

The Silent Victims: HIV in the Deaf Community

By Hali Kohls

ABSTRACT. Significant health disparities exist between the Hearing and Deaf Communities due to the fact that mainstream society is organized by the physically abled for the physically abled. This systematic oppression, coupled with the prevailing, gendered stigma against HIV/AIDS, led to devastating consequences in the Deaf community. Existing prejudices negatively affect interactions between health care professionals and Deaf individuals. This paper employs a Feminist theoretical perspective while analyzing past research and deconstructing the experiences of a middle-aged, dyslexic, gay, Deaf male living with HIV. It also highlights the need for more sociological and gender studies research on Deaf individuals as well as the creation of a formal Deaf Theory.

Over the last few decades the HIV and AIDS epidemic has created a national panic and has fed on the misunderstanding and silence surrounding the illness. Pervasive myths about HIV/AIDS significantly affect how one experiences being diagnosed and living with HIV/AIDS. Their experience is further influenced by their position in society. Health disparities illustrate how minority groups are disproportionately affected by this illness (Sheetz, 2004, p. 118).

Contributing to these inequities are barriers certain groups face when trying to access health care information and services. Studies show Deaf individuals frequent a general practitioner much less often than their hearing peers (Meador et al., 2005, p. 219). This handicaps them because they are less likely to learn about preventative

health care and are less likely to receive early diagnoses, resulting in overall poorer health.

This paper explores the unique social position of Deaf, gay men that puts them at an increased risk of contracting HIV and how their social standing influences their experiences their diagnosis. It deconstructs situations in which Deaf persons and the health care system interact and how that is affected by the social understandings of HIV/AIDS, deafness, and the intersections of homosexuality and gender. By employing the Feminist theoretical framework, it looks at how our society is organized to privilege the physically “abled”, subsequently killing members of the Deaf community.

Literature Review

The Deaf community was disadvantaged from the very beginning of the HIV/AIDS epidemic. It is hard to get an accurate number of Deaf persons affected by HIV or AIDS because the Center for Disease Control does not include deafness on their forms. It is estimated that anywhere between 7,000 and 25,000 Deaf are living with HIV or AIDS, but from the limited information that has been gathered, coupled with anecdotal reports, it seems the actual number is closer to 25,000. Although the epidemic struck the Deaf community at the same time as the hearing, it was not until late 1980's that services geared specifically towards Deaf patients were initiated (Sheetz, 2004, p. 119).

Even today HIV/AIDS educational material and information is largely inaccessible by members of the Deaf community. Infographics are designed predominantly for hearing people and often include very few visual aids. Although they are only written at an 8th grade reading level, on average Deaf individuals read at a 4th grade reading level and are highly visual learners (Peinkofer, 1994, p. 391). This is a significant reason for the limited HIV/AIDS knowledge still prevalent among American Deaf today. This lack of knowledge leads to fear and misunderstandings

about the risks of contracting HIV and what the diagnosis means, which often translates into stigmatization and discrimination (Peinkofer, 1994, p. 391).

The Deaf community was hit so hard by HIV/AIDS and taken so unaware that much frustration, confusion, and hopelessness still surrounds the diagnosis. Interviews with Deaf gay men show the high rates of infection and low levels of comprehension within the Deaf population (Mallinson, 2004, p. 30). Even those that demonstrated knowledge of safe sexual behavior seemed convinced that they would eventually contract, and likely die from, HIV/AIDS. It is obvious they felt little support from both the health care system and the Deaf community.

Communication barriers and considerable mistrust often complicate interactions between Deaf patients and health care professionals. The 1990 Americans with Disabilities Act requires physician's offices to provide and pay for interpreters when seeing Deaf patients (Iezzoni et al., 2004, p. 361). Unfortunately, this is not always the case. Some patients may choose to forego the translator, but others do not receive them because they do not recognize their full legal right to demand one.

Furthermore, Deaf patients find that the health care system does not offer them adequate support and compassion. HIV/AIDS is a scary diagnosis. Fear of the disease is augmented by the dissemination of inaccurate information about the disease. Many Deaf individuals, especially at the beginning of the outbreak, learned they had HIV or AIDS without knowing what that diagnosis meant. When they visited a doctor to learn more they were met with frustration and impatience at their lack of knowledge and difficulties communicating.

Up until recently the lay public misunderstood deafness. They were ostracized and perceived as the inherently different, unintelligent "other". Medical professionals took these biases into the lab with them and used their social authority to declare deafness a mental retardation. Deaf persons still encounter this stigma,

particularly when dealing with health care professionals.

According to Lisa Iezzoni and her co-authors, Deaf patients feel that most health care professionals hold prior assumptions about deafness (2004, p. 357). This prejudice that Deaf patients perceived prevented them from asking more in-depth questions and from sharing some of their concerns. This is immensely harmful because it affects the amount of information Deaf patients receive about their health status, preventative health behaviors and treatments. Interviews with hard-of-hearing individuals illuminate the different treatment patients receive based on their hearing abilities. Many respondents who had loss their hearing later in life noticed that doctors also began treating them as less intelligent (Meador et al., 2005, p. 221).

Similarly, many health care professionals feel they possess inadequate knowledge about Deaf culture. It is necessary for medical professionals to undergo Deaf cultural competency training so they can better serve the needs of Deaf patients (Hoang et al., 2011, p. 175). Their inability to do so contributes to the health disparities rampant among the Deaf population.

One contributing factor to the wide-spread misconception of Deafness, according to Kendra Smith and MJ Bienvenu, is the lack of a formal theory, developed by Deaf people, to systematically document and analyze their experiences, in an effort to change their political, social, and economic position in society (2007, p. 43). Other “emancipatory knowledges”, such as feminist theory, have been developed to explain the unsatisfied needs of subordinated groups and introduce effective solutions (Smith et al., 2007, p. 43).

Since the outbreak of the U.S. HIV/AIDS epidemic in the early 1980’s there has been a stigma attached to the diagnosis. At the beginning it predominately affected middle and upper class, white, homosexual males. It was quickly deemed a “gay” disease and even adopted the medical name of “GRID” (gay-related immune disease)

(Lorber et al., 2002, p. 109). Due to its association with homosexuality, and eventually IV-drug use, diagnosis of this illness became a marker for immoral behavior (Bird et al., 2013, p. 2194). In their time of great need, HIV-positive individuals are often marked as outcasts and denied support by their community

The Deaf Community is supposed to be where Deaf individuals can develop self-esteem, communicate easily, and share their Deaf culture (Mallinson, 2004, p. 32). Unfortunately, due to prevalent assumptions of gender and sexuality coupled with gross misunderstandings of the disease, HIV/AIDS is highly stigmatized within Deaf social circles. The Deaf community is relatively small and close knit, multiplying one's fears of their HIV-positive status getting out and spreading through the community quickly (Peinkofer, 1994, p. 391). This leads to less frequent utilization of interpreters in doctors' offices. Some fear that using an interpreter will compromise their confidentiality. This can result in patients purposely withholding medical information, which undermines how effectively a doctor can diagnose and treat the patient (Meador et al., 2005, p. 220).

Concepts of homosexuality and gender are inextricably intertwined in American culture. Masculinity is constructed as distinctly opposite from femininity. Therefore men who have sex with other men are often ridiculed as being unmasculine, weak, and overall inferior (Levine, 1998, p. 20; Mallinson, 2004, p. 32). Internalized homophobia is a common consequence of our heteronormative society telling individuals who are capable of same-sex love that they are "sick" or a deviation from "normal" (Levine, 1998, p. 22). The construction of "gay macho" celebrates frequent, anonymous, casual sex and an enthusiasm for partying and drug use (Levine et al., 1989, p. 146). Masculinity, both heterosexual and homosexual, often encourages risky behavior (including not wearing condoms), which significantly increases chances of contracting HIV/AIDS.

Gay men in the Deaf community often feel they are a “minority within a minority”. Many fear coming out of the closet would result in them being rejected by the Deaf community, the only social circle many can communicate easily and feel genuinely comfortable in.

Methodology

My research study was supplemented by an interview with a Deaf, gay, urban, HIV-positive, Black man that I will refer to by the pseudonym “Darius”. It is also important to mention that Darius is dyslexic and may have other learning disabilities. This has further disadvantaged Darius when trying to access educational sources and when trying to communicate with doctors by writing notes. He has been living with his HIV-positive status since his diagnosis in August of 1990. I compiled a series of open-ended questions to ask him and video-recorded the face-to-face interview. In the room with us were two women he works with at Pennsylvania School for the Deaf to help us record and interpret. An interpreter he knew well was vital because American Sign Language (ASL) is quite different from verbal English; it has its own vocabulary and syntax (Mallinson, 2004, p. 28). Therefore, translating ASL can be difficult and, by definition, very much up to interpretation. Having a friend there ensured more accurate interpretation of his experiences and feelings.

Findings

My interview with Darius offered new insights into how Deaf, gay men experience being diagnosed with and living with HIV. Throughout the interview three themes stood out: communication barriers when interacting with the health care system, existing stigma against homosexuality and associated gender assumptions, and the Deaf community’s significant need for attention.

Darius first decided to get tested for HIV in 1990 when many of his acquaintances were being diagnosed although he was exhibiting no symptoms. Before he was diagnosed he knew very little about HIV/AIDS, just like the majority of the Deaf population. The lack of knowledge led to fear and depression for Darius. “The first doctor I had to ask what [his diagnosis] meant and that I didn’t know. And he was kind of short with me and kind of mean with me and had an attitude with me.” This first interaction Darius had with his doctor about HIV reflects how many Deaf individuals feel doctors lack compassion and patience when dealing with a Deaf patient, particularly during such emotionally sensitive times (Mallinson, 2004, p. 33).

The second time he went to the doctor he brought a hearing friend with him to help interpret. This is a common strategy among Deaf individuals who would rather avoid using an interpreter (Mallinson, 2004, p. 33). At this point in his diagnosis Darius was protecting the privacy of his HIV-positive status. He sometimes still does this by attempting to communicate with his doctor by lip-reading or writing notes rather than asking for an interpreter.

There are times when Darius was being treated by a doctor and desperately needed an interpreter, but one was not available. Darius remembers,

One day I found blood in my pee and it scared me to death. I went to the doctor and wrote down everything that was wrong with me. I was dizzy. They were telling me to hurry up and I was writing notes. The doctor told me there was no interpreter there at the time. The male doctor told me he had to stick something up my penis. I was like, “what! What! What! You have to stick something up my penis?!” And then he stuck something up my penis. Then I could pee. Everything was fine after that, but let me tell you, that was an experience.

This is a good example of how Deaf individuals become very scared when they are interacting with health care professionals and either do not understand what is happening or cannot see what the doctor is doing (Iezonni

et al., 2004, p. 359). When a doctor is out of eyesight the Deaf patient is unable to read his or her lips. This failure to communicate is immensely important to understanding the Deaf community's general mistrust and fear of the health care system.

Darius' gay identity has a profound impact on how he experiences living with HIV. When I asked him when he knew he was gay, he spoke about playing dolls when he was little and how his parents already knew he was gay before he came out to them. I found this explanation fascinating because it reflected the beliefs he held about gender and sexuality. To Darius, his love for playing with dolls and fixing their hair illustrated his sexuality more than his first homosexual experiences at school.

Near the end of the interview I asked Darius what masculinity meant to him (a question that had not originally been on my script). His response: "I think of a strong, normal person. Not weak or flirtatious, But just really a firm, normal, strong person. Not gay and flirty and feminine with floaty wrists and all that. Just respectful, polite, and strong." He draws distinct lines between masculinity, strength, and the rejection of weakness. He also directly connected femininity with being gay and flamboyant. And, of course, to be masculine is "normal".

Darius explained that he had no way of knowing who had given him HIV because he was having a significant amount of unprotected sex with a variety of men. He says that he now uses condoms for protection, but when he was younger he was "wild" and only interested in having a good time. This is similar to research I came across that associated gay masculinity with risky behavior, multiple sex partners, and a concern for their sexual pleasure over safety (Lorber et al., 2002, p. 114; Levine et al., 1989, p. 144).

Social stigma against homosexuality was still highly pervasive when Darius was first diagnosed with HIV in 1990. He spoke more about his interactions with his doctors and how he feared being rejected. He did not like

the attitude of the first doctor he saw about his diagnosis and consequently did feel comfortable speaking frankly with the doctor about medical concerns.

His hearing friends helped him find a gay doctor, with whom Darius thought he would be more comfortable. The improvement was instantaneous. Darius feels comfortable asking all of his medical questions without fear of being rejected or mistreated for his gay identity. In this way, societal stigma against homosexuality and HIV/AIDS significantly influences the effectiveness of medical treatment one receives.

Although Darius' diagnosis was twenty-four years ago, a general lack of knowledge about HIV/AIDS is still prevalent in the Deaf community today. Darius was caught unaware by his illness, a terrifying experience he does not want others to have to go through. For five years he ran HIV/AIDS workshops out of his home. Like other HIV-positive individuals, Darius recognized a cultural lag in the Deaf population's understanding of HIV/AIDS and felt resolved to help his community (Mallinson, 2004, p. 33).

He remembers encountering stigma within the Deaf community: "Sometimes my other Deaf friends can be rude. Some of the deaf people that I know say, 'Don't kiss him. You might get sick.'" This experience of Darius reflects the misunderstanding that HIV/AIDS is highly contagious and that an HIV-positive individual is a danger to society (Bird et al., 2013, p. 2196). This is again untrue. HIV/AIDS is spread through the exchange of bodily fluids (i.e. blood, semen, etc.) or by the shared use of needles. These findings illustrate that more work needs to be done within the Deaf community to correct these rampant misconceptions of HIV/AIDS.

Conclusion

The Deaf community is significantly disadvantaged when it comes to receiving preventative health information, understanding treatments, and being at risk for a variety of

illness including HIV/AIDS. The primary reason for these disadvantages is how difficult it is for a Deaf individual to communicate with a hearing doctor. Interpreters are not always available or desired, even though physicians' offices are legally required to provide and pay for the services. Doctors should ask their Deaf patients what their preferred communication style is since preferences vary from person to person. When discussing medical issues, physicians should speak simply and routinely verify with the patient that he or she thoroughly understands what the doctor is saying. Overall, physicians need to undergo Deaf cultural competency training to be able to fully meet the needs of their Deaf patients (Hoang et al., 2011, p. 181). The need for a greater understanding of Deaf people and their culture extends beyond the medical field, however.

Within Deaf Studies, a formal Deaf Theory needs to be developed so scholars can systematically analyze the unique experiences of Deaf people and how they are disadvantaged in society. Similar to more recent forms of Feminist theory, Deaf theory would have to be interdisciplinary in nature because all people, including the Deaf, experience the same situations differently due to intersecting systems of oppression and privilege. Deaf individuals would need to be given a platform through which to take charge, so they can outline their *own* experiences, needs, obstacles, and possible solutions (Smith et al., 2007, p. 44).

Further activism needs to be completed in the Deaf community to correct the pervasive myths about HIV/AIDS circulating the social network. In one study I found many Deaf gay male subjects felt HIV/AIDS educational presentations in ASL would be more helpful and effective than brochures written in English (Mallinson, 2004, p. 31). People need to know the reality of an HIV-positive status and the preventative measures they can take to avoid contraction. The silence and stigma that surrounds HIV/AIDS contributes to less trust, less disclosure, less

communication overall, and inevitably more danger (Bird et al., 2013, p. 2197).

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