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Comparing regret of disclosing HIV versus sexual orientation information by MSM

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Abstract

Very little research has been conducted focusing on regret associated with disclosing either HIV-positive serostatus or sexual orientation information. The purpose of this study was to investigate the prevalence of regret related to the disclosure of serostatus and sexual orientation to family members among HIV-positive men who have sex with men (MSM) and to further explore the participant, family member, and relationship characteristics that influence the likelihood of experiencing regret. Almost half of participants indicated no regret with the disclosure of either HIV-positive serostatus or sexual orientation. Among those that did experience some regret, the prevalence of regret with at least one family member was similar for HIV-positive serostatus (39.4%) and for sexual orientation (37.3%). Suggestions for professionals working with HIV-positive MSM and implications for future research are presented.

Keywords

Disclosure; HIV/AIDS; Regret; Serostatus; Sexual Orientation

Introduction

HIV-positive men who have sex with men (MSM) are often affected by multiple minority status and the relevant stigmas associated with HIV status, sexual orientation, race and class. Whereas race and class membership are typically assumed, revealing one's HIV-positive status and sexual orientation to others is often a complex and difficult process. Disclosure of this highly personal information is often regarded as an anxiety provoking activity where negative reactions from others are anticipated. The burdens of dealing with multiple minority stigmas may be alleviated if one is able to receive additional support from family and friends. However, receiving such assistance requires disclosure.

There are numerous rewards and costs of disclosing potentially stigmatizing personal information. The rewards include the acquisition of emotional, social, and instrumental support. Furthermore, disclosing one's HIV-positive serostatus eliminates the need to hide

complicated adherence rituals from friends, family, and co-workers (Klitzman et al., 2004). The costs for disclosing are equally substantial. Sharing an HIV-positive diagnosis or a non-heterosexual orientation can provoke feelings of anxiety and threats to personal well-being stemming from violence, ostracism, isolation, stigma, parental worrying, loss of respect, rejection, discrimination, and degradation (D'Augelli, Hershberger & Pilkington, 1998; Hereck, Capitanio, & Widaman, 2002; Serovich, 2000).

Another potential outcome of disclosing sensitive information is the experience of regret. Regret is a negative, cognitively-based emotion which occurs when realizing or imagining that a present situation would have been better had a different decision been made (Zeelenberg, 1999). Conceptually, the anticipation of and/or the experience of regret are also considered to be perceived costs in the decision-making process (Janis & Mann, 1977). Very little research has been conducted which focuses on regret of disclosing either serostatus or sexual orientation. In fact, a search of the literature found no published empirical research investigating regret of disclosing one's sexual orientation to family.

Three published research studies were identified which address regret of HIV-positive serostatus disclosure. In one qualitative study of disclosure to young children, a majority (68%) of women did not regret disclosing. They did, however, regret certain aspects of the disclosure event such as preparation, context, and outcomes (Murphy, Roberts, & Hoffman, 2003). In a quantitative study of serostatus disclosure to social support networks including family members, friends, and sexual partners, Serovich, McDowell, and Gafsky (2008) also found relatively low prevalence of serostatus disclosure regret. Among the 73 HIV-positive women in the sample, 59% of participants experienced no regret, and 71% reported regret with less than 10% of their support network members. The highest percentages of regret were observed in neighbors, peripheral relations such as neighbors or a friend of a friend. Serovich and colleagues (2006) also examined the prevalence of regret in a sample of 76 HIV-positive men who have sex with men (MSM). Results indicated men also experienced very little regret. In fact, 63% reported no regret, and 75% of the remaining men had rates that were less than 7%. The highest percentages of serostatus disclosure regret were observed in disclosing to fathers and mothers. However, the authors noted that, "Out of 318 family members who knew, only 22 were associated with an experience of regret" (p. 137).

The purpose of this study was three-fold; the first objective was to describe the prevalence of serostatus disclosure regret among HIV-positive MSM in connection with disclosure to family and the associations of selected participant, family member, and relationship characteristics with the likelihood of regret. Secondly, the study seeks to extend this exploration to sexual orientation disclosure regret. Finally, the similarities and differences between the two phenomena are discussed.

Methods

Recruitment and Participants

Participants in this study came from a larger study of HIV-positive MSM disclosure to family and were recruited in two ways. First, advertising was conducted at local AIDS service organizations. Caseworkers were informed of the study and provided information about the project which they could distribute via flyers or through newsletters. Second, recruitment materials were made available at HIV-related venues and forums (e.g., AIDS Walk, gay pride festivities) held in the community. Recruitment efforts resulted in recruitment of 59 HIV-positive, adult MSM from a large Midwestern city. For this study, men who exclusively had sex with women, could not speak and understand English, and those under the age of 18 were excluded.

Participants were primarily white (61%), single (66.1%), men between the ages of 21 and 62 ($M = 43$ years, $SD = 8.9$). A majority (84.7%) identified their sexuality as gay, and 78% reported having sex only with men. At entry into the study, participants had been diagnosed with HIV for periods ranging from 13 months to 22.4 years ($M = 112.1$ months, $SD = 83.6$). With respect to monthly income, 20 men (33.9%) reported earning from \$0 to \$500, 18 men (30.5%) reported earning from \$501 to \$1000, 19 men (32.3%) reported earning over \$1000 per month, and 2 participants did not respond.

Procedures and Instrumentation

Participants completed an initial interview and questionnaire at the beginning of the study and were interviewed about their social networks by trained research associates in a private research office. Social network information was collected using an adapted version of the Barrera's Arizona Social Support Interview Schedule (Barrera, 1981). 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).

From each structured interview a list of family network members was constructed. Demographic data (i.e., age, sex) for each family member, the length of relationship, and the participant's satisfaction with each relationship was obtained by the interviewer. Then, participants were asked if each family member knew of their serostatus and sexual orientation (yes/no). If a family member knew, the participant was asked the mode of disclosure in each case, and whether or not they regretted (yes/no) this person knowing. When distinguishing between modes of knowing, 'first-hand' disclosure is defined as participants telling others themselves while 'second-hand' disclosure is defined as a third party disclosing the participants' HIV-positive serostatus with or without the participants' consent. The prevalence of regret was then computed as the percentage of the number of members with affirmative regret, over the number of members who knew.

Results

The men in this sample ($n = 59$) reported a total of 430 relationships with family members. Members of the participants' nuclear families including fathers, mothers, siblings, and children, accounted for over 60% of relationships ($n = 264$). Extended family members including grandparents, grandchildren, in-laws, aunts, uncles, nephews, and nieces comprised the remainder ($n = 166$).

Prevalence of regret among participants

In this sample, almost half of participants ($n = 28$; 49.2%) expressed no regret with any family members who were aware of either their HIV-positive serostatus or sexual orientation. For those participants who did express some regret, Table 1 provides a summary of the regret prevalence. The numbers of participants expressing regret associated with serostatus ($n = 23$, 39.4%) and sexual orientation ($n = 22$, 37.3%) with at least one family member were similar. Fewer than 10% of participants expressed HIV-positive serostatus regret ($n = 5$, 8.9%) or sexual orientation regret ($n = 4$, 6.8%) with 50% or more of their family members. Generally, the instances and percentages of regret for both types of regret were similar across all prevalence categories (i.e. fewer than 20% of family member, 20% – 50%, 50% or more). However, only 14 (23.9%) participants reported regret related to both serostatus and sexual orientation and 17 (28.8%) reported only serostatus or sexual orientation regret.

In Table 2, regret is examined based on selected participant characteristics. Generally, regret related to HIV-positive serostatus was more prevalent than regret related to knowledge of

sexual orientation. Of those family members who knew the participants' serostatus ($n = 209$), regret was associated with 21.5% ($n = 45$). Of the 348 family members who knew the participants' sexual orientation, regret was associated with only 11.8% ($n = 41$). The greatest proportions of serostatus regret were observed among participants who were single, those who identified as bisexual, and those who reported having sex with both men and women. With respect to sexual orientation, participants who were divorced, those who identified as bisexual, and those who reported having sex with both men and women were most likely to express regret.

Prevalence of regret among family networks

Table 3 provides results of both HIV-positive serostatus regret and regret related to sexual orientation, summarized by relationship type (i.e. father) and family member ethnicity. Results were then aggregated based on membership in the participants' nuclear or extended families. Among nuclear family members, 48.9% ($n = 129$) were aware of the participants' serostatus, and 78.4% ($n = 207$) were aware of his sexual orientation. Considering only those who were aware, serostatus regret was more prevalent (22.5%, $n = 29$) than sexual orientation regret (14%, $n = 29$). Results were similar for extended family members. Specific family members most likely to be associated with regret included fathers and grandparents. Caucasian family members were more likely to know the participants' serostatus ($n = 147$, 53.8%) and sexual orientation ($n = 241$, 88.3%) than those who were identified as African-American. Regret related to both serostatus and sexual orientation was also more common among Caucasian family members.

Odds of regret

Table 4 provides results of a multilevel logistic regression of regret on selected participant, family member, and relationship characteristics conducted in STATA/SE 9.0 (StataCorp., 2007). Analyses for HIV-positive serostatus regret included 46 participants and 187 relationships. The first model applied to the data included only those predictors related to the family member (i.e. age at time of disclosure, ethnicity) and participant (i.e. age at time of disclosure, income level). The likelihood ratio R^2 (Hosmer & Lemeshow, 1989) of this model was 0.453, indicating that the inclusion of the family member and participant variables resulted in proportional reduction in error of 45.3% ($\chi^2 = 130.7$, $df = 5$, $p < .05$). The inclusion of the 'mode of knowing' (e.g. first-hand or second-hand) and relationship satisfaction resulted in significant additional 29.2% reduction ($\chi^2 = 46$, $df = 2$, $p < .05$). While the odds ratios for the family member and participant variables were not significant, results suggested an important relationship between serostatus regret and 'mode of knowing'. Among the 209 family members who were aware of the participants' serostatus, first-hand disclosure by the participant accounted for a greater percentage of the sample ($n = 131$, 62.7%), yet these relationships were associated with less serostatus disclosure regret ($n = 22$, 16.8%) than those involving second-hand disclosure ($n = 23$, 29.5%). The odds of serostatus regret ($OR = 0.296$, $p < .05$) with first-hand disclosure were approximately one-third of the odds of regret with second-hand disclosure. Finally, participants were much less likely to regret knowledge of serostatus in satisfying relationships ($OR = 0.354$, $p < .001$).

Random-effects logistic regression was again employed to explore the relationships between selected participant, family member, and relationship characteristics and sexual orientation disclosure regret. Analyses for sexual orientation regret included 59 participants and 428 relationships. The model for sexual orientation was generated through the simultaneous entry of all of the variables of interest including select family member characteristics (i.e. gender, ethnicity), participant characteristics (i.e. income), and relationship satisfaction. However, age at time of sexual orientation disclosure and mode of knowing were not available for analysis. Application of the model resulted in a 10.4% ($\chi^2 = 28.1$, $df = 4$, $p < .05$) reduction in error.

Both gender and relationship satisfaction were significantly associated with sexual orientation disclosure regret. The odds of regret in family relationships with females ($OR = 0.596, p < .05$) were about 60% the odds of regret with male family members. As satisfaction with the relationship increased, the probability of regret decreased ($OR = 0.618, p < .05$).

Discussion

Results indicate that approximately half of the sample of HIV-positive MSM experienced no regret that their family members were aware of their serostatus or sexual orientation. This finding suggests that regardless of the potentially stressful decision to disclose and the initial reactions experienced, men are often satisfied with their decision to disclose their HIV-positive serostatus and their sexual orientation to their family members. Of those who experienced regret, few reported instances with more than half of their family members.

More family network members were aware of the participant's sexual orientation than their HIV-positive serostatus and a much smaller proportion of those family members were associated with regret. However the pattern of regret across relationship types was almost identical for both HIV-positive serostatus knowledge and knowledge of sexual orientation. That is, among nuclear family members, mothers and fathers were most likely to know about participant HIV-positive serostatus and sexual orientation, and fathers were the most likely to be associated with regret.

It is unclear why particular types of relationships tend to elicit higher reports of regret. Men may regret disclosure with some family members more than others because of perceived differences in their abilities to cope with the emotional burden that knowledge of a positive serostatus may place on them. Alternatively, participants may fear negative reactions such as blame, abandonment, or denial of support from some family members and not others. Such contrasting explanations may have important implications for the health and emotional well-being of HIV-positive MSM and their families and should be explored further.

It was anticipated that characteristics of participants, family members, and relationships (e.g. mode of knowing, relationship satisfaction) could influence the likelihood of experiencing regret. Participant characteristics were not significantly associated with either HIV-positive serostatus or sexual orientation. Family network member and relationship characteristics were differentially significant for HIV-positive serostatus regret and sexual orientation regret.

HIV-positive serostatus regret

The mode of knowing and satisfaction with the relationship were the only significant predictors of HIV-positive serostatus regret. This finding is in contrast with previous disclosure research involving HIV-positive MSM and women. Prior studies (Serovich et al., 2006; Serovich et al., 2008) found that whether or not disclosure occurred first- or second-hand was not significantly related to regret which may be a result of small samples sizes. Given that mode of knowing was a significant predictor of experiencing HIV-positive serostatus regret, regret may be more closely related to how the disclosure is handled or who discloses rather than the decision to disclose or the resulting reactions. In cases where HIV-positive MSM decide not to disclose, or to delay disclosure, to some family members as a way of minimizing or avoiding regret, they may also increase the likelihood of disclosure by others without their explicit consent, and thus, unintentionally increase the likelihood that they will regret the disclosure.

Participant's reported satisfaction with their family relationships was also associated with HIV-positive serostatus regret. Unfortunately, due to the nature of data collection in the study, it is not possible to determine whether participants' dissatisfaction with the relationship preceded, or resulted from, disclosure and regret. That is, the participants' satisfaction with the

relationship may result from a positive disclosure experience that is not associated with regret. Alternatively, participants may be more likely to experience disclosure as a positive experience in relationships that are more satisfying. Though data limitations prohibit the untangling of these relationships in the current study, their significance in predicting regret suggests a fertile area of investigation for future researchers.

Sexual orientation regret

Both gender and relationship satisfaction were significantly associated with sexual orientation regret. The odds of regret in family relationships with females were about 60% of the odds of regret with male family members. There are a number of plausible explanations for this finding. First, research has shown that men are likely to hold more negative views of persons with a homosexual orientation than women (Kite & Whitely, 1996). As such, disclosure to male family members may result in more negative reaction and consequences which engender regret or deterioration in the relationship. Second, if we assume that second-hand disclosure is a significant predictor of regret in sexual orientation disclosure, it is plausible that male family members were more likely told by someone other than the participant. It was also found that as satisfaction with the relationship increased, the probability of regret decreased. As disclosure of HIV-positive serostatus, it was not possible to determine the temporal or causal nature of the associations between relationship satisfaction, disclosure of sexual orientation, and regret.

Compared to previous research on regret with HIV-positive MSM (Serovich et al., 2006), the percentage of men who experienced no HIV-positive serostatus regret in this study was similar; however overall experience of regret was higher in this sample. That is, when men in the current study reported experiencing regret of disclosing their HIV-positive serostatus to family, they were also more likely than men in the previous study to report experiencing regret with other family members. One plausible explanation for this result is that the men in this study were recruited to participate in an intervention to learn about and gain skills for disclosing to family. Therefore, it is plausible that these men perceived that they would have difficulty disclosing to family or have had difficult experiences disclosing in the past which impacted their report of experiencing regret. To the best of our knowledge this is the first empirical investigation of regret associated with disclosure of sexual orientation. Therefore, we are unable to compare the results of this study to prior research.

Limitations—The interpretation of results from this study should be undertaken with caution due to the presence of a number of limitations. First, disclosure of sensitive information such as HIV-positive serostatus or sexual orientation is a complex phenomenon. Therefore, numerous factors such as timing and the environment in which disclosure occurs could affect outcomes that in turn result in the presence of regret. This study did not account for these variables which limits the interpretability of the results. Second, information for the study was obtained from the results of a larger longitudinal study of HIV disclosure. As a result, our analysis of regret associated with disclosure of serostatus and sexual orientation was limited to the data obtained from that study. Therefore we were unable to explore many possible causes of experienced regret. The analysis of sexual orientation disclosure was particularly affected, as data on the ‘mode of disclosure’ and the age of both participant and family member at disclosure were not known. Third, given that the sample for the study was not selected at random, the results of this analysis may not be generalizable to the larger population of persons living with HIV. Fourth, while the number of family members was relatively large, the size of many of the relationship-based groups (i.e. sons, grandparents,) was small. These small samples limited the ability to analyze group-based differences. This issue, along potential model specification problems and potential associations among modeled predictors, suggests that the results of the logistic regression should be interpreted with caution.

Implications—There are several implications from this study. The significance association of second-hand disclosure and increased HIV-positive serostatus regret highlights the need for disclosure interventions to teach skills for disclosure and emphasizes that helping professionals should work with HIV-positive MSM to discuss disclosure and to encourage these men to take control of their personal health information. Men should be counseled that while second-hand disclosures are highly probable, individuals have the right to request that informed family not disclose to others without their permission. Health information, even within families, should be deemed private though not completely concealable. Future researchers should consider assessing the mode of knowing and time-to-disclosure for assessing sexual orientation regret in order to provide further insight into the dynamics of sexual orientation disclosure and regret, particularly given the discrepancy between the significance of mode of knowing from this sample in comparison with previous research.

Finally, given that relationship satisfaction was a significant predictor of regret for both HIV-positive serostatus and sexual orientation, further exploration of the disclosure decision-making process and the experience of regret both immediately after disclosure and in the long term is desirable. Given the contextual complexity associated with disclosure in interpersonal relationships, improvements to the measurement of characteristics at the participant, family member, and dyadic level, as well as their temporal effects, must be undertaken. It is important for researchers to understand disclosure as a dyadic event and outcomes of disclosure are likely to be impacted by the relationship with or the characteristics of the person being told. Professionals who work with HIV-positive MSM should consider this complexity when assisting persons with their disclosure decisions.

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Table 1

Instances of HIV-positive serostatus and sexual orientation regret by participant, with participant as unit of analysis

Regret Prevalence Category	No. of Men	HIV-positive Serostatus Regret		Sexual Orientation Regret		
		% of All Men (n=59)	% of Men with HIV Regret (n=23)	No. of Men	% of All Men (n=59)	% of Men with SO Regret (n=22)
At least one family member	23	39.4%	100.0%	22	37.3%	100.0%
Fewer than 20% of family members	10	16.9%	43.5%	8	13.6%	36.4%
20% – 50% of family members	8	13.6%	34.8%	10	16.9%	45.5%
50% or more of family members	5	8.9%	21.7%	4	6.8%	18.2%

Table 3
Prevalence of HIV/SO regret by selected family member characteristics, unit of analysis is family member

	No. of Family Members	HIV Regret				SO Regret			
		Number Who Know HIV	% Who Know HIV	Number Regret Knowing HIV	% Regret Knowing (of those who know)	Number Who Know SO	% Who Know SO	Number Regret Knowing SO	% Regret Knowing (of those who know)
All Family	430	209	48.6%	45	21.5%	348	80.9%	41	11.8%
All Nuclear Family	264	129	48.9%	29	22.5%	207	78.4%	29	14.0%
<i>Father</i>	39	22	56.4%	9	40.9%	35	89.7%	10	28.6%
<i>Mother</i>	47	33	70.2%	7	21.2%	42	89.4%	9	21.4%
<i>Brother</i>	85	32	37.6%	7	21.9%	57	67.1%	9	15.8%
<i>Sister</i>	77	34	44.2%	6	17.6%	61	79.2%	0	--
<i>Son</i>	9	3	33.3%	0	--	6	66.7%	0	--
<i>Daughter</i>	7	5	71.4%	0	--	6	85.7%	1	16.7%
All Extended Family	166	80	48.2%	16	20.0%	141	84.9%	12	8.5%
<i>Grandparents</i>	11	6	54.5%	2	33.3%	10	90.9%	3	30.0%
<i>Grandchildren</i>	3	0	--	0	--	0	--	0	--
<i>In-laws</i>	12	7	58.3%	2	28.6%	10	83.3%	1	10.0%
<i>Aunt/Uncle</i>	65	24	36.9%	4	16.7%	53	81.5%	4	7.5%
<i>Cousin</i>	47	21	44.7%	5	23.8%	43	91.5%	2	4.7%
<i>Nephew/Niece</i>	18	15	83.3%	2	13.3%	16	88.9%	1	6.3%
<i>Other Family</i>	10	7	70.0%	1	14.3%	9	90.0%	1	11.1%
All Ethnicities	430	209	48.6%	45	21.5%	348	80.9%	41	11.8%
Non-minority									
<i>Caucasian</i>	273	147	53.8%	36	24.5%	241	88.3%	31	12.9%
Minority									
<i>African-American</i>	142	61	43.0%	9	14.8%	95	66.9%	8	8.4%
<i>Hispanic</i>	2	1	50.0%	0	--	2	100.0%	0	--
<i>Other</i>	13	0	--	0	--	10	76.9%	2	20.0%

Table 4

Odds ratios for HIV and SO regret by select network member, participant, and relationship characteristics

	HIV Regret			SO Regret		
	Odds Ratio	SE	95% CI	Odds Ratio	SE	95% CI
Network Member Characteristics						
Age at Disclosure	1.040	0.015	(1.008, 1.073)	--	--	--
Gender						
Female	0.626	0.257	(0.280, 1.401)	0.596**	0.156	(0.356, 0.997)
Male						
Ethnicity						
Minority	1.263	0.883	(0.320, 4.970)	0.444	0.246	(0.150, 1.315)
Non-minority						
Participant Characteristics						
Age at Disclosure	0.955	0.030	(0.899, 1.015)	--	--	--
Income	1.374	0.391	(0.798, 2.366)	0.809	0.104	(0.629, 1.041)
Relationship Characteristics						
Mode of Knowing						
First-hand Disclosure	0.296**	0.139	(0.118, 0.745)	--	--	--
Other						
Satisfaction	0.354***	0.074	(0.235, 0.533)	0.618**	0.109	(0.438, 0.873)

Note: The population-averaged model was adopted, with Huber-White's sandwich estimator used to obtain standard error estimates. Variables in *italics* are the referent groups. Age was entered quantitatively in units of 1 year; satisfaction was entered using a 5-point Likert scale ranging from 1=*very satisfied* to 5=*very unsatisfied*. Significance

p<0.001,

**
p<0.05