Original Research

Self-Disclosure of HIV Status to Sexual Partners: A Qualitative Study of Issues Faced by Gay Men

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**Objective:** This study aimed to explore the range of issues faced by HIV-positive and HIV-negative gay men concerning HIV serostatus self-disclosure to sexual partners. **Methods:** In-depth semistructured interviews of 1–2 hr each were conducted with 26 HIV-positive and 15 HIV-negative gay men who were recruited from a larger cohort of gay men followed longitudinally for several years at a major medical center. Interviews were audiotaped, transcribed, and content-analyzed by two independent raters. **Results:** Several themes emerged concerning how disclosure was viewed, who and what was told, why disclosure occurred, and how disclosure decisions related to sexual behavior. Variations occurred in when and why men disclosed, and in the contents and definitions of their disclosures. Men disclosed using codes and indirect hints. Various rationalizations arose for not telling as well. Many men adopted the position that they do not tell, but practice safer sex, yet definitions of safer sex varied such that what some men consider safe, others do not. **Conclusion:** Recognition thus needs to be increased among clinicians, researchers, patients, and others that definitions of disclosure and of safer sex can vary significantly. The data have critical implications for designing appropriate interventions to limit the further spread of HIV.

**KEY WORDS:** HIV; self-disclosure; gay men; risk behaviors; stigma.

INTRODUCTION

HIV infection—private, confidential information—if revealed, can lead to rejection and stigmatization. Yet when HIV status is not disclosed to sexual partners, safer sexual practices may not be followed, and further spread of the disease may result. Thus, HIV-positive individuals often experience significant conflict and distress over what to say about their serostatus to others, particularly sexual partners. HIV-negative men may feel uncomfortable asking their partners as well. Previous quantitative studies have suggested that HIV-positive persons often do not disclose their HIV status to sexual partners and others. Yet few qualitative studies have been done to assess how individuals view and handle these difficult issues of self-disclosure. How do gay men perceive and approach the psychological and ethical dilemmas involved? What decisions are involved in sexual situations, for example, as to whether, when, what, and whom to ask or tell concerning HIV status? This study was designed to shed light on the range of patterns, meanings, and implications of HIV disclosure among gay men.

Several quantitative studies have suggested that HIV-infected individuals often do not disclose their status to others. Perry et al. showed that of gay men recently learning they were HIV-positive, 90% who had past sexual partners made no attempt to inform them of the test result (1). Stempel et al. showed that after 1 year, a sample of gay men had informed only 56% of their new sexual partners of their status (2). Marks et al. found that failure to disclose status occurred in conjunction with unprotected receptive and insertive anal intercourse, and that self-disclosure was less likely as the number of sexual partners increased (3). Moreover, study participants tended to
disclose their positive HIV status when they believed their partners were seropositive, and appeared less likely to disclose to partners thought to be seronegative (3, 4). HIV-positive gay and bisexual men were also more likely to have unprotected insertive anal intercourse with seropositive than seronegative partners (5). Spanish-speaking Latino men have been found to be less likely than English-speaking Latino men or White men to disclose HIV status and sexual orientation to significant others, especially family members (6). Other research among gay men as well as heterosexual men and women has found that those who disclose to all partners are more likely to be women, Caucasian, or Latino rather than African-American, have high spousal support, low support from friends, and a lower number of sexual partners (7).

Difficulties with self-disclosure have been found among both symptomatic as well as asymptomatic men (8) and when disclosures were to family members and others besides sexual partners alone (9, 10). Rejection does not always occur from main partners (11).

Yet little in-depth qualitative data have been analyzed concerning these issues. Qualitative research methods have been successfully used to elucidate how individuals view and approach the meanings and complex interpersonal aspects of illness (12). Qualitative data and narratives of individuals’ experiences can also reveal how individuals within a particular social or cultural situation or setting view a phenomenon, thus shedding light on the perspectives of these individuals themselves, as opposed to the viewpoints of researchers (13). Sobo presented qualitative findings examining issues of disclosure among small-town southwesterners, reporting, for example, on one focus group consisting of three women and one gay man (14). Yet norms and practices may vary among gay men, and between small towns and larger urban centers, which have much higher incidences of HIV infection. Gay men also constitute a particular subculture that may shape approaches to self-disclosure.

Goffman describes (15) how individuals learn to conceptualize and manage stigmatized or “spoiled” aspects of their social or personal identities. Some individuals attempt to “conceal” symbols of stigma, and to “pass,” while others socialize more fully with similarly stigmatized individuals. How gay men with HIV view and handle decisions concerning disclosure of potentially stigmatizing HIV infection has not been fully studied. Similarly, Parsons describes “the sick role”—a social role characterized by certain exemptions, rights, and obligations, and an impaired capacity to function (12, 16, 17). HIV-positive individuals may not perceive or want to perceive themselves as sick, though others may view them as such, resulting in tension and conflict (18). Green found in a street survey of the general public in Edinburgh, Scotland, more liberal attitudes toward HIV than persons with HIV thought existed. However, people with HIV still experience and fear rejection from potential sexual partners, and the possibility of being a sexual partner with a person with HIV was not examined in this study (19).

In general, social norms dictate that individuals not always divulge medical problems—particularly those involving personal behaviors. Disclosing a disease may mean divulging other aspects of one’s life that may potentially be embarrassing or have negative repercussions. This area has been understudied among other diseases, and clearly has additional complications with regard to HIV.

Thus, several gaps remain in the understanding of issues concerning disclosure among gay men. What are the range of issues that gay men face—from their own perspectives—concerning disclosure with sexual partners? How do HIV-positive men view and make difficult disclosure decisions? What are the components of HIV disclosure decision-making? What are the specific contents and definitions of disclosures? These issues have critical implications for HIV transmission and prevention. To understand how men view and approach these decisions can help clinicians and researchers develop appropriate interventions to assist men in dealing with these issues, thus furthering efforts to prevent HIV transmission.

METHODS

Participants were recruited from a cohort followed longitudinally since 1988 at a major medical center in New York City as part of a research study of HIV-positive and HIV-negative gay men. Data gathered from these men on a variety of psychological and medical variables have been previously reported (20). A self-report questionnaire was developed concerning issues of self-disclosure and was administered in conjunction with a biennial follow-up appointment that was part of the longitudinal study. All members of the cohort completed the questionnaire between July and December 1993. Participants were asked on the questionnaire if they would be willing to be interviewed in-depth about these issues.