (Integrated National Disability Strategy, 2007). However, it is believed that the prevalence is very high, considering that South Africa has one of the largest number of HIV positive people in Africa (HIV/AIDS and Disabilities in South Africa, 2008).

In South Africa, where the prominent mode of HIV transmission is sexual contact, HIV is not considered to be a pressing issue for disabled people. They are mistakenly perceived as not being sexually active, and in some instances are thought to be asexual and hence not at risk of HIV infection (World Bank, 2004). This probably accounts for why individuals with disabilities receive less attention in HIV prevention and AIDS outreach programmes. Nonetheless, the Global Survey on Disability and HIV/AIDS conducted by Yale University and the World Bank has shown that Individuals with disabilities have equal or greater exposure to all known risk factors for HIV infection (Groce, 2004).

People with disabilities are observed to show little variance from the able bodied population. Adolescents and adults with disabilities are as likely as their non-disabled peers to be sexually active. Homosexuality and bisexuality appear to occur at the same rate among individuals with disability as among the non-disabled (UNICEF, 1999). Men and women with disabilities are even more likely to be victims of violence or rape, although they are less likely to be able to obtain police intervention, legal protection or prophylactic care (Groce & Trasi, 2004). Poverty due to unemployment was also identified for the marked increase rate of HIV/AIDS among people with physical disabilities. This usually occurs when people have to give sex in exchange for cash or other benefits (Community Agency for Social Enquiry, 2005; Department of Social Development, 2006).

Therefore, the exclusion of people with disabilities from HIV/AIDS prevention and care is shortsighted. Given the size of the global disabled population, an estimated 10% of the world's citizens, the AIDS crisis cannot be addressed successfully unless individuals with disability are routinely included in all AIDS outreach efforts (Public Health at a Glance, November, 2004). An argument to urgently include the need of people with disabilities in the fight against HIV/AIDS pandemic has become plausible. Groce (2005) explains that, 'the HIV/AIDS epidemic has left no country untouched and no group of people unaffected. While all are at-risk, the epidemic has disproportionately had an impact on populations that are poor and marginalized. The need to address HIV/AIDS has thus become a key concern for those advocates, professionals and organizations which work with marginalized communities, this is nowhere more truly than in the case of the link between HIV/AIDS and disability' (Groce, 2005, p. 65).

2.4 Views on disabilities

2.4.1 Introduction

The conceptual understanding of disability has evolved over recent years. Most people's understanding of disability stems from the experiences they have had in their own cultures and societies and those using this resource will thus most likely have different conceptions of

disability (World Bank, 2008). The views around the etiology of disability across the world are varied. 'Some causes are common in developed countries while others are mostly common in developing countries, in Africa, the major causes of physical disabilities are related to poverty, war, toxic chemicals (such as kitchens without chimneys), malnutrition and many more' (Abang, 1992, p. 12).

Various schools of thought that explain factors thought to be responsible for causing disabilities. Variations are found amongst traditional beliefs, medical claims, social construction and psychoanalytical positions.

2.4.2 Traditional religious and superstitious beliefs about the causes of disability

Historically, wide spread superstitious and religious beliefs exist about the causes of disabilities, all over the world (Abang, 1992). For example, 'the belief that God or Allah is influential in determining disability and that a disabled child is a gift or a blessing is for example common amongst Mexican American and African American families' (Kalyanpur, 1999, p. 111). A euphemistic explanation of the cause and impact of disabilities by Medieval Christians was the belief that 'people with disabilities possess special gifts bestowed by the grace of God' (Cusack, 1997, p. 414). These various beliefs tend to perform a functional purpose and positive believe assumed to help the caregiver cope better with the problems posed by these children. On another hand, the belief that the child was ordained to be disabled might result in parents being less enthusiastic about seeking rehabilitation services to minimise the effects of the disability. In Africa, there is widespread belief that the cause of disabilities is a punishment from God. In Xhosa as well as the Zulu belief, the role played by witchcraft and spirits as being responsible for the causes of disability is also highly upheld. In indigenous Zulu cosmology, disease and disability can be interpreted as either natural or spiritual (Hanass-Hancock, 2008). Similar beliefs are common around neighbouring countries like Zimbabwe, where the causes of disability are ascribed to both witchcraft and ancestral spirits, as well as to God and natural causes (Drews, Foster & Chituna, 1996; Jackson & Mupedziswa, 1988). Confusion about the etiology of disability is also described by Jackson et al (1988) who reveal that a belief in witchcraft is also present in those who profess Christianity. Caregivers with mixed beliefs, thus resort to praying to

God as well as consulting traditional healers and health professionals (Jackson et al, 1988). In view of this, meaningful empirical explanation of disabilities may be desirable. This would provide alternative explanations to the cultural beliefs as supported by traditional healers, who are perceived to identify the source of the problem and give the solution with their remedies usually focused on overcoming the causative spiritual power and to sustain moral value.

2.4.3 Medical views on physical disabilities

According to Abang (1992, p. 18), medical descriptions suggest that ‘physical disabilities have their onset in two phases namely the congenital and the adventitious’. She describes the congenital phase as those disabilities present from birth. Factors responsible for these forms may occur from the time of conception to parturition (birth). Conditions like blood incompatibility, chromosomal abnormality, or illness of the mother are dominant factors (Obosi, 1995). Medical research has begun to delve into causes of birth defects and found that while some conditions are genetic in origin many others result from intra-uterine or birth accidents. Conditions such as haemorrhage at the first trimester of pregnancy, prolonged labour, poor delivery conditions, alcoholism, drugs, as well as the problem of aging may be responsible for cases such as cerebral palsy, Down syndrome and mental retardation (Wiesinger – Ferris, 1989). The adventitious forms of disability that occur later in life may be the result of accidents, armed conflict, emotional and social disturbance, poverty, ignorance, poor hygienic conditions, prolonged illness and many more (Abang, 1992; Obosi, 1995).

An in-depth classification of physical disabilities was made by Hallahan & Kauffman (2000). They identify this major classification as neurological conditions, musculoskeletal conditions, and other health impairments. In their explanation, they define neurological conditions as damage to the central nervous system (brain or spinal cord) which leads to cases like cerebral palsy, seizure disorder (or epilepsy), and spinal bifida. The Musculoskeletal conditions such as muscular dystrophy, juvenile rheumatoid arthritis, limb deficiencies or amputations, and a wide variety of other deformities or degeneration of muscles or bones affecting the ability to move, walk, stand, sit, or use the hands or feet normally.

Other health impairments include a wide variety of infectious diseases and chronic problems such as diabetes, asthma, cystic fibrosis, immunodeficiency (including HIV and AIDS),

hemophilia, fetal alcohol syndrome, and the malfunction or failure of vital organs. However, other conditions like infectious disease, congenital conditions or malformations, and developmental problems or chronic health problems that are poorly understood may also be responsible for physical disabilities (Obosi, 1995).

A wide variety of disabilities, especially those associated with traumatic brain injury may result from vehicular accidents, gunshot wounds, burns, falls, and poisoning. Substance abuse and physical abuse by caretakers, infectious diseases, and substance abuse by the mother during pregnancy may also result in physical disabilities (Abang, 1992). Knowledge about these challenges have brought about advances in medicine for reducing or eliminating physical disabilities resulting from the diseases, injuries, and chronic conditions. Consequently, this has lead to increase in the number of children surviving congenital anomalies, accidents, and diseases with severe disabilities (Fox, 2009).

2.4.4 Social construction of disabilities

Priestley (1999) explains that disability is a product of social construction. In contemporary society, the term “disabled” evokes certain images and expectations. An individual so labeled is likely to be viewed as an object of pity or, if among the “rare” success stories, praised as an heroic figure. In either case, a central, but often overlooked fact is that disability, like gender or race, is a socially constructed category (Goffman, 1963). It is true that disabled persons are, in some way, different. Usually this difference takes the form of a deficiency in some socially valued attributes such as a physical impairment or difficulty in ambulation or mobility. However, the word “disabled” has cultural meanings that are much more profound and far- reaching. In practice, the label “disabled” is often equated with deviance (Adkins, 2003).

Disability is a stigma, a discrediting category that carries with it the ascription of characteristics that devalue the individual so labeled in ways that have little to do with the “objective” disabling condition (Goffman, 1963). Consequently, disability can thus be considered a socially constructed condition. This was confirmed by Albert (2005) when he explained that disability should be broadly understood and conceptualized as a social construct in much the same way that gender, race and ethnicity are socially constructed. This construction originates in an almost

exclusively negative interaction of a person with his or her environment. Some examples of the interaction are discrimination and social isolation, as well as attitudinal and structural barriers which constitute the broader limitation for maximal social adjustment for people with physical disabilities (Adkins, 2003).

The professional interaction with the public has also been cited as one of the factors reinforcing the social construct of disability. As “experts, their opinions have the ring of authority” (Adkins, 2003). Among other motivations, disability workers may have an interest in emphasizing the dependent aspects of their clients in order to secure funding (Scott, 1969).

A few writers raise concerns about the views of the professional worker like Lobbyist and Advocacy group toward clients. They point out that rehabilitation agencies and workers are political players. They compete for funds and, in so doing, design and implement policies acceptable in political terms. There is pressure to present the disabled as “needy” and deserving of public assistance (Albrecht, 1976) conversely, portraying the physical disabled person as victim, rather than a beneficiary of service delivery in the society. This is often not likely to be well received by those who have power to make funding available (Albrecht, 1976; Hahn, 1988).

The prevailing model among rehabilitation professionals as well as the general public are such that reduce people with disabilities to the problems arising from a disabling condition e.g., lack of ability to travel, work, or participate in other normal activities due only to the disability. Hence, the individual with disabilities is defined as “damaged goods” and must accept this view and learn to cope (Scott, 1969, Albrecht, 1976).

Discussions of cultural concepts of disabled persons are mostly confined to either historical overviews or to arguments for changes in the manner in which disabled persons are viewed. Hahn (1988, p. 25) argues that images of disabled persons derive from what he terms the “moral ordering of the body” in capitalist society. By this, Hahn means morality is linked to images of physical perfection (i.e., beauty and strength). Such associations help to maintain capitalist hegemony by inducing people to emulate the “accepted” image. In the process, the physically disabled person becomes the “other” and is viewed as “not quite human” (Hahn, 1988, p.29). A final reason offered for the persistence of individualized conceptions of disability is that they support an ideology equating physical perfection with personal value. The disabled become the

“Other” in ways that enable those in power, for example, rehabilitation workers, to remain in power by discrediting the disabled’ (Hahn, 1980) cited in Adkins (2003, p. 26).

It is these various social and cultural ideologies that inform why social scientists begin to see disability from a different lens. Consequently, they contextualize the construction of disability under the social models, an assumption that ‘the problems faced by the disabled are the result of socially created barriers whether attitudinal or physical and can be reduced or eliminated by social change’ (Adkins, 2003, p. 15).

2.4.5 Psychoanalytical view on disabilities

Although disability studies receive much interest, efforts to develop theoretical perspectives have been limited. Some writers take an economic/political approach that views the disabled as a disadvantaged minority (Baldwin, 1997) cited in Adkins (2003, p. 11). Others have adopted a psychological framework, as when the focus is on the disabled person as the “Other” (Gorden & Rosenblum, 2001). Hence, disabled persons are labelled as unproductive, unable to develop normally in the cognitive and social skills, and prone to depression and other emotional problems (Cudlick, 2001).

Watermayer et al (2006) explains the construction of disability from the psychoanalytical point of view. The effects of disability on individual are linked to the notion and images of disability as attached to ideas of vulnerability, frailty and damage. Consequently, people’s internal struggles are brought rapidly near the surface of consciousness. Rather than identifying these fears and struggles as people’s feeling in an unconscious moment, the tendency is to experience these feelings as if pertaining to the disabled person. In such circumstances, a disabled person is being related to in a manner informed in no way by the nature of their life, but rather as a container or vessel for the fear of the observer (Watermayer et al 2006, p. 16)

In view of the foregoing, disability is seen to be easily translated into a supposed inherent inferiority and a justification for scrutiny, coercion, and exclusion. Significant changes will only begin when large numbers of disabled persons have been able to successfully overcome the

disadvantages they face. Hence, the self- concept of the disabled person may be an important predictor of success in their efforts to begin to adjust in society (Scott 1969).

2.5 Socio – economic impact of disability

Individuals with disabilities are among the most stigmatized, poorest, and least educated of all the world's citizens (Groce, Trasi, & Yousafzai, 2003). One person in ten and an estimate of 600 million individuals live with a disability significant enough to make a difference in their daily lives. Of this population, 80% live in developing countries mostly without social systems to support them (Groce, 2003). Their burdens are tremendous in addition to the impacts of physical, impairments; persons with disabilities often face stigma, discrimination, violence and poverty. They must cope with inadequate health services and have limited access to education. They experience the deprivation of opportunities in all aspects of life, including access to essential services (Helander 1999).

The outcomes of the 2005 World Summit, The United Nations Millennium Declaration and its Millennium Development Goals, and the Programme of Action of the 1994 International Conference on Population and Development consistently excluded people with disabilities. In this regard, the United Nations Secretary-General stated: “Unless persons with disabilities are brought into the development mainstream, it will be impossible to cut poverty by half by 2015” (United Nations, 2005).

The World Bank estimates that people with disabilities make up 20% of the World's poor. Routinely they are the poorest of the poor (Elwan, 1999). Women with disabilities and disabled members of ethnic and minority communities face additional marginalization (Nelson, 2003). This cycle of disability and poverty is profound and worldwide. The commonest form of employment for individuals with disability continues to be begging (Abang, 1992; UNICEF, 1999). Furthermore, globally, figures show that only three per cent of men with disabilities, and only one per cent of women with disabilities are literate (Helander, 1999). Where education exists, it is often sub-standard, and dropout rates double or triple those of non-disabled children (UNICEF, 1999; Groce 2003).

Mulindwa (2003) found, regarding reproductive health of people with disabilities in Uganda, that socio economic problems associated with persons with disabilities such as poverty could be attributed to the inability of people with physical disabilities to engage in agricultural activities due to their physical body weaknesses. Because of their disabilities they are unable to cultivate large pieces of land and thus find it hard to earn a living from agriculture, which is the mainstay of the Ugandan economy. Furthermore, 'they tended not even to be hired for casual labour by agricultural employers because of the general belief that people with physical disabilities are too weak to conduct farm activities' (Mulindwa, 2003, p. 21). In other situations where people with physical disabilities make efforts towards gainful employment they are confronted with the poor public transportation with little effective provision for people with disabilities (Nelson 2005; Philander & Swartz, 2006).

In South Africa during apartheid, the situation was even more precarious as it created the conditions of poverty and discrimination experienced by people with disabilities. The living experiences of black and white disabled people under apartheid were very different and reflected the general inequality between them (Philander & Swartz, 2006). For the majority of black disabled people, their lives were about struggling on a daily basis to cope with the poverty, deprivation and violence of the apartheid system, a struggle compounded by their disability. However it is important to recognize that under apartheid, all disabled people, black and white were discriminated against and marginalized because of their disabilities and had very limited access to fundamental socio- economic rights such as employment, education and appropriate health and welfare services. This kind of discrimination and marginalization occurred because disabled people in general were seen as a people who were sick or need care rather than as equal citizens with equal rights and responsibilities (Howell, Chaklen & Alberts, 2006).

Not only were many black people disabled through the repressive and structural violence of apartheid (Cork, 1988), but once disabled they faced inadequate rehabilitation and health services in apartheid hospitals and then were discharged back into the same conditions of deprivation and discrimination which led to their injury in the first place, where there was little or no follow up and after care. This situation consistently kept people with disabilities under the

yoke of poverty (Du Toit, 1992). Although there is a new era of freedom, the backlog of the apartheid era still continues to haunt the nation, causing a state of distorted development (Midgley, 1995).

People with physical disabilities are yet to be fully capacitated with requisite skills to access job opportunities or be self employed (INDS, 1997). On average, disabled people receive less education and have lower literacy rates and education qualification than the non disabled population (Elwan 1999; DFID, 2000). Because disabled people are associated with a lower education and literacy level than the rest of the population, when disabled people are employed, they are likely to be under – employed relative to their level of training and they are thus less likely to have savings and other assets than the non disabled population (Emmett, 2006). Employment rates for disabled persons are usually lower, and both employment and income appear to be negatively associated with the severity of disability.

In conclusion, the onset of disability is associated with an added risk of entering poverty, as well as a decrease in the proportion of people leaving poverty (Burchardt, 2003) cited by Emmett, (2006: p. 213). In other words, becoming disabled increases the risk of those who were not poor before the onset of disability to become poor, and diminished the odd of those who were already poor for escaping poverty (Emmett, 2006).

2.6 Sexuality and disability

According to the World Bank (2005), sexuality refers to the interplay of physical, psychological, social, emotional, and spiritual makeup of an individual. It also encompasses gender, gender role, gender identity, sexual orientation, sexual preference, and social norms as they affect physical, emotional, and spiritual life (World Bank, 2005). According to the Planned Parenthood Federation of Canada, (2008), everyone is sexual from birth to death. However, being sexual does not mean being sexually active. Hence sexuality encompasses how persons feel about themselves, their body image, and their ability to be emotionally intimate with others, in addition to their reproductive choices (DPSA, 2004).

People with physical disabilities suffer significant social oppressions and are stigmatized in many socio-cultural contexts, especially in the context of attempt to negotiate sexual intimacy (Groce, 2003). Women with disabilities in some cultures, have little choice in the selection of sexual partner. Furthermore, some people with physical disabilities are even less empowered due to the overprotection of their parents (Nelson, (2005). Nevertheless, human beings are born with sexual drives regardless of culture, sexual orientation and disability status.

Due to the limitation imposed on the sexuality of people with disabilities by social standards and the prescribed notions about sexuality, people with disabilities are often confused about where, or if, they fit into the category of sexual desirability (Mona, 2002). Individuals are bombarded with messages from the media, discussing and defining the ideals of masculinity and femininity. Rarely, if at all, do these images include persons with disabilities (Mona & Gardos 2000). Thus, ‘disabled persons may have difficulties constructing not only their gender identity but their sexual sense of self’ (Shuttleworth, 2007, p. 184).

The sexuality of persons with physical disabilities has thus been a topic explored by both psychological and medical researchers for the past 25 years (Swartz, Scheineder, & Rohleder, 2006). A physically disabled individual engaging in sexual activity has been an image not easily entertained by mainstream society. Nevertheless, an individual born with or who acquires a physical disability during his or her life span continues to have sexual instincts. For example, despite the incorrect assumption that people with disabilities are believed to be sexually inactive, those with physical disabilities and women with disabilities in particular are likely to have more sexual partners than their non-disabled peers (Milligan & Neufeldt, 2001). Hence, the issue of sexuality is an important fact of existence and there is no difference between the desire to feel sexually attractive by able-bodied and disabled persons (Mona, 2000). Disabled populations should thus freely express their sexuality and be included in all matters relating to sex education.

A growing body of research equally indicates that they are actually at increased risk for every known risk factor for HIV/AIDS (World Bank, 2004). If it is accepted that sexual expression is natural and important part of human life, then perceptions that deny sexuality for disabled people denies a basic right of expression. In addition, this perception of people with disabilities as non-

sexual can present barriers to safe sex education as well as prevent them from sound information about prevention and protection against HIV/AIDS (South African AIDS council, 2008).

The two issues that most often emerged when discussing the sexuality of people with disabilities have been the difficulty they experienced in meeting social expectations of normative functioning and control as well as male gender role expectations (Douard, 1995). In fact, 'normative function and hegemonic masculine expectations (as well as other factors) implicitly structure the contexts of desirability in many societies, stacking the deck against people with disabilities in their search for sexual intimacy' (Shuttleworth, 2007, p.184).

A complication in an intimate relationship with a person with physical disability is the incorrect or inappropriate construction of them as a child developmentally and physically. Shakespeare, Gillespie-Sells, & Davies (1996) maintain that there is a symbolic between limitations of physical functioning and control and being a child. Since children are generally not considered sexual beings in many part of the world, implicit in this association are two possible interpretations: (1) that disabled people with limited physical functions are also asexual; or (2) that disabled people with limited physical functions are not desirable as sexual objects because they are not seen as adults (Shuttleworth, 2007).

In contrast however, sexual attractiveness and expression may not be of great importance to persons with physical disabilities, when compared to able-bodied individuals as it is an altogether different experience (Mona, 2000). Disabled persons comprise a community of individuals with a unique culture, filled with social expectations different from able-bodied individuals. These differences are most notable in societal norms and behavioural expectations, including specific assumptions regarding the sexuality of this group. More clearly, these differences are not based upon differences in being human or possessing human emotions, but lie within the realm of what is deemed sexually desirable (Mona, 2000). Yet a critical constructionist approach to studying the intersection of disability and sexuality has been slow to emerge (Teunis & Herdt, 2007).

2.7 Disability and reproductive health care

2.7.1 Introduction

Reproductive and sexual health care services include family planning, counseling, pre-natal care, safe delivery and post-natal care, prevention and appropriate treatment of infertility, prevention of abortion and the management of the consequences of abortion, treatment of reproductive tract infections, sexually transmitted diseases and other reproductive health conditions; and education, counseling, as appropriate, on human sexuality, reproductive health and responsible parenthood (International Conference on Population and Development (ICPD), 1994). Access to these reproductive health services is a vital component of women's empowerment. This involves the right to decide the "number and spacing of their children and to have access to the information and education on reproductive care and means to enable them to exercise these rights" (Reproductive Health briefing, 2009).

With the advent of the independent living movement in the 1970's, many women with disabilities began living independently (Ellen, 2001). This required that persons with physical disabilities should gain the same services, aids, or benefits from their reproductive health care providers as those persons without disabilities. As women with disabilities began to work, date and marry, their need to know about sexuality including contraception, pregnancy, breast cancer screening, sexually transmitted diseases and menopause became important to them (Mona, 2000). However, obtaining these services was not easy to accomplish (Ellen, 2001). There has been reported scarcity of information on all aspects of gynaecological care needed and received by women with disabilities. Much of the literature has been anecdotal, describing subjectively the experiences of disabled women (Gittler, Barzansky & Beckmann, 1989).

In addition, the sexuality and the emotional responses of people with physical disabilities have received little serious attention in scholarly discussions (Mona, 2000). Often, textbooks and journals on sexuality and perhaps on reproductive health care rarely give any significant information about the people with disabilities (Mona, 2000). Consequently, there have been complaints by women with physical disabilities that their physicians do not attend to their reproductive health care needs (Nosek & Howland, 1997).

Similarly, people with disabilities have been reported to be missing out on traditional sex education and valuable information about reproductive education (Martorella & Portugues, 1998). Parent's anxiety has also been cited for precluding the raising of sexuality issues for fear of promoting sexual behaviour in their children (Committee for Children with Disabilities, 1998). Other factors limiting the opportunity of people with physical disability to obtain reproductive health care are physical, non-physical and architectural barriers (Ellen, 2001). As a result, people with physical disabilities are faced with problems such as unwanted pregnancy and complications during childbirth emanating from their exclusion from the reproductive health awareness programmes (Mulindwa, 2003).

2.7.2 Non – physical barriers to reproductive health care

Women with physical disabilities have often lived a life of isolation and invisibility (Gill, Kirschner, & Reis, 1994), protected by their parents, and never expected to marry, reproduce or have intimate relationships (Becker et al., 1997). These women may have been treated in medical settings in a dehumanizing and infantilizing manner (Gill et al, 1994). Whenever there is a possibility of marriage, especially in a predominantly superstitious environment, what is acceptable in the community is for a disabled person to marry another disabled person so that together they share their 'curse' (Nelson, 2005).

Therefore, women with disabilities may have a history of negative experiences from childhood in dealing with the health care system (Becker et al., 1997). Even today, physicians who treat women with disabilities for their reproductive health care needs often assume women with disabilities are asexual, especially if the woman has a severe disability (Nosek, Rintala, Young, Howland, Foley, Rossi & Chanpong, 1996).

Physicians sometimes assume that if a woman with a disability makes an appointment seeking prenatal care she will want to terminate her pregnancy (Welner, Gynecological Care, 1993), cited by Ellen (2001). Since women with disabilities are treated as asexual beings, physicians do not always ask the standard questions that should be asked in a reproductive health care setting. Such as, "are there any contraceptive needs or issues that we need to discuss?" (Ellen 2001).

2.7.3 Physical /architectural barriers

Some authors report that people with physical disabilities, seeking reproductive health care services and other types of health care services, have difficulty getting physically into physicians' offices (Gynecological Care, 1993). The set-up of examination rooms and the breadth of corridors may be a problem for individuals with disabilities, especially if they are in wheelchairs. Ramps and raised signage on elevator buttons, accessible toilet stalls, and accessible water fountains are important (Ellen, 2001).

Some of the offices are structurally inaccessible or have inaccessible equipment, once inside an examination room in the physician's office; persons with physical disabilities may have difficulty transferring to high examination tables. The transfer may therefore be impractical and unsafe. Staff members in the physician's office may not have the training to assist individuals with physical disabilities to make the transfer and may not have the proper equipment to do the transfer sliding boards and transfer lifts (Gans et al., 1993).

Other physical barrier is located in the distance to local clinic or hospitals where there is need to use public transport. Most of the health units are very far from people with physical disabilities, therefore, they are not able to access reproductive health services from such places because of distance and the difficulties of public transport that are quite expensive and not disability friendly (Mulindwa, 2003).

2.7.4 Unwanted pregnancies

According to Ellet (2001), persons with disabilities should be able to access information and counseling on the effects of pregnancy and childbirth in their bodies, appropriate medical care during pregnancy and delivery, care for the child, genetic heredity issues and mental well-being. This is the reason for arguing that policies should be put in place to ensure that persons with disabilities have access to sexual and reproductive health information and services, including family planning and maternal health (WHO, 1981).

Mulindwa (2003) reports that it was found that many women with disabilities are abandoned by their partners when they become pregnant, while some others become pregnant after episodes of

rape. This leads to unwanted pregnancies, with a resultant high incidence of single parenthood among women with disabilities.

2.7.5 Complications during pregnancy and childbirth

According to Groce (2003), while it is widely believed that women with disabilities are neither sexually active nor capable of bearing children, in fact, the majority of them are both sexually active and capable of pregnancy and childbirth, and thus have reproductive health needs. Nevertheless, fertility rates have been examined in only a few types of disabilities, but where such evidence exists, the results indicate that these rates are similar to rates for women without disabilities (Stuifbergen & Tinkle, 2004).

The World Health Organization (2009) reports that, every minute, more than 30 women are seriously injured or disabled during labor, thus rendering vast numbers of women in the developing world physically and socially disabled. For every woman who dies from complications of pregnancy, between 30 and 100 more live with painful and debilitating consequences. This problem is more critical among women with disabilities in view of their disabilities and physical difficulties for self support, for example, a woman with quadriplegia who has limited use of hands would have to depend on spousal support or medical personnel during delivery, which are often not available (Allen, 2003). However, those 15 – 50 million women generally go unnoticed (WHO, 2009). Broad-based reproductive health for all women can ensure that preventable disability arising from complications of labor and pregnancy are averted (Allen, 2003). Maternal education during the antenatal period has also been shown to have positive links with children's immunization and care, thus, preventing disability in the newborn (WHO, 2009).

2.7.6 Sexual exploitation

Mulindwa (2003) reports that failure to get sexual/marriage partners were also mentioned particularly among the male and female with physical disabilities. This frustration has led to risky and reckless behaviour among many women with disabilities themselves. A typical response was: "Girls with disabilities offer themselves to men because they think that no man would ever approach them for true love. They live recklessly in a bid to be fulfilled sexually like

their able-bodied counterparts consequently, exposing themselves to the risk of contracting HIV/AIDS.

People with physical disabilities were also reported for mentioning their failure to get the partners they truly love as a hindrance to their enjoying quality reproductive lives (Cichocki, 2009). They also experience some form of “forced marriages”, which keep them longing and experimenting with other men and women and hence running a risk of contracting HIV or even total failure to be happy with their spouses (Nelson, 2005).

The links between poverty and disability figured prominently in the disability knowledge and research programme. This reveals that disabled people are more likely than other people to live in grinding poverty (Albert, 2005). This creates a platform where people with physical disabilities who are poor sometimes have sex in exchange for money or special favour (Soul City, 2004, p. 11). A further sexual abuse on people with disabilities indicates that most men want to experience sexual intercourse with a disabled woman because they are considered at less risk of sexually transmitted infection (STI). They were also reported at times to be in danger of sexual exploitation from the hand of their caregivers (Patrick & Matonhodze, 2005). The failures to recognise the sexuality of people with physical disabilities inform these series of inhuman treatment meted to them (Human Rights and Equal Opportunity Commission, 1997).

2.7.7 Reproductive health care for people with physical disabilities

The disparities in reproductive health care access and quality that persons with physical disabilities face may be accounted for by some combination of limitations in reproductive health care education (Gill & Brown, 2002). Hence, an urgent attention is thus needed by removing the discriminatory attitudes on the part of health care providers and the need to begin to offer comprehensive reproductive health education where the rights of people with disabilities are asserted (Mona, 2000).

Patient satisfaction is an essential measure of quality of care, and has been associated with enhanced decision-making involvement and improved compliance with medical recommendations. Improving communication between the health care provider and patient may increase patient satisfaction, particularly if the health care provider engages the patient with

empathy, friendliness, attentiveness, and positive reinforcement, while encouraging patient questions (Kopac & Fritz, 2005).

Health care providers should engage in direct communication with patients with physical disabilities to investigate concerns from the perspective of the patients. In addition, to identifying patients concerns and detailing their history, health care providers may need to solicit information about sensitive or taboo subjects, such as sexual behavior or abuse that have been ignored or discouraged by significant others. The establishment of healthy rapport will ease patients' anxiety and/or fear of negative judgment when discussing such topics (Lewis, 2002, p.174).

Other considerations for specialists when providing patients with physical disabilities services for reproductive health care should include information on menstrual hygiene and changes in behavior related to menstruation, assessment of sexual knowledge and experience, and reproductive health disorders associated with specific genetic syndromes (Paransky & Zurawin, 2003). In addition, is the need to develop necessary policies to ensure that persons with disabilities have access to sexual and reproductive health information and services, including family planning and maternal health. It equally requires that public health facilities and programmes for reproductive health are made accessible for people with physical disabilities (World Bank, 2004).

2.8 Socio-cultural attitudes towards people with disabilities

Myths and misconceptions around HIV/AIDS and disabilities

In anthropology, 'myths are studied as fractured sources of oral history, clues to a society's dominant values, or even as a social charter' (Marshall, 1998). This informs why in some cultures it thus seems to be problematic to work on the risk of HIV/AIDS infection within the disabled population because it is an area filled with myths (Groce, et al 2006). Disabled people are rendered largely invisible in many communities, and are largely overlooked in efforts by the global development to improve the human welfare and living standard (Heuman, 1998).

In indigenous Zulu cosmology, disease and disability can be interpreted as either natural or spiritual, with the social values of pollution and protection being highly influential (Hanass-

Hancock, 2008). For example, the custom of ritual ancestor worship can raise the acceptance of disability. This has been reinforced in the mind of many people with disability such that they are considered to be special beings. Some were thus groomed to be Sangomas (traditional doctors and diviners). This idea of semi – divinity made some people with disabilities to remain in denial, believing that their disability protects them from HIV (Hanass-Hancock, 2008).

Among the Buganda in Ugandan according to Kisekka (1976), the concept of asexuality of people with physical disabilities leads to the assumption that women with physical disabilities will remain virgin. Their partners then prefer having these “virgins” as sex partners on the grounds that they are disease-free. These conceptions offer double tragedies for people with physical disabilities because they are often victims of sexual abuse and rape.

There is another cultural belief that sleeping with a virgin will cure HIV (Groce & Trasi, 2004). The Virgin cleansing is a myth that has occurred since at least the sixteenth century, when Europeans believed that they could rid themselves of a sexually transmitted disease by transferring it to a virgin through sexual intercourse. Brothels in Victorian England were “stocked with intellectually disabled ‘virgins’ because it was believed that a syphilitic man could lose the infection by having sex with them (Smith, 2003).

Individuals with physical disabilities are also at increased risk of virgin rape because of lack of legal protection. ‘Police, lawyers, judges, and even rape-crisis counselors often have no knowledge of how to help people with disabilities, officials often dismiss individuals with disabilities who report rape, assuming them to be confused or victims of a misunderstanding’ (Sobsey, 1991, p.35). Before the advent of HIV/AIDS, women and men with physical disabilities suffered equal, or up to three times greater, risk of rape by strangers or acquaintances, than their non-disabled peers (Groce, & Trasi, 2004). The majority of people with disabilities, especially women, have experienced sexual violence and coercion in the context of power inequalities and environments that foster abuse. Other cases of rape and sexual harassment of people with physical disabilities has also been reported from boys at hostel, residences and communities (Philander & Swartz, 2006).

Although no epidemiological data are available, interviews with disability advocates, service providers, and the review of published reports, found reports of virgin rape of disabled

individuals in association with HIV/AIDS in countries from sub-Saharan Africa, south and south-east Asia, North America, and Europe with more of such rapes been reported over the past 5 years (Yale University/World Bank April, 2004).

Another factor responsible for the virgin rape of people with physical disabilities anchored on the belief that sex with virgin does cure an HIV-infected person (Murray & Burnham, 2009). This myth has gained considerable notoriety as the perceived reason for certain sexual abuse of vulnerable people with physical disabilities and child molestation occurrences, especially in Africa (Meel, 2003, Groce et al. 2004). In similar manner, men with physical disabilities are often excluded from circumcision rituals that symbolise the passage to adulthood, they are often excluded as they are believed to be asexual, and they then face being labelled 'boys' for the rest of their lives. This will become more significant with the recent recognition of the role of male circumcision in reducing the risk of HIV infection in men (South African National Aids Council May 2008).

2.9 Conclusion

According to Mona (2000), it may be argued that disabled persons need even greater attention and support than non-disabled persons in order to live a healthy sexual life. With many incorrect notions such as the asexuality of people with disabilities, the false claim of virgin cleansing, the false assumptions that HIV is confined to homosexuals, prisoners, prostitutes and the 'divine image of disability' are the erroneous beliefs that must be corrected to eliminate the idea that people with physical disabilities are not at risk of HIV/AIDS. Consequently, there seems to be an urgent need to design and evaluate the existing HIV prevention programs for people with physical disabilities (Buysse & Ickes, 1999). However, it may be difficult to know the best methods to do so without a detailed research that explores the perceptions and experiences of people with physical disabilities about HIV/AIDS.

Therefore, designing, implementing and evaluating HIV prevention programs for people with physical disabilities in South Africa, has become imperative in view of the prevailing circumstances that show that this part of the world is most affected by the epidemic (Yousafzai, Dlamini, Groce, & Wirz, 2004). If the impact of HIV/AIDS on non-disabled South Africans is rated among highest in Sub-Sahara Africa, in spite of the education and information available, it

is likely that people with disabilities are facing even greater challenges. This is in view of the records showing that there are limited facilities available for reaching and educating people with physical disabilities on awareness protection and prevention of HIV/AIDS (Groce & Trasi, 2004).

Finally, the lack of sex education for adolescents and adults with disabilities based on false notions that they are not sexually active has severely limited their ability to understand safer sex messages and to negotiate safer sexual behaviours (Groce, 2005). The same incorrect assumption has been attributed to the reason why HIV/AIDS prevention and care services of this large group of people with physical disabilities has been neglected (Yale/World Bank Global Survey, 2004).

CHAPTER THREE: RESEARCH METHODOLOGY

3.1. Aim and objectives

The main aim of the study was to explore the experiences and perceptions of people with physical disabilities about HIV/AIDS in an urban South African university context.

The objectives of the study were to:

- i. Explore the knowledge base of people with physical disabilities in a university environment about HIV/AIDS
- ii. Identify the knowledge about services offered to people with physical disabilities in an urban university environment on HIV/AIDS
- iii. Explore the views about services offered to people with physical disabilities in an urban university environment on HIV/AIDS
- iv. Explore the challenges and barriers faced by people with physical disabilities in accessing services for HIV/AIDS in urban university environment
- v. Explore the views of caregivers about the experiences of people with disabilities about HIV/AIDS in urban university environment

3.2 Research design and methodology

3.2.1 Research design

In order to explore the perception and understand the experiences of people with physical disabilities about HIV/AIDS, a qualitative approach was used with an exploratory design. This type of design was selected as the most appropriate means of describing perception and experiences as well as identifying attitudes, beliefs and practices and also permits the researcher to determine any patterns or common themes arising from the data (Babbie & Moutton, 2001).

Qualitative research according to De Vos (1998) seeks to describe and understand social issues and phenomena. Hence, the researcher use of qualitative research enables him to increase his familiarity with the topic while taking into consideration the principle of objectivity and value neutrality in the interpretation of data.

Exploratory research in similar vein is conducted to gain insight into an unexplored situation, phenomenon, community or individual so as to formulate a problem or develop a hypothesis (De Vos, 1998). This approach was selected in order to gain a first hand and holistic understanding of participants' experiences by means of a flexible strategy of problem formulation and data collection. Qualitative exploratory design approach was used in this study to gain insight and understanding to the experience and perception of people with physical disabilities in urban university community about HIV/AIDS.

There are conflicting opinions on the principle of objectivity (Rosenthal & Rosnoy, 1991). It has been argued that, true objectivity is neither attainable, nor desirable in social research. Since it is not really possible to divorce personal values, assumptions and judgments from the process of research, it is potentially more harmful to deny or ignore the influence of these factors on our construction of reality or the facts. This position places worth on subjective understanding and value, arguing that social researchers have duty to effect social change rather than merely reporting on and accepting the 'objective' facts (Sarantakos, 1998).

3.2.2 Research methodology

3.2.2.1 Sampling procedure

In order to render sufficiently rich material and because the study focused on experiences and perceptions of people with physical disabilities, purposeful selection was employed (Miles & Huberman, 1994). Currently, the University of the Witwatersrand has a disability unit serving students with various types of physical disabilities who are eligible for selection as participants. Ease of access to participants was the major reason for the choice of the Disability Unit. The researcher's registration at the university from which the participants were drawn also made access to these students and staff members via the Disability Unit Director non-problematic.

The main selection criteria of the participants were that they were students and staff members of the university. Second, they were students and staff members with physical disabilities, while the only exception is the non-disabled staff member included on the basis of long years of working experience with people with disabilities. This later criterion was imposed because such self-selection suggested that these participants had identified with the perceptions and experiences of people with physical disabilities on HIV/AIDS issues. This is also indicated their

willingness to serve as lobby group towards addressing the needs and services for people with disabilities on HIV/AIDS.

The study sample was made up of 12 students among the 18 students with physical disabilities registered with the Disability Unit of the University of the Witwatersrand. Others participants included two staff members with physical disabilities and one non-disabled staff member from the Disability Unit in the university. Fifteen participants were thus included in the study, ages between 18 to 42 years. In total, four male participants and eleven female were interviewed. The racial distribution was two white, one Asian, one coloured and eleven black participants. Their physical disabilities included cerebral palsy, muscular dystrophy, spinal lypomia, temporary orthopaedic disability (accident) and paraplegia.

A non-probability sampling method was used for this study. This is a sampling method where the chance of selecting a particular individual is not known because the researcher did not know the population size or the members of the population (De Vos, 1998). Non-probability purposeful sampling therefore is based entirely on the judgment of the researcher in that a sample is purposeful and composed of elements that contain the most characteristics, representative or typical attributes of the population (Rubin & Babbie, 2005, p. 247).

An application letter (Appendix B) seeking approval was sent to the Director of the Disability Unit in the University to allow the researcher to conduct a research study by interviewing students with physical disabilities registered with the Unit and the staff members' working in the Unit. Following the approval letter from the Disability Unit Director to recruit participants from the unit (Appendix B), selection of the participants was based on an invitation to all students with physical disabilities using the unit facilities and staff members working in the unit through the distribution of the participants' information sheet (Appendix D). The participants' information sheet explains the purpose of the research as well as the demand that will be placed upon them should they agree to participate. Those who indicated their intention to participate were required to sign consent forms as well voluntary consent forms for audio taping (Appendix E & F). All the participants that signed and submitted their consents forms were included in the study.

3.2.2.2 Research instrument

The instrument used for data collection in this study took the form of face to face semi structured interview (Appendix A). The interview allowed for each participant to be asked the same set of questions which yielded similar textual data about the perceptions and experiences of people with physical disabilities regarding HIV/AIDS awareness campaign, prevention and protection services.

The semi-structured interview schedule was selected as the most appropriate method of data collection as it was likely to afford personal interaction that would engender a sense of trust and cooperation. This was particularly important as it was anticipated that questions regarding sexuality and HIV/AIDS might be considered sensitive by some participants (Rosenthal & Rosnow, 1991). It was also anticipated that participants would find it less intimidating or threatening to answer questions in a face-to-face interview. There were further reasons for using face-to-face interviewing. First, face-to-face interview typically yields higher response rates than questionnaires that need to be filled out by the participants (Babbie & Mouton, 2001).

Face-to-face interviews also afford the researcher the opportunity to address misunderstandings and clear up ambiguities if and when they occur during an interview. The researcher is therefore able to ensure that the participant understands the purpose of the question and the participant's response is relevant to the question been asked. Interviews also allowed the researcher to ask for more details or clarification if the response of the participant is not clear. This opportunity to clarify misunderstanding is vital within a local context wherein the language and culture of the interviewer and interviewee are seldom the same (Babbie & Mouton, 2001).

Interviews also allowed the researcher to probe or give verbal prompts so that the participant is encouraged to elaborate further when given open-ended questions. Finally, face-to-face interviews provide the opportunity to observe the participants' reactions to certain questions and to observe the general surroundings and atmosphere of the organization (Babbie & Mouton, 2001).

3.2.2.3 Methods of data collection

The researcher secured permission for audio taping the response of the interviewee which was later transcribed by the researcher. Transcribing soon after an interview allowed the researcher to add in comments about what was happening during the interview, and made notes about body language and other cues that added to the meaning of the respondents' words.

The questions were asked verbally and the participants' responses were recorded in writing as well as audio recording. The interviews were conducted in the consultation room at the University's Disabilities Unit. This allowed for participants privacy. Each interview session lasted between thirty to forty minutes. The choice of this method was guided by the need to make the process participatory, interactive, created atmosphere for the researcher and the respondent to learn from each other and give basic information about HIV/AIDS where necessary.

3.3 Method of data analysis

As there are few rules in the analysis of qualitative information (Bryman, 1999; Blanche & Kelly, 1999), that there are various ways of analyzing qualitative studies. Blanch & Kelly (1999) state that data collection and analysis tend to gently fade into one another at times and seem co-dependent. It was for these reasons that numerous writers influence the analysis of this study. Approaches advocated by different authors may all have slightly different nuances but all stipulate an approach that focuses on the importance and value of coding extracting themes from the interview transcripts (Henning, 2004; Bryman, 2001; Blanch & Kelly, 1999 and Robson, 1993). The approach that was utilized could thus be defined as thematic content analysis.

According to Kruger (1988), thematic content analysis is an appropriate method for analyzing texts transcribed from interview and group discussions. The study made use of a kind of critical thematic content analysis, allowing for identification of descriptive, interpretive and discursive elements. Since the aim of this study was to make inferences and draw interpretations regarding the perceptions and experiences of people with disabilities about HIV/AIDS, content analysis seemed an appropriate approach. Thematic content analysis is the term used to describe a more interpretive application of the content analysis method and involves the identification of various themes which are in turn categorized and finally elaborated upon on the basis of systematic scrutiny (Bannister, Burman, Parker, Taylor & Tindall, 1994). The basic structure below

provided the manner in which the analysis of this study proceeded. The process was circular in its function with many of the stages influencing one another and overlapping. Furthermore it must be noted that the researcher completed the interviewing, transcribing and analysis of the study thus staying close to the data. Hence the interview transcripts were analysed by use of various steps.

First, the initial audio tapes were transcribed verbatim. After the transcription the researcher began with what Henning et al (2004) calls open coding. In this part of the process the entire texts were read for purpose of the researcher gaining a global impression of what had been said. Blanche & Kelly (1999) believe that, at this point it is important for the researcher to immerse himself in the work and make additional notes and brainstorm possible direction and ideas. This defining process was both inductive and deductive (Blanch & Durrheim, 2002). Deductively, the texts were analysed openly in the context of the literature covered in the review to allow for the possible emergence of previously unidentified themes. Doing this allowed the researcher to gain a holistic impression of his data rather than focusing on specific interview only. Thus the researcher was able to identify a range of themes and those most common were highlighted.

After the first readings, possible themes were written down on a separate page. It is important that these are to be written down in the language of the participants rather than in the abstract terminologies (Blanche & Kelly, 1999). These provide a rough idea of final themes that were likely to emerge. These were very rudimentary categories, but were clustered under general headings according to similarities to other potential themes or ideas elicited in the transcripts. Throughout this and subsequent stages various notes were written in the margins of the transcribed interviews. These helped guide the thinking of the researcher and provided a good index of where certain thoughts had stemmed from.

The focus of this research was upon themes and consequently, thematic units were defined. Guba & Lincoln (1985) suggest that a “theme” is an assertion about some subjects. This assertion may be explicit or implicit. With this conceptualization in mind, thematic units were defined in term of their logical coherent around a specific topic germane to the perceptions and experiences of

people with physical disabilities about HIV/AIDS. An attempt was made to analyse the interview transcripts to locate the presence of body languages and materials relating to the themes. For example laughter and rhetoric questions were noted in the responses. These were used to add breadth to the context interpretation during the discussion.

Those themes which occurred most regularly at the interviews which include examples of both identification with and contestation of the perceptions and experiences of people with physical disabilities about HIV/AIDS were selected for discussion and interpretation. In the discourse analysis, a loose adherent to the methodology of Bannister et al, (1994) was followed. The researcher aim to describe how pertinent discussion operates to naturalize the things they refer to, in other words how they attempt to construct the things they refer to in such a way as to make questions to them appear perverse and nonsensical. This is particularly relevant to the discourse surrounding perceptions and experiences of people with physical disabilities about HIV/AIDS. Those who benefit from the discourse as well as those who are disadvantaged by it were borne in mind and the degree to which participants take up position as a functional space and time to maximize their benefits and minimize any disadvantage were explored. This includes attention to those who support the discourses and under what circumstances, as well as those who discredit the discourse, and under what circumstances this discrediting and contestation occurs.

3.4 Limitations

The study was limited to participants from one specific university community. Consequently, the results may not be generalized to other institutions of higher learning in the country. However, as this was a qualitative study, the interest was in the specific responses of the participants.

Interviews are time consuming and are not as economical as other methods such as questionnaires or telephonic interviews (Rosenthal & Rosnow, 1991). For this reason, it was necessary for the researcher to limit the number of interviews conducted in order to make the project personally manageable. It is acknowledged that the sample would then be small and consequently the results would be less generalised to the population as a whole.

It is also possible that the presence of the researcher might have led to the participants providing what they saw as desirable responses to some of the questions. However, the researcher ensured that questions were asked in such a way that participants felt comfortable and he assured them that their honest responses were important.

A further limitation related to the open ended nature of the responses and their interpretations. The researcher had to ensure that he cautiously reflects on his own ideas and thoughts and their contribution or influence on the process of analysis.

CHAPTER FOUR: DATA PRESENTATION AND ANALYSIS

4.1 Biographical details

The study sample consisted of different distributions of gender race and physical disabilities as found in the tables below:

Table 3: Age distribution

Age	18 -20	21-30	31-40	41+	Total
Number	5	7	2	1	15

The majority of the participants were over 21 years of age. This help to reflect the mature responses of people that have the knowledge and awareness about HIV/AIDS infection.

Table 4: Gender distribution

Male	Female	Total
4	11	15

Although the participants were predominantly female, effort was made to balance the participants' distribution along gender. This was for the purpose of securing balance responses that will not be biased against gender status.

Table 5: Physical disabilities distribution

Type of physical disability	Number
Cerebral palsy	6
Muscular dystrophy	1
Spinal lypomia	1
Paraplegia	4
Orthopaedic/ Accident	2
Total	14

The degree of physical disabilities of participants were in various categories from moderate to severe, while the nature of the physical disabilities ranged from cerebral palsy, muscular dystrophy, spinal lypomia, temporary orthopaedic disability (accident) and paraplegia. However, a non- disabled staff member who had worked in the unit for a long time was included in the study.

4.2 Results and discussion

4.2.1 Category 1: Awareness and knowledge about HIV/AIDS

Theme	Responses
HIV/AIDS is universal	<i>“HIV/AIDS is a global disease that has assumed pandemic ratio”</i>
Meaning of HIV/AIDS	<i>“When one is HIV positive, it means he or she has got HIV virus in his system”</i> <i>“HIV is Human Immunodeficiency Virus – a type of retrovirus that causes AIDS”</i> <i>“Acquired Immune Deficiency Syndrome - An infectious disease of the immune system caused by human immunodeficiency virus (HIV)”</i>
Transmission mode	<i>“It is medical condition that is transmitted through blood from sexual relationship, blood transfusion sharing of sharp objects like needle or from mother to child”</i>
Terminal nature of HIV/AIDS	<i>“HIV/AIDS is incurable, though an HIV positive can help prolong his or her life by living a healthy life style before developing a full blown AIDS”</i> <i>“AIDS is the period when HIV has become aggravated, giving room to opportunistic diseases to wear down the immune system which eventually leads to death because it is incurable.”</i>

There was great awareness about HIV/AIDS among the participants. However, not all of them understood the meaning of the various acronyms. There was a high level of knowledge that HIV

is mostly spread through having sex with an infected person. Other modes of HIV transmission are however, not well known by all the participants. For example, unsafe blood transfusion was mentioned by only a few participants. The sharing of unsterilized sharp objects such as syringes (needles), barbing clippers, razor blades, etc, as means of HIV transmission were only moderately known. The vertical transmission of HIV from mother to child during pregnancy and breast feeding was the least known mode of transmission among the participants. The participants had the knowledge that HIV is characterized by a decrease in the CD4 cells count, which causes a severe immunodeficiency that leaves the body susceptible to a variety of potentially fatal infections that develop to AIDS. They also understood that AIDS patients can be identified with series of sicknesses such as loss of weight, tuberculosis, whooping cough, body rashes and many other sicknesses which eventually lead to death because no cure has been found.

4.2.2 Category 2: Link between physical disabilities and HIV/AIDS

Themes	Responses
Link misunderstood	<i>"I do not believe my disability will one day make me HIV positive"</i>
	<i>"but that is not disability it must be another kind of sickness"</i>
Poverty	<i>"'when you are poor, you are forced to take anything that comes your way just to survive' 'because people with physical disabilities are largely poor due to their condition of disabilities, they are likely to fall victim of sex for material or financial gain"</i>
Marital responsibilities	<i>"Anyway, who will marry a poor man let alone disabled? How would he possibly be able to provide for the home when in fact many in rural places depend on hand out from disability grant for survival?"</i>
Lack of confidence to negotiate safe sex	<i>"I think we should have a conference on increasing boldness and self esteem among people with disabilities"</i>

Low self esteem	<i>“There is casual attitude by female with physical disabilities to request for condom because they feel honoured to sleep with a man especially with non disability and care less to discuss condoms with their partners”</i>
Cultural inhibitions	<i>“I don’t feel comfortable asking for condom from the Clinic staff you know, it is like asking my mother “can I go and have sex” Somehow ridiculous, what do you think?”</i>
Accident	<i>“My friend on Wheel Chair was involved in an accident on his way home from work. Unfortunately, the next person to him in the taxi was HIV positive hence there was blood contact; he contracted HIV from that incident”</i> <i>“when we fall many people may want to help even though unsolicited, during these emergencies most helper do not take necessary precaution which may allow for blood contact”</i>

Link between disability and HIV/AIDS misunderstood: Many of the respondents initially found it difficult to see the relevance of linkages between physical disabilities and HIV/AIDS. During questioning, they assumed that it was implied that a person with disabilities would develop HIV/AIDS – this explained their initial responses. After explaining to participants that the question related to whether the onset of physical disabilities can be a predisposing factor toward contracting HIV/AIDS, participants agreed that there are linkages between physical disabilities and HIV/AIDS for many reasons.

Poverty: Some of the participants explained that poverty was the major factor through which people with physical disabilities are coerced into accepting anything even though undignified just to make end meet. This claim has been supported by Groce, (2003) and Elwan, (1999) that extreme poverty associated with disability was cited as a factor forcing some into sex work. The inability of people with physical disabilities to engage in physical activities due to their physical

body weaknesses often denied them of being employed, they may not even be hired for casual labour by employers because of the general belief among people that people with physical disabilities are too weak to engage in any serious work involving physical activities (ESCAP, 1995; Mulindwa, 2003). In addition, people with physical disabilities are among the most chronically poor groups of the population in the world. This high level of poverty pre-disposes them to HIV/AIDS such that women have to engage in sexual activities with multiple sexual partners in anticipation of financial and other forms of support (Abang, 1992; UNICEF, 1999; Elwan, 1999; Nelson, 2003).

Marital responsibilities: The thought of many participants was that men with physical disabilities were too poor to afford basic marital responsibilities such as to pay ‘lobola’ (the bride price) and be able to acquire wives like other men. Consequently, they are exposed to looking for sexual engagement with just any available partners. It was also mentioned that the rate of divorce is very high among people with disabilities because when men with physical disabilities manage to get married, time comes when they cannot fulfill all the requirements as the head of the family which further exposes their spouse to outsiders or eventually losing their wives, thus putting them at the risk of contracting HIV/AIDS. In his finding Mulindwa (2003) supported the above claim when he reported that failure to identify faithful sexual partners and later on spouses remains a major problem affecting people with physical disabilities. This exposes them to sexual exploitation while some are used as commercial sex workers.

Confidence and low self esteem: Although there is widespread knowledge of protection through the use of condom among people with disabilities in the university environment, yet almost all the respondents believe that there is very low usage of condom by both women and men with physical disabilities mainly because many of them are of the view that people with physical disabilities lack confidence to negotiate safe sex, because of fear and stigma suffered in the process of securing a condom. They explained that the common trend of social barrier due to stereotype and marginalization reinforced low self esteem among people with physical disabilities Groce (2003) confirmed that, the problem of self confidence and personal self worth continue to hunt people with physical disabilities, couple with societal wrong assumption that people with physical disabilities are not sexually active. In some cultures, women whether they

have disabilities or not have no choice when it comes to the selection of a sexual partner. It becomes a double tragedy when with physical disabilities (Nelson 2005).

Cultural inhibitions: Another feeling shared by participants is the cultural inhibition that they are wrongly construed as not sexually active, and that their empowerment was curtailed by the overprotection of their parents. Some believed that, as the service providers at the Campus Clinic were generally older women, it was difficult to talk about sex or request condoms. This is considered disrespectful in African culture; alternatively, the feeling of shame associated with having people with disabilities engaged in sexual behaviour inhibits this request. This claim was confirmed by Mona (2000), who maintains that, a physically disabled individual engaging in sexual activity has been an image not easily entertained by mainstream society.

Traumatic accidents: Having an accident was also pointed as one of the factors that could make a person with disability contract HIV/AIDS. Because people with physical disabilities are limited in mobility if they are involved in an accident with an HIV positive commuter there is the possibility of flow of blood hence the person with physical disability may not be able to move away.

4.2.3 Category 3: Views about preventative measures

Themes	Responses	
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Abstinence	<i>“The most effective way to ensure that you will not be infected is by practicing abstinence, in other words, not having sexual intercourse unless you are married”</i> <i>“On no account should you be pressured to have sex by your peers or your partner. You should not feel ashamed or shy to say “No” because you need to respect your body and your sexuality”</i>
Number of partners	<i>“Although I am a guy, I really do not fancy going out with many ladies, apart from financial burden, it exposes one to great risk in this age of HIV/AIDS”</i>
Faithfulness	<i>“I think the problem of faithfulness is largely with guys especially when you are dating a non-disabled person who probably may think he is doing you a favour”</i> <i>‘Well it may be difficult especially if your partner is the type that can be enticed with money or material gain’</i>
Safe sex	<i>“If you must do it, please condomise!”</i> <i>“Until you are tested and you are sure of your partner’s faithfulness do not stop using condom just because you have used it twice or thrice, you cannot conclude that now you have known your partner”</i>
Alternative method	<i>“Penal intercourse is not the only way to have sex; there are other sexual methods that can be practiced just to keep safe”</i>

Medical testing	<i>“Having an HIV antibody test will allow you to know whether you are HIV negative or HIV positive”</i>
Illegal drugs and injection	<i>“The best way for such drug users to reduce the risk of infection is not to share needles and syringes, and to avoid mixing drugs in shared containers, like spoons and bottle caps”</i>
Sharing sharp objects	<i>“Before you take injection from the clinic ensure that the doctor or nurse uses a new syringe if possible ensure the syringe is open right in your presence”</i>
Precaution with blood	<i>“It is advisable not to touch blood, otherwise use latex gloves to prevent contact. This will help to avoid contracting HIV or to pass it to a person to be helped if you are living with HIV”</i>
Awareness campaign	<i>“I don’t think people with physical disabilities are less prone to contracting HIV/AIDS, it is only reasonable to have us in mind when projects and plans are made to combat the scourge of the epidemic much more that we appear more vulnerable”</i>

Abstinence: The views of the participants on preventative measures and strategies for reducing the risk of HIV/AIDS were clear about the fact that everyone is at risk of getting HIV. According to them, to be physically disabled offers a double tragedy in view of the extensive vulnerability

that they are exposed to in contracting the disease. They all agreed that sex is not something to be rushed into or shared with just anybody. Some of the participants advocated for abstinence as the best option to keep safe from sexually transmitted diseases. It was echoed that there are many other ways to enjoy somebody's company and show affection towards him or her other than just having sex. In the wake of HIV/AIDS pandemic, many traditional leaders have endeavoured to revive the age old cultural tradition of virginity testing. Although 'this practice has received some challenges by those who think in the contrary that it violates the privacy of the young girls or result in young people opting for anal and oral sexual activities, which may also be avenue for getting affected by HIV' (Ross, 2008, p. 390). Nevertheless, since the practice is voluntary, the dignity and respect accorded to this practice may enhance abstinence and prevent pre-marital sexual relationship hence, a preventative measure against HIV/AIDS.

Number of partners and faithfulness: The participants agreed that for those who cannot abstain, it is essential that they do not have multiple sexual partners. Because when one is limited to one partner, it safeguards from the risk of HIV/AIDS. The respondents also echoed the need for faithfulness in relationships. They agree that both partners must ensure faithfulness in their relationship. These claims are most essential in the wake of significant social oppression and stigmas suffered by people with physical disabilities in many socio-cultural contexts, perhaps more within the contexts of dating and romance and in their attempt to negotiate sexual intimacy, this explains why non-disabled consider it a favour when dating a person with disability (Tennis & Herdt, 2007). Mulindwa (2003) confirms that it is hard for people with physical disabilities to find faithful partners because they are disabled. Hence men think they are not like able-bodied women, while men with physical disabilities report that beautiful girls despise them and think they are not worth being taken as serious and capable partners.

Safe Sex and alternative method: Participants agreed that if someone decides to have sex especially in a new relationship, it is important to use condoms until both partners have been tested negative. The respondents view that, condom is very important because if eventually one of the partners is HIV positive; the use of condom will help them to continue to have sex without affecting each others. Oral sex was considered to be less risky than vaginal or anal sex, but if either of the partners has sore in the mouth or on the penis, vagina or anus, it is possible to get HIV through oral sex.

Medical testing: Many participants agreed that it is necessary to have medical test periodically to know one's HIV status. They agreed that if someone is HIV positive, he/she can prevent others from getting it if he knows his/her status, in the same vein he/she can get care, support and treatment for opportunistic infections as well as get antiretroviral treatment as soon as possible to help prolong and improve the quality life. In addition, it is necessary to help prevent the transmission of the virus to the baby in the womb because a pregnant woman who knows she is HIV positive can reduce the chances of HIV being passed on to her baby by taking informed decisions about treatment and breastfeeding.

Illegal drugs and injection and sharing sharp objects: Participants all agreed that people with disabilities are particularly suppose to be more careful when taking injection especially those who are diabetic and need to check their sugar level from time to time. Drugs are illegal as agreed by all respondents. It was considered harmful and should be avoided. However people who inject drugs, or whose partners do, are at risk of contracting HIV. Person who chooses to inject drugs can prevent HIV by using clean needles and syringes each time. People with physical disabilities should also avoid sharing razor blades, unsterilized clippers at barbing saloon, manicure and pedicure as well as tattooing objects because the HIV virus can be passed on through infected blood. These claims was supported by the Global Survey on Disability and HIV/AIDS conducted by Yale University and the World Bank which has shown that Individuals with disabilities have equal or greater exposure to all known risk factors for HIV infection (Groce, 2004) with individuals with disability likely as non-disabled people to use drugs and alcohol (UNICEF, 1999).

Taking precaution with contact with blood: People with physical disabilities are seen to be very kind and all willing to help others. However, they must take precaution when handling blood especially when assisting an injured person. Like any other person, people with physical disabilities could be at risk of blood infected with HIV. It was agreed that in case of need for blood transfusion it must be ensured that thorough screening of blood is done before transfusion to unsure safety from HIV.

Awareness campaigns: Finally, all the participants agreed that people with physical disabilities should attend awareness campaign for better education and understanding of further means to prevent them from contracting HIV/AIDS. They however decry the low attention given to them.

This was confirmed by Groce (2003) when she stated that, a hallmark of the HIV/AIDS epidemic has been its impact on vulnerable populations. Individuals with disability have been almost entirely overlooked despite the fact that they are at equal or increased risk of exposure to all known risk factors for HIV (Groce, 2003).

4.2.4 Category 4: Available services on HIV/AIDS

Theme 1: Tailored services.

The majority of the participants responded that there were no tailored services available on HIV/AIDS for people with physical disabilities in the University. Some of the responses were:

‘I have not yet seen any specific HIV/AIDS services tailored specifically to people with physical disabilities like we do have on the area of academics’

‘I suppose because of our disabilities that is why we have some of these resources here to bridge the gap with non-disabled students, but nothing similar have been put in place to address HIV/AIDS for us.’

‘Because we have always been in this situation almost from birth, home and outside community, it did not matter much when we found similar situation in the university, the circle of disconnection just continues.’

‘Although, there are no specific tailor made services for people with physical disabilities, yet there are services available in the university for all students including disabled students alike’

Theme 2: Services of the Disability Unit

Participants explained that the services at the Disability Unit at the University are specifically directed toward assisting students with disabilities who are experiencing any challenges in their academic life. The responses were as follows:

‘We are here to assist students who express challenges on their education and related issues such as mobility and orientation around the campus. We do not have mandate to offer HIV/AIDS awareness campaign, counselling or related services neither do we have the expertise to do so. They are comfortable I think with Campus clinic’

‘There is HIV awareness programme for people with physical disabilities at the beginning of the academic year during orientation week as well as the last week of the year in November’

The majority of the participants responded that there are no tailored services related to HIV/AIDS specifically for people with physical disabilities. Some agreed that this is part of the circle of marginalisation and exclusion that people with disabilities usually encounter in all sphere. Nevertheless a respondent who was a staff member of the disability unit responded that, the need for tailored services for people with physical disabilities has not been considered urgent in view of the need for proper mainstreaming as well as objection from some categories of people with disabilities who believed that providing special services for people with disabilities is cable of creating further division from the larger society.

The response regarding the perceived lack of tailored services informed the request to know if the Disability Unit offers any related services on HIV/AIDS. Participants explained that services to people with disabilities at the university are indispensable, but none related specifically to medical challenges specifically for people with disabilities. They stated that in addition to the Campus Clinic, Mobile clinic occasionally visited the university to offer general awareness campaigns about HIV/AIDS in the university.

Some of the participants pointed out that people with physical disabilities are often not able to attend HIV/AIDS awareness programmes because how cumbersome it was to move around. Similarly, they expressed that end of the year awareness campaigns for HIV/AIDS might also not be attended as many students leave for holiday immediately after exams. It was clear that participants were aware of services on HIV/AIDS for the entire university community, but that they felt that there was a lack of tailor-made services for students with disabilities. This perhaps falls within the larger circle of exclusion and marginalisation of people with disabilities as confirmed by Grocer, et al, (2006) and the World Bank (2004).

4.2.5 Category 5: Barriers to accessing HIV/AIDS services

Themes	Responses
Physical and architectural barriers	<i>'some of the available ramps are narrow with sharp gradient that can allow someone on wheel chair to roll back which can result in a fall accident'</i> <i>'for the mobile clinic, the van is not wheelchair friendly, one cannot enter for test, access is difficult for those on wheel chair'</i>
Human barriers	<i>'Non-disabled people often crowded the available ramps making it difficult for us to navigate our way through'</i>
Location of services	<i>'It is tiring to walk down that far especially for those on Wheel chair'</i>
Social barriers	<i>'people look with surprise when they see people on wheel chair coming for HIV test'</i> <i>'Sometime one notices expression of surprise and confusion of staff in the clinic. This is perhaps because they have always been relating with non – disabled'</i>
Cultural barriers	<i>"HIV/AIDS carries a heavy stigma, you are looked down upon and tacitly excluded from all social and community participation, this is</i>

Service bottleneck	<i>a double tragedy for people with physical disabilities who are already grappling with discrimination”</i> <i>‘you see some us are from close community, and culturally conservative to discuss matters relating to sex or HIV with an outsider, that includes going for HIV test and counselling’</i> <i>‘because the services are largely constructed for normal people, commonly, the practices require that you make proper booking before coming to clinic’</i>
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Physical and architectural barriers: The participants unanimously responded that in view of lack of tailored services for the needs of people with physical disabilities, it is probable that programmes and projects were planned and developed largely with able people in mind. Hence they were of the opinion that places where HIV/AIDS services are provided like Campus Health and the Wellness Clinic, the Emthonjeni Centre and CCDU could be made more accessible by expanding the breadth of the ramps and corridors and reduce the gradient of those ramps that may be difficult for people using manual wheelchairs. Another problem associated with the ramps is the lack of education by non-disabled people on the use of ramps in the campus. Participants complained that, large numbers of students are yet to understand the priority of the use of the ramps in the campus.

Participants also shared a perception that sometimes staff members at clinics are competent in their own right merit but may not have sufficient training to assist individuals with physical disabilities for example support when there is need to make unusual transfers from wheelchairs to examination beds.

Human barriers: Some lifts on the campus were reported to have their elevator buttons raised beyond the limit of someone on a wheel chair. They also perceived that many of the doors to services points were not wheel chair friendly. Some had heavy doors at the entrance without automatic sensors for opening. In this regard Gans et al. (1993) cited by Ellen (2001, p. 193) stated that the set-up of examination rooms and the breadth of corridors may be a problem for individuals with disabilities, especially if they are in wheelchairs. Ramps and raised signage on

elevator buttons, accessible toilet stalls, and accessible water fountains are important (Matson, Holleman, Nosek & Wilkerson, in Ellen (2001).

Location of services: The participants understood that the Campus Clinic acts as a reference service for local clinics and hospitals. People with physical disabilities are faced with challenges of using public transport that are not disabled friendly. The large size of the university was perceived as a further challenge with most of the health and service units located far from lecture rooms and hostels. This was supported in findings of Mulindwa (2003), who found that people with physical disabilities have challenges in accessing reproductive health services because of distances and the difficulties of public transport that are quite expensive and not disability friendly.

Social barriers and service bottleneck: The incorrect notion that people with physical disabilities are not sexually active was acknowledged by most of the respondents. The oversensitive reaction to people with disabilities was equally perceived by the participants as an added stigma against people with physical disabilities. While the participants were of the opinion that mainstreaming is important for people with physical disabilities, they were concerned about the way that service delivery seemed to give no preference to people with physical disabilities who lacked the capability to access services on equal grounds with non-disabled people. This type of social exclusion and marginalization of people with physical disabilities according to Heuman (1998) has a far reaching effect on their inclusion in services and awareness campaign about HIV/AIDS. Other researchers have suggested that the disparities in health care access and quality that persons with physical disabilities face may be accounted for by some combination of limitations in health care, discriminatory attitudes on the part of health care providers and sometimes painful medical options to a patient with multiple physical functioning (Ellen, 2001).

Cultural barriers: A large percentage of the participants agreed that culture plays a great role in individual sexual behaviour and interaction. Some expressed that it is culturally disrespectful in Africa to enter into discourse about sexual matters with an adult. There was also a perception that to be HIV positive meant that the person is immoral. This was another obstacle to consulting for HIV services. This claim is supported by some writers that, this circle of discrimination and cultural marginalization is perhaps not limited to South Africa with similar beliefs common

around the neighbouring countries (Drews, Foster & Chituna, 1996; Jackson & Mupedziswa, 1988).

4.2.6 Category 6: Attitudes and reactions of caregivers

The interview probed for the perceived attitudes and reactions of the service providers. The participants are of the view that discrimination and marginalization faced by people with physical disabilities in the university environment is similar to their experiences in the local community. These themes follow their responses.

Theme 1: Shock and pity

The response was:

‘As usual and common among non – disabled they consider it abnormal to see people on wheel chair or crutches come to test for HIV. Consequently they are subject to pity, shock and or ridicule’

Theme 2: Emotional immaturity

Some of the responses were:

‘Some of the service providers lack emotional maturity’

‘Some are tempted to overreact when handling people with disabilities’

Theme 3: Ignorance

Response was:

“Whenever some people see you on wheel chair they concluded that you are stupid or sick in the brain as well. This part explains why ordinary achievement of people with physical disabilities receives undue attention and publicity”

The participants perceived that some people wrongly think that disability renders people immune to HIV infection, because of the impression that people with physical disabilities are a community in isolation from society and the environment challenges. Some are of the view that some health personnel, are less skilled and ignorant on how to interact with people with physical

disabilities on HIV/AIDS service. For instance they may be inpatient or fail to understand a person with cerebral palsy whose speech had been impaired.

Others explained that people with disabilities faces devaluation from HIV/AIDS service providers when some staff members attempt to provide overshadowing support because of inability to meet some sets of standard like non -disabled. Hence, disability is localized and diffused as being the whole personality of the affected.

The above claims are widely confirmed by many researchers. Disability is viewed as a stigma, a discrediting category that carries with it the ascription of characteristics that devalue the individual so labelled in ways that have little to do with the “objective” disabling condition (Goffman, 1963). In the public mind, physical disabilities are equated with physical limitation, marginal health, limited interest in sexuality and poor reproductive potential (Chance, 2002; Zaczek – Farber, 1998). This is probably due to our preconceived traditional belief that disabilities are taboo. Hence, people with physical disabilities are less likely than others to be informed about HIV/AIDS (Mulindwa (2003).

4.2.7 Category 7: Vulnerability to HIV/AIDS

The themes emerging from this discussion points to the perception of participants that people with physical disabilities are as vulnerable to HIV/AIDS as everyone else.

Theme1: Unfaithfulness:

Examples of a response were as follows:

“People believe they can get you easily and cheap. They take advantage of you because you are with disability”

“People befriend you because they need something from you and not for serious love hence there is no commitment in the relationship”

Theme 2: Peer pressure

Response was as follows:

“I think generally, students in the university are more promiscuous, they are erratic with their numbers of boyfriends. They have one this week and another next week perhaps because they are younger”

Theme 3: Rape and sexual harassment

Responses were:

“I broke up with my first boyfriend because he thinks he was doing me a favour and I must always be available to satisfy his sexual desire. I consider that this does not put us on equal footing for mutual respect, at most he just wants to be using me”

‘Some may say yes this is disabled but you can tell a rapist does not really care, all that matters is to satisfy his lustful desire’

Theme 4: Social value and expectation

Responses were as follows:

‘Women with physical disabilities are not recognized as being "women" enough’

‘Disabled people are often not in control of their own sexuality and rights because we are not well informed’

‘People are always willing to think for us you know!’

The general unfaithfulness especially by non-disabled men dating people with physical disabilities was widely reported. Participants’ partners were often found to be dating other people. This practice, for female participants, of sharing a man with many partners put them at further risk of contracting HIV/AIDS. Peer pressure in the university was mentioned as added difficulty in the risk of contracting HIV/AIDS because most students are young and there is a tendency to want to experiment with smoking, alcohol, drugs, tattoo and body piercing as well as sex.

A few participants denied that rape was a factor and maintained that rapists may have added sympathy and therefore not engage a physically disabled person in forced sex. However, the majority of the respondents agreed that rapists do not care about physical appearance. The perception was that rapists wanted to fulfill their sexual desire. On the other hand, men with disabilities sometimes felt that they had a lower status than other men and found themselves under pressure to prove their manhood. To prove that being disabled does not make a person asexual, may result in some people engaging in risky sexual behaviours such as having multiple partners. In other ways, women with disabilities were reported as being devalued and disrespected, especially in a sexist and patriarchal African society.

This is confirmed by Mulindwa (2003), who maintains that the frustration of trying to obtain acceptance and social value in a patriarchal society has led to risky and reckless behaviour among many women with disabilities where girls with disabilities offer themselves to men because they think that no man would ever approach them for true love. Many have experienced some form of forced marriages, which keeps them longing and experimenting with other men and women and hence running a risk of contracting HIV. The cultural belief that sleeping with a virgin will cure HIV, also account for why people with physical disabilities might be easy targets of rape by those that hold the belief for virgin cleansing (Groce & Trasi, 2004).

4.2.8 Category 8: Security and preventative measures.

Themes	Responses
Establish HIV/AIDS unit	<i>'Able and disabled alike are vulnerable and are all at the risk of HIV/AIDS in the university'</i> <i>'The university should introduce "Voluntary Counselling Testing" (VCT)'</i>
Avoid walking alone	<i>'People with physical disabilities should not walk alone around the campus because walking in group and in support of non disable person will help deter any assailants or rapist'</i>

Increase lighting	<i>'Increase lighting around the campus'</i> <i>'The authority should always replace dead globes as well'</i>
Reproductive health care information	<i>'Because people with disabilities have been consistently marginalized, this requires that attention be given towards providing accessible awareness campaign on HIV/AIDS'</i>

All the participants were of the view that all, without exception, are at the risk of HIV/AIDS. However, people with physical disabilities face an added difficulty that requires urgent attention. A larger percentage of the participants advocated for an HIV/AIDS unit which must be accessible to people with physical disabilities.

A further risk expressed by participants was moving around alone at night. In view of the foregone the participants advised that the university should increase the lighting system around campus and ensure that faulty lights are repaired. In addition, it was recommended that Close Circuit Television (CCTV) should be mounted all around the campus and that there should be an increased number of security guards to patrol the campus in the night.

Some participants lamented the assumption that everyone has the awareness and knowledge of HIV/AIDS. They suggested that more effort should be made to ensure that every one is adequately informed about HIV/AIDS. This should include information on sexuality and reproductive care especially for people with physical disabilities.

4.2.9 Category 9: Roles and responsibilities of people with physical disabilities

Theme 1: Participation

Some of the responses were:

'People with physical disabilities should join the existing organization run by non disabled people to advance their needs, among the provisions for the general public. This includes campaign for awareness, protection and prevention of HIV/AIDS'

'It is easier and more appealing when you see a person with disabilities involved in a campaign'

Theme 2: Sense of identity

The response was as follows:

'The sense of identity encourages people to listen when you see a person with physical disabilities organizing and directing a campaign for HIV/AIDS awareness'

Theme 3: Take charge

The responses were as follows:

"Since I was born, people always decide for me what I should and should not do, the school to go, the course to read and perhaps they will decide the man to date and marry... (Laughter)"

"You see, whenever some people see you on wheel Chair, they just conclude that you are stupid or something is also wrong with your brain and that is why they just want to help you when you do not request or need one"

The participants agreed that part of the responsibility for lack of awareness, prevention and protection from HIV/AIDS should be borne by people with physical disabilities as well. Hence, people with physical disabilities should be at the forefront of safeguarding themselves. This requires that people with physical disabilities should participate in HIV/AIDS training workshops within and outside the University. A collaborative effort like this will help reduce the stigma of exclusion and discrimination against people with disabilities. It will also serve as a medium to educate and correct the wrong impression that people with physical disabilities are not sexually active and immune to HIV/AIDS.

Some respondents made a plea for an exclusive HIV/AIDS awareness campaign for people with physical disabilities. In view of the discrimination that persons with disabilities often suffer, they were often not enthusiastic when non-disabled people appear to be deciding on disability matters without consulting them. Participants were also of the opinion that they should be involved in policy formulation and initiation in view of the fact that they are more vulnerable and at risk of HIV/AIDS epidemic. Finally, all the respondents agreed that people with disabilities should not wait until there is general or public awareness campaign. Everybody should make it a point of duty to talk to one another, counsel and advice friends by sharing the latest information known about HIV/AIDS with others.

CHAPTER FIVE: SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

5.1 Summary

This study found that awareness and knowledge levels about HIV/AIDS among people with physical disabilities in the University environment are relatively high. However, this awareness and level of knowledge about HIV/AIDS seems not to have matched behavioral change due to various social and cultural factors such as peer pressure, ‘youthful exuberance’ and inhibiting perceptions and assumptions relating to culture, which continue to place them at risk of contracting HIV/AIDS.

The study found that in the case of the participants, their physical disabilities were not perceived as predisposing factors for HIV/AIDS. However, people with HIV/AIDS can develop disabilities due to the lowering of the CD4 count and the inability of the anti- bodies to repel opportunist illnesses. The patient is rendered disabled as a result of illness causing a vicious cycle of disability and HIV & AIDS.

Participants were of the view that there are inadequate HIV/AIDS services available for them in terms of their special needs. Participants were generally limited to the services available for non-disabled people at the Campus Wellness Clinic, Career and Counseling Development Unit (CCDU) and the Emthonjeni Center. These services perceived as being inaccessible to people with physical disabilities because of architectural and other barriers such as inadequate levels of skill and specialist knowledge about needs of people with disabilities. Furthermore, age differences between service providers and recipients were also mentioned as constituting a cultural barrier that prevents some people with disabilities from seeking counseling on sex related issues.

Regarding architectural barriers, these included gradients and breadth of ramps, with lifts having their elevator buttons raised beyond the limit of someone on a wheel chair, doors to services points that are not are not wheel chair friendly (some have turning doors at the entrance while some doors are heavy without automatic sensor for opening).

Generally, participants perceived people with disabilities as facing many problems relating to various social sectors. Furthermore, socio-cultural inhibitions appeared to be a barrier to people with physical disabilities seeking consultation or requesting services relating to HIV/AIDS from available services providers. Participants with physical disabilities had the perception that there existed stigma and discrimination even in the University environment, which led to them not feeling free to participate in reproductive health care services and initiatives. Participants felt that non-disabled members of the University community were not properly educated about the special needs of people with disabilities and the use of facilities intended for people with disabilities. Issues like long distances to the locations of services and consequent inaccessibility still posed a problem to participants.

Participants had the view that people with physical disabilities are equally and sometimes even more vulnerable and more at risk of exposure to and contracting HIV/AIDS than non-disabled others. In this regard, participants felt that they may be the victim of myths and false stereotypes such as the false notion that people with disabilities are not sexually active and thus regarded as virgins leading to increased risk of being raped by people who believe that sleeping with a virgin can help cure HIV. They also perceived themselves to be at greater risk of rape due to greater vulnerability and inability to defend themselves.

Participants felt that such stigmatization and discrimination seemed to have impacted negatively on participants' self confidence and personal pride, which in turn allowed people to take advantage of them as objects of sexual satisfaction.

The study further found that having a physical disability was perceived as having a negative influence on behaviours of some partners such as infidelity. Furthermore, there appeared to be a trend of frequent change of sexual partners among people with physical disabilities in their attempt to prove their sexual capability and to find acceptance. These behaviours then place people with disabilities at a greater risk of contracting HIV/AIDS.

Participants also viewed personal safety and security as well as specialized preventative measures as important. They felt that unlimited access was necessary to HIV/ AIDS information

and Voluntary Counseling and Testing (VCT), as well as additional lighting and security measures across the University campus.

Finally, the study found that participants were of the view that that they should be at the forefront of safeguarding themselves. As much as there are several organizations advocating for protection, rights and provision of services for people with disabilities, they felt that it was imperative for them to be personally involved in HIV/AIDS awareness campaigns towards protection and prevention.

5.2 Conclusions

The experiences and perceptions of participants in the study, namely people with physical disabilities or working in the field of disability at the University of the Witwatersrand, Johannesburg, are very similar to the general experiences of people with physical disabilities outside the university community. The exceptions in their experiences relate to the area of awareness and knowledge. High levels of knowledge and awareness about HIV/AIDS were found among participant in the study. A large number of them understood the meaning of the acronyms, modes of transmission and some of the ways to prevent the spread of the pandemic.

There seems to be a lack of specialized and tailor-made services regarding HIV/AIDS for people with physical disabilities at the University. Services that are available for the general University community are simultaneously offered to people with physical disabilities.

Generally, many people with physical disabilities are still faced with the challenges of architectural barriers. Such barriers pose a severe constraint on the ease of access, both physically and psychologically, to people with disabilities. Given the sensitivity involved in seeking help around issues of reproductive health, such barriers may pose an unnecessary and additional constraint.

The perceived difficulties in interaction with health and counseling personnel also contributed to less utilization and access to services regarding HIV/AIDS for participants generally. Thus the cycle of marginalization of people with physical disabilities may continue even in a University environment.

Given the potential risk factors of people with physical disabilities contracting HIV/AIDS, the effective prevention of HIV/AIDS among people with physical disabilities is of crucial importance. However, the prevention of HIV/AIDS is a worldwide health problem and the prevention of HIV/AIDS for people with physical disabilities requires specific prevention efforts. HIV/AIDS is considered a threat to overall development in many of the hardest hit nations, complicating efforts to reduce poverty, improve access to education and health care, address gender inequality, and maintain national security as well as address the needs of people with disabilities.

5.3 Recommendations

The broad impact of the HIV/AIDS pandemic is one of its salient features. Consequently, governments and organizations in many parts of the world are devising strategies to counteract the spread of the epidemic. Nevertheless, there have been few HIV/AIDS interventions that have directly targeted (or indirectly included) individuals with disabilities and almost none of these interventions have been systematically monitored or evaluated. There is thus an urgent need for intervention with this excluded group of people with physical disabilities, who need to be more involved in all programmes of action devoted to HIV/AIDS awareness campaigns, protection and prevention services.

This study makes various recommendations, for the purpose of service delivery for people with physical disabilities in the urban university environment as well as for further studies. These centre around adaptable infrastructure, education and awareness programmes specifically for the prevention of HIV/AIDS among people with physical disabilities. Unless persons with disabilities are brought into the development mainstream, such development cannot be achieved without taking into account the needs of persons with disabilities, who are full members of society and citizens with human rights (United Nations, 2005).

Recommendation for services

Make adaptable information for awareness available: The larger percentage of people with physical disabilities are not yet HIV positive. Hence, it is vital that everything possible is done to prevent new infections. Education and awareness campaigns, counseling and behavioural change, condom distribution and testing are among the important ways to prevent the spread of HIV/AIDS among this group.

Various methods seem to be uniquely appropriate for people with physical disabilities in the university environment. These include innovative ways of disseminating information about HIV/AIDS such as through pamphlets, billboards, radio, television, workshops and drama. Religious leaders in churches, mosques and other places of worship should periodically include HIV/AIDS in their messages and preaching.

Behavioural change: people with physical disabilities should be encouraged to seriously consider behavioural change. Interventions designed to prevent the transmission of HIV/AIDS could best be realised through the reduction of risk behaviours. These include abstinence from sexual behaviour before long term commitments to relationships; to remain faithful to one sexual partner; to resist all peer pressure and all habits that involve using drugs and abuse of alcohol; resisting pressure to have sex by peers or partner.

Mobile campaign and voluntary counselling and testing (VCT): A mobile campaign around university campuses, with adaptable resources accessible to people with physical disabilities is recommended to ensure that they are not left out of these important information about protection and prevention of HIV/AIDS. Voluntary Counselling and Testing services should ensure that service providers locate people with disabilities in their respective departments, offices and halls of residence or visit the Disability Units to provide individualised counselling and testing for HIV/AIDS.

Make condoms available and accessible for people with physical disabilities: It is recommended that condoms be made available in facilities and locations around campus where people with physical disabilities can have free access to these.

Availability of Anti-retroviral treatments: Because these drugs are expensive, it is recommended that their availability be funded by the government and educational authorities and be made accessible to people with physical disabilities.

Provide appropriate post exposure service: Precaution and prophylaxis is recommended in cases of rape or accidents. It is recommended that this practice specifically be extended to people with physical disabilities who are often in danger of rape, sexual assault, and accidental falls and specifically, for those arising from isolated or episodic injecting drug use and consensual sexual exposure in the university environment.

Educate the public about disability: University communities should be orientated to know that ramps and sensor doors installed are primarily made for people with disabilities. This also includes accommodating and allowing them to enjoy those services that are in popular demand by every member of the university community.

Provide more security control in the campus: This should include efficient lighting systems across campus, mounting of close circuit television monitors (CCTV) in strategic places as well as attend to general security measures specifically related to people with disabilities.

Adaptable infrastructures: Persons with physical disabilities should be provided with adaptable infrastructures such as ramps; wide corridors; lifts with accessible buttons and sensor doors; wheel chair friendly buses. This would also facilitate access to important services such as the Career and Counselling Development Unit (CCDU), Emthonjeni Centre and the Campus Wellness clinic.

Recommendation from the participants

Educational services and human resources: HIV/AIDS education and services as it relates to people with disabilities should be integrated to an even greater extent into the curriculum for rehabilitation and health professionals. HIV policies, guidelines and programmes should be designed and implemented to be accessible to all persons with disabilities, and it should be made mandatory that all HIV programmes incorporate access to information, support and services for persons with disabilities.

Counsel on legal services: Ratify and incorporate into national law instruments that protect and promote the human rights of persons with disabilities, including the Convention on the Rights of Persons with Disabilities (UNAIDS and OHCHR 2006). Incorporate the human rights and needs of persons with disabilities into national HIV /AIDS strategic plans and policies. Prohibit all forms of discrimination against persons with disabilities which may hinder access to health services such as sexual or reproductive health education and services.

Roles of people with physical disability in HIV/AIDS awareness campaign: People with physical disabilities should be encouraged to join existing awareness campaigns for protection and prevention of HIV/AIDS. Beyond joining the existing campaign groups, it is also recommended that people with physical disabilities should champion the awareness campaigns for protection and prevention of HIV/AIDS. Service providers should take active steps to include people with physical disabilities in HIV/AIDS campaigns.

Programme evaluation: It should be ensured that the National AIDS Monitoring and Evaluation system has the necessary resources to evaluate the response to the HIV epidemic within the context of disability, as well as the HIV needs and rights of persons with disabilities. It is also recommended that comprehensive HIV/AIDS programmes should be developed for people with physical disabilities in Universities. Such programmes should be monitored and systematically evaluated to identify strengths and weaknesses in service provision.

Recommendation for further Studies

It is important that services offered by institutions such as Universities, relating to HIV/AIDS and specifically for people with disabilities should be monitored and evaluated. Furthermore, preparatory to designing, implementing, and evaluating HIV prevention programmes for people with disabilities further qualitative and quantitative research should be carried out to accurately determine the most appropriate approach for such services.

This will further contribute to the design and implementation of policies, programs and strategies relating to HIV/AIDS that address the needs of people with physical disabilities. Such findings will also offer guidelines for designing such specific interventions for reproductive health and HIV/AIDS programmes.

REFERENCES

Abang, T.B. (1992). *Handbook of Special Education in Developing Countries*. Jos University: Adex Press.

Adkins, W. (2002). *Representing Disability: Representations of Blindness and Deafness in print Media*. MA thesis, Department of Sociology, Georgia State University, Atlanta: Georgia.

Adkins, W. (2003). The Social Construction of Disability: A Theoretical Perspective. *All Academic Research Inc. Vol. 1. New York: Random House*.

Americans with Disabilities Act of 1990, 42 U.S.C. Sec. 12182 (b)(1)(A)(iii) (1995); Non-discrimination on the Basis of Disability in State and Local Government Services, 28 C.F.R. Sec. 35.130 (b)(2) (2001).

Albert, B. (2003). Lessons from the disability knowledge and research programme. *Disability Knowledge and Research, June, 2005*.

Albrecht, G. (1976). *The Sociology of Physical Disability and Rehabilitation*. Pittsburgh: University Pittsburgh Press.

Anderson, B.A. (2004). *Reproductive Health - Women and Men's Shared Responsibility*. Jones & Bartlett Publisher: Washington.

Ashani, D.J. (1996). *Provision of Services for the Disabled in Nigeria: Political Implication*. Unpublished project for B.Ed (Hons.) submitted to the Department of Special Education University of Jos, Nigeria.

Babbie, E. & Mouton, J. (2001). *The practice of Social research*. Cape Town: Oxford University Presss, South Africa.

Banister, P., Burman, E., Parker, I., Taylor, M. and Tindall, C. 1994. *Qualitative methods in psychology: a research guide*. Buckingham; Open University Press.

Barnes, C. (1996). *Theories of disability and the origins of oppression of disabled People in western society*. In *Disability and society: Emerging issues and insights*, ed. L. Barton. New York: Longman.

Baynton, D. C. (1993). *Savages and Deaf-Mutes': Evolutionary Theory and the Campaign Against Sign Language in the Nineteenth Century*. Pp. 92-112 In *Deaf History Unveiled: Interpretations from the New Scholarship*, edited by John Vickery van Cleve. Washington: Gallaudet University Press.

Becker, H., Stuifbergen, A., & Tinkle, M. (1997). *Reproductive health care experiences of women with physical disabilities: a qualitative study*. *Archives of Physical Medicine and Rehabilitation*, 78 (12, Suppl 5): S-26–S-33.

Beckmann, C.R.B., Gittler, M., Barzansky, B.M., & Beckmann, C.A. (1989). *Gynecologic health care of women with disabilities*. *Obstetrics and Gynecology*, 74 (1): 75–79.

Blanch, T. & Kelly, K. (1999). *Research in practice, applied methods for the social sciences*. Cape Town: University of Cape Town.

Boschert, S. (2004). Some Ca Increasing in Post-HAART Era. *Clinical Psychiatry News*

Brenner, A. & Kokalik, J., (1979) *The Effect of Megadoses of Selected B Complex Vitamin on Children with Hyperkinesis*. *Journal of Learning Disabilities: USA*.

Bryman, A. & Bell, E. (2003). *Business research method*. London: Oxford University Press.

Buysse, A., & Ickes, W. (1999). Topic-relevant cognition and empathic accuracy in laboratory discussions of safer sex. *Psychology and Health*, 14, 351-366.

Carabine, J. (1992). 'Constructing Women': Women Sexuality and Social Policy. *Critical Social Policy*, 34:23-37.

Cartwright, C. & Ward, E., (1989). *Educating Special Learners*. Wadsworth Publishing, Belmont:California.

Centre for Actuarial Research, South African Medical Research Council & Actuarial Society of South Africa- CARSA, & MRCASSA, (2006). *The Demographic Impact of HIV/AIDS in South Africa - National and Provincial Indicators for 2006*: Johannesburg: Republic of South Africa.

Chance, R. (2002). *To Love and be Loved; Sexuality and people with Physical Disabilities*. Journal of Psychology and Theology. 30, 195 – 208.

Cichocki, M. (2006). *An HIV Timeline - The History of HIV*. About.com Guide, 12, 1-4

Cichocki, M. (2009). *What is AIDS and what causes it?* About .com Guide, 9, 3-5

City Vision. (2004). *Debate on Sexual Crimes*. 13 (1).

Community Agency for Social Enquiry (2005). *We Also Count: The extent of moderate to severe reported disabilities and the nature of the disability experience in South Africa*. Disability Survey for the Department of Health. CASE.

Committee of Children with Disabilities (1996). *Sexuality education of Children and Adolescents with Developmental Disabilities*. America Academy of paediatrician, 97,275 - 278.

Consultative Paper '1', (1999). *Inclusive Education*. Department of Education. Pretoria.

Crino A, Schiaffini R, Ciampalini P, Spera S, Beccaria L, Benzi F, (2003). *Hypogonadism and pubertal development in Prader-Willi syndrome*. Europe Journal of Paediatrics. 2003, 162, 327-333.

Cudlick, H. (2001). *Psychoanalytical perspective on Learning Disability*. Learning Disability Quarterly: New York, W.W. Norton, and Co

Cusack, C.M. (1997). *Graciosi: Medieval Christian Attitudes to Disability*. University of Sydney: NSW, Australia.

De Vos, A.S., Strydom, H., Fouche, C.B., & Delport, C.S.L. (2005). *Research at grassroots for the social sciences and human services profession*. (3rd ed.) Pretoria: Van Schaik
Department of Social Development. (1997). *White Paper on Social Development*. Pretoria: DoSD.

Department of Social Development, (2004). *A Comparative Analysis of 1996 and 2001 Census Data on Vulnerable and Special Target Groups*. Pretoria: DoSD.

Department of Education, (1999). *The consultative paper 1 on inclusive education*. Pretoria: DoE.

Department of Education, (2001). *Education White Paper 6: Special Needs Education. Building an Inclusive Education and Training System*. Pretoria: DoE.

Disabled People South Africa, (2004). *Resource Manual for Disability and HIV/AIDS*

Training. Johannesburg: Republic of South Africa.

Dormans, J.P. & Pelligrino, L. (1998). *Caring for Children with Cerebral Palsy: A Team Approach*. Paul H. Brooks Publishing: USA.

Dorrington R.E., Johnson L.F., Bradshaw D. and Daniel T. (2006) *The Demographic Impact of HIV/AIDS in South Africa. National and Provincial Indicators for 2006*. Cape Town: Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa.

Douard, J. (1995). *Disability and the persistence of the "normal."* In *Chronic illness: From experience to policy*, ed. S. K. Toombs, D. Barnard, and R. Carson. Bloomington: Indiana University Press.

Drews, R.S., Foster. G. & Chituna J. (1996). *Cultural practices associated with death in the North Nyanga District of Zimbabwe and their impact on widows and orphans*. *Journal of Social Development in Africa* 1996; 11:79- 86.

Du Toit, M. (1992, September). *DPSA Position Paper*. Paper presented at Veteran's National Conference. Johannesburg: Republic of South Africa.

Economic and Social Commission for Asia and the Pacific, ESCAP. (1995). *Working towards reducing poverty and managing globalization*. UN ESCAP.

Ellen G, J. D. (2001). *Guide to Getting Reproductive Health Care Services for Women with Disabilities Under the Americans with Disabilities Act of 1990*. *Sexuality and Disability*, 19 191 – 208.

Elwan, A. (1999). *Disability and Poverty*. Washington, DC: World Bank Social Protection Unit.

Emmett, T. (2006). *Disability, Poverty, Gender and Race* in Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. and Priestly, M. (Eds.) (2006) *Disability and Social Change – A South Africa Agenda*. Cape Town: HSRC Press.

Fiduccia, B.W. (1997). *Multiplying Choices: Improving Access to Reproductive Health Services for Women with Disabilities*. Oakland, CA: Berkeley Planning Associates.

Fisher, A. A., Foreit, J., With Laing, J., Stoeckel, J. & Townsend, J. (2002). *Designing HIV/AIDS Intervention Studies; An Operations Research Handbook*. The Population Council Inc: USA.

Foucault, M. (1978). *The history of sexuality, An introduction*. Trans. R. Hurley. New York: Pantheon Books.

Fourie, P. (2006). *The Political Management of HIV and AIDS in South Africa*. Palgrave Macmillan: UK.

Free online English dictionary and encyclopedia, (2009). *Definition of Physical Disabilities*. www.thefreedictionary.com.

Gill, C.J., & Brown, A.A. (2002). *Health and aging issues for women in their own voices*. In: Walsh PN, Heller T editor. *Health of women with intellectual disabilities*. Oxford: Blackwell Publishing.

Gill, C. J., Kirschner, K. L., & Reis, J. P. (1994). *Health services for women with disabilities: barriers and portals*. In, Dan, AJ, editor, *Reframing Women's Health Multidisciplinary Research and Practice*. Thousand Oaks, CA: Sage, pp. 357–366.

Giddens, A. (1992). *The transformation of intimacy: Sexuality, love and eroticism in Modern Societies*. Stanford, Calif.: Stanford University Press.

Goffman, E. (1963). *Behavior in Public Places: Notes on the social organization of gatherings*. The Free Press: New York.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster.

Gordon, B. O. & Rosenblum, K.E. (2001). *Bringing Disability into the Sociological Frame: A Comparison of Disability with Race, Sex, and Sexual Orientation Statuses*. *Disability and Society* 16:5-19.

Groce, N. E. (2003). HIV/AIDS and people with disabilities. *Lancet*, 361(9367), 1401-1403.

Groce, N.E. (2005). HIV/AIDS and Disability. *Health and Human Rights*. 8:2; 215-225.

Groce, N.E. & Trasi, R. (2004). Rape of individuals with disability: AIDS and the folk belief of virgin cleansing. *The Lancet*, 363:1663-1664.

Groce N.E. Trasi, R. Yousafzai, A.K. (2006). *Guideline for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts*. <http://globalsurvey.med.yale.edu>. 2006.

Guthrie, T. (2001). *Summary of Literature: Disability and Chronic Illness Prevalence in Children in South Africa*. Child Health Policy Institute, South Africa. 2001.

Hahn, H. (1988). Can Disability Be Beautiful? *Social Policy* 19:26-31: USA.

Hallahan, D. P., & Kauffman, J.M. (2000). *Exceptional Learners: Introduction to Special Education*. (8th ed.) Boston: Allyn & Bacon.

Hanass-Hancock, J.(2008). *Invisible—the notion of disability in the context of HIV/AIDS in KwaZulu-Natal, South Africa*. Humboldt University: Berlin.

Helander, E. (1999). *Prejudice and Dignity: An Introduction to Community- Based Rehabilitation*. New York: UNDP, Second Edition.

Henning, E. (2004). *Finding your way in qualitative research*. Pretoria: Van Schaik

Heumann, J. (1998). *Human Rights and Disabilities*. Paper Presented at the seminar on Human Rights for Persons with Disabilities from a North and South Perspective. 1998. August 23. Stockholm.

Household Survey, (1996). *October 1996 Household survey*. Pretoria: Republic of South Africa.

Howell, C., Chalklen, S. & Albert, T. (2006). *A history of the disability rights movement in South Africa* in Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestly, M. (Eds.) (2006) *Disability and Social Change – A South Africa Agenda*. HSRC Press: Cape Town

Iheanacho. I J, (1986). *Administration of Special Education: Organisational Issues in Nigeria*. CECTA Press: Enugu Nigeria.

ILO, (2002). *In focus Programme on Skills, Knowledge and Employability/Disable Programme*. International Labour Organization. November, 2002.

Inter Press Service News Agency (2006, May). *Health South Africa: a burden that will only become heavier*. Johannesburg: Republic of South Africa.

Integrated National Disability Strategy, (2007). South Africa Government Information

Internal Medicine Services. (2002). *Sexually Transmitted Diseases Services*. Royal Adelaide Hospital: Adelaide, Australia.

Inter Press Service News Agency, (2006). *Prevalence and impact of HIV in South Africa*.

International Conference on Population and Development (ICPD), (1994). *Access to reproductive and sexual health services including family planning*. Cairo. September 1994.

Irwin, A., Millen, J, & Falows. D, (2003). *Global AIDS: Myths and Facts*. South End Press: Cambridge MA.

Jackson, H. Mupedziswa, R. (1988). Disability and rehabilitation: beliefs and attitudes among rural disabled people in a community-based rehabilitation scheme in Zimbabwe. *Journal of Social Development in Africa* 1988; 3:21- 3.

Jansen, M. (2004). *How to make HIV/AIDS programmes more disability friendly and inclusive*. Disability and HIV/AIDS. National STI/HIV/AIDS, Congress: Amsterdam.

Kalyanpur, M. (1999). Special education epistemology as a product of western culture: implications for non-western families of children with disabilities. *International Journal of Rehabilitation Research* 1999; 22:111-8.

Kisekka, M. N. (1976). Sexual Attitudes and Behaviour among Students in Uganda. *Journal of Sex Research*, 12, 104-116.

Kruger, R.A. (1988). *Focus group: A practical guide for applied research*. Newbury Park. CA: Sage.

Leon, G. (1992). *Understanding Social Problems, Policies and Programmes*. University of Carolina Press.

Mamshela, M. (1992). *Women's Property Rights in Lesotho: A Basic Human Rights or Privilege*. Paper presented at the 15th SAUSSC in Masero, Lesotho, 14-17 December 1992.

Marshall, G. (1998). *A dictionary of sociology*. Oxford: Oxford University Press.

Martorella, A., & Portugues, A.(1998). Prevention of Sexual abuse in Children with Learning Disabilities. *Child Abuse review*, 7, 355 – 359.

McCabe, M. P.(1999). Sexual knowledge, experience, and feelings among people with disability. *Sexuality and Disabilities*, 1999, 17,157-170.

Meel, B. L. (2003). Mortality of children in the Transkei region of South Africa. *The American journal of forensic medicine and pathology*: 2003, 24(2), 141-7.

Midgley, J. (1995). *Social Development: The Developmental Perspective in Social Welfare*. London U.K.: Sage Publisher.

Milligan, M., & Neufeldt, A. (2001). The myth of Asexuality: A survey of Social and Empirical evidence. *Sexuality and Disability*, 19, 91 – 109.

Mona, L.R. (2000). Sexuality and Disability, History and Practice. *My pleasure. Com*. 2002.

Mouton, J. (2003). *Disabled persons - Predictors for the risk of contracting HIV/AIDS and primary prevention strategies*. Unpublished MA dissertation: University of Stellenbosch.

Mulindwa, I. N. (2003). *Study on Reproductive Health and HIV/AIDS among Persons with Disabilities*. Kampala: Uganda.

Murray L, Burnham G. (2009). Understanding childhood sexual abuse in Africa. *Lancet*; 373: 1924–26

Nelson, D. (2003). Women, Sex and Disability – a triple taboo. *Disability Knowledge and Research*. May 2003.

Nelson, D. (2005). Why disabled people are crucial to development. *Disability Knowledge and Research*. November 2005.

NFPDN & VSO-RAISA, (2003). *HIV & AIDS and disability*: national conference, Namibia.

Nosek, M.A., & Howland, C.A. (1997). Breast and cervical cancer screening among women with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 78 (12, Suppl 5): S-39–S-44.

Nosek, MA, Rintala, DH, Young, ME, Howland, CA, Foley, CC, Rossi, D, & Chanpong, G. (1996). Sexual functioning among women with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 77 (2): 107–115.

Office of the Deputy President, (1997). *White Paper on an Integrated National Disability Strategy*. Pretoria: Republic of South Africa.

Ozaji, E. (1992). *Handbook of Special Education for non – professionals*. Jos. Adex Press.

Paransky, O. L., Zurawin, R. K. (2003). Management of menstrual problems and contraception in adolescents with mental retardation: *A medical, legal, and ethical review*. 2003, 16, 223-235.

Parker, R., Barbosa, R. M., & Aggleton, P. (2000). *Introduction The politics offender, sexuality and power*, ed. R. Parker, R.M. Barbosa, and P. Aggleton. Berkeley and Los Angeles: University of California Press.

Philander, J., & Swartz, L. (2005). Blind Adolescent and HIV – a key Information Study. Unpublished Manuscript cited by Rohleder & Swartz, in *Disability and Social Change – A South Africa Agenda*. Cape Town: HSRC Press.

Philpott, S. & McLaren, P. (1997). *Disability South African Health Review*, Health Systems Trust: Durban.

Planned Parenthood Federation of Canada, (2008). *Sexuality and Youth with Physical Disabilities*. <http://www.ppfc.ca/ppfc/content.asp>.

Priestly, M. (2006). *Developing Disability Programme in Disability and Social Change – A South Africa Agenda*. Cape Town: HSRC Press.

Public Health at a Glance, (2004). *Disability and HIV/AIDS*, November, 2004.

Republic of South Africa National AIDS Council, (2008). *HIV/AIDS and Disabilities in South Africa*.

Rohleder & Swartz, (2005) *HIV/AIDS and Disability Cited in Disability and Social Change – A South Africa Agenda*. Cape Town: HSRC Press.

Rosenthal, R. & Rosnow, R.L. (1991). *Essentials of behavioral research: Methods and data analysis* (2nd. ed.). New York: McGraw-Hill.

Ross, E. (2009). *Refresher Course in Research for Postgraduate Studies*. Lecture notes. Social Work Department, University of the Witwatersrand: Johannesburg.

Rubin, A. & Babbie, E.R. (2005). *Research Method for social work*. United States of America: Brooks/Cole.

SA Advertising Research Foundation -SAARF, (2004, March). *All Media Products Survey*. Johannesburg: Republic of South Africa.

Sarantakos, S. (1998). *Social Research*. (2nd Ed). China: Macmillan Publishers.

Save the Children & UNICEF, (2001). *Child HIV/AIDS Services: A Directory of Organisations in South Africa*. Save the Child: UK.

Schatz, J & Ogunmefun, C. (2004). *The impact of HIV/AIDS on older Women above 65 years; care givers*. Unpublished proposal submitted to the Department of Population and Demography, University of Witwatersrand: Johannesburg South Africa.

Scott, R. A. (1969). *The Making of Blind Men: A Study of Adult Socialization*. New Brunswick, NJ: Transaction.

Shuttleworth, R. P. 2000). The search for sexual intimacy for men with cerebral palsy. *Sexuality and Disability* 18 (4): 263-282.

Shuttleworth, R. P. (2004) *Disability and Sexuality - Toward a Constructionist Focus On Access in Disability and Sexuality Research*. University of California, San Francisco and Berkeley.

Sidiropoulos, E. (2006). *Africa's Tsunami, Tuning the Tide on AIDS*. South Africa Institute of International Affairs: Braamfontein South Africa.

Smith, C. (2003). *The virgin rape myth: a media creation or a clash between the myth and HIV treatment?* IASSCS International Conference on Sex and Secrecy, Johannesburg, South Africa, 2003, June 22–25, 2003.

Sobsey, D. (1991). *Violence and abuse in the lives of people with disabilities*. Baltimore: P Brooks.

Soul City Institute for Health and Development Communication, (2005). *HIV and AIDS Prevention*.

South Africa Research Foundation, (2004). *Aids Research and Evaluation*. SARF: Johannesburg.

South African AIDS Council, (2008). *HIV, AIDS and Disability in South Africa*. November, 2008. *Care and Treatment*. Jacana Media: Johannesburg.

Statistics South Africa, (1996). *Household Survey, October 1996*. Pretoria: Government Printer.

Statistics. South Africa, (2001). *Population distribution of people with disabilities*. Pretoria: Government Printer.

Statistics South Africa, (2003). *Census 2001*. Pretoria: Government Printer.

Swain, J., French, S. & Cameron, C. (2003). *Controversial issues in a disabling society*. Philadelphia: Open University Press.

Swartz, L. & Schneider, M. (2006) *Tough Choices: Disability and Social Security in South Africa* in Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestly, M. (Eds.) (2006) *Disability and Social Change – A South Africa Agenda*. HSRC Press: Cape Town.

Swartz, L., Schneider, M. & Rohlede, P. (2006). *HIV/AIDS and disability: new challenges*. In Watermeyer et al (eds) *Disability and social change: a South African Agenda*. HSRC: Cape Town.

Tate, D.G., Riley, B.B., Perna, R., & Roller, S. (1997). Quality of life issues among women with physical disabilities or breast cancer. *Archives of Physical Medicine and Rehabilitation*, 78 (12, Suppl 5): S-18–S-25.

The New York Times (2004, 29th July), ['South Africa 'recycles' graves for AIDS victims'](#)

Twersly, Jacob. (1947). *The American War-Blind As Aided by the Federal Government*. Archives of the American Foundation for the Blind: New York.

UNAIDS/WHO (2006). *The Impact of AIDS on People and Societies*. UNAIDS Report on the Global AIDS Epidemic.

UNICEF, (1999). *An Overview of Young People Living with Disabilities*. New York: UNICEF Inter-Divisional Working Group on Young People.

United Nations, (1990). Disability Statistics Compendium, Statistics on Special Population Groups: *Series Y: No. 4*. New York: United Nations.

Watermeyer, B. Swartz, L. Lorenzo, T. Schneider, M. & Priestley, M. (2006). *Disability and Social Change; a South African Agenda*. Cape Town. HSRC Press.

Whyte, S., & Ingstad, B. (1995). *Disability and culture: An overview*. In *Disability and culture*, ed. B. Ingstad and S. Whyte. Berkeley. Los Angeles: University of California Press.

Wiesinger – Ferris, R. (1989). Partnership between the Developed and the Developing Countries to Promote Special Education and Disability Prevention. *International Journal of Special Education* 4:101 – 9.

World Bank. (2003). *Adolescents and Youth with Disability: Issues and Challenges*. International Policy and Programs. Washington: The World Bank Group.

World Bank. (2004). *Capturing Hidden Voices: HIV/AIDS and Disability*. Washington: The World Bank Group.

www.avert.org, (2009). *Facts about HIV and AIDS*.

Yousafzai A. & Edwards K. (2004). *Double Burden: A situation analysis of HIV/AIDS and young people with disabilities in Rwanda and Uganda*. London: Save the Children.

Zacijek – Farber, M. (1998). Promoting Good Health in Adolescents with Disabilities. *Health and Social Work*. 23, 203 – 213.

APPENDIX A

Semi - Structured Interview Schedule

Demographic details:

Age:

Gender:

Nature of disability:

Category of research study participant:

Student with disability	Staff member with disability	Staff member of Disability Unit

1. What do you understand by HIV/AIDS?
2. What do you think about the link between HIV/AIDS and disability?
3. What measures do you think should be taken to prevent people with disability from been infected with HIV/AIDS?
4. What information do you think should be included about HIV/AIDS in awareness campaigns and protection and prevention services for people with disabilities?
5. How and where can people with physical disabilities access HIV/AIDS services?
6. What are the barriers (physical, social, cultural) to accessing HIV/AIDS services?
7. How do caregivers and service providers respond to people with physical disabilities when they come for their services?
8. How sensitive are service providers to the specific needs of people with physical disabilities?
9. What services are available for people with physical disabilities in relation to HIV/AIDS?
10. To what extent do you think that people with physical disabilities in university environment are vulnerable to HIV/AIDS?
11. What services do you think people with physical disabilities in a university environment have access to in the area of HIV/AIDS?
12. What do you think the government should do to protect people with physical disabilities from HIV/AIDS?

13. What do you think the university should do to protect people with physical disabilities in their community from HIV/AIDS?
14. What steps do you think people with physical disabilities should take to safeguard themselves from HIV/AIDS?
15. What roles do you think that people with physical disabilities should play in providing awareness campaigns, protection and prevention services for people with physical disabilities about HIV/AIDS?
16. What do you think will be the reaction of people if a person with physical disabilities is tested positive of HIV or living with AIDS?
17. What would your reaction be if you discovered that a person with physical disabilities is tested positive for HIV or is living with AIDS?
18. Any other comments?

Appendix B

APPLICATION FOR PERMISSION TO CONDUCT RESEARCH

My name is Dolu Johnson Ashani and I am postgraduate student registered for the degree of Masters of Arts in Social Development in Social Work Department at the University of Witwatersrand. As part of the requirement for the degree, I am conducting research into the perception s about HIV/AIDS by people with physical disabilities in the university environment in Johannesburg, Gauteng, South Africa. It is hoped that this information may enhance social workers/developers understanding of the experiences of people with disabilities and help to improve services for caregivers.

I therefore wish to request permission to conduct some interviews with approximately five staff members with disabilities and approximately ten students with disabilities that use the services of the unit.

As the interview will include sensitive issues, there is possibility that some of the participant may experience some feelings of emotional distress. Should there be need for supportive counseling following the interview, I have arranged for free counseling services at the Emthonjeni Centre at the University of the Witwatersrand. They may be contacted at 011 717 4513.

Should there be any question regarding the study, I shall answer them to the best of my ability. I may be contacted on 0827264430. Should you wish to receive summary of the study, an abstract will be made available on request. I have attached copy of the interview questions for your perusal.

Thanking you in anticipation for your permission to allowing me conduct the research at your Unit.

Yours truly,

Dolu Johnson Ashani

Student No. 0408013D

Supervisor: Linda Smith

Contact Detail: 011 717 4483

Appendix C

LETTER OF APPROVAL FROM UNIVERSITY DISABILITY UNIT

Appendix D

PARTICIPANT INFORMATION SHEET

Title of study: The perceptions about HIV/AIDS by people with physical disabilities in the University environment in Johannesburg, Gauteng South Africa.

Dear Participant,

My name is Dolu Johnson Ashani and I am a postgraduate student registered for the degree of Masters of Arts in Social Development in Social Work Department at the University of Witwatersrand. As part of the requirements for the degree, I am conducting research into the perceptions about HIV/AIDS by people with physical disabilities in the university environment in Johannesburg, Gauteng, South Africa. It is hoped that this information may enhance social workers/developers understanding of the experiences of people with disabilities and help to improve services for caregivers.

I therefore wish to invite you to participate in the study. Your participation is entirely voluntary and refusal to participate will not be held against you in any way. If you agree to take part, I shall arrange to interview you at a time and place that is suitable for you. The interview will last approximately one hour. You may withdraw from the study at any time and you may also refuse to answer any questions that you feel uncomfortable with answering.

With your permission, the interview will be tape recorded. No one other than my supervisor will have access to the tape and on completion of the study, the tape will be destroyed. Please be assured that your name and personal details will be kept confidential and no identifying information will be included in the final research report.

As the interview will include sensitive issues, there is possibility that you may experience some feelings of emotional distress. Should you therefore feel the need for supportive counseling following the interview, I have arranged for free counseling services at the Emthonjeni Centre at the University of the Witwatersrand. They may be contacted at 011 717 4513.

Please feel free to ask any question regarding the study. I shall answer them to the best of my ability. I may be contacted on 0827264430. Should you wish to receive summary of the study, an abstract will be made available on request. I have attached copy of the interview questions for your perusal.

Thank you for taking the time to consider participating in the study.

Yours truly,

Dolu Johnson Ashani

Student No: 0408013D

Supervisor: Linda Smith

Contact Detail: 011 717 4483

Appendix E

CONSENT FORM FOR PARTICIPATION IN THE STUDY

I hereby consent to participate in the research project; the purpose and procedure of the study have been explained to me. I understand that my participation is voluntary and that I may refuse to answer any particular question or withdraw from the study at any time without any negative consequences. I understand that my response will be kept confidential.

Name of participant: _____

Date: _____

Signature: _____

Name of Researcher: Dolu Johnson Ashani

Appendix F

CONSENT FOR AUDIO –TAPING OF THE INTERVIEW

I hereby consent to tape-recording of the interview. I understand that my confidentiality will be maintained at all times and that the tape will be destroyed two years after any publication arising from the study or five years after completion of the study, if there are no publications.

Name: _____

Date: _____

Signature: _____

Name of researcher: Dolu Johnson Ashani

Appendix G

CLEARANCE CERTIFICATE FROM UNIVERSITY ETHICS COMMITTEE