

EXPERIENCES OF SOCIAL EXCLUSION AMONG YOUNG DEAF ADULTS INFLUENCING THEIR BELIEFS AND PERCEPTIONS OF HIV/AIDS

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Abstract

This paper reports on a Master's study whose aim was to capture the beliefs and perceptions of young deaf adults about HIV/AIDS in the Cape Metropole and surrounding areas. The study utilised the explorative, contextual and qualitative descriptive study design. Purposive sampling was implemented and data were collected through focus groups and in-depth interviews. Data were analysed using content analysis. Ethical considerations were adhered to. The main findings of the study indicate that numerous myths and misperceptions about HIV/AIDS prevail among deaf people. This paper advocates for policymakers to include deaf people, particularly sign language users, in HIV-prevention programmes.



## **EXPERIENCES OF SOCIAL EXCLUSION AMONG YOUNG DEAF ADULTS INFLUENCING THEIR BELIEFS AND PERCEPTIONS OF HIV/AIDS**

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### **INTRODUCTION**

Disability is defined by the World Health Organisation (1998) as a limitation that a person has in one or more functional activities. In South Africa the Integrated National Disability Strategy White Paper includes deaf people in the definition of disabled persons, based on their sensory impairment, which refers to their hearing loss (Government of South Africa, 2007). In the document a person is defined as “deaf” when that person has little or no functional hearing and depends on visual rather than auditory communication (Government of South Africa, 2007). Deaf individuals have a wide range of hearing impairments, there being not one, but three main types of hearing loss: (i) conductive hearing loss, which occurs when sound is not conducted efficiently through the outer-ear canal to the eardrum and the tiny bones (ossicles) of the middle ear; (ii) sensorineural hearing loss occurs when there is damage to the inner ear (cochlea), or to the nerve pathways from the inner ear to the brain. This is the most common type of permanent hearing loss; (iii) mixed hearing loss, which arises when conductive hearing loss occurs in combination with sensorineural hearing loss (American Speech-Language-Hearing Association, 1997-2013).

The deaf community is therefore very diverse, since there are variations in the cause and degree of hearing loss, in the age of onset of deafness, educational background, communication methods, and the way individuals feel about their hearing loss. Yet in spite, or because, of these differences, deaf people comprise a distinct culture, known as deaf culture, and they share many common values, beliefs, rituals and concerns. In the deaf community however, there is widespread ignorance about HIV/AIDS. This can be attributed largely to their economic marginalisation, inferior education, poverty, gender inequality, gaps in health care and substance abuse (Butler, Skelton & Valentine, 2001).

Williams, Holmbeck and Greenley (2002), furthermore, reported that HIV/AIDS constituted a primary source of morbidity and mortality not only among disabled persons but also among young adults. Out of the 40 million disabled and non-disabled individuals who were diagnosed in 2006 with HIV globally, 10 million were young adults (Joint United Nations Programme on HIV/AIDS, 2006). The findings of a recent study undertaken by the United Nations Children’s Fund (UNICEF), published in 2011, revealed that in 2009 an estimated 890,000 (combined figure) young adults from Nigeria and South Africa were infected with HIV. This in essence amounts to 2 500 infections every day. The majority of these new infections occurred in 20 countries in sub-Saharan Africa. Nigeria and South Africa account for one out of every three of these new infections. The report also indicated that internationally young women comprise more than 60 percent of all young people living with HIV, a number which has gone up to 71 percent in sub-Saharan Africa (UNICEF, 2011).

Young adults are therefore seen to be at particular risk for HIV infection and transmission. Young adulthood is a critical development stage in human development, as two of the most important events in young people's lives are developed during this period. These are cultivating love relationships and intimacy (Bellin & Stephens, 2006). Since young adults are perceived to be, and are, the current and future workers, as well as the future parents and leaders of the country, HIV infections are said to contribute significantly to the economic and social deterioration of a country, particularly in a developing country. In addition to attempting to maintain and sustain healthy relationships, young adults are also faced with many threats related to situational factors, such as regional, cultural background and political factors. These factors render them vulnerable and may negatively influence their ability to negotiate sexuality, in particular safe sex (Esat, 2003).

In this context, young deaf adults face two equally reinforcing experiences. They encounter all the developmental tasks that come with young adulthood, which include achieving new and more mature relationships with others in their age group, achieving a masculine or feminine social role and identity, accepting their individual physique, achieving emotional independence from parents and other adults, preparing for marriage and family life, preparing for a career, and acquiring a set of values and an ethical system as a guide to behaviour. In addition to these challenges and tasks, young deaf adults have to deal with the additional challenges resulting from their disability, especially those relating to barriers in communication, specialised education, inaccessible health services, and limited and inferior work opportunities (Bisol, Sperb, Brewer & Kato 2008). Similarly, because deaf people are a closely-knit minority within a given society because of their communication, cultural and other similarities, they are commonly excluded and marginalised from the broader society as well as from HIV/AIDS awareness and prevention campaigns geared towards the broader society (Siple, Greer & Holcomb, 2004). This paper intends to highlight the findings of a social work Master's research study undertaken by the first author with a purposive sample of the deaf community of Cape Town, Vredenburg and Paarl.

## **LITERATURE REVIEW**

### **International studies on HIV/AIDS and deafness**

On an international level a number of research studies have been published on deafness and HIV. During the late 1970s and early 1980s the first studies on HIV/AIDS and deafness came mostly from the USA. The research focus of these studies was deaf people as the population and HIV/AIDS as the problem. Experts in this era estimated that the deaf population was about eight years behind the hearing population in terms of HIV/AIDS knowledge and awareness (Fitz-Gerald & Fitz-Gerald, 1979). In the 1990s Peinkofer (1994:390-392) revealed in an important study that large numbers of deaf and hard-of-hearing people were in danger of becoming infected with HIV as a result of language barriers, their unique culture, and the paucity of community services, educational programmes and general information directed to this population.

At the beginning of the 21<sup>st</sup> century more studies came to the fore in the USA. Recent studies in the American deaf community revealed that 9 to 10 percent of Americans have hearing loss, and that deafness is the second most common disability in the United States (Meador & Zazove, 2005). In addition, research found deaf persons to have altered health care utilisation patterns and to experience significant communication difficulties with medical practitioners (Moinester, Gulley & Watson, 2008). They were also widely perceived as a silent, non-English speaking group by many physicians, who often experienced misunderstandings on the part of deaf patients about the virus and treatment recommendations (Moinester *et al.* 2008). Deaf people were seen to have their own culture and social mores, who use sign language and typically have low English-language reading levels. In the findings of these studies it became apparent that sign language differs substantially from English in crucial ways, including its idioms and grammar. Deaf people were thus regarded as disadvantaged in terms of accessing HIV/AIDS information (Meador & Zazove, 2005).

Similarly Crowe (2003), who conducted a study in Washington DC with deaf persons in focus groups, revealed that they had difficulty in explaining the difference between HIV and AIDS, and that there was also confusion about birth control, sexually transmitted infections (STIs) and HIV prevention. Deaf participants in her study had a vague understanding of the HIV testing procedure, being aware only that the doctor would draw blood but unable to provide more detail about the actual process. When members of the focus groups of Crowe's study were asked how they first learned about HIV, they indicated that they had learned through various ways including schools, family, friends, counsellors, staff at community centres, books, television and newspapers. It was found, however, that the information gathered was not always accurate. The following barriers to deaf people's accessing accurate information were reported: difficulty in understanding English in printed and verbal format, and the absence of sign language interpreters (Crowe, 2003).

Moreover, Bisol *et al.* (2008) measured and compared HIV/AIDS knowledge and health-related attitudes and behaviours among deaf and hearing students in Southern Brazil. There were 42 deaf participants who attended a special non-residential public school especially for the deaf, and 50 hearing participants who attended a regular public school. Participants were all between the ages of 15 and 21. The study revealed that deaf participants scored lower on HIV/AIDS knowledge. Other findings in the study that caused concern included the high rate of sexual abuse reported by deaf participants as well as a large number of young deaf individuals reporting that they had friends who had AIDS (Bisol *et al.*, 2008).

Bat-Chava, Martin and Kosciw (2005) also utilised focus groups and individual interviews in New York. Many of the themes elicited in this study were similar to those which emerged in the above-mentioned studies: deaf persons are less knowledgeable about HIV/AIDS than hearing people, and they have communication difficulties with medical personnel. New themes which emerged within this study revealed that oral deaf or hard-of-hearing participants have little more knowledge than those participants who used sign language. These reflect differences between young deaf people using sign

language and those using other forms of communication both on the level and quality of education, and in English language proficiency. Another new theme that emerged in this study was the increased vulnerability of deaf men who have sex with men. Discrimination and stigma were found to be rife against such persons, based on their disability and compounded by their sexual orientation (Bat-Chava *et al.*, 2005).

Research on HIV/AIDS and deafness was also undertaken outside of the USA and these studies did not contradict or call into question the earlier American literature on this subject; they simply reinforced the findings in different countries. In India a research study revealed that deaf people in that country have a very limited awareness of sexually transmitted diseases (Patel & Gopinath, 2000). Low levels of literacy and inadequate knowledge of HIV/AIDS were also reported amongst Canadian deaf individuals (Esmail, Krupa, MacNeil & MacKenzie, 2010).

Studies on deafness and HIV/AIDS on the African continent also started to emerge in the early part of the 21<sup>st</sup> century. These research studies, like those done in the USA and elsewhere, did not differ significantly from the findings documented internationally; they only expanded and focused more on the impact of HIV/AIDS on deaf communities in various parts of Africa (Mulindwa, 2003; Munthali, Mvula & Ali, 2004).

### **AFRICAN STUDIES ON HIV/AIDS AND DEAFNESS**

A cross-sectional survey of 191 rural and urban hearing and deaf adults in Swaziland found that deaf people are more likely to believe in incorrect modes of HIV transmission (e.g. hugging and airborne transmission), and HIV prevention (e.g. avoiding sharing utensils and eating healthy foods). Almost all the deaf participants (99%) reported difficulties in communicating with health-care facility staff, which often resulted in less use being made of HIV voluntary counselling and testing services (Yousafzai, Dlamini, Groce & Wirz, 2004).

A similar research study in Kenya with 1 709 deaf respondents, found that 80 percent of the respondents found themselves at risk because of the false beliefs relating to HIV/AIDS. Kissing and sharing utensils with an HIV-positive individual were listed as possible modes of transmitting HIV (Hanass-Hancock, Nixon & London, 2009). These findings are similar to those of a smaller study undertaken in Cameroon in 2008 by Touko (2008) with 126 deaf participants, and which produced some disturbing findings. Firstly, the average age for first sexual experience and intimacy of young deaf persons was about a year earlier than the national average of 16.5 years. Secondly, 80 percent of the deaf participants were sexually active without full knowledge of how to practise safe sex. Additional findings suggested that only 50 percent of participants had some basic knowledge about sexually transmitted diseases (Touko, 2008).

During 2010 a follow-up study was undertaken by Touko, Mboua, Tohmuntain and Perrot in Cameroon. A total of 118 deaf participants were interviewed for the behavioural component, using sign language as a means of data collection, while 101 participants underwent HIV serology testing. The results recorded showed that 80 percent of the respondents were sexually active. All the respondents, male and female,

reported having had sexual intercourse before the age of 15 years (Touko *et al.*, 2010). Another important finding indicated that more than half of the respondents, both men and women, had engaged in multiple concurrent sexual relationships in the 12 months prior to the study. Careful analysis of data related to each individual's most recent casual sexual intercourse highlighted a critical situation: more than half of the deaf respondents did not use a condom during sexual intercourse.

Groce, Yousafzai and Van der Maas (2007) undertook a study in Nigeria. This study was similar to the one that was undertaken in Southern Brazil by Bisol *et al.* (2008). Fifty deaf and fifty hearing participants were requested to complete a survey. Similar to the international studies already described, deaf members of the population had considerably less understanding and access to accurate and reliable information about HIV and AIDS (Groce *et al.*, 2007).

An additional challenge for deaf people was also explored by the International Bank for Reconstruction and Development (2010) in South Africa, Uganda and Zambia. This study found that there is a problem concerning the translation of concepts of HIV/AIDS into sign language, in particular the notion of being "HIV positive" or "HIV negative". One of the misconceptions among the deaf community which constituted the population for this study was that being HIV positive is a good thing and HIV negative is a bad thing (International Bank for Reconstruction and Development, 2010).

These findings from Africa speak strongly to the need for the development of interventions that include people with disabilities in public health, and HIV/AIDS strategies that address their specific vulnerabilities (Groce *et al.*, 2007).

### **SOUTH AFRICAN STUDIES ON HIV/AIDS AND DEAFNESS**

Although the body of South African literature on HIV/AIDS and deafness is small in comparison to that of international studies, these limited research studies have shown similar results to the international studies and those conducted elsewhere in Africa. Two South African researchers, Mall and Swartz (2012), confirmed that the relationship between the deaf adolescent and his or her parents could be, and was in several cases, hampered by communication difficulties. The parents in their study all believed that their deaf children were at risk of HIV infection. Mall and Swartz (2012) thus stressed the desperate need for HIV/AIDS education for the deaf community. Mall's (2012) doctoral thesis explored HIV-prevention needs of deaf and hard-of-hearing persons in the South African context. Her study included qualitative interviews with employees of deaf organisations, educators of deaf and hard-of-hearing adolescents, and deaf or hard-of-hearing adolescents themselves, in relation to sexuality and HIV-related issues. The results indicated that deaf organisations have an interest in the HIV-prevention needs of the deaf community, including those in deaf schools. However, these organisations have experienced obstacles in delivering HIV education to deaf learners, mainly because of the religious ethos that is present in schools. Sexual intercourse outside of marriage is regarded as immoral and frowned upon. Training on sexuality and HIV/AIDS is therefore discouraged and this disadvantages deaf people who engage in sexual exploration with limited or no knowledge of the risks involved (Mall, 2012).

This disadvantage is substantiated by Meletse (2012), who is a deaf AIDS activist and was the first deaf African in South Africa to self-identify as HIV positive. Meletse provides his testimony in an article entitled “Impassioned fighter for the devil’s people”. He reports having his HIV-positive status disclosed to him by a doctor writing in large letters on a piece of paper and holding it up in front of his face. He received no counselling or any explanation of his treatment. He tested when he was 36 years old in 2002 (Meletse, 2012). He indicates that because of his sensory disability, mainstream HIV/AIDS awareness and prevention programmes has passed him by.

### **HIV/AIDS AWARENESS CAMPAIGNS AND THE DEAF COMMUNITY**

Despite the improved reach of awareness campaigns which are predominantly aimed at hearing, non-disabled persons, accurate, reliable and easily accessible knowledge about HIV and AIDS continues to be woefully inadequate. Across all age groups and sexes, less than half of all people surveyed in South Africa knew of both the preventative effect of condoms and that having fewer sexual partners could reduce the risk of becoming infected. More troubling still is the fact that accurate knowledge about HIV/AIDS has decreased significantly in recent years (Human Sciences Research Council, 2009). Moreover, HIV/AIDS awareness programmes disseminated via the electronic media, in particular radio and television, are found to be inappropriate and ineffective for the deaf audience. The programmes on television can only be effective for this audience if a qualified interpreter, and/or one skilled in SASL, is employed. In most countries, however, this service is not available and deaf people are totally overlooked (Matlosa, 2006). Glaser and Lorenzo (2006), in their South African study on the development of literacy with deaf adults, also perceived the print media as ineffective with regards to HIV/AIDS. They found that some deaf people have very low literacy levels. Another challenge to disseminating knowledge about HIV/AIDS is the fact that most pamphlets and posters do not acknowledge deaf persons at all (Trafton, 2006). While the print media show pictures of the various vulnerable groups that are at risk of HIV and AIDS, including people of all races, ages and sexual orientation, very few of the pictures represents a person using sign language or wearing a hearing aid. This serves to further propagate the myth that deaf people are not infected or affected by HIV and AIDS, and significantly impedes progress in combating the pandemic (Trafton, 2006).

Because of the lack of in-depth awareness of HIV/AIDS (Human Sciences Research Council, 2009), a number of researchers have endeavoured to study people’s unique beliefs and perceptions around the disease, as both an HIV/AIDS awareness and preventative exercise.

### **FEMINIST THEORY AND SOCIAL CONSTRUCTIONISM**

Feminist theory is one of the major contemporary sociological theories which analyses the status of women and men in society with the purpose of using that knowledge to improve women’s lives. Feminist theorists have also started to question the differences between women, including how race, class, ethnicity, disability and age intersect with gender. Feminist theory is primarily concerned with giving a voice to women and highlighting the various ways in which women have contributed to society (Hooks,



2000). Feminist theory is particularly applicable to research into deaf persons' experiences, since both deaf people and women have been viewed at various times throughout history as inferior (Hooks, 2000). Furthermore feminist theories have been influential in examining and analysing political and social institutions that have undermined and marginalised women and other social groups over the centuries. Hartsock (1983:40) concluded that "feminism as a mode of analysis leads us to respect experience and differences, to respect people enough to believe that they are in the best possible position to make their own revolution". Feminism thus contests the invisibility of deaf women, and other oppressed and marginalised groups, within the hierarchies of power and authority, and assumes that the 'ruling group' does not understand the realities of women who are disabled, oppressed and marginalised.

Gardiner (2005) sees the most significant achievement of the 20<sup>th</sup> century with regards to feminist theory as being the concept of gender as a social construction. According to this theory, masculinity and femininity are loosely defined, historically variable, and regarded as social ascriptions to persons with certain types of bodies. These labels do not reflect the natural, necessary or ideal characteristics of people with similar genitals. This concept has transformed ancient assumptions about the inherent characteristics of men and women. The concept has also challenged the very division of people into categories of "men" and "women". Feminist theories seek to understand the causes, means and results of gender inequality and then endeavour to develop effective ways to improve the conditions of women and other marginalised groups through the implementation of various strategies. In other words, feminist and post-structuralist theories "deconstruct" power relations by dismantling the norm and through promoting a politics of change. These theories present the possibility to researchers of an innovative approach to research, and more particularly to disability, sexual identities and health practices in relation to HIV/AIDS. In this theoretical context it is both valuable and crucial for HIV/AIDS awareness and prevention efforts targeting disabled persons to consider the intersections of sex, sexual practice/orientation and gender (Butler, 2004).

## **METHODOLOGY**

As highlighted earlier, this article draws on the findings of a Master's thesis completed by the first author, who explored the beliefs and perceptions held by young deaf adults about HIV/AIDS. A qualitative research approach was chosen and utilised to allow for the complexity of the issues, for depth of understanding, and for flexibility in the process of the exploration of issues and perceptions with the young deaf adults who participated (Neuman, 2000). This approach facilitated empowerment of young deaf participants as each belief and perception is recognised and recorded. In the current study qualitative research with deaf people allowed for a focus on thick descriptions (Plummer, 2001) from small samples of participants rather than on data from large samples, as is typical of quantitative research. The research process consisted of various stages: identifying the study area and setting, recruiting a sign language interpreter, recruiting participants, conducting interviews and analysing the data.

The research design included the contextual, exploratory and qualitative descriptive study designs. The contextual research design was used in this study, as it allowed for the emergence from the participants of the cultural and social meanings attached to the beliefs and perspectives regarding HIV/AIDS that have developed within the deaf community over time. The contextual research design works from the premise that the participants are the experts in terms of perceiving and describing their experiences and this study accorded them this role. An exploratory study is conducted when very little is known about the situation being investigated, or insufficient or no information is available on how similar research issues have been solved in the past (Neuman, 1997). In such cases, extensive preliminary work needs to be done to develop a familiarity with both the topic and the research population.

As stated previously, the qualitative descriptive research design, which is slightly different from the quantitative descriptive design, was also utilised for this study. In quantitative descriptive research designs subjects are usually measured once and the study establishes only associations between variables. On the other hand, the qualitative descriptive design was used to provide an in-depth description of the beliefs, perceptions as well as the themes that were explored (Sandelowski, 2010). Correspondingly, Neergaard, Olesen, Andersen and Sondergaard (2009) suggest that all research essentially has three main purposes which are, inter alia, to describe, explain and validate findings. Qualitative descriptions are therefore very useful to achieve the purposes of research; they emerge subsequent to creative explorations, and function to organise the findings so that the findings can correspond with explanations. The description of the data collected from participants was particularly beneficial to this study, as it often uncovered knowledge that might not have been noticed or encountered otherwise (Neergaard *et al.*, 2009).

The purposive sampling type was chosen for this study primarily because the researcher considered some participants to be more suitable for the research than others (Neuman, 2000). The participants considered most suitable for this research study were persons who were born deaf and who cannot hear or speak at all, with ages ranging from 18 to 34. The reason these specific criteria for the participants were chosen was so that the research was accessible in terms of providing a sign language interpreter. and so that the responses could reflect those within the deaf community who share equal disability status and similar characteristics. The sample consisted of both female and male participants, so that a gender balance was obtained. Participants were residing in the greater Cape Town area, which includes the northern and southern suburbs, Paarl and Vredenburg. Participants were voluntarily recruited through two organisations: the deaf Community of Cape Town (DCCT) and the Deaf Federation of South Africa (DEAFSA). A total of 92 (48 females and 44 males) participants were included; 87 participants participated in 9 focus group discussions and 3 male and 2 female key informants were interviewed.

The data-collection procedures for this research included focus group discussions and in-depth interviews with key informants, which enabled triangulation for the purposes of establishing reliability and validity. Triangulation is a technique which allows for

research to be conducted through utilising multiple methods (Guion, Diehl & McDonald, 2011). Triangulation is primarily used to increase the researchers' understanding of the issues and strengthen their confidence in the findings of a qualitative study (Guion *et al.*, 2011).

All the interviews were transcribed verbatim as soon as possible after the focus group discussions and in-depth interviews, so that information was not lost and discussions were still fresh in the memory of the researcher. Secondly, codes were applied to the data and all the data were organised into themes. Initial themes that emerged were colour coded. This was followed by the cut-and-paste method (Tracy, 2013): themes were sorted and placed in relevant groupings. Thirdly, the data were interpreted, which included looking for meaning and relationships within the data (Thorne, 2000), and integrating the theoretical framework and empirical studies for the purposes of controlling the literature survey. The final step was assessing the trustworthiness of the study. Credibility was achieved through allowing the participants to judge the results and findings (Shenton, 2004). In terms of transferability, the characteristics of the context and participants of this study are described in detail in order to allow for adequate comparisons (Shenton, 2004). Dependability was achieved through a clearly defined audit trail of data collection, analysis and interpretation (Golafshani, 2003). Confirmability of the research study is found in the neutrality of the data (Golafshani, 2003). This study allowed findings to be confirmed by deaf persons from Paarl and Vredenburg as well as the academic research supervisor and the sign language interpreter used in the study (Golafshani, 2003).

Deaf persons were involved in an appropriate way in informing and shaping the research process, and were respected and treated as the 'experts' in the research and not merely as the passive objects of research (National Disability Authority, 2009). Accessibility to the research process for deaf participants required providing sign language interpretation to them so that they could use their indigenous means of communication (National Disability Authority, 2009). Participants in this study were also fully informed, in sign language, about the purpose, aims and objectives of this research study. Written consent was obtained from each participant prior to the focus group sessions and individual interviews. Participants were required to undertake not to divulge any information discussed in the focus group. The fact that a sign language interpreter was used in the study for data collection was also included in the consent form (Dixon, 2005). Participants reserved the right to continue to participate or to withdraw from the study if and when they needed to without fear of negative repercussions. The confidentiality of participants was assured at all times. Participants were assured that the Dictaphone recordings would be destroyed after all the information was documented successfully (Dixon, 2005). Pseudonyms instead of participant's real names were used to further ensure confidentiality and anonymity. Moreover no harm was incurred during the study. A contingency plan was in place, however, should any person be traumatised or negatively affected by the study. In such a case, a referral procedure would be followed for appropriate debriefing. No payment was offered to participants. Participation in this study was voluntary and no participant was compelled to take part in this study.

Finally, because this study included three HIV-positive persons, the first author had to pay particular attention to their vulnerability and took steps to protect them by making sure that they were physically fit to participate and at no time forced or coerced them to participate or to disclose any information with which they were not comfortable (Wolf & Bernard, 2001). They participated freely, and each one had publicly disclosed his or her status long before the research was initiated. The approval of the University of Western Cape's Ethics Committee was sought at the very beginning of this study and, once this was obtained, the researcher followed the approved ethical requirements strictly.

## **FINDINGS OF THE STUDY**

There were a number of themes that emerged from the study, but for the purposes of this paper the focus will firstly be on myths, misperceptions and incorrect beliefs about HIV/AIDS transmission and HIV-positive persons that prevail among deaf persons. The finding relating to the strong desire to become a parent despite the risk of HIV/AIDS infection and transmission will also be unpacked in this section. The second theme that will be presented focuses on deaf women's beliefs and perceptions about their vulnerability to HIV/AIDS infection. The final theme explored deaf persons' experiences of social exclusion which have impacted directly and indirectly on the formation of their beliefs and perceptions of HIV/AIDS transmission.

### **MYTHS, MISPERCEPTIONS AND INCORRECT BELIEFS ABOUT HIV/AIDS**

The first theme identified was the myths, misperceptions and incorrect beliefs about HIV/AIDS. The sub-themes that emerged include deaf participants' inaccurate beliefs and perceptions about the symptoms and stages of HIV/AIDS, the deaf participants' mixed beliefs about HIV-positive persons, and the strong desire to become a parent despite the risks of HIV/AIDS transmission and infection.

#### **Deaf participants' inaccurate beliefs and perceptions about the symptoms and stages of HIV/AIDS**

Most of the participants were very unclear about the symptoms and stages of HIV/AIDS infection. The responses to the questions related to this topic were very vague, general and far-fetched. Confusion was noted about HIV/AIDS symptoms and tuberculosis symptoms, as seen in the following quote: "People who cough out green sputum." The correct stages and symptoms of HIV infection could not be described with any accuracy or specificity by any of the participants. There was a strong focus on the last signs and symptoms of HIV infection, which are easily discerned.

The belief that a person who is infected with HIV will have a short life is another old and outdated myth about HIV/AIDS still prevalent within the deaf community. In addition, deaf persons believed very unusual myths and had misperceptions around HIV/AIDS transmission, encapsulated in the following quotes: "If they put a slice of orange in the vagina and it turns red, then the person is HIV positive"; "You must not wear condoms because the white powder on the condom is worms and can make the men sick"; "Condoms are not good for sex, the oil on the condoms should rather be used

to clean CDs and to apply on dry skin; the oil is also good to heal sores on the skin”; “HIV positive is something good because the word positive means good”; “A person can have AIDS when he never washes”; “HIV is caused by mental illness”; “I don’t have HIV, it will never happen to me”. These quotes reflect the lack of “education” among the deaf community on the HIV/AIDS pandemic.

### **Deaf persons’ mixed beliefs about HIV-positive persons**

In the deaf community an HIV-positive person is usually constructed as bad and immoral, and as someone who must be avoided in order to avoid HIV infection. The future of an HIV-positive person is seen as bleak, short and mostly unproductive, as described in the following quotes: “HIV/AIDS are not good, and someone who has it should be left alone and should not be touched”; “It is very bad; I will be very shocked and will never approach the person ever again”; “An HIV-positive person is too weak and will be better off receiving a disability grant and staying home”; “All HIV-positive persons should be exiled while awaiting certain death.”

### **The strong desire to become a parent despite the risk of HIV/AIDS infection and transmission**

Most deaf young adults in this study expressed a very strong desire to have children. The participants were, however, unaware of the risk of contracting HIV by having unprotected sex in order to conceive, particularly if the HIV statuses of both sexual partners are unknown. This finding is of great concern, because it indicates the desire for pregnancy supersedes the risks of HIV infection. This emphasis on pregnancy has a strong cultural connotation, African women participants in the study indicated their fears of negative social consequences, including marital instability, stigmatisation and abuse, if they fail to conceive. Pregnancy was perceived by the deaf men as an important developmental accomplishment associated with young adulthood, without considering the consequences if the female partner happens to be HIV positive.

### **DEAF WOMEN’S BELIEFS AND PERCEPTIONS ABOUT THEIR VULNERABILITY TO HIV/AIDS INFECTION**

The second theme that emerged is deaf women’s beliefs and perceptions about their vulnerability to HIV/AIDS infection. Deaf men dominated the focus groups when questions were being answered relating to condom use and the practice of safe sex. Deaf men claimed that they were in control when negotiating sex. HIV/AIDS is perceived by them as something that the females “carry”. Themba (male focus group participant from Cape Town) claimed that “men don’t want to use a condom because there is so much oil and friction; that is why they just prefer not using one.” The assumption of male superiority in sexual encounters was echoed by Nathan (focus group participant from Cape Town): “If a girl asks me to use a condom I will say you are boring; I prefer skin to skin so that the both of us can feel.”

The females in this specific focus group did not challenge this; they remained quiet for the duration of the discussion. Rachel, (a female participant from Paarl), who was part of

a female-dominated focus group, described her subterfuge in a male-dominated sexual encounter:

Rachel: *“I had to use a female condom once because someone did not want to use a condom while having sex with me. I hid the fact that I had a female condom because I did not want him to know.”*

Researcher: *“What was the reason that you hid the female condom?”*

Rachel: *“I was afraid of his reaction and I did not want to make him cross.”*

Leila (key informant from Cape Town) gave her reason, based on fear, for agreeing not to use a condom: “I prefer to use a condom but I won’t push it or force the issue; maybe my boyfriend will think I’m sick or something and then he might leave me.”

The fear of possible physical abuse and rejection has led these women to remain silent and not to insist their partners use condoms. In so doing they are, however, being exposed to the risk of HIV infection by engaging in unprotected sex. While it could be argued that non-disabled women suffer similar risks of contracting HIV from such silence in the face of male domination, the experience of deaf women can lead to power inequalities that may be complicated by communication barriers and multiple “othering” processes (Groce, 2003). Compared to their non-disabled sisters, some women with disabilities are more likely to experience sexual violence in relationships and in institutions, and also experience more extreme social categorisation. For instance, because of their disability they could be categorised as being either hypersexual and uncontrollable, or de-sexualised and inert. These categorisations, and the inability of women to negotiate safe sex practices within a patriarchal system, place women with disabilities at extreme risk of HIV infection (Groce, 2003).

### **Deaf women’s fear of HIV infection from rape**

Their powerless position to negotiate safe sex because of communication barriers, both in households and in the larger society, contributes to the felt vulnerability of being raped by the female participants, as expressed by some female participants. Both Leila (key informant in Cape Town) and Siphokazi (focus group participant), when asked to specify the modes of HIV transmission, identified “rape” as a mode of spreading AIDS.

Groce (2004) notes that deaf women have few opportunities to learn to set boundaries and this can be exploited by deaf and/or hearing males as well as HIV-positive males. Deaf females are targeted for rape because of the belief that if a man rapes a virgin he may be cleansed of HIV infection. Deaf individuals are widely perceived as virgins and as easy targets because they have minimal, if any, legal protection and are confused with regard to their sexual rights (Groce, 2004).

The broader abled community may also perceive them as asexual beings who do not engage in sexual practices. The major factor that puts them at risk of rape and contracting HIV is the fact that they are deaf and cannot communicate. Perpetrators assume their victims will not be in a position to tell others what has happened because of their communication challenges. This situation is perpetuated because police, lawyers, judges and even rape crises counsellors often have no sign language communication

ability (Groce, 2004). This inability to appropriately report rape and abuse not only has legal implications, but can also mean that potential ARV prophylaxis will not be made available timeously to deaf individuals who have been raped (Groce, 2004).

## **DEAF PERSONS EXPERIENCES OF SOCIAL EXCLUSION IN THE MEDIA AND ELSEWHERE**

In this third theme participants shared about their experiences of social exclusion in a number of settings. Sub-themes highlighted social exclusion in the home, school, media, medical fraternity and from hearing persons. The reliance of deaf people on the deaf community for HIV/AIDS information is indicative of their experiences of social exclusion from other groups and resources.

### **Social exclusion of deaf persons in the media: “I wish I could understand what they say on television”**

HIV/AIDS awareness programmes on the electronic media, in particular radio and television, were found to be ineffective for most of the deaf participants, as demonstrated by some of their responses. Daniel (focus group participant from Cape Town), who had managed to secure satisfactory employment, had a lot to say about his frustrations with regards to the media. He commented angrily: “What good are the HIV programmes on television? There is never a sign language interpreter there. How do ‘they’ expect us to understand?” Natasha (focus group participant from Paarl), a 19-year-old young woman, expressed similar sentiments about the media: “I wish I could understand what they say on television. I look at the pictures but there are no subtitles or interpreter; then I just leave it.” Raymond (key informant from Cape Town) fervently exclaimed: “I try to follow the advertisements on the TV, then I don’t understand or follow. They should have a deaf person or an interpreter so that we can understand what the adverts and programmes is about, so that we can know what’s going on with HIV in Africa. We also want to know. At least I want to know.”

These responses indicate that the programmes on television can only be effective if a qualified sign language interpreter or deaf person is employed in their presentation. However, in most countries, including South Africa, this service is not available, and deaf people are totally overlooked (Matlosa, 2006).

The print media was also found to be ineffective to deaf participants as demonstrated by the following participants. Ebrahim (key informant from Cape Town) reported: “I previously viewed HIV/AIDS as a myth, but when I look in the newspaper and see these pictures and these funny images then I see it’s real, but what it really is I don’t know.” Jake (focus group participant from Cape Town) thought that “if only they can make health pamphlets deaf-friendly then maybe I can also know about this.” When Jake was asked what he meant by the term ‘deaf-friendly’ he said “more pictures, signs and basic English words.”

### **Experiences of social exclusion in the medical fraternity**

Mangi, who originally comes from the Eastern Cape but has stayed in Cape Town for the last two and a half years, spoke out in one focus group session about his

mistreatment. When the researcher asked “What are your beliefs about HIV/Aids treatment?” he replied, “I don’t know about that HIV treatment but I hate to be sick, because I hate to go to the clinic.” When asked why he feels this way he said, “Because I am ignored or chased away and those people make me feel like I’m an animal, something less than a human.”

This statement ignited a heated debate around this topic which led to some participants expressing feelings of sadness and despondency as outlined below:

*“Your file already say in large letters ‘deaf and dumb’. I hate that word ‘dumb’; I am only deaf NOT dumb, but they still call out your name, then when you don’t respond then you must sit there the whole day, and by 16h00 when you go there and try to communicate then they become rude and make as if you are the idiot. How do they expect you must hear when your name is called? Why is deaf and dumb then written on the file, can’t they see I can’t hear?”*

Saabier, from Cape Town, an otherwise confident 19-year-old Muslim male, described a humiliating experience at the hands of a member of the medical establishment which impacted on his self-esteem:

*“I once had a very delicate health problem and tried to go to the doctor on my own. The receptionist wrote on a piece of paper I need to bring a hearing person with because they cannot communicate with me; they didn’t even try. I was so embarrassed, but out of desperation I had to ask my mother to go with me. The doctor still asked me to undress in front of my mother. I don’t know what the point was because I still had to lip-read my mother anyways, and up to this day I don’t know what was really wrong with me.”*

The International Bank for Reconstruction and Development (2010) noted that, because deaf people cannot access information on HIV and AIDS anywhere else, the importance of efficient and accurate communication and information in medical settings cannot be over-emphasised. It is through language that patients generally convey their medical needs to the doctor. It is also through language that a doctor acquires the necessary information that he or she requires in giving proper treatment and advice on HIV and AIDS and other related illnesses. This breakdown in communication between deaf people and service providers can have serious consequences. If not addressed, the language barrier can undermine the effectiveness of health-care provision systems and have a knock-on effect on the rate and prevalence of HIV/AIDS transmission. In order to avoid this situation, deaf people are forced to seek assistance from a family member or an interpreter to help them acquire the desired information, such as the case of Saabier. Sign language interpreters are a very scarce and expensive commodity, not easily accessible to, or affordable by, deaf persons. Matlosa (2006) postulates that, because deaf people feel stigmatised by doctors, they are less likely to ask questions about HIV and AIDS, and the fact that family members have to accompany them could impact on their right to privacy and confidentiality.



### **Deaf persons' experiences of social exclusion from hearing persons**

Some deaf participants reported that they feel that they are ridiculed and looked down upon by the hearing community at large, even within the arena of HIV/AIDS. In addition, participants were of the view that some deaf people feel isolated from hearing people, because they cannot communicate with them. In this context, a sense of inferiority is noted. One participant saw hearing people as having an advantage over deaf people in terms of HIV/AIDS knowledge. De Andrade and Baloyi (2010) confirm this perception. They found in their study that deaf adolescents, in comparison to the hearing adolescents, have insufficient and distorted knowledge about HIV transmission and did not fully comprehend the consequences of infection (De Andrade & Baloyi, 2010). Raymond (key informant of Cape Town) said: "I will feel bad if I must be HIV positive because sometimes deaf people are teased by the hearing people and cannot approach medical help because of their communication barriers." Daniel (focus group participant from Cape Town) revealed his sense of inferiority to his hearing counterparts in terms of knowledge about HIV when he said that he thought that "the hearing people know everything about this HIV thing but they don't tell us."

### **Reliance on the deaf community for HIV/AIDS information**

After the elimination of parents, school and the media as effective sources of HIV/AIDS awareness and information, the deaf community itself was seen by many participants as their chief resource for accessing information relating to HIV/AIDS. Ebrahim (key informant from Cape Town): "Back in the day there was no talk of HIV/AIDS, when I came to the Bastion of the deaf and saw the deaf people talking about the new thing HIV, I was shocked." This was reiterated by Mangi (participant in focus group in Cape Town): "It is only when I came to the Bastion and saw other deaf people in the waiting room signing about HIV/AIDS that I became aware of its existence".

Because of their hearing disability, participants indicated that they mostly interact with each other because of their communication, language and cultural similarities. The quality of HIV information shared along the deaf grapevine cannot always be trusted. This is mainly because of the lack of appropriate educational material for special needs children, as well as the social exclusion of disabled persons from their local geographical and social communities, as well as from HIV/AIDS knowledge, services and resources (Philander & Swartz, 2005).

## **CONCLUSIONS AND RECOMMENDATIONS**

Many myths and misperceptions about HIV/AIDS transmission among deaf persons were found in the study, and the myths surrounding HIV/AIDS prevention were particularly disturbing. The strong desire to become a parent despite the risk of HIV/AIDS infection and transmission is an equally serious issue. These findings place deaf young adults at risk, because they indicate that they are sexually active and do engage in sexually compromising behaviour without being protected adequately for sexually transmitted infections. This is due to a lack of accurate knowledge, which impairs their ability to make informed decisions especially when negotiating safe sex. This suggests that it is vital that deaf persons should obtain the necessary knowledge,

life skills and access to services to protect themselves from HIV/AIDS, without which they are extremely vulnerable to HIV infection.

There were gender differences noted within the research in terms of certain perceptions to do with HIV/AIDS. This difference was obvious when it concerned sexual exploration and experience. Male superiority in sexual exploration was viewed as an accepted practice and some women were portrayed as submissive and powerless. Women seemed to be a particularly vulnerable group within the deaf young adults group, as it became apparent that they do not share equal status with their male counterparts and are in a disadvantaged position in terms of negotiating safe sex. Although this situation is similar to that of abled women, deaf women have an added disadvantage because of their sensory disability. Men's reluctance to use condoms during sexual intercourse was a very disquieting issue for young deaf women in relation to HIV/AIDS transmission. Deaf women participants reported that they do not oppose men on this issue, but merely accept it or find alternative solutions such as using female condoms. Fear of rejection and physical abuse were found to underlie this passiveness. Some women were worried about the fact that HIV/AIDS can be transmitted through rape. They had numerous questions in this regard, which highlighted their concerns and sense of vulnerability.

The majority of the participants noted an extensive lack of information on sexuality and HIV/AIDS from appropriate sources, including parents, schools, the media and medical facilities. This is regrettable, since it was found that deaf young people want to learn from these sources, but due to communication barriers were unable to access appropriate and accurate information. Participants indicated that the absence of sign language or sign language interpreters leaves them at a disadvantage in communicating with health-care workers. Participants expressed feelings of oppression and discrimination at the hands of the medical establishment. These were encapsulated by one participant's view that he would rather be sick and stay at home than go to a medical facility. In this context the study revealed that not all deaf people are comfortable with asking their hearing family members and friends to accompany them on visits to doctors to act as interpreters. They felt that their confidentiality and rights to privacy were not respected. This indicates an area that needs to be addressed by the health system, as health-care workers should not only play a role in HIV/AIDS education but also in other important health aspects. Participants expressed a strong desire to access information in their own language and from other deaf people, and wanted the presence of trained deaf people when HIV/AIDS awareness and prevention campaigns are presented to them, so that they can identify and relate to the information.

The inclusion of sexual and HIV/AIDS education programmes in the curriculum in deaf schools should be mandatory. The deaf cultural grapevine should be acknowledged, respected and transformed to become a resource for disseminating appropriate information. Health-care workers and community medical facilities need to increase their accessibility work with deaf persons around HIV prevention and treatment. Confidential HIV testing and counselling by individuals fluent in sign language should be made available to deaf persons.

In summary, the paper advocates for the following:

- The creation of an enabling environment for all deaf people;
- Building resilience and a sense of empowerment among deaf persons, among deaf women in particular;
- Contesting unequal gender norms through the implementation of women and gender programmes, and encouraging and promoting positive gender relationships;
- Challenging the agents of social exclusion at all levels of society; a means of redressing the situation would be, for example, to make it mandatory that life skills that embrace diversity and disability be taught at schools;
- Parent skills training and sign language training should be provided to parents of deaf children. The government (especially the Department of Education and Social Development) and the NGO sector should be approached to fund these programmes as part of their response to disability within communities. Parents should also be taught how to provide life skills, which includes discussions around sexuality and HIV/AIDS with their deaf children;
- HIV/AIDS education materials and methods need to be designed in South African sign language;
- The deaf cultural grapevine should be acknowledged, respected and transformed to become a resource for disseminating appropriate information;
- Health-care workers and community medical facilities need to increase their accessibility work with deaf persons around HIV prevention and treatment;
- Confidential HIV testing and counselling by individuals fluent in South African sign language should be made available to deaf persons;
- Increasing protection of various kinds for deaf people, such as making police services and the judicial system more accessible for deaf persons in terms of accommodating their communication needs;
- Exposing deaf persons to positive rules, expectations and role models. Instilling a sense of hope in the future;
- Continued lobbying by deaf organisations for the inclusion and improvement of service delivery to deaf persons across all spheres of life (UNAIDS, 2002).

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