

GAY MEN'S REPORT OF REGRET OF HIV DISCLOSURE TO FAMILY, FRIENDS, AND SEX PARTNERS

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The purpose of this study was to examine whether HIV-positive MSM experience regret as a consequence of disclosing their HIV serostatus. Participants for this study were 76 HIV-positive MSM involved in a longitudinal study of HIV disclosure ($N = 139$). Men with at least one network member that was aware of his HIV infection were included in the analyses.

Results revealed that overall, HIV-positive men do not regret family or friends knowing about their serostatus (63%). The observed proportion of regret events was practically negligible (4.2%). Compared with friends, the odds of experiencing regret were greater in the immediate family, with coworkers, and casual sex partners but was not significantly different in the extended family or committed sex partners. Despite disclosure being regarded as an anxiety provoking activity and negative reactions are typically anticipated, HIV disclosure appears to elicit very little regret to a wide variety of social network members. Furthermore, there were no differences in the occurrence of regret whether the HIV-positive person disclosed personally or if someone else disclosed for them. In both instances regret was remarkably low.

Disclosure of an HIV status to family and friends can be an overwhelming process fraught with apprehension, anxiety, and worry. Reasons people decide to disclose are numerous and the outcomes can be either beneficial or costly. Benefits include acquired social support (Kalichman, DiMarco, Austin, Luke & DiFonzo, 2003; Simoni, Demas, Mason, Drossman, & Davis, 2000; Turner, Hays, & Coates, 1993) active coping (Penedo et al., 2001), and improved well being (Paxton, 2002). Disclosing one's serostatus also frees the individual from hiding medicine taking rituals from friends, family, and co-workers and may increase access to assistance with home related chores and errands, health care, housing, and medical attention. Negative emotional consequences of disclosure that have been documented include rejection,

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abandonment, and isolation (Lovejoy, 1990; Stulberg & Buckingham, 1988; Zuckerman & Gordon, 1988). Evidence suggests that negative social consequences, such as fear expressed by others, ostracism, and degradation may continue to be experienced by individuals who are HIV-positive (Hereck, Capitanio, & Widaman, 2002). Costs in terms of stressors within the individual's family network, such as denial, anger, guilt, and uncertainty are also associated with HIV (Frierson, Lippman, & Johnson, 1987; Herek & Glunt, 1988; Macklin, 1988).

Research examining the decision to disclose or not to disclose has increased over the years; however, little attention has been paid to later consequences such as regret. In fact, after an extensive search of the literature only one published research study could be identified. In this study, Murphy, Roberts, and Hoffman (2003) qualitatively examined 47 HIV-positive women's feelings of regret after disclosure to their young children. Results indicated that the majority of the women (68%) did not regret disclosing, though, they did regret certain aspects of the disclosure event such as preparation, timing, context, and outcomes of the disclosure event.

Regret is a negative emotion caused by the comparison between what is (the actual outcome of a decision) and what might be (an imagined outcome) (Loomes & Sugden, 1982). Berndsen, van der Pligt, Doosje, and Manstead (2004) further distinguished regret as interpersonal (likely to occur as a result of doing harm to someone else) or intrapersonal (resulting from directly hurting oneself). Numerous studies have been conducted on the cognitive experience and processes of regret. For example, Gilovich and Medvec (1995) examined how certain cognitive processes can decrease the pain of regrettable experiences. Some of these processes are behavioral repair work such as taking steps to remedy regrettable actions or psychological repair work such as dissonance reduction.

PURPOSE

The purpose of this study was twofold. The first was to examine whether or not HIV-positive gay men experienced regret for having family, friends, or sexual partners know of their serostatus through either first or second hand disclosure. Knowledge of disclosure regret is valuable information for helping professionals seeking to assist HIV-positive persons with their disclosure decisions. The second purpose was to investigate whether or not characteristics of social and sexual network members influenced the likelihood of experiencing regret.

METHODS

PARTICIPANTS

Participants were 76 HIV-positive gay men who completed a longitudinal study of HIV disclosure ($N = 139$) and had at least one social or sexual network member that was aware of his HIV infection. Participants were recruited primarily from an AIDS Clinical Trials Unit (ACTU) associated with a large midwestern university. Recruitment by attending physicians and medical staff began in February of 1998 and continued through July of 2000. Eligible participants included HIV-positive men who reported either being gay or having sex with other men and were 18 years of age or older. Participants were primarily single (i.e., not partnered; 66%), Caucasian (86%) men between the ages of 21 and 61 ($M = 38$ years, $SD = 7$), who contracted HIV from unsafe sexual practices (80%). At entry into the study, participants had been diagnosed with HIV ranging from 1 month to 16 years ($M = 83$ months, $SD = 54$). These

men were well-educated with 57% having had some college education or a bachelor's degree and 23% completed some graduate work. More than 59% of the participants were employed, earning an average income of \$20,000 ($R = \$0-90,000$). The average social support network for these men had a median of 22 members. The largest network observed had 67 members; the smallest had 7 members. At the conclusion of the study 80% of the network members were aware of participants' serostatus, and 70% of these persons knew through firsthand disclosure.

PROCEDURES

Participants completed questionnaires regarding mental health, physical health, social support, disease progression, and sexual risk-taking behaviors. Participants completed an initial interview and questionnaire at the beginning of the study (Phase 1). Yearly, men took part in a structured interview, completed a questionnaire and sexual behavior calendar (phases 3, 5, and 7). Six months into each yearly wave of data collection, participants returned to fill out a questionnaire and sexual behavior calendar (phases 2, 4, and 6). Participants were interviewed about their social network by trained doctoral students in a private research office. Odd number phases took, on average, 3½ hours to complete and even number phases took, on average, 1½ hours.

INSTRUMENTS

Social network information was collected using an adapted version of the Barrera's (1981) Arizona Social Support Interview Schedule (ASSIS). Participants were asked with whom they would discuss personal issues, receive advice, borrow money, invite to socialize, garner positive feedback, request physical assistance, and experience negative interactions (i.e., argue or fight). In addition, they were asked with whom they had sexual interactions within the past 6 months. From each structured interview a list of social support network members was constructed. Demographic data (i.e., age, sex, and ethnicity) of each network member and the length of relationship and the participant's satisfaction with each relationship was obtained. Then participants were asked if each individual in their social network, including their immediate family, knew of their HIV diagnosis and how they were told.

Regret was assessed in phase 7 of the study. If a social network member knew of the participant's serostatus, the participant further indicated whether or not they regretted this member knowing. This was repeated for all the members listed in the social network members collected over the course of the study. The measure of regret was then computed as the percentage of the number of members with affirmative regret, over the number of members who knew. If no one in the network knew, the measure was undefined. No participant fell in this category.

RESULTS

Overall, 80% of the social network knew the participant's HIV serostatus and there was a very low incidence of regret. In fact, the majority of the men (63%) reported 0% regret and 75% of the men had regret percentages that were less than 7%. That is, in a typical network of 22 members (with 18 who are aware of their HIV infection) the participant experienced not more than one occurrence of regret. The highest reported regret percentage was 37.5%. This participant had 17 members, of which 16 knew their HIV status, but only 10 were reported as firsthand disclosures.

TABLE 1. Percentage of Regret Instances by Relationship Category

Category	N	Know (%)	Regret (%)
All Family	427	74.5	5.2
All Nuclear	305	77.2	8.2
Father	50	70.0	11.4
Mother	66	78.8	11.5
Brother	104	74.0	9.1
Sister	81	85.2	4.3
Child	4	100.0	0.0
All Extended	111	66.7	2.7
Grandparents	13	76.9	10.0
In-laws	22	77.3	0.0
Aunt/Uncle	31	61.2	5.0
Cousin	20	65.0	0.0
Nephew/Niece	25	60.0	0.0
All Friends	580	88.6	2.3
Acquaintance	20	80.0	0.0
Friends	560	88.9	2.4
All Sex Partners	389	63.8	5.6
Current sex partner	80	86.2	2.9
Casual sex partner	226	48.6	6.6
Past sex partner	67	88.1	6.8
Sex partner	16	62.5	10.0
All Support Professional	146	100.0	0.0
All Work	162	49.4	7.6
Supervisor	37	54.1	10.0
Co-Worker	125	48.0	6.4
All Church	11	90.9	10.0
All Others	104	69.2	4.2
Peripheral	46	68.1	0.0
All Residence	58	70.7	7.3
Neighbor	44	61.4	7.4
Roommate	10	100.0	10.0
Tenant	4	100.0	0.0

For descriptive purposes, Table 1 contains the percentages of regret instances by relationship category. Generally, the observed percentages (i.e., less than 10%) were low. The highest percentages were observed in the nuclear family (8.2%), work environment (7.6%), and with sex partners without a current or committed relationship (6.7%). Members of the workplace network typically did not know (49.4%), yet their regret percentage is among the highest. Percentages of regret instances were smallest among HIV professionals and support group (0.0%), peripheral relations (0.0%), friends (2.3%), extended family (2.7%), and current sex partners in a committed relationship (2.9%). Peripheral relations refer to network members known through the family, partner, or friends. Out of a total of 1,397 members who knew, there were only 58 (4.2 %) regret cases.

To examine possible relationships between the likelihood of regret and network member's characteristics, odds ratios were estimated via a series of single-variable logistic regressions for correlated data. Independent variables considered were the network member's age, gender, race (i.e., Caucasian, non-Caucasian), mode of knowing (i.e., firsthand or secondhand disclosure), and relationship to participant (i.e., nuclear family, extended family, committed sex partners, casual sex partners, friends, work, others). In assessing the effect of relationship to participant, members belonging to the

TABLE 2. Odds Ratios for Regret and Network Member Characteristics

Variable	Odds Ratio	Standard Error	95% Confidence Interval
Age	1.01	0.01	(0.99, 1.03)
Race			
Caucasian	1.69	0.69	(0.77, 3.71)
Non-Caucasian ^a			
Sex			
Female	1.03	0.32	(0.57, 1.88)
Male ^a			
Mode of knowing			
Firsthand Disclosure	1.63	0.55	(0.84, 3.14)
Second-hand ^a			
Relation to participant			
Nuclear family	4.04	1.70	(1.77, 9.20)
Extended family	1.25	0.97	(0.27, 5.73)
Committed sex partner	1.34	0.77	(0.43, 4.16)
Casual sex partner	3.16	1.40	(1.32, 7.56)
Work	3.73	2.21	(1.17, 11.92)
Others	2.10	0.71	(1.08, 4.06)
Friends ^a			

Note. ^aReferent Groups. ^bAge was entered quantitatively in units of 1 year. ^cThe population-averaged model with exchangeable correlation structure was adopted; Huber-White's sandwich estimator was used to obtain the standard errors.

HIV professional support group were excluded because the category registered a 0% regret incidence. Results indicated that all the estimated odds ratios were not statistically significant, with the exception of relationship to participant (see Table 2). The 95% confidence intervals for the true odds ratios, ϕ , included the null value *one* in the case of network member's age ($0.99 < \phi < 1.03$), gender ($0.57 < \phi < 1.88$), race ($0.77 < \phi < 3.71$), and mode of knowing ($0.84 < \phi < 3.14$). With regard to relationship to the participant, the *friends* category was used as the referent. The estimated odds of regret connected with an immediate family member or a coworker knowing are four times as large as the odds associated with a friend knowing ($1.77 < \phi < 9.20$, family; $1.20 < \phi < 12.33$, *coworker*). The odds that regret is felt when a casual partner knows are three times as large as that of a friend ($1.32 < \phi < 7.56$). The odds of experiencing regret when either a member of the extended family ($0.27 < \phi < 5.73$) or a committed sex partner ($0.43 < \phi < 4.16$) knows are not significantly different from that of a friend. Details are provided in Table 2.

DISCUSSION

Results suggest that although disclosure is regarded as an anxiety-provoking activity and negative reactions are typically anticipated, HIV disclosure appears to elicit very little regret to a wide variety of social network members. Furthermore, there were no differences in the occurrence of regret for either first or second hand disclosure. In both instances, regret was remarkably low. Explanations for these results are copious. First, it is possible that individuals only disclose to persons, including sexual partners, whom they expect a positive, or perhaps neutral, reaction. In this case, regret for disclosing would be improbable. Individuals may also respond more positively than anticipated, resulting in a similar outcome. It is also plausible that the benefits of disclosure emerge over time and eradicate any initial consequences experienced. That is, HIV-positive persons may experience the relief of harboring a burdensome secret to sexual partners or the development of stronger bonds with family or friends that

outweigh any initial negative reactions. It is also plausible that persons disclose to adjust to the diagnosis because the value placed on personal relationships eventually supersedes immediate negative reactions.

Negative reactions from sexual partners, particularly those which are casual encounters, may be experienced as fleeting or easily dismissed with the acquisition of another partner or encounter. Reactions from family, friends, and committed partners may, however, be experienced for extended periods of time. Unfavorable attitudes that do not change over time may leave HIV-positive MSM to reconcile those reactions. When this occurs, it is possible that regret is not experienced because these men extricate themselves from such relationships resulting in a negligible impact on regret.

Results indicated that the highest incidences of regret observed were associated with disclosure to a parent and regret to family was significantly more likely than to friends. This result should not be surprising given the differential emotional bonds and experiences shared among family versus friends. Although it might be tempting to conclude that individuals should be careful in disclosing to family, this result should be viewed in context. Out of 318 family members who knew, only 22 were associated with an experience of regret. Thus, although difference between groups of social network members might exist, the magnitude of this differential should be considered. In fact, these results should be encouraging for helping professionals who work with HIV-positive MSM. When faced with patients who are fearful of disclosing to family and friends, it is encouraging to know that the majority of those who have disclosed do not regret doing so. Thus, although disclosure is difficult, the long-term consequences appear to be positive.

There are a few limitations to be noted. First, data for this study come from a small, urban, midwestern sample. Incidence of regret may vary by geographical or rural location. In addition, because these men were primarily Caucasian, little can be concluded about the effects of race or ethnicity on experiences of regret. Studies utilizing larger, more representative samples that include women and significant minority populations are encouraged.

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