Perceptions of HIV/AIDS: A Conversation with Deaf Adults in Kwa Zulu-Natal Province, South Africa

Marquessa Brown
Gallaudet University

Zethu Mkhize
University of Zululand

Follow this and additional works at: https://repository.wcsu.edu/jadara

Recommended Citation
Perceptions of HIV/AIDS: A Conversation with Deaf Adults in Kwa Zulu-Natal Province, South Africa

Marquessa Brown, Ph.D.
Gallaudet University

Zethu Mkhize, Ph.D.
University of Zululand

Abstract

The study used qualitative research methods to examine cultural beliefs, specifically those that are spiritual, as well as gender-related norms to explicate HIV/AIDS risk behaviors among deaf persons residing in rural and peri-urban areas of Kwa Zulu-Natal Province, South Africa. Existing findings, though limited, suggest that there are insufficient understandings among deaf South Africans about HIV/AIDS. While the deaf population exceeds 4 million, they are among the least educated, most illiterate, and least employed, and experience higher rates of poverty. These are all factors that may contribute to a greater incidence of HIV infection; however, there is a dearth of research that investigates risk behaviors for HIV/AIDS or contributes to the development of preventative measures for South Africa's deaf community. Research findings associated with hearing South Africans suggests that behavior is guided by several factors: cultural beliefs, level of poverty, and gender differences. This study using focus groups identified similar factors that may influence the behavior of the South African deaf community. Focus group discussions with deaf individuals (n = 8) are used to examine issues related to culture, traditional spiritual practices, gender norms, and poverty that increase the risks of HIV/AIDS. Data was analyzed using ethnographic methods and organized in a format that identified themes associated with each of the variables. Throughout the data analysis process emphasis was placed on comparing themes between the groups and identifying repeating patterns. Based on the findings, recommendations are made for the development of educational and prevention campaigns that target the deaf community.

Keywords: deaf, South Africa, HIV/AIDS

Little is known about South Africa's 4 million deaf inhabitants in the context of their knowledge about HIV/AIDS or the cultural beliefs that can result in HIV/AIDS risks behaviors, and though undocumented, they are believed to be at greater risk of experiencing the ravages of the AIDS virus. Recent statistics from the International Conference on Public Management, Policy, and Development (2003) indicate that 68% of the deaf population lives in informal settlements, 70% are unemployed, and 66% are illiterate, thereby making them part of the poorest segments of the population. As stated by Irwin (2003), poverty limits the options for protecting oneself,
and forces individuals into situations of heightened risk for contracting HIV/AIDS. Newhoudt-Druchen (2003) suggests that the deaf community may be at greater risk of AIDS because there is no clear understanding of what they know, particularly among those who are illiterate, and social development workers have not created effective educational campaigns for them. Newhoudt-Druchen further suggests that deaf people are less likely to participate in existing educational programs because they tend to have limited access to communication.

Groce, Yousafzai, and Van Der Maas (2007) state that there are a number of interrelated reasons for the low levels of access to information and services among persons who are deaf. In addition to limited access to communication, individuals who are deaf frequently have lower levels of literacy. This factor can impede their ability to understand AIDS information and sign language is rarely used by outreach workers. Another barrier to access to education programs and information about HIV/AIDS is the unavailability of interpreters in HIV clinics or testing centers. Persons who are deaf may be reluctant to seek assistance from clinics given the absence of interpreters and the challenges to maintaining their privacy when hearing family members or friends are needed to interpret confidential information. These communication barriers perpetuate conditions which necessitate a reliance on the “deaf grapevine” or a collection of stories, folklore, rumors, and gossip that circulates within the community. Unfortunately the information passed through this informal network can be inaccurate, thereby increasing the risk for HIV/AIDS. Bat-Chava, Martin, and Kosciw (2005), when examining HIV knowledge among persons who are deaf in the United States (New York), determined that the study population was frequently unaware or misinformed about how AIDS is transmitted, how it can be prevented, and who can get it.

Although there is limited empirical evidence related to the demographic or socio-cultural characteristics of deaf South Africans, available research findings indicate that they are isolated and marginalized in rural communities with limited access to mass communication. Most HIV/AIDS information is conveyed through television, a luxury that is not readily available to rural deaf South Africans. When televisions are available, the information may not include sign language interpreters, or is presented in print medium that many deaf people cannot understand because they are not literate in English. These factors may be prohibitive to the acquisition of accurate information. Kiyaga and Moores (2003) further indicate that limited access
to mass communication, the absence of communication within the family unit, and closing off enculturation may prevent deaf Africans from acquiring knowledge about HIV/AIDS and its causes, prevention, or treatment. The closing of enculturation and limited access to incidental learning thorough interactions with family and others in the community may also influence the degree to which deaf South Africans maintain cultural beliefs both spiritual and gender-related that mirror those of their hearing cohorts. As cogently stated by Kiyaga and Moores when referring to HIV/AIDS information among deaf Africans, “because of a lack of access to even the relatively limited mass communication that is available to hearing people and the absence of communication within family units, deaf individuals in sub-Saharan Africa may have no knowledge about the existence of HIV/AIDS” (p. 6).

Groce, Yousafzai, and Van Der Maas (2007), in their research on knowledge about HIV/AIDS among deaf Nigerians, found that deaf study participants were aware of AIDS and knew that it could be transmitted sexually. The researchers determined that participants, cut off from easy communication with the larger society, obtained information through the “deaf grapevine” (stories, folklore, rumors within the deaf population) and, as a result, other key information was either unknown or incorrect.

Poverty and illiteracy are widespread and believed to be another causative factor attributable to the rapid spread of AIDS. However, as a consequence of discrimination, deaf persons may experience a greater lack of access to education and employment, and are therefore more likely to experience abject poverty and to have less information about HIV/AIDS. In the article, *South Africa: New Comic Book on HIV/AIDS*, which was launched for the deaf community (IRIN, 2006), J.E. Cameron, a prominent South African HIV/AIDS lobbyist echoes the sentiments of Kiyaga and Moores, stating that deaf people are linguistically, socially and economically marginalized, and as a result information and education about HIV/AIDS largely bypasses the deaf community. He further suggests that deaf people are dying without HIV testing or treatment and family or community support. Thus, obtaining information about knowledge levels associated with HIV/AIDS and belief systems that may contribute to risks behaviors is critical to the development of accessible educational campaigns related to dangers and prevention of the disease in the South African deaf community.

It is anticipated that the studies' findings will strengthen understanding of the deaf community and guide the development of HIV/AIDS educational campaigns that are linguistically and culturally appropriate to better serve
this isolated population. While the socio-cultural conditions of deaf South Africans, that is, poverty, illiteracy, lack of knowledge about HIV/AIDS, and cultural belief systems (spiritual and gender) may be more pronounced as a result of deafness and discrimination, the conditions for many hearing South Africans are similar. The literature review therefore draws upon research findings related to knowledge about HIV/AIDS, spiritual and gender norms and the conditions of poverty that may result in HIV/AIDS risk behaviors among those whose socio-cultural characteristics are similar to those of rural deaf persons.

**Culture and Traditional Spiritual Practices**

People's culture, values, and traditions often guide behavior and methods of understanding illness and illness prevention. Among South Africans, particularly its poorest and least educated, traditional or indigenous knowledge systems may guide their beliefs about HIV/AIDS. Green (1994), based on interviews with Swazi healers, reported that South Africans believe that AIDS is fictitious and a European plot to trick Swazis into using family planning devices in order to reduce the size of their families. Swaziland natural healers indicated that people were responding to this belief by becoming defiant and more promiscuous. According to Hickson and Mokhobo (1992), family planning devices, specifically condom use, is often viewed as culturally unacceptable because fertility is important to Africans. The researchers indicate that family planning methods are contrary to African beliefs and practices that emphasize fathering children as a sign of masculine virility. Walker, Reid, and Cornell (2004) also report that South African, Tanzanian, and Batswana traditional healers, often referred to as a 'sangoma', don't believe in the existence of AIDS. They argue that illness is the result of one's rejection or abandonment of cultural or traditional practices, or that sickness results from contamination and exposure to Western devices such as condoms, pills, and injections. South African traditional healers further explain HIV/AIDS as being caused by a failure to comply with traditional rituals which require sexual abstinence and ceremonial cleansing following the death of a spouse and child birth. The reports of these authors suggest that AIDS is located within local cultural expectations, specifically the adoption of Western lifestyles and the rejection of traditional cultural values and practices.

Walker, Reid, and Cornell (2004) discuss the relationship between the spiritual dimensions of self and illness or misfortune through a paradigm of
witchcraft. Chronic and terminal illnesses are explained within a spiritual context of malicious or malevolent entities or substances that either cause harm or provide answers to questions related to the root causes of illness. Based on this explanation of illness, people, especially rural dwellers, frequently believe that one becomes sick as a result of something that was done to anger the spirits of ancestors. There may also be a belief that a displeased spirit will withdraw its protection and one therefore becomes ill. Other reports associated with HIV/AIDS and witchcraft in South Africa point to a particular kind of malicious spirit that inflicts a slow wasting syndrome, commonly known as poison or African poison that is intentionally transmitted. According to indigenous cultural beliefs, the poison is put in food to harm the intended victim and results in any number of events from bad luck, unemployment or sickness, to death. Campbell’s research (2003) with South African migrant gold miners found that they too believed that supernatural factors played a role in the development of ill health. Research participants were most concerned about the risk of being bewitched and falling ill if an acquaintance or neighbor became jealous of their good fortune, that is, employment in a country with a high unemployment rate. A participant in Campbell’s study being treated for a sexually transmitted infection (STI) reported that the STI was the result of being bewitched by a neighbor who had lost his job during a period of retrenchments. Also, according to the investigator, there is evidence to suggest that a commonly held belief among South Africans is that having a sexually transmitted disease is shameful and damaging to one’s reputation. This view has lead many to avoid doctors and to instead seek help from traditional healers (sangomas) who are thought to be able to cure sexually transmitted infections. Traditional healers treat them with ‘muti’ (herbal remedies) that are believed to cleanse the blood and flush the virus out of the system. Walker, Reid, and Cornell (2004) conclude that there is stigma associated with AIDS, and one is not likely to announce that they have AIDS and seek traditional medical care.

Given the symptoms of HIV with respect to the time between infection and the onset of AIDS, as well as the ability of some exposed to the virus to manage better or survive longer than others having opportunistic infections, an interpretation of AIDS through the paradigm of witchcraft is plausible. Furthermore, as suggested by Van Dyk (2001), beliefs related to spirits are reinforced when some with AIDS are seen as ill while there are no recognizable differences in the lives of others infected with the virus. The results of Kalichman’s and Simbayi’s (2004) research, however, suggests that
those who believe AIDS is caused by spirits have significantly less years of formal education than those who believe AIDS is caused by ancestral spirits.

Perhaps the most notable beliefs about AIDS in the context of culture are those that reinforce the notion that sex with infants and or children will cure the illness. Meier's (2002) report from the research findings of the University of South Africa (UNISA) indicate that workers (18% to 32% respectively in East London and Gauteng Province) believed the myth that sex with a virgin could cure AIDS. However, Johnson (2001) concludes that such beliefs are more prominent in rural areas and townships where it is common to see young women in their early 20's dying from the infection. This, according to the investigator, has made girls of younger ages vulnerable to men who believe that the cleanliness and pureness of a child will cure the virus. The unpublished findings of Mkhize (2004) suggest that increasing numbers of rapes of virgins may represent men's attempts to have sexual relations with younger girls in an effort to avoid HIV infection rather than to cure the disease. Karim and Karim (2008), by contrast, indicate that findings related to the relationship between this belief and HIV risk behaviors are contradictory. It is suggested that while there have been isolated cases where the practice of "virgin cleansing" has been the impetus for child rape, it is not the common motivation given the infrequent reports of this type of victimization and the decreased incidence of child rape in an era in which the epidemic has spiraled.

Culture and Gender Norms

The prevailing cultural norms place women at greater risks for AIDS, particularly under those circumstances when sex is viewed as a man's right or prerogative, and a woman's wishes are disregarded. Women are often prevented from controlling important decisions in their lives, including choices about when and with whom they will be intimate, or if a condom will be used. The findings from Peltzer's (2003) study reflect a belief among women that men make the decision about when to have sex and if a condom will be used. The findings further suggest that men are viewed as head of the household with women having no right to disagree with the husband's decisions. Traditionally, women are also perceived as child bearers who want to please their husbands or significant men in their lives, therefore as stated in Health 24 (2004), even if a woman is aware of HIV/AIDS risks, refusing a man sex can result in rejection and violence. The literature on gender and
cultural norms suggests that in situations where women are better informed of the risk factors, unprotected sex continues to be the practice. According to Karim and Frohlich (2000), the primary reason for women's failure to act based on knowledge is a belief that they have no right to refuse sex or demand condom use. The author's research findings also indicate that women are often aware of their husband's/boyfriend's infidelity, but remain in the relationship out of fear of violence or because of financial dependence on their partner. Furthermore, a wife's/girlfriend's insistence on a man using a condom can be seen as a sign of immorality or that she has too much knowledge about sex. The request for safe sex can then create suspicions of an affair and result in violence against the woman.

Gender inequality in sexual relationships, specifically among poor rural women is reinforced through an imbalance of power in the context of access to the means of reducing poverty and achieving equality, i.e., education, employment, and land ownership. The economic status of poor uneducated women with no resources may leave them with few options for survival other than dependence on husbands/boyfriends for necessities, i.e., food, shelter, money or supplies for their children, and security. Given this situation, HIV/AIDS prevention may not be a priority among women, and immediate survival is more urgent. As pointed out by Dunkle, Jewkes, Brown, Gray, McIntyre & Harlow (2004), women may also experience gender inequality and greater risk for AIDS in relationships with males who are five or more years older. The researchers found that communication was poorer in relationships having significant age differences; the women were unlikely to suggest condom use, and the diagnosis of AIDS was prevalent. Women's economic and social conditions critically impact their choices about healthy behaviors, and their social marginalization exerts a powerful influence on sexual behavior.

Culture Poverty and Fatalism

An explanation of high-risk sexual behavior focused only on the personal (gender norms) and interpersonal (spiritual or traditional norms) would be short-sighted. Given the ubiquitous nature of poverty, it too may account for the rapid spread of HIV/AIDS. As suggested by Susser (2009), economic and social conditions can limit the ability to adopt healthy behaviors. For the marginalized, isolated, and minimally educated populations most likely to live in poverty, struggles for survival may become more important than health precautions. As indicated by Irwin (2003), socio economically
marginalized communities with high rates of unemployment, job limitations, and discrimination experience a sense of fatalism. If one is unable to envision a better economic future, they may perhaps take more personal risk or become indifferent to practicing health enhancing behaviors. Furthermore, as reported by Mkhize (2004), there are few incentives to protect oneself against infection when living in deprived communities where HIV is only one of many threats to a healthy life.

The experiences of South African miners participating in Campbell's (2002) study reflect Mkhize's sentiments. Campbell's study participants were marginalized, low wage earners, who lived in overcrowded hostels and preformed dangerous tasks in gold mines. They articulated a sense of powerlessness and lack of control in terms of having an ability to protect themselves against HIV/AIDS. The findings further suggested that sexual risk-taking was one of the few opportunities for mine workers to assert their masculinity and exert control. Campbell concludes that disempowered people who have little control over their lives and who work under harsh conditions are less likely to take health precautions, as it may seem pointless given the daily struggles related to survival.

Gender-related norms hold expectations for men to be breadwinners and support their families financially. This economic need often forces men to migrate without their families to urban areas, and they sometimes practice circular migration. The practice involves having a partner or town wife in the urban setting and maintaining a wife and children in the rural setting (Karim & Karim, 2008), thereby fostering multiple sexual relationships and increasing the risk of HIV/AIDS. Migrant workers frequently travel long distances from rural areas, and the expense of travel can necessitate their living away from home for extended periods. The experience of loneliness and isolation coupled with the need for companionship can result in casual sexual liaisons or the taking of a second or third wife. Circular migration poses increased HIV/AIDS risks for all parties; the migrant worker, as well as the urban and rural spouse or spouses.

Methods

Participants

Two focus groups were conducted, one in a rural area and another in a peri-urban region of Kwa Zulu Natal Province, South Africa. Participants
were monetarily compensated for their time. The eight deaf study participants ranged from age 26 to 40, and self-identified as Indian or Zulu. All had completed standard 8 (10th grade). Of the three male focus group members, two were employed and one had recently lost his job as the result of retrenchment. All of the women were receiving monthly government grants of R1, 140.00 ($162.00).

Analysis

Focus groups were completed between March and May, 2010. Recruitment was carried out by the social workers at the Zululand Mental Health Society through face-to-face meetings with deaf consumers to explain the purpose of the groups and to offer assurances that group discussions would be limited to obtaining information about opinions or viewpoints and not personal experiences related to HIV/AIDS.

The unstructured topic guide interview schedule used was developed by Green (1994) for use with rural African populations and modified with permission. Participants were asked to respond to questions related to ways of getting AIDS, the symptoms of the illness, treatment options, and methods for prevention. Open-ended questions also addressed beliefs and attitudes about traditional medicine for preventing or curing the disease, and perspectives on gender differences associated with HIV infection. Focus groups were conducted in American and Zulu sign language, videoed, and transcribed by individuals proficient in both languages. Microsoft® Word transcribed videos were entered in Ethnograph 6.0 and coded to identify themes associated with the variables: spiritual practices, gender, poverty, and HIV/AIDS knowledge.

Results

Traditional Spiritual Practices

Participants were asked if deaf persons in their area used traditional healers or sangomas for advice or treatment of AIDS and other ailments. They believed that the behaviors of deaf people varied depending on religious beliefs. According to several participants, Christians don’t use traditional healers, but a person who is Hindu might go to a temple to determine why they’ve become sick. Others suggested that deaf people go to traditional healers and then to a doctor. Both males and females believed that deaf
people wait until they become sick before seeing a doctor, and they quickly die. However, a common theme among all participants was that deaf people, like “normal people”, will go to traditional healers to seek prayers and rituals that will make them better. Participants also thought that deaf people look for someone to blame and will find fault with hearing people, a neighbor or family member for their illness. One male replied: “If we are sick we go to hospitals, sangomas, traditional healers and we pray, but we know in the end nothing works and we will die anyway. There is no traditional healer or sangoma curing AIDS."

Gender

Customarily, sexual practices are not openly discussed in Indian or Zulu cultures, and participants were apprehensive about responding to questions related to choices of when and with whom to be intimate; female and male levels of comfort with asking for condom use with intimate partners; or the relationship between infidelity and AIDS risk. Male participants consistently indicated that males are the decision makers, and as stated by several, “it’s the man’s way”. Although women did not comment, they expressed concern about the rape of deaf women, primarily by “normal men”. Women believed that violence against deaf women put them at risk for HIV/AIDS. Three of the five females reported being told of someone in their area who had committed suicide after being raped. A Zulu female participant stated, “Sometimes it may be better to take your own life because there are communication barriers and you can’t report what’s happened to the police or hospital”. Another female added “women are afraid to tell their parents, especially their dad”.

As the discussions shifted to viewpoints about women and men having affairs or multiple intimate partners and the potential HIV/AIDS risk, participants became more engaged in dialog. Peri-rural individuals believed that having multiple partners was as common among deaf people as with others in South Africa. They shared stories about young deaf women who didn’t have money and had relationships with so-called “sugar daddies” to get food, support, and things for themselves. Males also believed it was common practice for men to have multiple partners, though there was agreement that promiscuity is a big problem for getting AIDS. However, females humorously shared opinions that it is not only young deaf girls who marry older men or have them as boyfriends, but young boys are also with older women for money. Rural focus group members had no knowledge
of persons in the deaf community having multiple partners, but agreed that deaf girls between the ages of 15 and 17 marry men more than 35 years older. All participants thought that women sometimes ask men to use condoms, but based on cultural beliefs, most of the time they will not ask. As stated by three women, “If you tell your partner to use condoms, you are telling him/her that you have been somewhere else.”

**Poverty**

While focus group participants offered no direct evidence symbolizing a relationship between poverty as a risk factor for HIV/AIDS, and economic and social conditions, i.e. marginalization, isolation, minimal education, and unemployment, they had the same socioeconomic characteristic as their hearing cohorts. Given the demographic similarities, the deaf community may also place day-to-day survival above practicing health-enhancing behaviors.

**Knowledge**

Investigations associated with the degree of knowledge about HIV/AIDS (Groce et al., 2007; Kiyaga and Moores, 2003) suggest that the deaf community possesses limited information due to communication barriers. Those findings were supported by participants’ responses denoting minimal understanding about transmission, prevention, and testing. When asked about AIDS symptoms, a common response was “people change, they lose weight, become skinny, things get worse, and we die.” Inquiries about their sources of information indicated that older participants obtained information from reading or speaking with friends, while younger, primarily rural group members, received HIV/AIDS education from school. Both rural and peri-urban groups agreed that pre and post HIV/AIDS counseling were important, and several had made use of counseling services, using a family member as an interpreter. Rural participants reported that counseling was available at clinics with a social worker fluent in isiZulu sign language, but added, “Some who go to the clinic and those who don’t continue to die from the disease.”

Focus group members did not think sufficient information was available to them about the illness and its treatment for several reasons. The first was that deaf people in South Africa are isolated and miss important information, and second, they did not think there were enough interpreters fluent in
the regional sign languages. A very vocal male stated: “For example, I am communicating with you in ASL, but a deaf person from another area, Zulu, Xhosa or the Transvaal (former Northern Province) would not understand me because our languages are regional. We can’t get information from deaf people in other provinces and there are not many interpreters in hospitals or clinics that can help with all of the languages.” Third, there were commonly held concerns about confidentiality and the importance of independently obtaining information, counseling, and treatment. There was agreement that deaf people do not want to rely on parents and friends to interpret private information about their HIV status, and as a result, they “keep quiet”, don’t discuss illness, and often will not go to clinics. A shy 27-year-old participant expressed fear of becoming infected, but was not sure that she would go to a doctor for testing.

Discussion and Recommendations

The findings, though limited in scope, suggest that the risk behaviors associated with HIV/AIDS among the larger South African population are similar for the country’s deaf population. The beliefs reflecting the use of traditional healers, patriarchal decision-making in matters of intimacy and condom use, and the relevance of poverty for the spread of the disease did not differ. However, as reported by the study participants, communication barriers limit access to information and knowledge. The findings from this study further support what is already understood about HIV/AIDS and deafness in relation to gaps in knowledge, lack of assessable health services, and accurate information, and they speak strongly for the development and training of regional deaf HIV/AIDS peer educators and outreach workers.

Contact Information

Marquessa Brown
Gallaudet University
800 Florida Ave. NW
Washington, D.C. 20002
marquessa.brown@gallaudet.edu

Zethu Mkhize
University of Zululand
Private Bag X1001
KwaDlangezwa 3886, South Africa
References


