

1 BACKGROUND INFORMATION

1.1 The scourge of the HIV and AIDS pandemic

The HIV and AIDS pandemic is without doubt a serious global health threat of which the burden is being most felt in sub-Saharan Africa. According to UNAIDS (2008), of the estimated 33 million adults and children who are infected with HIV worldwide, 22 million of those are living in sub-Saharan Africa. The peak of the global pandemic can be found in South Africa, where an estimated 5.7 million people are living with HIV and AIDS.

The HIV and AIDS pandemic has had particular impact on vulnerable populations, such as women and children. This is clearly evident within sub-Saharan Africa, where nearly 90% of all HIV positive children reside and where an estimated 61% of adults living with HIV and AIDS are women (UNAIDS, 2008). Despite the reported decline in new infections amongst women attending antenatal clinics, young people between the ages of 15-24 years still have the highest rate of infection throughout the African continent (UNAIDS, 2008; SANAC, 2007; Pettifor et al, 2004).

As in the case of South Africa, Pettifor et al (2004) report that provincially, KwaZulu Natal (KZN) has the highest prevalence of HIV infection amongst 15-24 year olds at 14.1% (see Fig. 1).

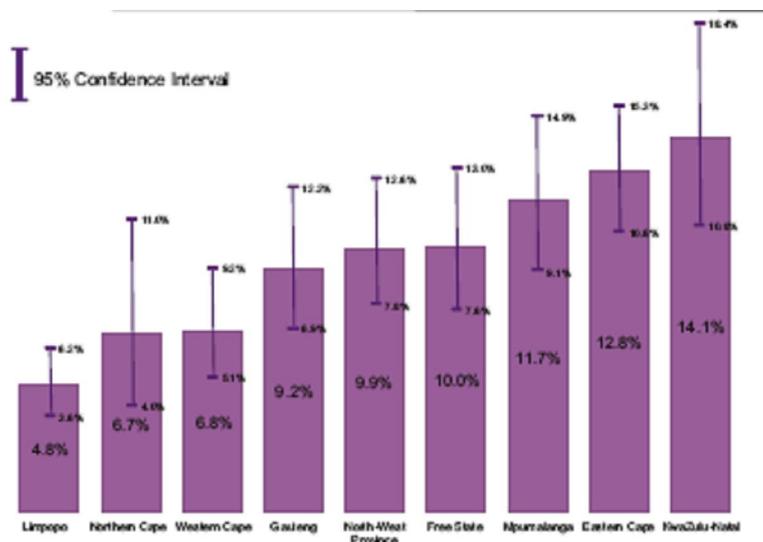


Fig 1. South African provincial HIV infection rates amongst 15-24 year olds

These rates are often related to the high levels of sexual risk taking amongst this age group. Coombe (2002) for example, points out that in rural KZN, 76% of girls and 90% of boys are reportedly sexually active by the time they are 15 or 16 years old. Furthermore boys started sexual intercourse before girls and had more partners and often had a history of sexually transmitted disease.

Interestingly, little is known about one of the world's most vulnerable groups – youth with disabilities. A recent global HIV and AIDS and disability survey conducted in 57 countries, found that the risk factors associated with disability such as poverty, social stigma, unemployment, poor access to education and health care, are similar to those for HIV and AIDS (Groce, 2004). In view of this, it can be seen that people with disabilities are at equal, if not increased risk of HIV infection, and that this is a problem that is still largely unrecognised by both the AIDS and the disability advocacy communities.

1.2 Disability, education and HIV

Of the 2.5 million people who have a permanent physical, mental, sensory, intellectual or communication disability in South Africa an estimated 4-5% of them are between the ages of 14-35 years of age (StatsSA, 2001). According to the Department of Education of South Africa (2004), a large proportion of youth with disabilities are not in formal education. Schneider (2000) also reports that youth with disabilities under the age of 18, are likely to only reach primary level education and very few are likely to reach Grade 12. Education plays a crucial role in the development of skills, knowledge and identity. Without education it inevitably leads to youth with disabilities being unable to participate in the social and economic mainstream of society.

Kelly (2002) puts forward that education, in particular school education, has a significant role in reducing the high prevalence rates of HIV amongst the youth. For example in Zambia, Bankole et al (2004) found the prevalence rate for HIV decreased amongst 15-19 year old women with some education. Furthermore, Klepp et al (1997) reported that the inclusion of HIV education in the primary school curriculum in Tanzania resulted in students later sexual debut.

Outside of school, non-disabled youth are exposed to ideas of sex and HIV information from a range of sources such as magazines, television, radio, newspapers, billboards and through talking with friends and family (Francis and Rimmensberger, 2005). There are also organisations such as loveLife, which provide innovative ways to stimulate discussions and complement HIV prevention in schools and at home (Zisser and Francis, 2006). Changes in youth culture have also influenced perceptions of youth identity and how they relate to issues surrounding sex and HIV and AIDS. For example, Pettifor et al (2004) point out that unlike the past where the youth of South Africa mobilized against political issues, a less politically focused youth culture has now emerged with an emphasis on music and sports icons, popular entertainment, brands and consumerism. Although some of these sources can be misleading, popular youth culture plays a pivotal role in influencing youth's understanding of themselves, gender norms, sexual identity and their relationships with others.

The situation for youth with disabilities is very different from their non-disabled peers. For instance, youth with disabilities who do not attend school not only lose out on basic reading and writing skills but also on receiving vital education around sexual and reproductive health and HIV. According to UNICEF (1999), where sex education is taught at home, youth with disabilities often receive little information because it is believed that they do not need such knowledge or will become promiscuous if it is provided.

Even if in school, Collins et al (2001) found that youth with disabilities were less likely to receive health education and were often excluded from sex education classes. This lack of education has resulted in significantly lower rates of knowledge about HIV prevention. For example, Yousafzai et al (2004) conducted a comparative study between disabled and non-disabled youths' knowledge and perceptions of HIV and AIDS in Swaziland. The results found that in contrast to the non-disabled youth, those with disabilities lacked knowledge about HIV and AIDS and were misinformed about modes of transmission. Groce et al. (2005) found a similar situation amongst the Deaf population in Nigeria, who believed that HIV can be prevented through hand washing and eating healthy food, as well as avoiding hugging, kissing and using dirty utensils.

In contrast however, Philander and Swartz (2006) found in a key informant study amongst 15 young people with visual impairments in South Africa, that they had a good knowledge about how HIV is transmitted. Nevertheless, the participants in the study reported that illiteracy and inadequate education were conducive to increased risky behaviour amongst people with disabilities.

Knowing the influence of a media driven youth culture on the development of young people's sexuality, little is known about how youth with disabilities relate to this culture or develop their sexual identity. According to Groce (2004) this social exclusion limits youth with disabilities opportunities to set boundaries and ultimately lowers their sense of self-worth. This often compromises their ability to refuse when coerced to have sex or try drugs and ultimately increases their risk of HIV infection.

1.3 Disability, sexuality and HIV & AIDS

The lack of involvement of disability in HIV and AIDS education campaigns is a result of the widespread belief that people with disabilities are perceived to be 'asexual' (Shakespeare et al., 1996; Anderson and Kitchin, 2000). The myth of the asexuality of people with disabilities appears to be associated with two key lines of thinking. First, for people with physical disabilities, because of actual or presumed sexual dysfunction, gratification opportunities are considered so limited that sexual needs are either deemed to be absent or subjugated. Second, although their sexual function is typically intact, individuals with intellectual disabilities are thought to have limited social judgment, and therefore, lack the capacity to engage in responsible sexual relationships (Milligan and Neufeldt, 2001).

Given the notion of asexuality and considering that sexual contact is the most prevalent cause of HIV infection in South Africa, people with disabilities are presumed to be at very low risk of contracting the virus (Swartz et al, 2006). As a result, sex education programs for those with disabilities are rare and very few HIV and AIDS educational campaigns target or include the disabled population. As highlighted by Groce et al (2006), where HIV and AIDS educational campaigns are on radio or television, groups such as the Deaf and the blind are at a distinct disadvantage. Furthermore, these

campaigns are often perceived as confusing to those with intellectual disabilities, who find it difficult to understand such complex information (Robertson et al., 1991).

Numerous research studies have however, contradicted this notion. For example, Jackson and Wallace (1999) found that women with disabilities were less likely to get married and were more likely to have multiple sexual partners than their non-disabled cohorts. Furthermore, Yousafzai and Edwards (2004) found in their study of experiences of HIV and AIDS among young people with disabilities in Rwanda and Uganda, that women with disabilities were more prone to rape and sexual abuse compared to their non-disabled peers.

Unfortunately, many health professionals still fail to address the issues of sexuality and disability. Swartz et al (2006) suggest that this could be related to the fact that health professionals receive insufficient training in dealing with issues of sexuality in relation to disability and are therefore anxious about raising the issue. This lack of knowledge and anxiety could be seen as a barrier by which people with disabilities are prevented from receiving adequate information relating to sex and HIV. This notion was highlighted in a study conducted in Zambia, whereby women with disabilities reported having attracted a lot of negative attention from nurses whilst attending reproductive health services, which inevitably discouraged them from using such services (Smith et al, 2004).

Similarly, the disability movement has also been slow to react to issues of sex and HIV and AIDS. Many disability support groups and disability advocates perceive the discourse of sex and sexuality as a taboo topic and rather focus their attention on other social-economic concerns. Shakespeare (2000) attributes this to the fact that within the realm of the Social Model, the private lives of people with disabilities were not seen as being equally worthy of concern compared to ending issues of disability oppression, poverty and social injustice. In retrospect, it is put forward that if the disability movement, which has been instrumental in bringing about social change, had equally taken up the issue of disabled sexuality as a civil rights issue, then maybe people with disabilities would be better informed not only of their sexual identity, but their risk of HIV infection.

1.4 Project description

The issue of HIV and AIDS is an issue of basic human rights and public health and as suggested by Groce et al (2006 p.4), ‘the inclusion of individuals with disability in HIV/AIDS outreach efforts simply cannot wait until all other groups in the population are addressed’.

Taking this into account, CREATE has received funding from Irish Aid to run a 3 year project to educate youth with disabilities about HIV and their sexual and reproductive rights. The project will also include skills training for parents of children with disabilities, which will better equip them to deal with issues related to sexuality and HIV. This project will take place in the uMgungundlovu District of KwaZulu Natal (KZN).

Considering the misconceptions of asexuality and the fact that youth with disabilities are often excluded from HIV outreach programmes, very little is known about what youth with disabilities living in KZN understand about HIV and AIDS, or what they understand in terms of their risk of the virus. In view of this, the following baseline study was conducted in order to establish current knowledge of HIV amongst youth with disabilities in the uMgungundlovu District. The data collated from this study will not only inform the training workshops, but will also provide a background by which to monitor and evaluate the 3-year project.

1.5 Research Question

- What do youth with disabilities living in uMgungundlovu district understand about HIV and their sexual and reproductive rights?

1.6 Research Objectives

- To identify the level of knowledge about HIV and AIDS amongst youth with disabilities in uMgungundlovu district
- To identify the understanding and experiences of relationships amongst youth with disabilities in uMgungundlovu district

- To identify where youth with disabilities gain information about HIV and AIDS in uMgungundlovu district
- To establish the level of knowledge about sexual and reproductive rights amongst youth with disabilities in uMgungundlovu district

2.0 UMGUNGUNDOLOVU SITUATION ANALYSIS

uMgungundlovu District is situated in the KwaZulu Natal province on the east coast of South Africa, 81 km west of Durban. The District is made up of seven sub-districts (Municipalities), which are Impendle, Mkhambathini, Mpozana, Msunduzi, Umngeni, uMshwati and Richmond (see map below for outline of sub-districts). Situated in Msunduzi municipality is the primary urban centre Pietermaritzburg, which is not only the seat of the uMgungundlovu District Municipality's administration, but is also the thriving, modern capital of KwaZulu-Natal.



These sub-districts are made up of various dwellings ranging from traditional farmland communities, informal rural settlements to upmarket urban areas. The rural and peri-urban areas are primarily inhabited by black/ African people. The majority of the occupants in these areas are Zulu-speaking and the main languages spoken are isiZulu and English.

Throughout the rural areas of Umgungundlovu district, the homes are predominately made up of mud huts with large

distances between homesteads. Many of the homes have limited access to water and electricity. The roads are usually dirt roads and public transport can be limited. Although there are a variety of schools in the area, access to employment opportunities are poor, with most people having to travel great distances to find work in Pietermaritzburg. In terms of health care, most of the rural communities are served by a few clinics and are far from hospitals. There is also a strong emphasis on traditional leadership and values.

The peri-urban areas are made up of a range of housing from small brick houses to informal shacks, with most having access to water and electricity. Most roads are tarred and public transport systems are good, providing easy access to Pietermaritzburg and possibilities of employment. There is a range of schools in the area, including resource schools for children with disabilities.

2.1 Current disability statistics in South Africa

a) Disability percentage by province

The table below outlines the percentage of people with disabilities by province and by sex. It can be seen that there 5% of the KZN population are people with disabilities and that this is equally divided between males and females (StatsSA, 2001).

Courtesy of StatsSA (2001)

b) Disability percentage by Municipality in uMgungundlovu District, KZN (Table 1)

Municipality	Number of persons 2001	Number of persons 2007*	Estimate of persons with disabilities**
UMshwathi	108 422	113 054	5 653
UMngeni	73 896	84 781	4 239
Mpofana	36 820	31 518	1 576
Impendle	33 569	39 401	1 970
Msunduzi	552 837	616 730	30 836
Mkhambathini	59 067	46 570	2 329
Richmond	63 223	56 772	2 839
TOTAL	927 846	988 837	49 442

* Figures extrapolated based on mid-year population surveys

** Based on a 5% national average

From the above table it can be seen that Umgungundlovu District has an estimated 49,442 people with disabilities, equating to about 5 % of the population in the district (which is in line with provincial and national percentages). This percentage is largely made up of people with physical impairments.

3 METHODOLOGY

3.1 Study design

In order to gain information for this study, a qualitative research method design was implemented with an emphasis on using a participatory approach. Given the fact that the rights of people with disabilities are often ignored, Turmusani (2004) articulates that using a participatory approach in disability research can stimulate awareness about people with disabilities within the disabling societal structure. Furthermore, participatory approaches are increasingly being used in sexuality research throughout developed and developing countries (Reddy, 2004). Taking into account these considerations, it was felt that a participatory approach could provide a powerful example through which to make the previously silent voice of youth with disabilities heard and confront set socio-cultural ideas of disability and sexuality.

3.2 Study procedure

Before commencing any form of data collection, it was essential to achieve community entry by working with traditional leaders and ward councillors in each of the sub-districts of uMgungundlovu district. This was achieved by organising meetings in each of the sub-districts with traditional and political structures, youth coordinators and representatives of parents of children with disabilities. Within these meetings, the background to the project was outlined along with the requirements for the baseline study.

Overall, the response was very positive with many councillors reporting incidents where they felt that youth with disabilities were being exploited in relation to sex and HIV.

After gaining community entry and permission to conduct the project, focus groups were then carried out with youth with disabilities. According to Powell et al (1996, cited in Gibbs, 1997), a focus group is 'a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the research'. Unlike other research methods, focus groups allow the researcher to obtain several perspectives on a given topic at the same time. Gibbs (1997) points out that

interaction is a fundamental component of focus groups because the interaction of participants highlights their view of the world and their beliefs and values. This interaction also allows participants to re-evaluate and review their own understanding of their experiences. Despite this advantage, Rifkin and Pridmore (2001) argue that a problem with conducting focus groups is that one or two people may dominate the group making it difficult for others to participate. In this case the chances of introducing bias are high because participants may only give answers to please more dominant members or the researcher.

Altogether, a total of seven focus groups were carried out with youth with disabilities. The focus group discussions attempted to find out from participants what they understood about HIV and AIDS. To initiate these discussions, a picture of the 'AIDS red ribbon' was used, in which participants were asked to think about where they had seen this before and what it meant to them. Participants were also encouraged to discuss what they understood in terms of sexual and reproductive rights for persons with disabilities.

Throughout these discussions, the researcher did not lead the group but rather used reflective probing questions based on participants' responses (see appendix 1). There were between 2 and 6 participants per focus group. Each focus group was conducted in isiZulu and took approximately 1 to 1 ½ hours to complete. The focus groups were also tape-recorded and fully transcribed.

3.3 Study participants

To gain access to the participants, the non-random method of purposive sampling was used. The particular characteristics or subject criterion entailed that participants were male or female youth with disabilities between the ages of 12 to 24 years. Although attempts were made to gather data from a range of different impairment groups, we were only able to gather information from those with physical and intellectual impairments. Table 2 outlines the total number of participants per sub-district, their age, gender and type of impairment.

Area	Participants	Total
Impendle	18 years, female, physical disability 18 years, female, post polio 15 years, female, amputee 17 years, female, physical disability	4
Mkhambathini	20 years, male, physical disability 19 years, female, physical disability 22 years, female, intellectual disability 24 years, female, intellectual disability	4
Mpofana	12 years, male, intellectual disability 21 years, male, post polio 16 years, male, intellectual disability 17 years, male, intellectual disability 23 years, female, paraplegic	5
uMshwati	24 years, female, paraplegic 23 years, female, post polio 19 years, female, intellectual disability 19 years, male, intellectual disability 21 years, male, post polio	5
Msunduzi	23 years, female, post polio 22 years, male, post polio 20 years, female, physical disability 17 years, male, intellectual disability 20 years, female, physical disability	5
Richmond	23 years, male, post polio 24 years, male, post polio	2
Umgeni	24 years, male, intellectual disability 16 years, female, intellectual disability 14 years, female, epilepsy 16 years, male, intellectual disability 16 years, female, intellectual disability 18 years, male, physical disability	6
TOTAL		31

Table 2: Summary of Study Participants

Participants were selected by key informants in each of the sub-districts. Rifkin and Pridmore (2001:116) articulate that key informants are ‘people in the community who, because of their position...have information about community problems’. Within this study, key informants were made up of youth coordinators, Community Rehabilitation Facilitators and leaders of parents of children with disability support groups.

3.4 Data analysis

To analyse the transcripts from the focus groups, the data was coded into different conceptual categories. Miles and Huberman (1994, p.56) define codes as ‘tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study. Codes usually are attached to ‘chunks’ of varying size – words, phrases, sentences or whole paragraphs, connected or unconnected to a specific setting’. Through assigning codes the researcher is therefore able to categorise the data into identifiable themes and highlight significant findings in relation to the research question.

Once the data had been thoroughly labelled with codes, codes were then clustered around themes. Here it was useful to “map” the codes into a table, so as to demonstrate interconnectedness between codes. This helped to highlight interactions, identify meta-themes and revise/group codes where necessary. Thus the steps in qualitative data analysis followed a sequence of reading, coding, displaying, reducing and interpreting (Miles and Huberman, 1994).

4 RESULTS

4.1 Introduction to Results

Within the following section the key interpretative themes that emerged through analysing the transcripts from the focus groups are presented. The results are set out into four sections, which are a) knowledge of HIV & AIDS, b) sex and sexuality, c) experiences of relationships and d) knowledge of disability and sexual rights. The results are given in a summary form in table 2 (see page 15) and relevant quotations taken from the various transcripts are also presented.

4.2 Knowledge of HIV & AIDS

4.2.1 Exposure to Information

Generally in all the sub-districts it would appear that participants had been exposed to information on HIV and AIDS from a variety of sources. The majority of participants received information from the media (i.e. TV, radio and books), schools, local clinics, family and friends. Only one participant mentioned getting information from loveLife campaigns:

“I heard it from the people who came to teach at school” (Female, 20 years, physical disability)

“I got it at school, on TV, the radio and newspapers” (Male, 24 years, post polio)

“I read it in a book from the library. It talks about illnesses that people have and I listen to the HIV educator who talks about what happens when you have HIV”
(Male, 16 years, intellectual disability)

Despite being exposed to HIV information, one participant reported having doubts about the information they received:

“We listen to the radio and watch TV, but we are not sure on how true the information really is” (Female, 24 years, paraplegic)

Furthermore, it was also clear that some participants, although exposed to HIV information, still did not understand what HIV and AIDS really was as highlighted in the following conversation with an 18 year old male with a physical disability:

SI: I don't know what it [HIV] is...I know AIDS
I: Ok, what is AIDS?
SI: It looks like an AIDS sign
I: But what is AIDS?
SI: It's a number

4.2.2 Knowledge of HIV Risk Factors

When asked about those risk factors which may put participants at risk of HIV, majority of the participants were able to correctly identify various modes of transmission:

“If you inject yourself with an already used injection you might get HIV” (Male, 12 years, intellectual disability)

“It's transmitted through blood. If sometimes to help someone who is injured they can get HIV if they have an open wound” (Female, 24 years, paraplegic)

“Alcohol is the other thing that puts you at risk...maybe you are at the bar or party and you are now drunk and see this girl and take her home. You have sex with her without using a condom because you are drunk” (Male, 23 years, post polio)

One participant also pointed out certain traditional ceremonies may also put you at risk:

“The other things I know that could put you at risk is that if you are at home and the traditional healer is doing the cutting to you as a family. You mustn't use the same razor, everybody in the family must have their own razor” (Male, 22 years, post polio)

Although participants were able to identify risk factors, many of them were unsure about the etiology of the virus:

“I want to know exactly how a person gets HIV, I know by intercourse, but how does it get in the body and make you sick?” (Male, 23 years, post polio)

“How true is that when you are pregnant and HIV positive, the baby can be HIV negative if you take a pill?” (Female, 23 years, post polio)

Despite participants having some awareness of risk factors, there were also many misconceptions surrounding modes of transmission in all the sub-districts. For instance, many participants reported assisting, or even just touching someone with HIV without using gloves would put them at risk of the virus.

“It’s transmitted in many ways, like bathing someone who is positive if you’re not wearing gloves” (Female, 19 years, intellectual disability)

A few also reported sharing items used by persons with HIV may also expose them to the virus:

“You must not use a toothbrush that has been used by an HIV positive person” (Male, 18 years, physical disability)

“If you eat with a spoon used by someone with HIV, you can get it” (Female, 22 years, intellectual disability)

Numerous participants throughout the sub-districts also reported the uncertainty over some risk factors and methods of protection that they had heard of:

“Is it true if you have unprotected sex and then take a shower, you won’t get HIV?” (Female, 18 years, post polio)

“Is it safe for me to receive help from someone who is infected, being a disabled person, in things I struggle to do myself? Like for example cooking” (Female, 19 years, physical disability)

“What are the chances of me getting HIV by sleeping with a blanket used by an HIV positive person?” (Female, 24 years, intellectual disability)

4.3 Sex and Sexuality

Throughout the sub-districts, the majority of participants reported being sexually active, even as young as 16 years old. Many of these participants had gone on to have at least one child. Some of the male participants also reported having more than one partner at a time.

4.3.1 Sex Education

Some of the participants reported receiving sex education and information about puberty whilst in school:

“They [teachers] said that if you begin to have sex at a young age, your body doesn’t function the way it should” (Female, 18 years, physical disability)

“(laughs) she [teacher] told me that as I was growing up about the pubic hair under your arm pits and down there. Then as a boy or young man, when your getting mature, you’ll dream about having sex with an old lady and...then you’ll be a grown up by then. After dreaming about having sex with a lady, you have to be careful, because if your really making love to that person you are mature now, you are a real man and you could make a baby [laughs]” (Male, 24 years, post polio)

“They also tell us when in a relationship you must not have many partners and the first time I saw a condom was in school” (Female, 15 years, amputee)

A few participants had received mixed information about sex from their parents:

“My mother once told me that I have to finish school before having a girlfriend” (Male, 16 years, intellectual disability)

“My mother told me to listen to what she says at home and not sleep with boys on the street because they will get you pregnant and say the child isn’t theirs and you’re the one who will suffer” (Female, 14 years, epilepsy)

“Parents have told us that when you turn 21, they will give you the key. They tell you that you’re now grown up you can do what you want because you are at the stage where you can have the key” (Male, 18 years, physical disability)

Despite this, there were many participants across the sub-districts who had not received any sex education or information about puberty, leaving some with uncertainties about sex:

“I just want to know how long...how many minutes or hours must a man or a woman make love so that the woman can fall pregnant?” (Male, 23 years, post polio)

4.3.2 Unprotected Sex

The vast majority of those that reported being sexually active stated that they had unprotected sex with their current or previous partners. The reasons for this differed between male and female participants:

Male

The reasons given by those male participants who reported having unprotected sex ranged from issues of trust through to the dissatisfaction with using condoms:

“After a long time I realised she [girlfriend] was a nice lady and I stopped practicing, that’s why we have a baby...you see I trust her that’s why we stopped practicing safe sex” (Male, 24 years, post polio)

“No I don’t [practice safe sex]...but just imagine your body in latex (laughs), its like your wearing tights! (laughs)” (Male, 22 years, post polio)

“I don’t see the importance of using [condoms]...I only had one girlfriend and I didn’t use it” (Male, 19 years, intellectual disability)

Female

Unlike the male participants, many of the female participants reported wanting to practice safe sex, however were unable to because their partners refused:

“We did use condoms but he [boyfriend] would insult me when I suggested to use it and call me names. So I would sometimes sleep without a condom” (Female, 17 years, physical disability)

One 18 year old participant with a physical disability did not insist on using condoms through fear of losing partner:

S2: I did use it but I realised that he would dump me if I keep asking for a condom every time

I: So you were risking your life for him?

S2: I'd say so...yes, I was afraid of losing him. He didn't necessarily like it [safe sex]

In one of the sub-districts, the key informant explained that one female participant with an intellectual disability was raped at the age of 14 years old and now has a child.

4.4 Experiences of Relationships

The majority of participants throughout the sub-districts had been in some form of heterosexual relationship, usually with a non-disabled partner. Some of the men reported having more than one partner. In terms of experiences within relationships only a few participants actually felt they had a positive experience of relationships despite their disability:

“The boyfriend I have now doesn't have a problem with my disability, even though he is not disabled” (Female, 17 years, physical disability)

“It's the respect [girlfriend] has for me despite the fact that I'm different because of my disability, she mustn't love me because she feels sorry for me” (Male, 20 years, physical disability)

Negative experiences

Most of the participants who were in relationships reported negative experiences, which included the following reasons:

- Physical abuse: e.g. *“He [boyfriend] beats me, he wants me to listen to him even though he’s talking rubbish”* (Female, 20 years, physical disability)
- Financial abuse: e.g. *“She [girlfriend] is just after my money, using me like an ATM. She only wants my money...when I want to see her she is not available”* (Male, 24 years, post polio)
- Physical impairment: e.g. *“What I don’t like about my partner is that he sometimes tells me that he will find other people better than me who can walk”* (Female, 18 years, post polio)
- Multiple partners: e.g. *“He [boyfriend] likes other women. He has many girlfriends...he wants me to be faithful to him though!”* (Female, 19 years, intellectual disability)
- Low self-esteem: e.g. *“You find this guy with a disability going to a girl who is sleeping around...they go to this girl because they think she is the only girl who will have sex with them”* (Male, 24 years, post polio)

4.4.1 Community Attitudes

Throughout the sub-districts, many participants felt that the local communities had very negative attitudes towards people with disabilities and relationships, especially in relation to women with disabilities:

“...where the female is disabled, he only uses her and wants something from her like money and wants her to have his children, without the intention of marrying her. He does not see her as his life partner and has someone on the side he intends to marry” (Female, 19 years, physical disability)

“Many problems usually arise in relationships where the [non-disabled] man is in a relationship with a disabled woman. The [non-disabled] women are usually more understanding and accept the situation. The problem with [non-disabled] men is that even though he loves her, he is ashamed of her disability” (Male, 20 years, physical disability)

Some participants with physical disabilities reported on how their partners would not want to be seen with them in public, for instance:

“What use to upset me is that he [boyfriend] would walk with me only at night. We never walked when people were watching. He pretended he doesn't know me in front of people. When we walked in town, he would walk the other way and I would run after him on crutches asking him to wait for me, but he wouldn't. He would only wait for me when there was no one around” (Female, 20 years, post polio)

4.4.2 Same-Sex Relationships

In one of the sub-districts, a participant pointed out their lack of understanding with regards same-sex relationships:

“I want to know how can two people of the same sex be in love, because our parents aren't of the same sex!” (Male, 17 years, intellectual disability)

4.5 Knowledge of Disability and Sexual Rights

4.5.1 Disability Rights

In relation to general disability rights, four out of the seven sub-district focus groups had some awareness of their rights, especially with regards to:

- Education: e.g. *“I know I have the right to go to school and learn using computers”* (Male, 12 years, intellectual disability)

- Dignity & Respect: e.g. *“You have to love and respect yourself as a young person and know about your future. You also have the right to speak out when someone is discriminating against you. They should respect you as you are”* (Male, 17 years, intellectual disability)
- Employment: e.g. *“I have the right to have a decent job even though I go to a school for the disabled. I can also get into politics and do what I’m capable of without being limited by my disability”* (Female, 18 years, post polio)

4.5.2 Sexual and Reproductive Rights

With regards to their sexual and reproductive rights, nearly all the participants could not identify a single right. One participant did however point out that she was aware of them apart from the right to refuse unsafe sex:

“I didn’t know I had the right to say no to sex without a condom” (Female, 23 years, post polio)

5 DISCUSSION

5.1 Introduction to Discussion of Findings

The following section will outline a discussion of the results set out in the previous section, in relation to the objectives of the study and other relevant literature. This section will aim to evaluate the current knowledge of HIV and relevant experiences of youth with disabilities living in uMgungundlovu district. The section will also include a critical evaluation of the research methods used within the study and possible limitations encountered during its execution.

5.2 Discussion on Knowledge of HIV And AIDS

Overall it would appear that youth with disabilities living within the seven sub-districts of uMgungundlovu district are exposed to information on HIV and AIDS from a variety of different sources. Interestingly, many of the participants indicated school and the media as being the main places in which they learnt about HIV. This is very different to Collins et al (2001) study whereby youth with disabilities were often excluded from health education classes in school. Despite this exposure, it was clear that many of the participants still lacked clear understanding of what HIV and AIDS were and some even doubted the authenticity of the information they had received.

In relation to modes of transmission, several of the participants were able to identify many of the commonly known risk factors such as unsafe sex, exposure to contaminated blood and needle stick injuries etc. Although they were aware of these risk factors, it did not reflect within their behaviour, especially in relation to sexual activity where there were high incidences of unsafe sexual encounters. This therefore highlights a serious gap between exposure to knowledge on HIV and actual behaviour change, which is a common problem experienced by many youth HIV programmes. For instance, in a study amongst non-disabled secondary school students in KZN, James et al (2007) found that although students levels of knowledge about HIV and means of protection were high, there was a significant deviation in their reported sexual behaviour.

Similar to other studies on knowledge of HIV and AIDS amongst youth with disabilities in Nigeria (Groce et al, 2005) and Swaziland (Yousafzai et al (2004), it would appear that many participants in the current study also had misconceptions surrounding modes of transmission. Most of these misconceptions related to interactions with persons who were HIV positive such as sharing utensils e.g. spoons, combs, blankets etc. through to even assisting someone who is infected in basic activities of daily living. In consideration of these misconceptions, there is a concern that this may increase stigma towards those who are living with HIV and their isolation from the wider community. Throughout Africa it is well known that stigma drives the HIV and AIDS pandemic. According to Parker and Birdsall (2005), stigma involves the social expression of negative attitudes and beliefs that contribute to processes of rejection, isolation, marginalisation and harm of others. In respect of this, HIV, AIDS and disability share a common problem of stigmatisation. Just like those living with HIV and AIDS, people with disabilities are also feared and misunderstood. Furthermore, in many African communities disability is seen as a ‘punishment for sin’, a curse, or as a consequence of not fulfilling the wishes of ancestral rites. As a result, in some communities people with disabilities are often hidden away not only out of shame, but the fear of ‘contaminating’ other non-disabled individuals with an ‘unwanted disease’ (Chappell and Johannsmeier, 2007). Given these beliefs surrounding HIV and disability, it may possibly be argued that being disabled and having HIV and AIDS could create a ‘double stigmatisation’.

5.3 Discussion on Sex and Sexuality

Despite societal and medical beliefs that people with disabilities are asexual, it is clear from the current study that this really is a myth, especially considering that the majority of participants were sexually active. Both male and female participants reported being sexually active from as young as 15 years old, with many incidents of teenage pregnancies. These results coincide with a national survey conducted by loveLife on the sexual behaviour of non-disabled young people in South Africa, where it was also found that 67% of those between the ages of 15-24 years were sexually active (Pettifor et al, 2004). Many of the young men in the current study also reported having more than one partner at a time, which again is not dissimilar to studies that examined the experience of their non-disabled peers (Harrison, 2008).

The majority of participants who reported being sexually active in the current study, had practiced unprotected sex with their previous or current partners. Interestingly, the reasons for having unprotected sex differed between male and female participants. For instance, the male participants often commented about being able to trust their partner and therefore not needing to use condoms. Further still, some reported that condoms were uncomfortable to wear. These points coincide with Leclerc-Madlala (2002), study amongst non-disabled youth living in KZN, in which she found strong associations between condoms and notions of unfaithfulness, lack of trust, lack of love, disease and incompatibility with manliness. In view of these factors, it would appear that barriers against safer sex practices are the same for both non-disabled and disabled male youths and continues to be an area of concern, irrespective of their awareness of HIV messages.

In relation to young females with disabilities, many of them retold accounts of how they had tried negotiating safe sex with their partners with very little success. This situation, which again is not dissimilar to their non-disabled counterparts, highlights the gender-based inequalities of power in regards to sexual relationships. In accordance with Harrison et al (2006), these gender inequalities render women more vulnerable to violence and acquiring HIV. Taking into consideration the current study and the low status often given to women with disabilities in communities, it is contended that young disabled women are probably even more vulnerable than their non-disabled peers.

Despite the similarities in sexual experience to non-disabled youth, very few disabled youth in the current study had received any form of sex education. Furthermore, many participants, especially those with intellectual disabilities, had not received any information about the physical and emotional changes that occur during puberty. The lack of information with regard to sex and puberty could be attributed to the misconception that youth with disabilities are seen as 'child-like' and should not be told about sex. In addition, they are often perceived to be over-sexed and talking about 'it' will result in uncontrolled sexual behaviour (Milligan and Neufeldt, 2001). These beliefs, have left many youth with disabilities without adequate support and have increased their vulnerability to abuse as evident in the current study, whereby one of the participants was raped at the age of 14 years.

5.4 Discussion on Experiences Of Relationships

Unlike the few male participants who reported being in a stable love relationship, the majority of female participants gave very negative accounts of their experiences of relationships in which their partner treated them badly. These often included situations of physical and financial abuse, and their partners having a series of other non-disabled partners. Several participants with physical impairments also reported incidents whereby their partner was too embarrassed to be seen with them in public during the day.

These results undoubtedly reveal the negative attitudes communities have towards the subject of people with disabilities and relationships, especially in relation to women with disabilities. Similar results were also found in a study conducted by Seymour (1998) who compared the sexual experience of men and women after spinal injury. The study found although men were more physically affected by their injuries, they experienced less rejection than women in terms of forming relationships. Seymour (1998) attributes these results to the varying ideas and values societies place on the roles of men and women. For example, in most societies women are traditionally perceived as being caregivers and as a result are more likely to care and love a man with a disability. Women with disabilities, although perceived to be viable sexual partners are not recognised as being 'woman' enough to be able to care for a family or carry out domestic duties and therefore do not make suitable marriage partners. This leads to a situation whereby young women with disabilities have a series of sexual partners, which combined with the inability to negotiate safe sex, increases their exposure to HIV (SANAC, 2008; Groce, 2005).

Although the focus has been on the negative attitudes of communities, it is also important to acknowledge the lack of self-esteem and confidence some of the participants had in relation to relationships. This not only highlights their lack of sex education, but also their acceptance of themselves and their capabilities of forming loving relationships. As aptly denoted by Finger (1992 – cited in Shakespeare, 2000:160) 'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about—and formulate strategies for changing—discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction'. On reflection, it is contended that although the disability movement has

put a lot of emphasis on changing the physical environment and promoting civil rights, it has failed to recognise the importance sexuality also has in building an individual with disabilities self esteem.

Interestingly in one of the rural sub-districts, one of the participants also spoke of their confusion surrounding the issue of same-sex relationships. Although seen as a taboo subject amongst many traditional African communities, homosexuality is still an issue that affects both non-disabled and people with disabilities alike. The failure to talk about it amongst communities, including people with disabilities, creates many misconceptions and discriminatory attitudes towards those that are gay, which in turn increases their isolation. As a result of this isolation and fear of public discrimination, many are afraid to come forward to seek advice, which could put them at increased risk of HIV.

5.5 Knowledge of General and Sexual Rights

In relation to knowledge of disability rights, it would appear that the majority of participants had some idea of their basic rights, especially with regards to education, employment, dignity and respect. The importance of youth with disabilities knowing their rights is reflected in international legislation such as the UN Convention for the Rights of Persons with Disabilities (2006). This Convention, which was ratified by South Africa in 2007, aims to ensure all rights and freedoms of all people with disabilities are enjoyed, respected and protected.

Apart from Article 23 of the Convention, which briefly mentions the rights people with disabilities have to get married, in analysing the Convention critically, there is no reference to the rights of people with disability and their sexual and reproductive health. This is rather surprising considering the current global HIV and AIDS pandemic and the fact that many youth with disabilities, as highlighted in the current study, are unaware of their sexual and reproductive rights.

5.6 Limitations of The Study

Within the following final section, the limitations of the methodology used for this study will be outlined.

- Equal representation of all types of impairments

Although this study tried to include all types of impairments, it was unfortunate that those with a visual and hearing impairment were not included in any of the focus groups. One reason for this could be as a result of the key informants not having adequate contact with people with visual or hearing impairments in their communities.

- Use of focus groups only

Focus groups have often been used in the collection of data surrounding the sensitive topics of sexuality and HIV. However, it was clear from this study that some of the participants felt uncomfortable in discussing personal issues in front of their peers. On reflection of this, it is felt that individual interviews should have also been used within the collection of data.

6 CONCLUSION

The following section of this report will include a summary of the main points and an overview of the findings and their implications in the education of youth with disabilities in relation to HIV and AIDS.

The aim of this baseline study was to establish what youth with disabilities living in the seven sub-districts of uMgungundlovu district currently know about HIV and AIDS. Furthermore, it aimed find out their experiences in relation to sex and relationships, and also their knowledge of sexual and reproductive rights. The study highlighted that youth with disabilities have generally been exposed to messages about HIV and are aware of basic risk factors. However, despite this exposure, they have many misconceptions surrounding modes of transmission and some are even unsure of the authenticity of the information they have received. The study also revealed a gap between knowledge of HIV and actual behaviour change, especially in relation to sexual practices. This then calls into question the effectiveness of current HIV information and their relevance to people with disabilities.

On reflection, it is clear that participants' experiences of sexual relationships are very similar to those of their non-disabled peers. However, due to negative community beliefs surrounding disability and sexuality, low self-esteem and lack of awareness of sexual and reproductive rights, youth with disabilities appear to be more vulnerable to abusive and unhealthy relationships. In view of this and their lack of sex education, it can be deduced that youth with disabilities are at increased risk of HIV compared to their non-disabled peers.

Table 4 (as seen on pages 32-33) highlights the strengths and weaknesses in knowledge and experiences of HIV and relationships in each of the seven sub-districts. Furthermore, it also sets out the current gaps in knowledge which need to be addressed in future youth with disability workshops.

6.1 Recommendations For Future Practice

By reflecting on the findings as outlined in Table 2 and the discussion section, the following recommendations are put forward:

- In view of the lack of behaviour change amongst youth with disabilities, HIV training material that actually reflects the needs of youth with disabilities need to be developed. Furthermore, national HIV programmes that target youth such as loveLife, need to be challenged with regards the inclusion of youth with disabilities in their media campaigns.
- Given the lack of education surrounding puberty and sex, it is essential that the youth with disability workshops include basic issues of how their body changes during puberty, understanding sexual feelings, reproductive health and sexually transmitted infections (STIs)
- In an attempt to protect youth with disabilities from abuse, they must be educated not only about their general rights, but also about their sexual and reproductive rights. Furthermore, they need to be made aware of appropriate services such as Childline, Lifeline etc. who can assist them in cases of abuse.

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