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BRIEF REPORT

Women's Report of Regret of HIV Disclosure to Family, Friends and Sex Partners

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Abstract The purpose of this study was to examine whether HIV-positive women experience regret as a consequence of disclosing their HIV serostatus. Participants for this study were 73 HIV-positive women involved in a longitudinal study of HIV disclosure. Results revealed that overall, participants experienced little regret. Fifty nine percent of women experienced no regret and 71% had regret percentages that were less than 10%. Results indicated that all estimated odds ratios were not statistically significant, with the exception of relationship satisfaction and relationship to participant.

Keywords HIV disclosure · Regret · Women

Introduction

Numerous studies have examined rates of HIV disclosure by infected women to family members (Armistead et al. 2001; Black and Miles 2002; Crosby et al. 2005; Murphy et al. 2001; Schrimshaw and Siegel 2002; Simoni et al. 1995; Sowell et al. 1997; Sowell et al. 2003). These studies have demonstrated that rates of disclosure by women to family and friends mirror those of men. That is, rates vary by family member and are typically lower than to sexual partners. In one study, rates of disclosure by women to friends (78%) surpassed all other family targets and female family members were more likely to be told than male family members (Simoni et al. 1995). In addition, nuclear family members were more likely to be informed than extended family. Similarly, Sowell and colleagues (1997) reported that 65% of their sample of women had disclosed to all parents, 51% to all siblings, 40% to all children and 17.5% to all other relatives. Reported rates of disclosure to children have ranged from 30% (Armistead et al. 2001) to 66% (Schrimshaw and Siegel 2002).

Theoretically, rewards of disclosing are multiple and can result in the acquisition of numerous resources. These resources may be emotional, physical, and social in nature. For example, emotional benefits might include the acquisition of social support, relief from sharing a burdensome secret, and the intrinsic reward of educating others about HIV or the risks of having sex (Siegal et al. 2005). Furthermore, disclosing one's serostatus eliminated hiding complicated adherence rituals from friends, family, and coworkers.

Costs for disclosing one's serostatus are potentially substantial. Sharing an HIV-positive diagnosis can provoke feelings of anxiety and threats to personal well-being and can result in fear of violence, ostracism, isolation, stigma, parental worrying, loss of respect, rejection, discrimination, and degradation (Beauregard and Solomon 2005; Coleman 1994; Gielen et al. 1995; Jenkins and Galindo 1995; Kimberly et al. 1995; Siegal et al. 2005). Costs in terms of stressors within the individual's family network include denial, anger, guilt, and uncertainty (Frierson et al. 1987; Herek and Glunt 1988). In addition, consequences can be confounded by fear or actual loss of societal benefits including employment, insurance, housing, and child custody (Anderson 1989; Herek and Glunt 1988; Zuckerman and Gordon 1988).

Regret is a negative, cognitively based emotion that is experienced when realizing or imagining that a present situation would have been better had a different decision

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been made (Zeelenberg 1999). Theoretically, the anticipation of and experience of regret is considered a cost in the decision making process (Janis and Mann 1977). Only two published research studies could be identified which address regret associated with HIV disclosure. In one qualitative study of HIV-positive women the majority (68%) did not regret disclosing to their young children, however, they did regret certain aspects of the disclosure event such as preparation, context, and outcomes (Murphy et al. 2003). Serovich and colleagues (2006) examined regret patterns of 76 HIV-positive men who have sex with men (MSM). Results indicated men experience very little regret. Compared with friends, the odds of experiencing regret were greater in the immediate family, with co-workers, and casual sex partners, but were not significantly different in the extended family or with committed sex partners.

The purpose of this study was to examine whether HIV-positive women experienced regret for having family, friends, or sexual partners know of their serostatus through either first or second hand disclosure. In addition, we were interested in investigating whether or not characteristics of social and sexual network members influenced the likelihood of experiencing regret. This is important because disclosure is a dyadic event and outcomes of disclosure are likely to be impacted by the relationship with or the characteristics of the person being told. Disclosing one's serostatus is a risky endeavor; thus it is important to understand the ramifications. Regret is one indicator of acceptability of risk or outcome associated with a risky action. Practically speaking, understanding the role of regret in disclosure of HIV serostatus can assist helping professionals working with individuals making disclosure decisions. Furthermore, in general few studies have focused on outcomes beyond reactions to disclosure, yet if interventions are going to be developed a better understanding of this outcome is imperative.

Methods

Participants

Participants for this investigation came from a larger 7-wave HIV disclosure study of 125 women. Participants were recruited primarily from an AIDS Clinical Trials Unit (ACTU) associated with a large university and AIDS Service Organizations (ASO's) throughout a Midwestern state. Recruitment began in October of 2001 and continued through March of 2004. At the clinics flyers were posted waiting rooms and attending physicians and medical staff approached potential participants and informed them about the study. ASO's included information about the study in newsletters and posted flyers in waiting rooms. Because of the diversity of recruitment strategies employed a refusal to participate rate could not be computed.

Regret was measured at wave seven therefore only women who completed the study could participate. Of the 125 women, six died during the study, six requested to be removed, 30 were lost to incarceration, relocation, hospitalization or drop out and an additional 10 did not complete the regret questions resulting in a final sample of 73 women available for this study. Participants were primarily African-American (74%) women between the ages of 18 and 63 ($M = 39.3$ SD = 9.3), who self-reported contracting HIV from unsafe sexual practices (89%). The majority reported being single (30%). At entry into the study, participants had been diagnosed from 1 month to 23 years ($M = 94$ months, SD = 57.5). These women were well-educated with 45% having some college education or a bachelor's degree and 3% having completed some graduate work. The average social support network included a median of 19 members. The largest network had 54 members, while the smallest had eight members. At the conclusion of the study, 81% of the network members knew of participants' serostatus, and 57% of these persons knew through first-hand disclosure.

Instruments

Women's social network information was collected using an adapted version of the Barrera's Arizona Social Support Interview Schedule (ASSIS; Barrera 1981). Participants were asked with whom they would discuss personal issues, receive advice, borrow money, socialize, garner positive feedback, request physical assistance, and experience negative interactions (i.e., argue). In addition, they were asked about sexual interactions within the past 6 months. From each interview a list of network members was constructed. Participants indicated the nature of the relationship to the network member and meeting date. The length of relationship was calculated by months and it represents duration between the date of first meet and the date of the interview. Relationship satisfaction for each network member was assessed on a five point, Likert-type scale (1 = *Very Satisfied*, 5 = *Very Dissatisfied*). Then, participants were asked if each individual, including their immediate family, knew of their HIV diagnosis and if they disclosed or someone else did. Regret was assessed with one dichotomous question "Do you regret that this person knows of your HIV status". Regret was then computed as the percentage of the number of members with affirmative regret, over the number of members who knew.

Results

Overall, 81% 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 women (59%) reported 0% regret and 71% had regret percentages that were less than 10%. That is, in a typical network of 26 members (with 21 who are aware of their HIV infection) participants reported not more than one occurrence of regret. Out of a total of 1,145 members who knew, there were only 99 (8.6%) cases of regret. The highest reported regret percentage was 87.5%.

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 neighbors, peripheral relations, extended family, and nuclear family. Peripheral relations refer to network members known through the family, partner, or friends such as the partner of a sister or the brother of a friend. Among all sex partners the percentage of regret was 9.0%. Percentages of regret instances were smallest among HIV professionals and support group members, friends and church members.

To examine possible relationships between the likelihood of regret and network member's characteristics, odds ratios were estimated via multiple logistic regressions for correlated data. Independent variables were the network member's age, gender, race (i.e., African-American, non-African-American), mode of knowing (i.e., first or second hand disclosure), satisfaction with network members, length of relationship, and relationship to participant. Results indicated that all estimated odds ratios were not statistically significant, with the exception of satisfaction with network members and relationship to participant (see Table 2). The 95% confidence intervals for the true odds ratios, θ, included the null value 1 reflecting significance in the case of network member's age, gender, race, mode of knowing, and length of relationship. One unit increase in satisfaction with family member (more satisfaction) was associated with a 0.43 decrease in odds ratio of regret of knowing. With regard to relationship to the participant, the HIV support professional category was used as the referent because this group had the lowest instances of regret. The estimated odds of regret connected with a person in the "others" group (i.e. peripheral relationships, neighbors) were three times larger as the odds associated with HIV support professionals knowing. The odds of experiencing regret when a family member, a friend, a sex partner, a supervisor or colleague, or a church member knows were not significantly different from that of HIV-professional support members.

Discussion

The purpose of this investigation was to better understand HIV-positive women's experiences of regret that others know of their serostatus. Results suggest that while a large

Table 1 Percentage of regret instances by relationship category

Category	*N*	Know (%)	Regret (%)	Category	*N*	Know (%)	Regret (%)
All Family	**620**	**79.2**	**11.6**	**All Friends**	**385**	**79.0**	**4.3**
All Nuclear	*453*	*79.7*	*11.4*	Acquaintance	10	60.0	16.7
Father	53	71.7	15.4	Friends	375	79.5	4.1
Mother	60	86.7	11.8	**All Sex Partners**	**111**	**91.9**	**9.0**
Brother	76	81.6	4.8	Married partner	17	88.2	6.7
Sister	106	90.6	16.7	Sex partner	57	96.5	3.7
Son	74	74.3	10.9	One Night Stand	2	0.0	0.0
Daughter	84	69.0	7.0	Past sex partner	35	91.4	19.4
All Extended	*167*	*77.8*	*12.4*	**All Support Prof.**	**184**	**98.9**	**4.0**
Extended Parents	5	40.0	0.0	**All Work**	**30**	**43.3**	**8.3**
Extended Child	14	78.6	9.1	Supervisor	11	27.3	0.0
Grandparents	10	100.0	30.0	Co-Worker	19	52.6	11.1
Grandchild	17	29.4	20.0	**All Church**	**27**	**80.8**	**4.8**
In-laws	40	77.5	20.0	**All Others**	**77**	**60.3**	**23.4**
Aunt/Uncle	23	91.3	9.5	Peripheral	53	60.4	25.0
Cousin	26	96.2	8.0	*All Residence*	*24*	*58.3*	*21.4*
Nephew/Niece	27	74.1	5.0	Neighbor	20	50.0	30.0
Other Family	5	100.0	0.0	Roommate	4	100.0	0.0

Table 2 Odds ratios for regret and network member characteristics

Variable	Odds ratio	SE	95% Confidence interval
Age	0.99	0.01	(0.97, 1.01)
Sex			
Female	1.56	0.27	(0.92, 2.64)
Male			
Race			
African-American	1.34	0.26	(0.81, 2.22)
Non-African-American			
Mode of Knowing			
First-hand Disclosure	0.82	0.25	(0.50, 1.33)
Second-hand			
Satisfaction	0.57	0.09	(0.47, 0.67)**
Length of Relationship	1.00	0.001	(0.99, 1.01)
Relation to Participant			
Nuclear Family	2.03	0.60	(0.62, 6.64)
Extended Family	2.58	0.55	(0.87, 7.65)
Friends	0.97	0.51	(0.35, 2.66)
Current Sex Partner	1.17	0.79	(0.25, 5.52)
Ex-Sex Partner	2.37	0.75	(0.55, 10.24)
Work	1.45	1.15	(0.15, 13.93)
Church	1.52	1.13	(0.16, 13.93)
Others	3.65	0.57	(1.19, 11.17)*
Professional Support			

Note:Variables in *italics* are the referent groups. Age was entered quantitatively in units of 1 year; length of relationship was entered quantitatively in units of 1 month; satisfaction was entered 5 point likert scale ranging from1 = *unsatisfied* to 5 = *satisfied*. The Population-Averaged Model with exchangeable correlation structure was adopted; Huber–White's sandwich estimator was used to obtain the standard errors, * $P \leq 0.05$; ** $P \leq 0.001$

percent of social network members were aware of these women's serostatus, the majority reported little regret. This suggests that though disclosure is distressing and anxiety-provoking, the experience is not particularly regretful.

The reasons for low rates of regret may be similar to those suggested by others (Serovich et al. 2006) and can fall into two categories: (a) the target of disclosure was accepting or eventually became accepting or (b) the reaction was negative but the woman adjusted and hence experiences no regret. That is, women may not be regretful because they received the support and services that they needed. These issues are compelling and warrant attention by future researchers.

Others have suggested that the relative importance of relationships may negate any undue discomfort of immediate negative outcomes of disclosure (Kimberly et al. 1995; Serovich et al. 2006). In accordance, satisfaction with the relationship with the network member and the network member's relationship with the participant were both significant predictors of regret. The more satisfied the women were with the relationship, the less likely regret was reported. Therefore, it is not surprising that regret is more likely to be experienced when peripheral relationships and neighbors know of one's serostatus. These people may be included in the network by circumstances, so an individual may perceive these relationships as less important than others in her network. It may not be as important for peripheral relationships or neighbors to be aware of a woman's serostatus. The odds of experiencing regret when a family member, friend, current or past sex partner, a supervisor or colleague, or a church member knows of one's serostatus are not significantly different from that of HIV-professional support members. Future researchers should explore why differential experiences in regret may occur and how regret is experienced by HIV-positive women. Strategies could then be developed to manage regret when it is experienced.

There were no significant differences in regret between first and second-hand disclosures. This suggests that having others assist with disclosure, in part or totally, may relieve a burden without adding unnecessary additional stressors. However, the participant with the highest experiences of regret (87.5%) had 18 members, of whom 16 knew her HIV status, but only 4 were reported as first-hand disclosures. Unfortunately, from the data available we cannot discern why regret was so high in this case. While it is tempting to speculate that regret may be closely associated with control over personal information the only indicator we have of this is whether the disclosure was first or second hand. For the overall sample mode of disclosure was not a significant predictor of regret. This finding suggests that more focused and potentially qualitative investigations are necessary.

The women in this study experienced more regret (8.6% of all network members) than a similar sample of MSM (4.2%) (Serovich et al. 2006). In addition, differences between these two samples emerged across all relationship categories for highest instances of regret. HIV-positive MSM experienced the highest instances of regret to mothers and fathers. For the men, odds ratio revealed that regret was 4 times more likely to be felt after disclosing to nuclear family than to friends.

Data for this study came from an urban, mid-western sample. Incidence of regret may vary by geographical or rural location. Furthermore, the element of time was not thoroughly investigated in this study, as the regret information was gathered at the end of the study. Therefore, as we previously suggested, there may have been time for the disclosure information to marinate among network members, and the women's emotional responses to any initial negative reactions may have lessened over time. Additional research is needed to examine regret over time and to explore whether subsequent disclosures are affected by previous experiences of regret.

The results from this study should be considered encouraging for both HIV-positive women and professionals who assist them with their disclosure decisions. Helping professionals can assist women who are fearful of disclosing by working with them to identify individuals in their social network who may be supportive. It is also encouraging for professionals to know that the majority of those who have disclosed do not regret doing so.

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