Women's HIV Disclosure to Family and Friends

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Abstract

Previous researchers have documented rates of HIV disclosure to family at discrete time periods, yet none have taken a dynamic approach to this phenomenon. The purpose of this study is to take the next step and provide a retrospective comparison of rates of women's HIV disclosure to family and friends over a 15-year time span. Of particular interest are the possible influences of social network and relationship characteristics on the time-to-disclosure of serostatus. Time-to-disclosure was analyzed from data provided by 125 HIV-positive women. Participants were primarily married or dating (42%), unemployed (79.2%), African American (68%) women with a high school diploma or less (54.4%). Length of time since diagnosis ranged from 1 month to over 19 years ($M=7.1$ years). Results pointed to statistically significant differences in time-to-disclosure between family, friends, and sexual partners. Additionally, females and persons with whom the participant had more frequent contact were more likely to be disclosed to, regardless of the type of relationship. The results of this study underscore possible challenges with existing studies which have employed point prevalence designs, and point to new methods which could be helpful in family research.

Introduction

FOR WOMEN LIVING WITH HIV (WLWH), the decision to disclose serostatus to friends, family, and sexual partners may have important ramifications in all areas of life. Receiving an HIV diagnosis has a great emotional impact, and those who are newly diagnosed may struggle initially, choosing to delay disclosure until they have dealt with the emotional shock of diagnosis.¹ The decision may be particularly stressful to women with children. For example, seropositivity in mothers has been associated with higher levels of depression.²⁻⁵ Low-income women and minority women are also particularly impacted, expressing greater levels of stress, anxiety, and depression.^{2,5} Reported depressive symptoms in WLWH are further related to higher degrees of perceived stigma and physical symptoms associated with the disease.⁴ Additionally, concealing HIV status has also been shown to exact a toll on persons living with HIV due to a perceived loss of control, the associated risk that the target of the disclosure may find out from another first and the risk of potential violence.⁶⁻⁸ Finally, serostatus disclosure has been linked to improvements in medication adherence, physical health, and access to health care.⁹

Studies of disclosure have shown that characteristics of both seropositive women and their network members are

important considerations in the disclosure decision. Specifically, WLWH may first need to consider their own needs for social support as well as their self-perceived disclosure skills. They may also consider the age, health, current circumstances, and physical proximity of the partner when making the disclosure decision.¹ Personal characteristics like general supportiveness or attitudes like open-mindedness associated with specific individuals may also be predictive of disclosure.¹⁰ Interpersonal characteristics are an important consideration in the disclosure decision. Women weigh the nature of the relationship with the potential person individually, considering the relationship role (e.g., family, friend, partner) and the closeness of the relationship.^{1,10} As such, it is important to situate the process of disclosure within the context of unique, interpersonal dyads.

The study of serostatus disclosure in WLWH is further complicated by the fact that these dyadic effects also occur within social networks. Thus, the decision to disclose may also depend on network-level characteristics. Women who perceive their social support network as large and supportive are reported to experience less difficulty in disclosing.¹¹ The network perspective is particularly relevant to the study of serostatus disclosure when considering the mode by which disclosure occurs. While disclosure may occur as the result of direct action by an HIV-positive individual (i.e., first-hand

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disclosure), it may also occur through an indirect path within the individual's social network (i.e., second-hand disclosure). The potential loss of privacy and control associated with second-hand disclosures of this type is often an important consideration in the decision to disclose. For WLWH, disclosure may occur first in cases where they prefer to tell the person first-hand.⁶ Conversely, women may avoid disclosure to persons who they believe may be prone to revealing their HIV status to others.^{10,12}

A review of the extant literature reveals that much is known about the rates and predictors of disclosure by WLWH.^{5,10,13,14} However, limitations imposed by research designs and analytical methodologies applied call into question the precision of these reported figures. Prior studies provide estimates that are descriptive of the prevalence of disclosure among various categories of relationships at a specific point in time, and often do so at the cost of imposing assumptions which may not be tenable within the context of disclosure. For example, in a study of 322 WLWH in the southern United States by Sowell and colleagues¹⁰ it was reported that the prevalence of disclosure of serostatus by African American WLWH to their siblings was significantly lower than in women from other ethnic groups. Although the estimate reported does account for the potential effect of ethnicity on disclosure, it is still confounded by the potential effects of time-since-diagnosis and other time-varying explanatory variables on disclosure prevalence. To some degree, the incorporation of time-varying explanatory variables can address this concern. In one example, O'Brien and colleagues¹⁵ reported the observed odds of disclosure among a sample of 269 persons living with HIV based on immune-suppression (CD4 count) and time-since disclosure variables. As this was a cross-sectional study, values at baseline were predictors in the logistic regression model, with disclosure as the dichotomous outcome. The study reported that lower self-reported CD4 counts were predictive of higher levels of disclosure to main partners, but lower levels of disclosure to friends. However, this observation is made despite the potential for CD4 counts to change over time. In order to interpret the resulting odds ratios, assumptions must be made about the interrelationships between time-varying predictors and outcomes. Unfortunately, the limitations imposed by cross-sectional data make it impossible to test these assumptions.

Studies of disclosure present another problem for analysis in that each study participant provides multiple observations involving multiple dyadic relationships. This situation gives rise to contextual effects within the individuals (persons living with HIV) and individual members of their social networks. Most social networks are comprised of many of these interpersonal dyads, resulting in data which are hierarchically structured (i.e., network members nested within individuals). This underlying structure violates the assumptions of many standard regression approaches. Failure to incorporate such structures into the analytical design may result in aggregation bias, misestimated precision resulting in type I or type II error, or the inability to detect and model the heterogeneity of regression between individuals under study. Such limits in methodology also prohibit the rich conceptualization of the effect of context.¹⁶

In order to work toward an understanding of the time-related and contextual effects of explanatory variables on the

disclosure process, researchers must employ new strategies for data collection and analysis. Event-history models, when applied to data collected with an event orientation, provide a powerful alternative to traditional logistic regression models. In the case of serostatus disclosure, questions dealing specifically with whether or not disclosure occurs, and when it does, how much time elapses between the date of diagnosis and the date of disclosure can easily be addressed in this framework.

Despite the potential benefit of these models, in a review of the recent literature on serostatus disclosure, only two applications of these techniques to disclosure data sets were found.^{17,18} Among these studies, important limitations were observed. First, two of the studies involved the disclosure process observed among MSM. Research on the influence of gender on disclosure indicates that the disclosure patterns may differ significantly between seropositive men and women.^{13,19} Second, in the study involving women, only disclosure to family members was considered. This limitation makes it impossible to untangle the effects of family from effects specific to dyads. The current study extends the multi-level event-history methodology to a study of disclosure among the larger social networks of WLWH. The purpose of this study is to take the next step and provide a retrospective comparison of rates of women's HIV disclosure to family and friends over a 15-year time span. Of particular interest are the possible influences of demographic and relationship characteristics on the likelihood of HIV disclosure.

Methods

Participants and data collection

Participants were involved in a larger, longitudinal study of HIV disclosure conducted in a large midwestern city. Recruitment for the larger study was conducted from 2001 through 2004 through partnerships with local institutions serving the HIV-positive community, including AIDS service organizations, a children's hospital, and a clinical trial unit associated with a large university. Participants were approached by caseworkers, attending physicians, and medical staff and informed about the study. Eligible participants included WLWH who were 18 years of age or older. Recruitment efforts resulted in the enrollment of 125 eligible women.

The larger study involved completing questionnaires regarding mental health, physical health, social support, disease progression, date of diagnosis, and sexual risk-taking behaviors. Data for the study were collected at baseline, and once every six months for three years resulting in seven data collection points. While the study involved collecting data longitudinally, the data used in this study were largely retrospective. In order to reduce the amount of error inherent in the reporting of retrospective data, interviews were conducted by trained graduate students and specific procedures for data collection including the use of probes to stimulate recollection were instituted. As a part of the initial interview, participants were interviewed using an adaptation of Barrera's Arizona Social Support Interview Schedule (ASSIS).²⁰ 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 this structured interview, a list of social support network members was constructed and relevant information for

each network member (e.g., demographics, disclosure status) was obtained. The full ASSIS interview was administered only at baseline. However, at subsequent observations participants were asked to report additions to their social networks. When a new network member was identified, the participant was interviewed to obtain the relevant information.

Measures

Network member and relationship characteristics. The adapted version of the ASSIS was used to collect information specific to each of the network members reported by the participant. Information gathered about each network member included gender, ethnicity, and age at the time of the study. Network member age at the time of disclosure was subsequently calculated based on the date of disclosure. Specific relationship characteristics were also assessed, including relationship proximity, frequency of contact, and current relationship satisfaction. Proximity was measured using a 1–6 rating scale ranging from “live together” (1) to “several states away” (6). Frequency of contact was scaled using a 0–5 rating scale ranging from “no contact” (0) to “daily contact” (5). The measurement of the participants’ current satisfaction with the relationship was accomplished with the use of a 1–5 Likert-type rating scale ranging from “very dissatisfied” (1) to “very satisfied” (5). To evaluate the occurrence of the disclosure event, participants indicated whether or not disclosure had occurred, and if it had, the date and mode of disclosure (i.e., did the participant disclose personally, or was disclosure made by another person). For all personal disclosures, the month and year of disclosure was recorded.

Statistical analysis

Event-history (EH) methodology, also referred to as survival analysis, is a suitable alternative to logistic regression in modeling time-to-event data as it permits the modeling of both the transition across states (i.e., no disclosure to disclosure) and the length of the time-to-disclosure interval.^{21–24} Data from cases where the event has not yet occurred, called censored cases, are also used in the estimation. Recent extensions to the methodology are also available that can accommodate structured data sets with multiple events occurring within individuals.^{24–26} The application of EH to time-to-event datasets requires that special attention be paid to the defining the beginning and ending of the risk interval.²⁴ For the purposes of this study, two different points defined the beginning of the disclosure risk period. Where the participant already knew the network member at the time of diagnosis, the date of diagnosis was used as the beginning of the risk interval. In cases where the participants did not yet know the network member on the date of diagnosis, the date that they met was used. The end of the risk interval was identified as the date of disclosure. However, where the participant had not yet disclosed to the network member at the end of the study period, the date of the last participant interview was used. The length of the time-to-disclosure interval, or the time to censoring, was measured in months rather than days because retrospective data regarding diagnosis date, date met, and disclosure date were limited to month and year.

Analyses of time-to-event data were conducted in STATA version 11 (StataCorp, College Station, TX). Kaplan-Meier

type cumulative disclosure curves stratified by relationship type (i.e., family of origin, child, extended family, friend, and partner) were estimated and the log rank test used to test the equality of the disclosure curves. To assess the effects of predictors of interest on the time-to-disclosure, a multivariable Cox proportional hazard regression (CPH) model was used to estimate the hazard ratios and standard errors. In STATA, a semiparametric random effects model called a shared frailty model is used to account for correlation within participant networks.^{23,25,27} In the case of disclosure, the frailty term represents the relative differences in willingness to disclose among the participants. This approach does not specify a distribution for the baseline hazard, but does assume a gamma distribution for the shared frailty term. Incorporation of this random effects approach controls for the nonindependence in the willingness to disclose across members of each participants’ social network.

Results

Participant characteristics

Participant demographic characteristics. Participants for this study were 125 HIV-positive women. Eighty-five (68%) participants were African American, 31 (24.8%) were Caucasian, 5 (4%) were Hispanic/Latina, and 4 (3.2%) were of unknown ethnicity. Within the participant group, 31 (24.8%) of the participants had not completed high school, 37 (29.6%) had graduated high school or completed a GED, 43 (34.4%) had attended some college, 7 (5.6%) had graduated college, 3 (2.4%) had attended graduate school, and 4 (3.2%) did not report educational attainment. Twenty-six (20.8%) reported being employed. Self-reported monthly income for those who reported income ranged from \$0–6,600, with a median value of \$734. Forty-one (32.8%) of the participants were single, 42 (33.6%) were married/partnered, 23 (18.4%) were dating, and 19 (15.2%) were divorced/widowed. Length of time since diagnosis ranged in the sample from 1 month to over 19 years ($M=7.1$ years).

Participant network size. The size of the reported network varied across participants, with the smallest reported network consisting of 2 members, and the large reported network comprised of 41 members. The average network size for the participants in the study was 10 members. More than half ($n=67$, 54%) reported network sizes between 2 and 10, and slightly fewer than half ($n=58$, 46%) reported networks consisting of more than 10 members. Approximately 77% ($n=96$) included at least one partner in their social network. Of these, more than half ($n=54$, 56%) reported only one partner, 42% ($n=40$) reported 2 to 5 partners, and only two participants reported more than 5 partners. Of the 113 (90%) participants who reported at least one immediate family member in their network, more than 90% ($n=102$) reported from 1 to 5 immediate family members and the remaining 10% ($n=11$) reported from 6 to 10. More than 80% ($n=105$) of participants reported at least one friend in their social networks, with 85% of those ($n=89$) reporting from 1 to 5 friends, 10% ($n=11$) reporting 6 to 10 friends, and 5% ($n=5$) reporting more than 10 friends. Eighty-one participants (65%) included children in their social networks, and of these 59% ($n=48$) had more than one child. Extended family members were least

likely to be included in the social network, with only 52% ($n=65$) of participants including at least one extended family member.

Participant disclosure. Participants' disclosure to members of their social networks varied by the type of relationship. Overall disclosure to partners, children, and immediate family members was the most common. Of the 96 participants that included at least one partner in their social network, 85% ($n=82$) reported having disclosed to all of their partners. Only 3% ($n=3$) reported having disclosed to none of their partners. Among the 81 participants with children, almost 78% ($n=63$) reported having disclosed to all of their children, yet almost 15% ($n=12$) reported having disclosed to none of their children. Of the 113 participants who included immediate family in their networks, 74% ($n=84$) reported having disclosed to all, and only 6% ($n=7$) reported no disclosure. Disclosure to extended family and friends was less common. Of the 65 participants who included one or more members of their extended family, 63% ($n=41$) reported having disclosed to all extended family members and almost 25% ($n=16$) reported having disclosed to none. Of the 105 listing friends in their networks, 51% ($n=54$) reported having disclosed to all of their friends and 17% ($n=18$) had disclosed to none of their friends.

Network member characteristics

Eligible network members. A total of 2218 network members were reported by the participants. Of those reported, 469 were excluded because their relationship to the participant (e.g., pastor, social worker, therapist) was not relevant to the research, 456 were excluded because they were disclosed to by persons other than the participant or were deceased before the date of diagnosis. Extant research on mother's disclosure to children suggests that disclosure to very young children is rare^{1,28-31} and that children below kindergarten age may not be able to understand concepts such as illness and death.³² Given the likelihood that mothers delay disclosure to very young children based on age, 45 network members under the age of 5 were excluded. Finally, 23 were removed because of deficient data; either because no disclosure date was provided or because conflicting data were provided. Of the remaining 1225 eligible network members, 961 had been disclosed to by the participant, and 264 had not yet been told. Eligible network members included 369 members of the participants' families of origin (30.1%), 125 extended family members (10.2%), 169 of the participants' children (13.8%), 173 partners (14.1%), and 389 friends (31.8%).

Family of origin. The 369 family of origin members include mothers, fathers, sisters, and brothers of the participants. Stepmothers, stepfathers, stepsisters, and stepbrothers were also included in this group. Family of origin comprised 30.1% of the total eligible network member group. Approximately 82% ($n=302$) of family of origin members had been disclosed to by the participant, while the remaining 18% ($n=67$) were not aware of the participants' HIV status at the conclusion of the study. The average age of the family members was at the time of the study was 46.9 years ($n=348$), with a standard deviation of 14.8 years. The minimum age reported for a family of origin member was 11 years, and the maximum

was 91 years. With respect to ethnicity, 244 (66.1%) of the family of origin members were African American, 95 were Caucasian (25.7%), 18 were Hispanic/Latina(o) (4.9%), one was Asian American (0.3%), and the remaining 3% ($n=11$) were either listed as "other" ethnicity or ethnicity was not provided. Family of origin members included 212 females (57.5%), 154 males (41.7%), and three persons of unknown gender.

Extended family members. The 125 extended family members include aunts, uncles, cousins, nieces, nephews, grandparents, grandchildren, and in-laws. Extended family members comprised 10.2% of the total eligible network member group. Approximately 69% ($n=86$) of extended family members had been disclosed to by the participant, while the remaining 31% ($n=39$) were not aware of the participants' HIV status at the conclusion of the study. The average age of the extended family members at the time of the study was 39.6 years ($n=125$), with a standard deviation of 19.9 years. The minimum age reported for an extended family member was 6 years, and the maximum was 98 years. Eighty-seven (69.6%) of extended family members were African American, 29 were Caucasian (23.2%), 2 were Hispanic/Latina(o) (1.6%), and the remaining 5.6% ($n=7$) were not identified by a specific ethnic group. The group of extended family members included 89 females (71.2%) and 36 males (28.8%).

Participants' children. The group of 169 children of participants includes sons, daughters, stepsons, and stepdaughters. These children comprised 13.8% of the total eligible network member group. Approximately 83% ($n=140$) of the children had been disclosed to by the participant, while the remaining 17% ($n=29$) were not aware of the participants' HIV status at the conclusion of the study. The average age of the participants' children at the time of the study was 19.4 years ($n=169$), with a standard deviation of 9 years. The minimum age reported for a child was 6 years, and the maximum was 46 years. One hundred thirty-seven (81.1%) of the children were African American, 21 were Caucasian (12.4%), 6 were Hispanic/Latina(o) (3.6%), and the remaining 3.0% ($n=5$) were not identified by ethnic group. Of the group of children, 103 (60.9%) were daughters or stepdaughters and 66 (39.1%) were sons or stepsons.

Partners. The 173 partners of the participants included current and former husbands, boyfriends, casual sex partners, and lovers. Partners comprised 14.1% of the total eligible network member group. Approximately 86% ($n=149$) of partners had been disclosed to by the participant, while the remaining 14% ($n=24$) were not aware of the participants' HIV status at the conclusion of the study. The average age of partners at the time of the study was 39.5 years ($n=173$), with a standard deviation of 9.3 years. The minimum age reported for a partner was 19 years, and the maximum was 62 years. One hundred thirty-five (78%) partners were African American, 27 were Caucasian (15.6%), 4 were Hispanic/Latina(o) (2.3%), 2 were Native American (1.2%), and the remaining 5 (2.9%) were not identified by ethnicity. Five partners were female (2.9%), and the remaining (97.1%) were male.

Friends. The 389 friends of participants included current and former friends, family friends, and acquaintances.

TABLE 1. TIME-TO-DISCLOSURE FROM DATE OF DIAGNOSIS, OR DATE MET, BY RELATIONSHIP TYPE

Characteristic	Family of origin	Children	Extended family	Friends	Partners
Mean in months, (95% confidence interval)	49.1 (39.1/59.1)	50.7 (42.0/59.4)	64.7 (51.7/77.8)	40.4 (33.8/42.1)	26.3 (18.0/34.5)
Median in months, (95% confidence interval)	2 (1,3)	32 (25.6/38.4)	23 (8.0/38.0)	7 (2.9/11.1)	1 (0.0/2.0)

Friends comprised 31.8% of the total eligible network member group. Approximately 73% ($n=284$) of friends had been disclosed to by the participant, while the remaining 27% ($n=105$) were not aware of the participants' HIV status at the conclusion of the study. The average age of the participants' friends at the time of the study was 41.6 years ($n=389$), with a standard deviation of 11.8 years. The minimum age reported for a friend was 16 years, and the maximum was 78 years. Two hundred and fifty (64.3%) of these friends were African American, 119 were Caucasian (30.6%), 5 were Hispanic/Latina(o) (1.3%), 3 were Asian American (0.8%), 2 were Native American (0.5%), and the remaining 2.6% ($n=10$) were not known. Participants' friends were predominantly female (78.7%, $n=306$).

Disclosure curves

In order to investigate the disclosure of HIV serostatus disclosure to family members, data on children, friends, and partners were analyzed separately by relationship. The mean and median time-to-disclosure for each relationship type are presented in Table 1. With disclosure as the event of interest, Kaplan-Meier (Fig. 1) cumulative curves were utilized to create a graphic representation of the proportion of network members who had been disclosed to at a given time, based on their relationship to the participant. The log rank test confirmed significant differences in these proportions across relationship types ($\chi^2=38.02$, $p=0.000$). Disclosure to partners

occurred most rapidly, and the rate of disclosure continued to increase through the first 4 years after diagnosis. Disclosure to members of the family of origin exceeded disclosure to friends through 5–6 years after diagnosis. Though disclosure to children appears to be very low initially, at about 4–5 years after diagnosis, disclosure to children surpasses extended family and continues to increase steadily. Table 2 provides a focus on short-term disclosure trends during the first two years after diagnosis. During the first month after diagnosis, 46% of family of origin, 21% of children, 32% of extended family, 30% of friends and 45% of partners had been disclosed to by the participant. After one year, the greatest increase in the rate of disclosure (based on the initial disclosure percentage) occurred for friends (73%), partners (58%), and children (48%). During the same period, disclosures to family of origin (30%) and extended family (25%) increased at a more moderate pace. During the second year after diagnosis, the rates of disclosure to children (39%) and extended family (25%) were similar to the prior year, while rates of disclosure to family of origin, friends, and partners decreased. By 13 years post-diagnosis, more than 79% of all network members had been disclosed to, regardless of relationship type.

Cox proportional hazard regression

In order to investigate the influence of relationship type (i.e., family of origin, extended family, partners, friends) and other independent variables on the prediction of HIV

FIG. 1. Kaplan-Meier plot of disclosure probability by network member category with log-rank analysis.

TABLE 2. PERCENT AND RATE OF DISCLOSURE BY TIME PERIOD

	Family of origin	Children	Extended family	Friends	Partners
<i>Percent disclosure by time period</i>					
First month after diagnosis	46%	21%	32%	30%	45%
At 12 months after diagnosis	60%	31%	40%	52%	71%
At 24 months after diagnosis	68%	43%	50%	61%	75%
<i>Rate of increase during the time period^a</i>					
% increase from 1 to 12 months	30%	48%	25%	73%	58%
% increase from 12 to 24 months	13%	39%	25%	17%	6%

^aRate of increase computed by dividing the % disclosed to during the period by the % disclosed to at the beginning of the period (e.g., % disclosed at 12 months – % disclosed at 1 month divided by % disclosed to at 1 month).

disclosure over time, data were analyzed using a Cox proportional hazard regression model. This analysis provides estimates of the rate of disclosure across time, without having to specify a particular baseline hazard. Effects of individual independent variables on the relative risk of disclosure are reported as hazard ratios. The hazard ratio is interpreted as the rate of disclosure in one group compared to the rate of disclosure in another. With dummy coded predictors, hazard ratios greater than 1 indicate that the rate of disclosure is higher in the comparison group than in the reference group, while hazard ratios less than 1 indicate higher rates of disclosure in the reference group. With continuous predictors, hazard ratios greater than 1 indicate a positive relationship between the predictor and the hazard rate. Although the rate of disclosure is expected to change over time, the assumption of the Cox proportional hazards model is that the rate of change is proportional across groups, and the ratio between the disclosure rates is consistent across time. 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 performed. The null hypothesis of zero slope, and violation of the proportion hazard assumption, was tested both globally and individually for each network member. Both global ($\chi^2=33.56$, $p=0.000$) and individual tests for children ($\chi^2=29.63$, $p=0.000$) violated the proportion hazard assumption. As such, children were excluded in Cox proportional hazard regressions. Without children, both global ($\chi^2=2.61$, $p=0.046$) and individual tests failed to violate the proportion hazard assumption. The null hypothesis was not rejected and the proportion hazard assumption was not violated.

Predictors of disclosure

Multiple Cox regression was used to evaluate the effects of relationship and network member characteristics on the likelihood of disclosure. Hazard ratios resulting from this analysis are provided in Table 3.

TABLE 3. HAZARD RATIOS AND STANDARD ERRORS OF HIV-SEROSTATUS DISCLOSURE TO FAMILY MEMBERS, FRIENDS, AND PARTNERS

	Model 1	Model 2	Model 3
<i>Network member characteristics</i>			
Relationship type ^a			
Extended family	0.585 (0.079) ^d	0.542 (.075) ^d	0.505 (0.073) ^d
Friends	0.807 (0.075) ^e	0.711 (0.070) ^f	0.644 (0.069) ^d
Partners	1.212 (0.134)	1.429 (0.179) ^f	1.331 (0.186) ^e
Gender ^b		0.696 (0.066) ^d	0.714 (0.072) ^f
Ethnicity ^c		0.974 (0.074)	1.028 (0.042)
Age		1.002 (0.003)	1.002 (0.003)
<i>Perceptions of relationship</i>			
Satisfaction with relationship			1.072 (0.041)
Frequency of contact			1.091 (0.043) ^e
Proximity			1.000 (0.038)
Sample size	1056	1035	973
Model χ^2 /df	30.23/3	50.25/6	62.45/9
Model log-Likelihood	-5168.14	-5053.67	-4717.05
χ^2 test of Θ (1 df)	128.25 ^d	128.95 ^d	102.28 ^d
AIC	10342.28	10119.35	9452.096
BIC	10357.16	10149.01	9496.019

^aFamily of origin serves as the referent group.

^bFemale serves as the referent group.

^cCaucasian serves as the referent group compared to other ethnicities.

^d $p < 0.001$.

^e $p < 0.01$.

^f $p < 0.05$.

Relationship type. Relationship type was dummy coded with family of origin as the reference category and added as a predictor to the model. In each of the three regression models applied to the data, relationship type was a significant predictor of disclosure. When compared to disclosure to family of origin, disclosure to extended family members ($z = -3.97$, $p = 0.000$) and friends ($z = -2.30$, $p = 0.021$) was significantly less likely. There was no significant difference in the likelihoods of disclosure to sexual partners ($z = 1.75$, $p = 0.080$) and family of origin.

Network member characteristics. Network member characteristics, including gender, ethnicity, and age at time of disclosure were then entered into the predicting model (model 2). Among these, only gender was found to significantly affect the likelihood of disclosure. After controlling for relationship type, participants were significantly less likely ($z = -3.79$, $p = 0.000$) to disclose to male network members than female network members. Neither the network member's age nor ethnicity significantly affected the likelihood of disclosure.

Relationship characteristics. Relationship characteristics including physical proximity, frequency of contact, and satisfaction with the relationship were then added as predictors in the Cox regression model (model 3). After controlling for relationship type and for select network member characteristics, participants were more likely to disclose ($z = 2.20$, $p = 0.028$) as the frequency of contact with the network member increased. Neither the participant's reported satisfaction with the relationship, nor the physical proximity of the network member, significantly predicted the rate of disclosure.

Discussion

There are a number of interesting results from this study. First, this research revealed that during the first month after diagnosis, 46% of family of origin, 45% of partners, 32% of extended family, 30% of friends, and 21% of children had been disclosed to by the participant. These results run counter to point prevalence studies which suggest that friends are more likely to be told than family.¹⁴ Results based on event history analysis indicate that, while a larger proportion of friends may eventually be disclosed to, disclosure in the 2 years after diagnosis was actually more likely involve members of the family of origin. Additionally, the proportion of family members disclosed to remained higher than the proportion of friends who were told throughout the first 5 years after diagnosis. Given that the previous studies of disclosure in WLWH were conducted in the early 1990s, it is also possible that disclosure patterns have changed. This is particularly possible given that the social dynamics of the epidemic have changed over time. However it is also possible that limitations associated with the prior use of point prevalence designs could explain this difference.

Second, sexual partners were more likely to be told immediately than those in any other group and the trajectory of disclosure increased the most dramatically over time. It is important to note that the group of sexual partners included both current and ex-partners. Therefore, for some women disclosure entailed going back and finding previous partners.

For this study we did not assess the serostatus of the partners and thus it is not clear why partners were told. Plausible explanations include protecting them from possible infection, encouraging testing, seeking their support, the presence of a disclosure law requiring disclosure, or blaming them for infection. Future researchers might consider exploring the motivations behind women's disclosure to sexual partners. Such information could be vital for the development of interventions to assist women with disclosure to sexual partners.

Third, at 13 years postdiagnosis at least 79% of individuals in all categories had been told. Disclosure rates among WLWH have been reported in studies conducted in cities across the United States including Los Angeles,^{14,33} New York City,³⁴ and Miami.³⁵ Overall rates of disclosure to social network members from 46% to 69% have been observed.^{14,33-35} The higher rates of disclosure observed in this study may be reflective of the longer study period or of the midwestern location in which the study was conducted. These results demonstrate that, despite possible negative reactions or repercussions, WLWH steadily disclose their serostatus to a large proportion of their social networks over time. This suggests that women may be receiving some benefits from disclosure which affect their decisions about disclosure. Conversely, the costs associated with disclosure may not have been experienced as intensely. In this study we did not assess if disclosure became easier over time. Specifically, time-to-disclosure might be either shorter or longer for network members, like friends and partners, who the participant did not meet until after diagnosis. Future researchers could focus on changes in women's attitudes about disclosure and their effects on the likelihood of disclosure over time. Attention should also be paid to possible geographical or cultural differences in disclosure rates among WLWH. For example, conclusion drawn from midwestern populations may not generalize to women living in other regions of the country. This may be particularly true for area of the country where strong cultural or racial customs prevail.

Fourth, gender of the network member significantly predicted disclosure. After controlling for the effects of relationship type, participants were significantly less likely to disclose to male members of their social networks than to female members. There are numerous reasons for this. First, women may be more comfortable dialoging in general to female counterparts about health related issues. It is also plausible that disclosure is seen as a means of securing social support that women may be more likely to provide. Finally, women may perceive men as more judgmental and have greater fears of negative reactions from them. Future researchers who seek to better understand communication patterns between men and women might utilize sensitive topics such as HIV as a catalyst to better understand these dynamics.

While children were excluded in Cox proportional hazard regressions, it is interesting to note that high levels of disclosure were found for these family members. Initially only 21% were told, yet the increase from 12 to 24 months was 39% reflecting the largest increase in any group. This time delay to disclosure could be occupied by self acceptance of the diagnosis as well as an assessment of their child's maturity, social circumstances, and need to know. Clearly, future researchers should pay attention to the complexities in measuring disclosure to children (e.g., age confounds), and conduct these studies longitudinally. The successful application of the

multilevel event-history model demonstrates the value of the methodology in efforts to understand how persons living with HIV disclose their serostatus within their social networks. Unlike point prevalence estimates which mask the effects of time on disclosure, event-history models permit the examination of the ways in which disclosure behaviors change in the days, months, and years following a positive diagnosis. The ability to add a frailty term to the event-model, and thus to accommodate data that arise from individuals' interactions with families, friends, and other members of their social networks, make these models particularly attractive for use in family-based research. Assumptions made in conjunction with modeling, including the nature and distribution of the frailty term, should be more fully explored in future studies. Interpretative caution is suggested because of the retrospective nature of these data. Although participants were carefully guided through the disclosure interview process, it is plausible that precision of the disclosure dates was affected by errors in recollection. This might be particularly true for participants diagnosed several years prior to the study. To the best of our knowledge this is the only effort to attempt to capture an often difficult process occurring at a time of great discrimination, high anxiety, and emotion. Thus, while a prospective account would be most desirable, such data are not currently available. Future studies might take such a perspective so as to offer more precision to the understanding of this phenomenon.

Acknowledgment

This study was funded by a grant from the National Institutes of Health (R01MH62293) to the first author (JMS).

Author Disclosure Statement

No competing financial interests exist.

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