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LESSONS LEARNED FROM MORE THAN Two DECADES OF HIV/AIDS PREVENTION EFFORTS: IMPLICATIONS FOR PEOPLE WHO ARE DEAF OR HARD OF HEARING

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Abstract

In Contrast with the nearly 30 years of HIV/AIDS research with the hearing community, data on HIV infection among persons who are deaf and hard of hearing is primarily anecdotal. Although the few available estimates suggest that deaf and hard of hearing persons are disproportionately affected by HIV infection, no surveillance systems are in place to identify either frequency or mode of HIV infection within this population. Moreover, to date, all empirically validated HIV prevention interventions have relied on communication strategies developed for persons who hear. Therefore, understanding and developing-effective prevention methods is crucial for persons who are deaf or hard of hearing. The authors explore (a) factors among this population that may contribute to HIV-related behaviors, (b) four key concepts consistently included in successful interventions, and (c) practical ways in which to use this information to tailor effective intervention strategies for this population.

In the United States there are nearly 1 million individuals living with HIV/AIDS (Centers for Disease Control and Prevention [CDC], 2006). It is estimated that an additional 40,000 individuals are newly infected each year (CDC, 2002a). While efforts are underway to develop an HIV vaccine, there does not appear to be one on the horizon. Thus, prevention efforts that target HIV-related risk behaviors remain the most effective method of lowering incidence rates, particularly among vulnerable populations.

About 10% of the total U.S. population, approximately 31 million individuals, is deaf or hard of hearing (Boon, in press). Estimates are that 8,000 to 40,000 of these people are infected with HIV (Health Resources and Services Administration [HRSA], n.d.). A more precise estimate is not available, as the CDC does not specifically track the incidence or prevalence of HIV infection among persons who are deaf or hard of hearing. Thus, epidemiological information on HIV infection among this population is primarily anecdotal (Campbell, 1999).

Factors That Contribute to HIV Risk Behaviors Among Persons Who Are Deaf or Hard of Hearing

A number of factors may contribute to the HIV-related vulnerability of persons example, stem from the variety of communication strategies used by persons who are deaf or hard of hearing. Such strategies include the use of American Sign Language (ASL), Signed English, and

speechreading. Because these, and other communication strategies, are very different from each other, persons using one may have difficulty understanding persons using another.

Additional factors contributing to HIV risk among persons who are deaf or hard of hearing include substance abuse. Rates of substance abuse among this population are nearly 40% higher than rates seen among persons who are hearing (Peinkofer, 1994). This is very concerning because substance abuse and sexual risk behaviors are the principal routes of HIV transmission (CDC, 2002b), and they tend to co-occur such that substance abuse is strongly correlated with high-risk sexual behavior (Ostrow et al., 1990). It is argued that alcohol and other drugs have direct causal effects on sexual behavior and condom use by impairing individuals' judgment about possible risks and making them less sensitive to the concerns of partners (Strunin & Hingson, 1992).

A review of the literature on HIV risk among persons who are deaf or hard of hearing provides anecdotal evidence of increased drug and alcohol dependency in comparison to the hearing population (HRSA, n.d.; Heuttel & Rothstein, 2001). Other literature suggests that persons who are deaf or hard of hearing score lower than hearing populations on tests of HIV knowledge (Campbell, 1999; Luckner & Gonzales, 1993). Higher rates of substance abuse combined with limited knowledge of how HIV is transmitted may contribute to increased vulnerability to HIV Infection among persons who are deaf or hard of hearing.

Child abuse may be another factor that increases vulnerability to HIV Infection among persons who are deaf or hard of hearing. Research among children attending a language Institute has shown that more than half (54%) of deaf boys reported abuse, compared to 10% of hearing boys. Similarly, 50% of deaf girls reported abuse, compared to 25% of hearing girls (Sullivan, Vernon, & Scanlan, 1987). Although these findings are more than 20 years old, they are significant because burgeoning research among HIV positive and HIV negative populations strongly suggests a robust relationship between childhood abuse history and subsequent HIV related risk behavior (Gore-Felton & Koopman, 2002; Kalichman, Gore-Felton, Benotsch, Cage, & Rompa, 2004). Levels of risk behavior for HIV infection may be higher among persons who are deaf or hard of hearing, given the high rates of abuse reported among deaf children.

Among deaf men who have sex with men (MSM), additional vulnerability to HIV Infection is imposed through discrimination and stigma. Deaf MSM face stigma and discrimination on the basis of two separate characteristics: their hearing status and their sexual orientation. This increased social vulnerability of those who identify as MSM may make disclosing sexual orientation extremely difficult, which in turn could lead to anonymous and high-risk sexual interactions (Detennan, Kordus, & DeCarlo, 1999). Further complicating safer sexual practices among deaf MSM is the fact that many deaf MSM have hearing MSM partners, which may make it difficult to communicate about safer behavior (Peinkofer, 1994).

While much information has been generated during nearly three decades of HIV prevention research, very little empirical data has examined factors that contribute to increased HIV risk among people who are deaf or hard of hearing. Efforts to fill this information gap will have to apply the lessons learned from research with other populations. On the basis of this information, effective HIV prevention and intervention programs can be created that meet the urgent and unique needs of those who are deaf or hard of hearing.

Lessons Learned

One of the fundamental lessons learned in nearly 30 years of HIV prevention efforts is that, where HIV prevention interventions are concerned, "one size does not fit all." With each unique population for whom public-health professionals and others wish to create effective HIV risk reduction interventions, two basic questions must be answered: (a) What specific

pattern or patterns of HIV risk behavior can be observed within this population? and (b) What factors facilitate and maintain these patterns over time? Subsequently, if effective prevention programs are to be developed, patterns of risk behavior and concomitant HIV Infection within the community must first be identified within the community. Once prevalence and incidence of HIV Infection are documented, cultural, social, psychological, and economic factors that contribute to the development and maintenance of HIV-related risk behavior must be examined. Understanding the types and frequency of risk behaviors and the communal dynamics that foster such behaviors is instrumental in identifying specific needs within a community, prioritizing prevention efforts, and designing effective interventions.

Since the beginning of the HIV/AIDS epidemic, the CDC has implemented many surveillance programs and conducted numerous studies to monitor the occurrence of HIV infection, disease, and mortality, and to identify the behaviors that place people at risk. Although the CDC uses a number of factors to document HIV infection, including mode of exposure, sex, race/ethnicity, and age group, disability is not currently considered, and hence no specific data have been collected to assess seroprevalence among persons who are deaf or hard of hearing.

Throughout the U.S. AIDS epidemic, cognitive-behavioral frameworks have been used to guide the systematic examination of risk behavior among various groups. Because virtually no empirical data exist on patterns of FUV infection and unique determinants of risk behaviors among persons who are deaf or hard of hearing, recommendations are to use a cognitive-behavioral conceptual framework to guide risk assessment and identify prevention needs among people who are deaf or hard of hearing. Across cognitive-behavioral theories, four concepts have repeatedly been associated with HIV risk behaviors. Moreover, these concepts have been incorporated into HIV risk reduction interventions that have proven successful at reducing risk behavior among diverse populations. In general, successful interventions have been built on the premise that in order to achieve risk reduction, individuals must (a) perceive themselves to be at risk, (b) have the intention to perform risk reduction behaviors, (c) possess self-efficacy or the confidence that they can perform the risk reduction behavior, and (d) have sufficient social support to initiate and maintain these changes in behavior.

Perceived Susceptibility

Perceived susceptibility refers to an individual's subjective perception of his or her risk of developing a particular health condition or, as in the case of HIV contracting a virus. Perceived susceptibility is a fundamental component of several health behavior theories, including the Health Belief Model, the Transtheoretical Model, the Theory of Reasoned Action, and the Theory of Planned Behavior (Glanz, Rimer, & Lewis, 2002). Indeed, these models have been successfully applied to HIV prevention interventions with gay men (Allard, 1989; Aspinwall, Kemeny, Taylor, Schneider, & Dudley, 1991; Basen-Engquist & Parcel, 1992), women (Wilson, Jaccard, Levinson, Minkoff, & Endias, 1996; Winningham, Richter, Corwin, & GoreFelton, 2004), and adolescents (Devieux et al., 2002; Facente, 2001). Across these interventions, susceptibility has been consistently shown to be significantly associated with HIV-related risk behaviors.

Research findings across various populations indicate that a substantial proportion of individuals who report HIV related risk behaviors do not perceive themselves to be at risk for HIV infection (Bridgers, Figler, Vaughan, & Sawin, 1990; Winningham et al., 2004). Moreover, a prevailing assertion in prevention research is that among individuals reporting high-risk behaviors, perceived susceptibility is required before a commitment to behavior change can occur (Catania, Kegeles, & Coates, 1990). Therefore, HIV prevention interventions that incorporate a component aimed at heightening the perception of susceptibility to

contracting the virus are likely to be more effective at decreasing risk behavior and facilitating the adoption of safer behaviors.

Behavioral Intentions

Fisher's Information-Motivation-Behavior (IMB) Model and the Theories of Reasoned Action and Planned Behavior, along with a growing empirical literature, suggest that behavioral intentions are determinants of behavior (Glanz et al., 2002). According to the IMB Model and the Theory of Reasoned Action, behavioral intention is a function of two factors: attitudes and subjective norms. An individual's attitude (positive or negative) about a particular behavior will influence whether or not the person will engage in the behavior. However, attitude alone does not dictate behavior because behavior is also influenced by an individual's subjective norms or, put another way, the perceptions of one's social group related to engaging or not engaging in a particular behavior. Attitudes and subjective norms have been associated with risk reduction behavior among women (Salabarria-Pena, Lee, Montgomery, Hopp, & Muralles, 2003; Sneed & Morisky, 1998) and gay men (Mclaws, Irwig, Oldenburg, Mock, & Ross, 1996). Attitudes are formulated through underlying behavioral beliefs and outcome evaluations, while subjective norms are formulated through normative beliefs and motivations to comply. Effective HIV prevention interventions tailor intervention messages so that they uniquely address prevailing attitudes, beliefs, and social norms associated with HIV related risk behaviors as well as safer behaviors such as condom use.

Self-Efficacy

Fundamental to conceptual models that are based on cognitive-behavioral theories and one of the most studied constructs in public health and psychology; self-efficacy is the level of confidence an individual has in his or her ability to use specific skills to accomplish a desired goal (Bandura, 1977). HIV prevention interventions conducted among diverse populations have consistently found a relationship between self-efficacy and risk behavior. Among gay men, greater self-efficacy to engage in safer sex behavior was associated with greater risk reduction (Aspinwall et al., 1991; McKirnan & Peterson, 1989). Perceived self-efficacy to negotiate condom use predicts safer sex practices among adolescents (Basen-Engquist & Parcel, 1992; J. B. Jemmott, L. S. Jemmott, & Fong, 1992), as well as adults (Brafford & Beck, 1991; O'Leary, Goodhart, L. S. Jemmott, & Boccher-Lattimore, 1992). Research consistently demonstrates the influence of self-efficacy on the initiation and maintenance of behavior change within various contexts (Bandura, 2005; Strecher, DeVellis, Becker, & Rosenstock, 1986).

Social Support

Conceptualized in a variety of ways, social support can include quantitative dimensions of relationships (e.g., number of friends) as well as qualitative dimensions (e.g., feelings of connectedness; Heitzmann & Kaplan, 1988). Integral to the Transactional Model of Stress and Coping, social support has been shown to influence self-efficacy, the likelihood of active coping mechanisms (Holahan & Moos, 1986), and health outcomes (House, Landis, & Umberson, 1988; Reifman & Windle, 1995). It is important to note that the population and how social support is assessed matter with respect to risk behavior. For instance, there is evidence among adults already infected with HIV that domain-specific social support affects risk behavior among men and women differently. Women who feel more support from their partners report more unprotected sexual encounters, which suggests that social support is influenced by social norms that can lead to behavior that is detrimental to the individual or to others (Gore-Felton et al., 2002).

A broader approach using the identification and analysis of social networks has been instrumental in identifying the characteristics of social relationships beyond simple assessment of social supports that influence behaviors associated with health outcomes (Heckathorn, Broadhead, Anthony, & Weakliem, 1999; Morris, 1997). The Diffusion of Innovations Theory (Glanz et al., 2002) provides a conceptual framework for describing how social support, social networks, and social norms influence behavior, particularly behavior that is difficult to change. Studies across diverse age, gender, and sexual orientation populations have applied this framework using the Popular Opinion Leader Model, which galvanizes social networks to change social norms and provide social support to change HIV-related risk behavior among high-risk community populations (Kelly et al., 1997; Sikkema et al., 2000, 2005). Collectively, these studies provide empirical evidence of the efficacy of using community-level interventions in the context of social networks to influence social norms that affect high-risk behaviors.

Implications for Research and Prevention Among Persons Who Are Deaf or Hard of Hearing

Although behavioral scientists have amassed substantial information on successful HIV prevention strategies, not one published randomized, clinical trial among persons who were deaf or hard of hearing could be found. This evident lack of HIV prevention interventions specific to the needs of persons who are deaf or hard of hearing comes at a significant public-health cost, as anecdotal data indicate that the rate of HIV infection within this community is greater than the rate of HIV infection among the general population (HRSA, n.d.).

Determining actual rates of HIV-related risk behaviors and infection should be one of the first efforts in developing HIV infection interventions. Data collection could be conducted in Deaf schools, at statewide meetings of the Associations of the Deaf, or in other frequented venues. Although this data collection may be conducted by researchers outside the Deaf community, it must be endorsed by local leaders from the community if it is to be comprehensive.

Lessons learned from past HIV prevention efforts provide valuable theoretical and conceptual frameworks for identifying, contextualizing, and modifying risk behaviors. Indeed, one of the most important lessons learned is that “one size does not fit all.” HIV prevention intervention must be tailored to address the specific psychological, behavioral, and social context in which the virus is being transmitted.

For communities where little is known about HIV incidence and patterns of risk behavior, it is imperative that investigators and program planners take a multifaceted approach and consider both the unique characteristics of the new target community and lessons learned from other populations. As we have discussed earlier in the present article, the unique characteristics of the deaf and hard of hearing population revolve around varied communication strategies and cultural nuances. To date, all of the empirically validated HIV prevention interventions have relied on communication strategies developed for persons who were not deaf or hard of hearing. With a variety of languages and communication styles employed among people who are deaf or hard of hearing, it is important to understand which method or methods of communication will be most beneficial to the targeted population. It may be that visual presentation of HIV prevention materials is an effective strategy because it can be understood by individuals using diverse communication methods, including those with low levels of literacy.

Further, technology has increased the number of options available to health promotion efforts. The Internet is one of the fastest-growing systems for delivering information to high-risk, hard-to-reach populations. As more and more individuals use the Internet to meet, date, and select partners for various activities, it is not surprising that HIV prevention efforts have begun to use this same technology to promote and develop safer behaviors. Unfortunately, much of the

information on the Internet is written, and thus requires a certain level of literacy. Video clips and wave files may overcome barriers presented by low literacy levels. However, to be effective, these technologies require the user to have a high-speed Internet connection and a computer with substantial memory. This requirement often results in a “digital divide” along economic lines. Developing methods that can be easily accessed by persons who are deaf or hard of hearing and that incorporate various modes of communication, including the Internet, will increase the ability of health promotion programs to disseminate information and teach skills that will reduce risk behavior.

As is true of any culture, there are features of Deaf culture that can both challenge and support the implementation of HIV prevention interventions (Gaskins, 1999). As is the case with other minority groups, community-based organizations (CBOs) are likely to be an excellent resource in the development and dissemination of HIV prevention interventions that target persons who are deaf or hard of hearing. CBOs are likely to understand cultural factors and existing subcultures that facilitate or buffer risk behavior. For instance, It is not uncommon to find Deaf social clubs in communities of persons who are deaf and hard of hearing. Some clubs are housed in a permanent location, while others have no established “clubhouse” and instead meet at members’ homes. In larger cities, individuals will often form clubs based on a variety of characteristics or interests such as age, religious beliefs, or sexual orientation. Rainbow Groups, for example, comprise persons who are deaf and also gay, lesbian, or bisexual. Understanding the cultures and risk-related cultural factors within these clubs will facilitate development of interventions that are culturally appropriate.

Among people who are deaf or hard of hearing, there is a complex and highly efficient communication network often described as the “Deaf Grapevine” (Gaskins, 1999). Anecdotal evidence suggests that information perceived as important is quickly relayed through this network to persons with hearing loss all over the nation. Deaf persons also use smaller, segments of the network to share information about others in the community, thus maintaining group cohesion (Gaskins, 1999). Getting access to the Deaf Grapevine as part of an HIV prevention intervention may be a particularly efficient mode of relaying information and delivering skills-based curricula to high-risk individuals, particularly if combined with the technology of the Internet.

The obvious advantage of a communication network as extensive as the Deaf Grapevine is that information can be disseminated quickly and efficiently. Interventions that rely on communication via peers and community members that incorporate the use of the Deaf Grapevine may be particularly advantageous. Indeed, tailoring the Popular Opinion Leader Model to engage social networks via the Deaf Grapevine would leverage the influence of intact social networks to engage community members in a way that increases normative attitudes, beliefs, and behaviors associated with safer behavior. A word of caution, though—the cultural and social features that make the Deaf Grapevine a useful communication channel may also make it a detrimental communication channel in that as an informal source of information, It is susceptible to inaccuracy and misinformation (Bat-Chava, Martin, & Kosciw, 2005).

Further suggestions with regard to creating and implementing HIV prevention interventions tailored for persons who are deaf or hard of hearing come from the concepts shown to be effective with other population-specific interventions, as we have already discussed. For example, to address low perceived susceptibility, people in or connected to the Deaf community who have been infected or otherwise affected by HIV can share their stories. Additionally, panel discussions by HIV-infected members of the Deaf community can be hosted at statewide conventions of the Associations for the Deaf and at schools for persons who are deaf or hard of hearing.

With regard to self-efficacy, social support, and behavioral intentions, developing leadership within the Deaf community is vital. Leadership development specifically around this issue must be embraced by those already perceived as credible in the Deaf community. These leaders can help ensure that safer-sex messages become more visible by means of existing communication networks such as state-level association conventions, Deaf clubs, Web sites, listservs, and discussion boards used by persons who are deaf or hard of hearing. Further, once HIV education information is developed for this population, it can be incorporated into existing curricula geared toward people who are in programs for substance abuse or sexual assault.

Summary

Despite the fact that about 10% of all Americans are deaf or hard of hearing, delivering quality health care to this population has not been a focus of clinical or preventive research (Harmer, 1999). The reasons for this oversight, like most human dilemmas, are complex, involving socioeconomic, educational, and sociocultural factors (Harmer, 1999). However, the most fundamental reason is likely inadequate communication. For individuals who are deaf or hard of hearing and also members of ethnic minorities, it is not uncommon to negotiate three or more languages and cultures that reflect their home, their community, and their culture. Becoming proficient in these languages is challenging and can affect how one interacts with health care professionals, the type of health information that is received, and how health behavior is understood (Hindley, 1997).

Important next steps in reducing HIV-related risk behavior among communities of persons who are deaf or hard of hearing include putting a system in place to collect data on risk behaviors. Moreover, a call to action is needed to identify individuals and community programs that are immersed in Deaf culture that can collaborate with HIV researchers so that key factors that uniquely influence HIV-risk behavior can be identified. Once identified, these factors can be incorporated into HIV prevention interventions that are uniquely designed by and for diverse groups of persons who are deaf or hard of hearing. Interventions developed in this way will minimize the impetus to simply translate existing interventions that were developed by and for hearing communities, and thus allow novel interventions to be developed that are linguistically, culturally, psychologically, and socially tailored to diverse groups of persons who are deaf or hard of hearing.

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