

## Research Reports

# Needs, Barriers, and Concerns Regarding HIV Prevention Among South Africans with Visual Impairments: A Key Informant Study

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The HIV epidemic is the most serious threat to health internationally, with developing countries accounting for over 95% of new infections. Since HIV/AIDS was first identified, 20 million people have died of AIDS (Lamptey, Wigley, Carr, & Collymore, 2002).

Worldwide, there will be 45 million new HIV infections by 2010 (Goliber, 2002). Social factors contribute to the spread of the epidemic; economic powerlessness and social exclusion increase vulnerability (Campbell, 2003).

The predominant mode of transmission of HIV/AIDS in sub-Saharan Africa, which has the most infections, is unprotected heterosexual sex (World Health Organization, 2002). Since there is no cure for HIV/

AIDS, the prevention of infection is essential. In South Africa, HIV prevention programs have been widely disseminated, but scant attention is given to the needs of people with visual impairments. As of the 2001 census, 577,096 South Africans were visually impaired (that is, were blind or had low vision) (Statistics South Africa, 2003). This article reports on work preparatory to developing and evaluating an intervention focusing on the needs of this community.

Although people who are disabled are more likely to be socially excluded and marginalized--risk factors for HIV infection--there has been little research on their needs with regard to the epidemic (Blanchett, 2000; Groce, 2003; Health and Disability Working Group, 2004; Kelly, Ntlabati, Oyosi, Van der Riet and Parker, 2003; Narib, 2003). People with perceptual disabilities are commonly overlooked in the development of materials and educational programs on HIV/AIDS.

There are no data on the prevalence of HIV infection in any disabled population in Africa (Groce, 2003). Many believe that persons with disabilities are not sexually active (Groce, 2003; Kelly et al., 2002). However, people with disabilities may be at an increased risk for a range of factors, including the greater likelihood of being sexually abused and the lesser likelihood of marrying because of social taboos (Groce, 2003). It has been estimated that people with disabilities have a two-to threefold risk of being raped than do those without disabilities (Cheng & Udry, 2002; Groce & Trasi,

2004; Yousafzai, Dlamini, Groce, & Wirz, 2004).

Because of the dearth of literature on HIV prevention programs that are relevant to South Africans with visual impairments, we used informal networks to ascertain what work has been done in this area. There have apparently been three prevention initiatives in South Africa, all of which reproduced existing materials in braille, large print, or audio format. There does not seem to have been documented consideration of whether the content of programs should have been altered to accommodate the needs of people with visual impairments, nor were any programs evaluated.

It seems that there is an urgent need to design and evaluate HIV prevention programs for people with visual impairments (Buysse & Ickes, 1999). However, it is difficult to know what are the best methods to do so, especially since the literature is so sparse.

Therefore, preparatory to designing, implementing, and evaluating an HIV prevention program for adolescents with visual impairments in South Africa, we harnessed the views of key informants, who are described below. In this article, we report the results of the key informant study.

## **Method**

### **Participants and procedures**

The sample consisted of 15 participants, most of whom

were in senior positions of organizations and service providers in the field of visual impairment, affiliated with the South African National Council for the Blind. The participants worked at 11 service organizations representing three provinces that focus on rehabilitation, training, education, empowerment of youths, empowerment of women, and care of the aged; the average length of experience in this work was 17 years. More than 80% of them had visual impairments (congenital blindness or, in the case of 3 participants, congenital low vision). The participants ranged in age from 22 to 62 years, with a mean age of 45 years. One participant had previously conducted an HIV/AIDS education program.

Oral consent and permission for audiotaping were obtained; no participant refused to be interviewed. The first author conducted all the interviews using a semi-structured questionnaire. The responses were transcribed and analyzed using content analysis (Ryan & Bernard, 2000).

## **Results and discussion**

Six themes emerged from the data, commented on by all the participants. Each is discussed in turn.

### **Perceived risk of HIV/AIDS**

All the participants expressed the belief that HIV/AIDS affects all sexually active people, including people

with disabilities. About 93% said that people with visual impairments were more at risk than are those who are sighted. Contributing factors that they thought made people with visual impairments more vulnerable to HIV/AIDS included sexual relationships among the close-knit group of people with visual impairments (73%,  $n = 11$ ), the limited choice of sexual partners (60%,  $n = 9$ ), the lack of information on the HIV pandemic and preventive measures (87%,  $n = 13$ ), the alleged tendency of people who are blind to touch and feel as a means of gaining sensory information (which the participants said may lead to increased sexual activity) (40%,  $n = 6$ ), the lack of control that people who are visually impaired have over their lives (67%,  $n = 10$ ), low socioeconomic status (80%,  $n = 12$ ), low self-esteem (80%,  $n = 12$ ), lack of social skills (which is sometimes the result of overprotection) (80%,  $n = 12$ ), and fewer personal resources with which to protect themselves (80%,  $n = 12$ ). A third of the participants believed that the need for acceptance resulted in youths being sexually exploited. One participant said, "It gives a mental boost to a disabled girl to have a partner who is not disabled."

### **Factors that contribute to the risk of HIV/AIDS**

Sixty percent of the participants thought there may be more premarital and extramarital sex among people with visual impairments than in the general population, which, they thought, may be linked to a desire by visually impaired people to be accepted and,

consequently, a willingness to comply with their partners' wishes, especially in relationships between young visually impaired women and sighted men. Marital relationships may also be disrupted by late-onset visual impairment, according to the participants. Cultural gender roles were also mentioned. Extra-marital relations are practiced in certain communities, and sometimes sexual partners are arranged for women who are disabled.

The majority of the participants (93%) reported that they are aware that people with visual impairments, especially women, have experienced sexual violence and coercion in the context of power inequalities and environments that foster abuse. The participants alluded to date rape and to sexual relations among boys at hostel residences and communities where minors are allegedly left under the supervision of people who abuse them. In some groups, there are arranged marriages, which, the participants believed, could lead to partner abuse and extramarital sexual relationships.

### **The need for HIV prevention programs**

The majority of participants (67%) believed that concern about HIV infection is growing among people with visual impairments. All respondents highlighted their frustration with workshops that are designed for sighted people, which, they said, marginalized the needs of people with visual impairments and offered materials in inaccessible formats. Some participants

(27%) stated that many people with visual impairments are in denial, believing that their disability protects them from HIV.

All the participants thought that HIV/AIDS prevention programs that are tailored to the needs of people who are visually impaired are essential. They further contended that people with visual impairments should participate in the design of interventions for their own community. Only 20% were aware of any HIV/AIDS prevention initiatives for people with visual impairments (these were the programs mentioned in the introduction to this article; no other programs were identified).

Given that there are so few programs targeted to people with visual impairments, the participants were asked whether existing programs could be broadened to include the needs of this population. Just over half thought that because mainstream programs tend to marginalize people who are visually impaired, only specialized programs should be considered.

### **Barriers to HIV/AIDS prevention in the field**

All the participants reported that the lack of assertiveness and the dependence on support organizations of people with visual impairments contribute to the lack of reaction of the field of visual impairment to the problem of HIV. One participant said, "Visually impaired people have so much done for



them over the years to the point where they believe everything, even the threat of possible HIV infection, will be sorted out for them."

The majority of the participants (93%) believed that the general public holds myths about people with visual impairments, including beliefs about asexuality or abstinence, and 20% believed that the myth that sex with a virgin will cure AIDS, sometimes called a "virgin cleansing" (Groce, 2003), makes people with visual impairments targets for rape. In addition, 20% reported that people who are visually impaired believe that HIV is confined to homosexuals, prisoners, and prostitutes.

### **Economic and gender factors**

Twenty percent of the participants stated that in some cultures, women (whether they have disabilities or not) have no choice when it comes to the selection of a sexual partner. All said that women who are visually impaired are typically not empowered to select their sexual partners and are seen as easy targets by men. The participants linked this situation to the lack of assertiveness and interpersonal skills of visually impaired women (60%), lack of information on personal rights (26.7%), low self-esteem (86.7%), overprotection by parents (26.7%), and need to be accepted in relationships to boost their sense of self-worth (80%). In addition, public transportation is poor in South Africa, with little effective provisions for



people with disabilities. Thus, women are commonly dependent on others for transportation and mobility, a situation that can create the opportunity for abuse.

In addition to these factors, visually impaired women and girls are struggling with survival issues like unemployment. All the participants believed that the practice of trading sexual favors for money and basic supplies is an important factor in terms of vulnerability to HIV. Most of the participants (80%) believed that economic dependence contributes to gender-based violence.

### **Elements in the design of HIV/AIDS prevention programs**

All the participants emphasized the need for accessible formats, such as braille and audiotapes, and emphasized the importance of focusing on

- social skills: communication and assertiveness (including how to refuse sexual advances)
- enhancement of self-esteem
- instruction in the use of condoms
- discussion of appropriate sexual behavior
- strategies for personal growth.

A third of the participants emphasized that the

programs should be conducted in a positive, friendly, and educational environment and include all persons with visual impairments in the planning, irrespective of their educational levels.

## Summary

The objective of this study was to gauge the participants' views on areas that need to be included in the design of an HIV/AIDS prevention program for people who are visually impaired. All the participants considered HIV/AIDS to be a serious problem, and all believed that prevention is crucial. Furthermore, they thought that inadequate education, the lack of accessible information, and the ignorance of sighted people of the sexuality of people with visual impairments foster conditions that are conducive to risky behavior. They stated that illiteracy, the inability to read braille, impoverishment, and different levels of development are areas that need attention, as does mistrust of sighted people by people who are visually impaired, which is understandable, given their history of exploitation and marginalization. The participants stressed the needs of women and girls for enhanced self-esteem and relationship skills. They (rightly or wrongly) viewed people with visual impairments as insufficiently concerned about the risks of HIV--risks that are exacerbated by myths that are held both by the general population (for example, virgin cleansing) and by people with visual impairments (such as that only prostitutes, homosexuals, or prisoners contract HIV/

AIDS). Sixty percent of the participants (most of whom were visually impaired) apparently believed what is often regarded as a stigmatizing myth about people with visual impairments--that increased communication based on touch leads to greater promiscuity. Such beliefs must be addressed in interventions.

## **Conclusion**

This study gleaned opinions only from key informants, and it is not possible to assess how accurate these views are or even whether the participants were furthering stereotypes with their responses. However, the responses support the view that more work is needed in the area of HIV/AIDS prevention for South Africans with visual impairments. The difficulties reported are both technical (the lack of information in accessible formats) and social. The participants viewed social exclusion as an overarching risk factor. Key informant studies cannot claim to reflect reality unproblematically, nor were the participants selected for statistical representivity, but it is clear that these service providers believe that targeted HIV prevention programs need to be developed for people with visual impairments.

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