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Disclosure of Positive HIV Serostatus by Men Who Have Sex with Men to Family and Friends Over Time

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ABSTRACT

The purpose of this study was to examine retrospective reports of rates of HIV disclosure to family and friends over a 15-year time span. Participants included 116 HIV-positive men who have sex with men recruited primarily from an AIDS clinical trials unit associated with a large Midwestern university. Disclosure data were collected on all family members and friends. Results indicated that friends were disclosed to more often than family, but that at any point in time after diagnosis the relative risk of being disclosed to was not statistically significant. Furthermore, neither gender of the family member or friend, race, age at the time of disclosure, level of current satisfaction, nor age of the participant at the time of disclosure significantly influenced disclosure rates over time.

INTRODUCTION

RESEARCHERS HAVE consistently demonstrated that friends receive HIV diagnosis information from gay and bisexual men more frequently and at greater rates than family members.[1–5] This trend does not appear to vary by friend characteristics such as gender,[6] sexual orientation,[5,7] or characteristic of the discloser such as ethnic affiliation,[8,9] HIV status,[10] or symptomatology.[2]

While evidence for preferential friend disclosure is compelling, this body of literature suffers from numerous methodological challenges. First, most investigations have been cross-sectional estimates of percentages of family and friends knowing of the diagnosis at any given point in time.[1,2,6,8,9] Point prevalence studies are important as they provide a quick overview of disclosure patterns at discrete time intervals. Such studies, however, are limited because results would likely vary by how long participants had been diagnosed and in what year the study was conducted. For example, it is plausible that studies conducted in the late 1980s would produce different results from those in the late 1990s because of changes in medical treatment and overall public sentiment toward those with HIV. Furthermore, because individuals are living longer with HIV it could be assumed that studies conducted more recently included persons who have been diagnosed longer and thus have more opportunities for disclosure. Finally, because traditional family and friendship networks naturally evolve and grow in dissimilar ways, point prevalence studies can not capture these fluctuations. An investigation over time, whether retrospective or prospective, offers a more compelling and powerful understanding of how disclosure occurs to family and friends.

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Beyond point prevalence studies, the second most commonly used approach to studying disclosure are designed to follow newly diagnosed men for proscribed time periods such as 3 months,[3] 6 months,[10] or 12 months[5] and assess to whom participants had disclosed during these discrete time periods. These studies provided essential data as to who was disclosed to immediately postdiagnosis but their limited time perspective does not provide an understanding of disclosure over the life course.

Third, many studies[2,6,8,9,11] have utilized structured or closed interviews to evaluate disclosure. These methods asked participants to indicate if they had disclosed to specific targets (i.e., mother, father, sister, brother, current sexual partner, and friend). Disclosure measured in this manner provided data that indicated the rates of disclosure were higher for friends than family members. For example, Mason and colleagues[8] studied 398 men and found that 75% of friends were disclosed to while only 39% of mothers, 22% of fathers, 37% sisters, and 36% of brothers. Similar results were reported in another study[6] of 101 men, where 58% of male friends and 43% of female friends were disclosed to while only 24% of mothers, 8% of fathers, 31% of brothers, and 34% of sisters were told of an HIV diagnosis. Comparing friend and family disclosure by these means, however, may be unduly influenced by the obvious fact that participant's were allowed to select the friend of their choice to be included in the social network. Kalichman and colleagues[1] commented that these methods introduced a selection bias whereby participants self-selected a subset of friends, yet family is proscribed and thus not amenable to selection.

At least one exception to these approaches was an investigation conducted by Petrak and colleagues.[4] For this study participants were requested to name the 10 most significant people in their lives and identify which individuals knew of their HIV diagnosis. From these data, rates of disclosure were calculated and it was demonstrated that disclosure rates to family and friends increased over the first 4 years and then leveled off. The primary difficulty was the limited scope of the network assessed and the fact that this network consisted of the "most significant" persons deemed by the respondent and not the wider social network. Thus, conclusions drawn are only somewhat informative. One attempt to rectify this bias was reported by Kalichman et al.[1] in an investigation of men ($n = 233$) and women ($n = 98$). Using an open interview process, these researchers asked participants to make an extensive list of people in their lives. Using this methodology, rates of disclosure to family and friends more closely resembled one another. In fact, participants reported disclosing to 86% of friends, 79% of mothers, 65% of fathers, 78% of sisters, and 68% of brothers.

In a previous investigation[12] we demonstrated that over time mothers are the family member to be told in greatest proportion, yet the rate at which family members are told at all time points generally does not significantly differ from each other when accounting for characteristics of participants and family members. The purpose of this study is to provide a robust, retrospective comparison of rates of men's HIV disclosure to family and friends over a 15-year time span. Of particular interest is to statistically investigate possible influences of social network and participant characteristics on rates of disclosure.

MATERIALS AND METHODS

Participants

Participants for this study were 139 HIV-positive gay men recruited primarily from an AIDS Clinical Trials Unit (ACTU) associated with a large Midwestern university. Recruitment began in February 1998 and continued through July 2000. Attending physicians and medical staff approached potential participants and informed them about the study. 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. Each participant provided written consent prior to enrollment into the study. HIV status was confirmed through medical records received from each participant's physician. Human subjects' approval was granted by the University's Institutional Review Board.

For the current study, 23 participants did not mention at least one immediate family member or friend and were excluded from the analyses. The resulting sample of 116 participants were primarily single (i.e., not partnered; 70%), Caucasian (70%) men between the ages of 21 and 53 (M = 37 years, standard deviation [SD] = 7), who contracted HIV from unsafe sexual practices (83%). At entry, participants had been diagnosed with HIV ranging from 1 month to 16 years (M = 86 months, SD = 54). These men were well educated with 57% having some college education or a bachelor's degree and 25% having completed some graduate work. More than 60% of the participants were employed, earning an average income of $20,000 ($R$ = $0–$90,000).

Data collection

Participants were involved in a larger, 3-year longitudinal study of HIV disclosure. For a full discussion of the data collection procedures please refer to a previously published study.[12] Participants were interviewed by trained doctoral students about their social network using an adaptation of Barrera's Arizona Social Support Interview Schedule (ASSIS).[13] Participants were asked to 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 (those individuals mentioned during the four ASSIS interviews) was constructed. Demographic information (i.e., age, gender, and ethnicity) of each network member, 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 and friends, knew of their diagnosis. If a particular person did have knowledge of the diagnosis, they were probed to identify the discloser. If the participant was unsure if the network member knew, this was noted and if the network member did not know of the diagnosis, it was recorded as a nondisclosure. Ages at the time of disclosure for both the participant and their network member were calculated at the time of each disclosure.

Dependent measure

The dependent variable of interest is the event of disclosure by an individual with HIV of his serostatus to immediate family members and friends. Time to disclosure for each family member or friend known prior to HIV infection is measured in months from the date of HIV infection to the date of disclosure of HIV serostatus. For friends met after HIV infection, time to disclosure is measured in months from the date they met the individual to the date of disclosure of HIV serostatus. Survival analysis provides an estimate of the proportion of the sample that would have been disclosed to at various times. Family members and friends who have not been told of the participant's HIV status were treated as "censored" data. Censored data, however, are not considered missing data. Rather, labeling them censored takes into account that although the participant did not disclose their serostatus to a family member or friend, there is the potential that they could disclose this information to this individual in the future.

Independent variables

Family and friends. The 116 participants mentioned a total of 896 friends. Of these, only 23 were classified as "acquaintances" and 15 were classified as "best friends" resulting in insufficient numbers to run analyses separately by such categorizations. Thus, for this study friends were selected using two methods. In one case, two friends were randomly selected ("random"). In the second case, two friends the participant had known the longest were selected though limited to friends the participant had known for longer than 2 years ("longest"). In the case where a participant had only one immediate family or friend, the participant was limited to one of each. To minimize violations of independence, the 116 participants were limited to only 2 randomly selected immediate family, 2 randomly selected friends, and 2 friends whom they had known the longest and

for more than 2 years. Of the 116 participants, time to disclosure was obtained for 204 family members, 204 "random" friends, and 197 "longest" friends.

Family members included 62 mothers or stepmothers, 37 fathers or stepfathers, 61 sisters and 44 brothers. Family members were primarily Caucasian (75%) and ranged in age from 20 to 92 (M = 50 years, SD = 16). "Random" friends were primarily male (63.7%), Caucasian (74.5%), and ranged in age from 20 to 65 (M = 39 years, SD = 10). The length of time they knew the participant ranged from 1.5 months to 46 years (M = 10 years, SD = 9). "Longest" friends were primarily male (66.5%), Caucasian (75.6%), and ranged in age from 21 to 70 (M = 39.3 years, SD = 8.8). The length of time they knew the participant ranged from 2.5 to 46 years (M = 14.1 years, SD = 9.1). Relationship duration between the "random" and "longest" friends was significantly different [$t(382) = 4.46$, $p < 0.001$].

The focus of the present study is on direct disclosure of HIV status to immediate family and friends. Immediate family and friends were excluded from the analyses if they had been informed of the participant's serostatus by someone other than the participant, or if a valid date of disclosure was unavailable or unreliable. Family members identified as deceased prior to the participant's diagnosis with HIV were excluded.

Network characteristics. Demographic information provided in the structured interview was included in the model. The gender, race and age of the family member or friend at the time of disclosure and their level of current satisfaction with the relationship using a 1–5 Likert-type rating scale ranging from "very satisfied" (1) to "very dissatisfied" (5) were variables entered in this analysis. The age of the participant at the time of disclosure was also entered in the analysis.

Statistical analysis

All analyses were conducted using STATA® version 8.0.[14] Kaplan-Meier–type cumulative disclosure curves stratified by family member or friend are estimated and the log rank test used to test the equality of the disclosure curves. A multivariable Cox proportional hazard regression model was used to estimate the hazard ratios and standard errors. STATA uses a shared frailty approach that is a semiparametric random effects model that can account for within group correlation. The distribution of the baseline hazard function is not specified while the frailties or random effects are gamma distributed with a mean of one and a variance of Q that is estimated from the data and is testable. If the null hypothesis (Q = 0) is rejected then the correlation is considered significant and cannot be ignored. Thus, the nonindependence of one participant providing information regarding several family members or friends is controlled for in the statistical analysis. In this study, the frailty is the participant's degree of willingness to disclose to family members or friends. Relating to the current data, the nonindependence of one participant providing information regarding up to 4 family or friends is controlled for in the statistical analysis and computation of hazard ratios and standard errors.

RESULTS

Kaplan-Meier survival curves

In order to investigate the trajectory of HIV serostatus disclosure to specific immediate network members over time, data were analyzed separately by family member, "random" friend and "longest" friend using Kaplan-Meier survival curves. The cumulative disclosure proportions and mean time to disclosure for each type of network member are presented in Table 1. According to this analysis, it would be expected that 50% of immediate family members would be disclosed to within 10 months. In the same time period, it would be expected that approximately 49% of "longest" friends and 56% of "random" friends would be disclosed to regarding HIV status. A graphic representation of cumulative survival curve for family, "longest" friends and "random" friends is shown in Figure 1.

Cox proportional hazard regression

In order to investigate the influence of network role in the prediction of HIV disclosure

Table 1. Survival Analysis of Disclosure to Network Members

	Cumulative disclosure proportion (i.e., percent expected to be told)		
Time since HIV diagnosis	*Family*	*"Longest" friends*	*"Random" friends*
1 month	0.38	0.34	0.42
2	0.41	0.37	0.44
3	0.42	0.39	0.47
4	0.44	0.42	0.50
5	0.45	0.43	0.51
6 months	0.46	0.45	0.52
7	0.48	0.46	0.52
8	0.48	0.47	0.52
9	0.49	0.49	0.54
10	0.50	0.49	0.56
11	0.50	0.50	0.57
12 months–1 year	0.50	0.52	0.58
24 months–2 years	0.56	0.61	0.67
36 months–3 years	0.60	0.67	0.72
48 months–4 years	0.66	0.72	0.75
60 months–5 years	0.69	0.78	0.78
72 months–6 years	0.71	0.80	0.80
84 months–7 years	0.73	0.81	0.81
96 months–8 years	0.73	0.84	0.82
108 months–9 years	0.76	0.85	0.82
120 months–10 years	0.76	0.86	0.82
132 months–11 years	0.77	0.86	0.83
144 months–12 years	0.78	0.86	0.83
156 months–13 years	0.78	0.86	0.83
168 months–14 years	0.78	0.87	0.83
Mean (median) time to disclosure (months)	54.36 (12)	41.64 (5)	41.46 (11.5)
Total told/total censored (% told)	159/45 (77.94%)	170/34 (83.33%)	172/25 (87.31%)

over time, data were analyzed using Cox proportional hazard regression. This analysis provided estimates of the hazard rate (relative risk) without having to specify a baseline hazard. To determine if the proportion hazard assumption was violated, a test of the nonzero slope in a generalized regression of the scaled Schoenfeld residuals on functions of time was analyzed. The null hypothesis of zero slope, and violation of the proportion hazard assumption, was tested for family. Global tests for "random" friends χ^2 (1) = 0.19, $p > 0.05$] failed to violate the proportion hazard assumption. The null hypothesis was not rejected and the proportion hazard assumption was not violated. Results from family compared to "random" friends are presented below. Global tests for "longest" friends χ^2 (1) = 5.49, $p < 0.05$] violated the proportion hazard assumption. The null hypothesis was rejected and the proportion hazard assumption was violated. As such, Cox proportional hazard regressions were not run for family as compared to "longest" friends.

Random friends and family

Network role was coded using dummy variables. In relation to family, "random" friends served as the comparison group. Within group correlations were controlled for in all models. The effect of network role (model 1) on the time to disclosure is shown in Table 2. The hazard ratios were not statistically significant for comparisons of family to "random" friends (1.20). This ratio indicated that at all time points after HIV diagnosis, "random" friends had a 20% greater rate of being disclosed to in comparison to family. However, this risk was not statistically significant.

The network role model is elaborated in Model 2 by testing the influence of network

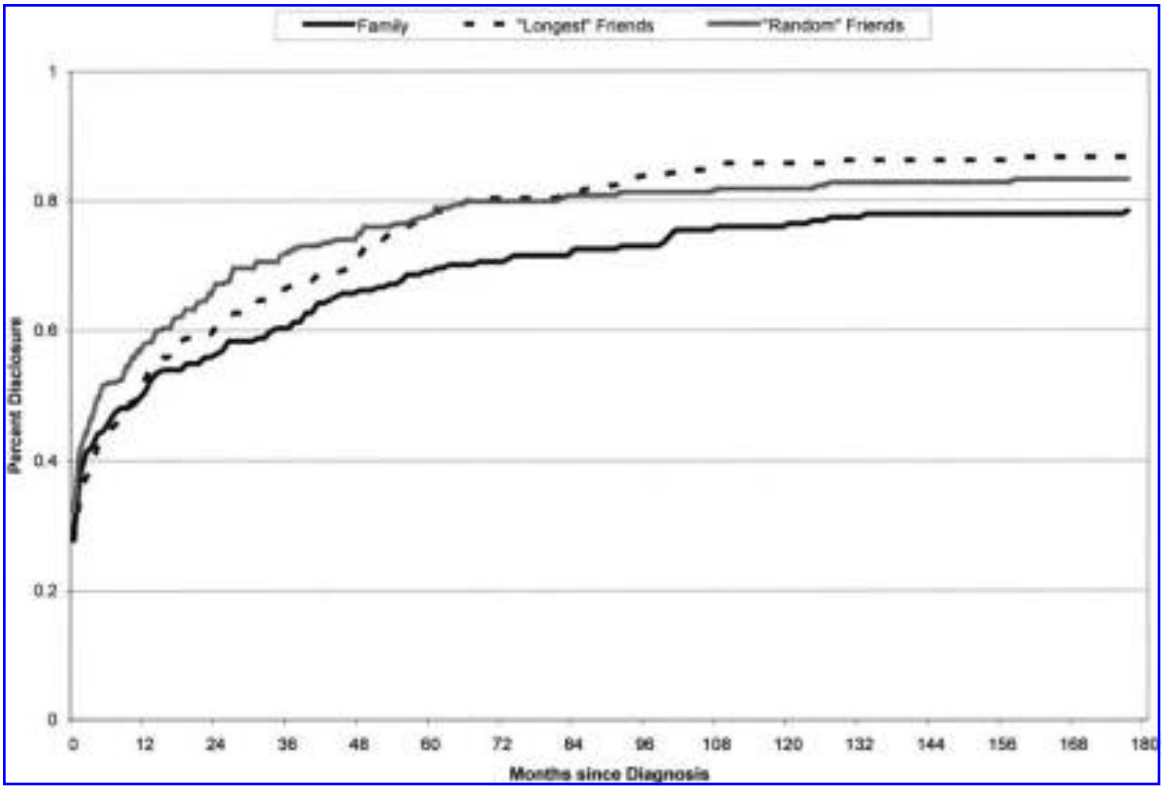

FIG. 1. Cumulative survival curve for family members, longest friends, and randomly selected friends. Note: At each time point, the line represents an estimate of the proportion of the sample (of family, random friends, longest friends) that would be disclosed to.

characteristics such as gender, race, age of family or friend, and current satisfaction on disclosure. Network characteristics of the family or friend were entered into the analysis (see Table 2). The hazard ratios among network role remained very similar for "random" friends, and again, no statistically significant differences were found for the hazard ratios between

TABLE 2. HAZARD RATIOS AND STANDARD ERRORS OF HIV-SEROSTATUS DISCLOSURE TO FAMILY MEMBER AND "RANDOM" FRIENDS

	Model 1	*Model 2*	*Model 3*
Network member[a]			
Family vs. friend	1.20 (0.14)	1.10 (0.14)	1.14 (0.15)
Gender[b]		0.94 (0.12)	0.88 (0.11)
Satisfaction with network member		1.01 (0.01)	1.01 (0.01)
Race[c]		1.11 (0.07)	1.12 (0.07)
Age of network member		0.99 (0.00)	0.99 (0.00)
Age of participant			1.00 (0.00)
Sample size	408	330	326
Model χ^2/df	2.48/1	6.8/5	9.66/6
Model log-likelihood	1794.34	1611.83	1585.66
χ^2 test of Q (1 *df*)	22.73***	6.73**	7.17**

[a]The family member serves as the referent group
[b]Male serves as the referent group.
[c]Caucasian serves as the referent group compared to other minorities.
*$p < 0.05$.
**$p < 0.01$.
***$p < 0.001$.

family and friends. Thus, neither the gender of the family or friend, their race, age nor the level of current satisfaction reported by the participant significantly influenced the hazard rates.

When the age of the participant was entered into the analysis in Model 3, the hazard ratios remained similar to those reported in Model 2 (see Table 2). No statistically significant differences were found for the hazard ratios between family and friends.

DISCUSSION

Disclosure rates to family and friends at discrete time points are generally well understood; however, accurate long-term disclosure estimates have not been calculated. In fact, this appears to be the first analysis comparing HIV disclosure to family and friends over time. Examining disclosure rates over time is important because it may provide a better estimate of overall disclosure to different network members versus the point prevalence studies. Interpretative caution may be required, however, because the majority of the data for this study was collected retrospectively. That is, once enrolled in the study participants were interviewed extensively concerning to whom and when they disclosed their serostatus. Although participants were carefully guided through the disclosure interview, it is plausible that erroneous data were provided. This might be particularly true for participants diagnosed several years prior to the study.

The purpose of this study was to provide a robust, retrospective examination of rates of men's HIV disclosure to family and friends over a 15-year time span and to investigate possible influence of social network and participant characteristics on rates of disclosure. The results of this study provide an interesting picture of disclosure to family and friends; one which is somewhat contrary to previously held notions by researchers and clinicians that HIV disclosure is significantly higher to friends than family. From Figure 1 and Table 1 it can be seen that if a point prevalence analysis had been conducted at discrete periods of time, differences in rates of disclosure might either be higher or negligible. For example, in this sample, the greatest difference in cumulative disclosure between family and longest friend is 11% at 8 years, yet there is no difference at 11 months. The greatest difference in cumulative disclosure between family and randomly selected friend is 12% at 3 years and only 3% at 2 months. Given that much of our knowledge base has emerged from point prevalence data, assumptions about disclosure to family versus friends should be revisited.

As a result of a violation of the assumption of proportionality, it was not possible to examine relative risk between family and "longest" friends. The cross-over in the data, however, is still important to note. From Figure 1 it can be seen that in the first year, family members are told in higher percentages, however, after the first year the trend changes. It is also interesting to note that half of all randomly selected friends were disclosed to within 4 months where as it took 10 months to tell half of all family and half of the longest friends. This suggests that in terms of disclosure, longest friends appear to be treated much more like family than typical friends. That is, the fears or concerns that individuals experienced around disclosure to family may be similar to long-term, valued friendships. Individuals may delay disclosure out of similar fears such as losing the relationship or needing to protect the recipient. Concerns about disclosing to other friends might not be as emotionally laden resulting in a quicker disclosure time.

Mental health professionals working with this community should not only consider types of friends available to HIV-positive gay men in assessing social support networks but be prepared to treat friendships differentially. While considerable respect for "family of choice" has been nurtured it is not clear that the translation of these persons being considered "family" has occurred. That is, longest friends might be a logical choice for clinicians to encourage disclosure but this negates the reality that these friendships may be different.

It is also interesting that the hazard rate is not significantly different between family and random friends. That is, the risk of being told as a random friend was 20% greater than being a family member, but that this is reduced

to 10% or 14% when including characteristics of the network and participant. The risk, however, is still not significant and stands in contrast to much of the previous research. That is, while the percent of disclosure between the two groups at any time varies, the rate at which they were told does not differ.

Three explanations can be inferred from these findings. First, while previously reported rates of disclosure to family and friends were consistent with those found here, tests of statistical significance were not typically conducted[3,6–8] Thus, while the visual examination of rates, particularly in point estimate studies, is important, conclusions about family and friends should be cautiously stated.

Second, the sample for this investigation was Midwestern. It is plausible that HIV disclosure rates in the Midwest are different than that of larger metropolitan cities such as San Francisco,[5,7] Los Angeles,[3,6,8,9] New York,[3] and other larger cities.[10] If it can be accurately assumed that many gay men migrate to larger coastal cities because of issues related to negative family attitudes around their sexual orientation, rates of disclosure to family are like to be lower. Conversely, if it can be assumed that men residing in Midwestern states are choosing to stay closer to their families, issues with disclosure decisions would be different. Clinicians should be mindful of this when translating research results into clinical practice.

It should be noted that we did not investigate physical proximity such as coresidency or degree of contact with family and friends. It is possible that for men who live great distances from their families, the need or desire to disclose their HIV status is curtailed. Thus, it is plausible rates of disclosure might be lower for family members or friends not proximally available to HIV-positive person. Similarly, in this study we did not investigate the degree to which family and friends were integrated into the person's daily interactional network. It is possible that random friends are more tightly interwoven into the everyday lives of these men versus family and longest friends who may be more disengaged. This variation in contact may be related to physical proximity but could also be associated with emotional closeness or frequency of contact.

Third, in this study family and longest friends were clearly defined. Randomly selected friends, however, were drawn from the pool of anyone whom a participant indicated as a friend and they disclosed to directly. Thus, while these were not persons met in support groups or through HIV networks or organizations the friendship may have formed either before or after the diagnosis. In fact, it is important to note that 39.7% of random friends and 63.2% of longest friends were known before the diagnosis. This suggests that it is plausible that friendships formed after the diagnosis may be different. That is, once a person is HIV-positive and forming new friendships, disclosure may come earlier as a means of either extracting or testing superfluous relationships. Future researchers might consider a closer investigation of this phenomenon as it may have an influential role not only in disclosure decisions but mental health outcomes.

As previously mentioned, the data used in this analysis is primarily retrospective. While a prospective description is most desirable, unfortunately, such data will never be available for this time period. This highlights the importance of prospective studies beyond one year, such as that conducted by Stemple and colleagues.[5] These investigations should carefully document disclosure decisions, reactions, and reasons for disclosure including what factors were involved and when the decision was made so that a more complete picture of this phenomenon can be captured.

Future researchers might consider numerous other issues when examining disclosure trends. First, similar studies should be conducted with other populations such as intravenous drug users and women, as well as recipients such as children or employers, to test if these trends are universal. Second, we did not inquire if network members knew the sexual orientation of the participant. Future researchers might incorporate disclosure of other stigmatized or confidential information to test if these trends hold irregardless of the content of the message. In addition, it is plausible that trends might also be influenced by the known or perceived HIV status of the recipient; however, this was not assessed in this study. Finally, stage of HIV disease among participants was not assessed.

It is plausible that late stage or symptomatic disease could force disclosure due obvious physical signs, symptoms, or hospitalizations.

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