Differential Disclosure Across Social Network Ties Among Women Living with HIV

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Abstract Women’s disclosure of their HIV serostatus across social network ties was examined in a sample of women living in Los Angeles (n = 234), using multivariate random intercept logistic regressions. Women with disclosure-averse attitudes were less likely to disclose, while women with higher CD4+ counts were significantly more likely to disclose, regardless of relationship type. Relative to all other types of relationships, spouses/romantic partners were greater than four times more likely to be the targets of disclosure. Women were more than 2.5 times more likely to disclose to a given network member if that target provided the woman with social support. Social network members whom women believed to be HIV-positive were more than 10 times more likely to be the targets of disclosure. The implications for how social roles and social identities are manifest in these results are discussed, including the implications such an interpretation has for future prevention research.

Keywords HIV/AIDS · Women · Disclosure · Social network

Introduction

In 2006, women in the United States accounted for 15,000 of the estimated 56,300 new HIV infections (Hall et al. 2008). Women of racial and ethnic minority backgrounds carry the disproportionate burden of the disease. Recent data report that HIV/AIDS prevalence among African American women (62.7 per 100,000) was nearly 18 times that of white women (CDC Division of HIV/AIDS Prevention 2008). The prevalence rate for African American women was greater than that of all other groups, with the exception of African American men. AIDS is the leading cause of death among African American women ages 25–34. For Latinas, HIV prevalence was approximately four times that of White women (CDC Division of HIV/AIDS Prevention 2008). For Latinas ages 35–44, AIDS is the fourth leading cause of death (CDC Division of HIV/AIDS Prevention 2007).

More than two decades into the pandemic of HIV/AIDS, women in the United States, particularly women of color, still face enormous challenges with respect to disclosing their HIV serostatus, be it to sexual partners, family members, friends, children, or health care professionals (see Arnold et al. 2008; Murphy 2008 for recent reviews). Women infected with HIV, must face their fears of rejection and abandonment which may follow disclosure (Gielen et al. 1997, 2000a; Lester et al. 1995). While fears of abandonment by partners and violence directed at women accompanying disclosure are more prevalent in many developing nations (Antelman et al. 2001; Asander et al. 2004; Brou et al. 2007; Medley et al. 2004; Visser et al. 2008), tragically, American women’s fears of such outcomes are justified, as reports of abandonment and violence against women who disclose in the United States have been catalogued (Gielen et al. 1997, 2000b; North and...
Rothenberg 1993; Rothenberg et al. 1995; Vlahov et al. 2004). Apart from violence, everyday experiences of stigma related to HIV/AIDS diagnosis engenders a reluctance to disclose among many women (Chin and Kroesen 1999; Clark et al. 2003; Gielen et al. 1997, 2000a; Sowell et al. 1997; Wolitski et al. 2008).

Despite an abundance of barriers to disclosure, most women in the United States have disclosed their serostatus to someone in their social network; be that an intimate sexual partner, parent, child, or friend. Rates of disclosure, however, vary widely across types of relationships, reflecting the weight of the decision and how selective women are about to whom they will disclose (Armistead et al. 1999; Kalichman et al. 2003; Serovich et al. 2007; Simoni et al. 1995, 2000; Sowell et al. 1997, 2003). In particular, rates of serostatus disclosure to sexual partners have been reported to range from 56 to 87% (Armistead et al. 1999; Simoni et al. 1995; Sowell et al. 1997, 2003). Disclosure to mothers ranges from 59 to 66% (Armistead et al. 1999; Kalichman et al. 2003; Simoni et al. 1995; Sowell et al. 1997), while disclosure to fathers is far less likely, 25 to 33% (Armistead et al. 1999; Serovich et al. 2007; Simoni et al. 1995; Sowell et al. 2003). There is a wide range of disclosure rates with children, varying by age and gender of the target child (Murphy 2008). Likewise, rates of disclosure to friends vary tremendously from sample to sample, ranging from 20 to 86% (Armistead et al. 1999; Simoni et al. 1995; Sowell et al. 1997).

The research on women’s HIV status disclosure has examined a number of individual-level variables as possible explanations for the differential rates of disclosure. Perhaps the most common explanation to have been examined is time since diagnosis, despite empirical support for this position having been mixed. The argument is that women who have lived with the disease longer are more likely to disclose and women at more advance stages of disease disclose to obtain support surrounding their disease (Kirshenbaum and Nevid 2002; Rotheram-Borus et al. 1997; Serovich et al. 2008; Simoni et al. 1995, 2000). Emotional distress has also been explored, the claim being that women suffering from emotional distress have less of an emotional reservoir to draw upon to engage in the difficult task of disclosure (Armistead et al. 1999; Comer et al. 2000; Kalichman et al. 2003; Rotheram-Borus et al. 1997). This line of work has also uncovered racial/ethnic differences in disclosure patterns. Spanish-speaking Latinas have been found to be less likely to disclose than English-speaking Latinas, White, or African American women (Comer et al. 2000; Simoni et al. 1995). African American women have been found to have lower rates of disclosure relative to White women, with respect to certain relationships (Sowell et al. 1997).

While these individual-level variables have been shown to be critical determinants of disclosure practices in some studies, it is important to remember that disclosure is inherently an activity engaged in within the context of a social relationship. The focus of so many studies on women’s differential disclosure across various types of relationships reveals an implicit understanding of the relational aspect of HIV/AIDS disclosure for women. Simply put, it matters a great deal to women to whom they disclose (Armistead et al. 1999; Kalichman et al. 2003; Serovich et al. 2007; Simoni et al. 1995, 2000; Sowell et al. 1997, 2003). Moving beyond the broad categories of mother, partner, child, or friend, recent work has demonstrated that relationships from which women derive more social support are more likely to be the targets of disclosure (Simoni et al. 2000) and women who report greater levels of social support, in general, are more likely to disclose (Crosby et al. 2005; Kalichman et al. 2003). In addition, relationships which women describe as more satisfying are more likely to be the targets of disclosure (Serovich et al. 2007). Moreover the HIV serostatus of the target (especially sexual partners) has been shown to be relevant to women. Many women cite fears of rejection from HIV-negative partners as a reason for non-disclosure (Sowell et al. 2003). These fears are not without warrant, as some women suffer violence after disclosing to sex partners (Gielen et al. 2000b).

A comprehensive explanation of women’s disclosure practices must incorporate both individual-level and relational explanations for why a woman discloses her serostatus. This paper examines the factors which are associated with disclosure in social networks for HIV-positive women of color (primarily Latina and African American). In particular, individual-level variables such as mental health, time since diagnosis, disease stage, and demographics are examined side by side relational variables, such as giving and receiving social support, the HIV-status of the target, and what role (e.g., sex partner, parent, friend, child, etc.) that target occupies. By doing so, a clearer picture emerges of the nexus of social and psychological processes which lead to disclosure to a particular target relationship in HIV-positive women’s social networks.

Methods

Participants

This study assessed the disclosure patterns of 234 women living with HIV/AIDS (WLH) recruited to be part of a family-based HIV intervention (TALK LA). The total TALK LA intervention sample included 339; however,
only the WLH who delineated their personal social network ties were included in the final analysis (n = 236, 2 were dropped because they did not report disclosure to their network ties). Eligible WLH were: (1) the mother or primary female caregiver of a child, ages 6–20; and (2) HIV-positive, based on self-report. Participants were recruited in Los Angeles County, California from January 2005 to October 2006 from HIV/AIDS clinics, general medical clinics, HIV/AIDS community-based organizations, peer referrals, and from the rosters of previous studies (refusal rate = 6.4). All data were self-reported and collected in face-to-face interviews by trained field staff using laptop computers.

Measures

Each WLH was asked to list up to five “friends” (i.e., targets) with whom she spent time in the previous week resulting in 565 network members across the 234 WLH. Incomplete information was reported for one network member leaving 564 members for the analyses. Participants were instructed as follows: “I want you to think about your friends that you spent the most time with in the last 7 days. Feel free to include your husband/partner or boyfriend, your relatives, or your children in this list if you consider them to be your friends.” The benefit of collecting and analyzing network-level data is that it allows for variation in disclosure between targets for any given WLH. If one were to instead sum the number of disclosures across all targets or report the frequency of disclosures among targets in the network, one can only assess the tendency to disclose at the level of the WLH. Whereas, using target-specific data allows for differences in disclosure to be assessed at the level of particular relationships.

The outcome variable disclosure to a given target member, e.g., target #1, in the network was assessed by asking: “As far as you know, does [target #1] know about your HIV status?” This variable is coded independently for each target member in the network.

Key network-level independent variables were also assessed independently for each target network member. Types of relationship was assessed based on the response to: “How would you characterize your relationship to [target #1]? (1) child, (2) friend, (3) husband/boyfriend/partner, (4) parent, (5) other relative, (6) acquaintance, (7) co-worker, (8) case manager/social worker, or (9) other. Having an HIV-positive network member was assessed by coding 1 for partner HIV-positive, relative to HIV-negative or unknown based on responses to: “As far as you know, has [target #1] ever tested positive for HIV?” Three aspects of social support were assessed, giving, receiving and reciprocal (both giving and receiving social support). Receiving social support was assessed with the item: “Has [target #1] helped you when you had problems?” Giving social support was assessed with: “Does [target #1] come to you when he/she has problems?” Targets that both received and gave support were coded as reciprocal.

Demographic variables included race/ethnicity, whether the interview was conducted in Spanish or English, the number of years of employment (categorized as employed or not), age, annual income per capita, having been married during lifetime, and the number of children sharing the residence. Health-related variables included CD4+ count, annual number of doctor visits, years since HIV diagnosis, and age at time of HIV diagnosis.

We assessed HIV-transmission behaviors based on the number of sexual partners and two indices of substance use during the past 6 months. We derived indices for the presence (1) or absence (0) of alcohol use and the presence or absence of hard drug use, defined as use of barbiturates, cocaine or crack, hallucinogens, heroin, inhalants, injection drugs, opiates or painkillers, party drugs, e.g., ecstasy, sedatives, or stimulants.

Mental health was assessed by: a question on whether or not the WLH received services during the past 6 months on an outpatient basis through counseling or hospitalization; and three symptom domains (global distress, anxiety, and depression) from the Brief Symptom Inventory (BSI; Derogatis 1993). Disclosure averse-attitudes, a Likert-measure assessed how often the WLH figured out ways to hide their serostatus, ranging from never (1) to always (5). The sum of responses to 13 Yes (1) or No (0) items assessed whether particular HIV-related incidences occurred during the past 6 months. This variable is a sum of perceived negative events related to a WLH’s HIV illness in the previous 12 months, ranging from being teased about her status, to violence and abandonment.

Data Analysis

Disclosure to network members was treated as a dichotomous outcome and regressed on social network-level measures (i.e., measures that varied across targets) and WLH-level measures (i.e., measures that only varied across WLH in the study) that were selected based on theoretical considerations. WLH-level measures were created based on standard individual responses to particular items. Network-level measures, on the other hand, are unique to each member of a given WLH’s network. Members of each WLH’s network cannot be assumed to be independent of one another (Wasserman and Faust 1994). Because the disclosure practices of WLH within her personal network are likely to be highly correlated, models included random intercepts for each WLH to model correlated disclosure patterns within the network. Covariates found to be significant in the univariable models were entered into a
multivariable model. All analyses were carried out in SAS software version 9.1. Random-intercept logistic regressions were fit in the PROC NLMIXED procedure.

Results

Turning first to individual-level descriptive statistics presented on Table 1, the majority of women in this sample ($n = 234$) were Latina and the majority of Latinas were Spanish-speaking. The women in this sample came from disadvantaged socio-economic circumstances; the majority did not graduate from high school and per capita household income was below the poverty threshold on average. CD4 positive counts on average were well above the clinical cut point for an AIDS diagnosis and women had been diagnosed with the disease on average for nearly a decade.

HIV-transmission risk behaviors were low. Most mothers either reported being abstinent (44%) or having one sexual partner (48%) during the past 6 months. About a quarter were using alcohol (26%) and 16% were using hard drugs during the past 6 months.

Table 2 presents descriptive statistics on the 564 partners nominated by the women in the sample. Reflecting the emphasis of the instrument on “friendship” ties, the most frequently nominated partner type was a friend, followed by a relative, child, and spouse/romantic partner. Over 80% of nominated persons were described as either giving and/or receiving social support, reciprocal ties describing 77% of the relationships on which women reported. Nearly three quarters of nominated persons were believed to be HIV-negative.

Table 2 also reports relative disclosure rates across various relationships. The relationship type which received the greatest percentage of disclosures was spouses/romantic partners, followed by children, acquaintances, and friends. Nearly three quarters of partners from whom women receive social support were the targets of disclosure. Finally, although HIV-positive persons constituted a minority of women’s nominated network members, over 90% of those persons were targets of serostatus disclosure.

Table 3 reports the results of univariable random-intercept logistic regressions on the odds of disclosure (OR) and 95% confidence intervals (CI). The variables included in this table were selected because previous literature has shown them to be important. Several variables were significant in these univariable models, which were not significant in the final multivariable model presented in Table 4. In particular, the odds of disclosure was associated with greater variation in the types of HIV-related incidences encountered, fewer children sharing the residence, and increased emotional distress. For all these variables the direction of the association remained the same.

### Table 1 Individual-level measures, women living with HIV/AIDS, Los Angeles 2005–2006 ($N = 234$)

| Category                              | $n$ (%) |
|---------------------------------------|---------|
| **Sociodemographics**                 |         |
| Mean age (SD)                         | 40.2 (8.6) |
| Interviewed in Spanish, $N (%)        |         |
| No                                    | 112 (47.9) |
| Yes                                   | 122 (52.1) |
| Race/ethnicity, $N (%)                |         |
| Latino                                | 148 (63.3) |
| White                                 | 11 (4.7) |
| A.A.                                  | 70 (29.9) |
| Other                                 | 5 (2.1) |
| Education, $N (%)                     |         |
| 8th gd or less                        | 74 (31.8) |
| Some high school                      | 66 (28.3) |
| High school                           | 30 (12.9) |
| GED                                   | 5 (2.2) |
| Higher                                | 58 (24.9) |
| Current job, $N (%)                   |         |
| Yes                                   | 57 (24.4) |
| No, unemployed                        | 97 (41.5) |
| No, retired/disabled                  | 80 (34.2) |
| Mean money received per capita (SD)   | 355.3 (298.9) |
| Every married, $N (%)                 |         |
| No                                    | 87 (45.5) |
| Yes                                   | 104 (54.5) |
| Mean children sharing residence (SD)  | 1.9 (1.4) |
| **HIV-related health, mean (SD)**     |         |
| CD4 count                             | 517.2 (598.4) |
| Viral load                            | 8208.2 (27027.5) |
| Years since HIV diagnosis             | 8.4 (5.1) |
| Age of HIV diagnosis                  | 31.9 (9.0) |
| **HIV-related experiences**           |         |
| HIV-related incidences, mean (SD)     | 1.7 (2.1) |
| Disclosure-averse attitudes, mean (SD) | 2.8 (1.7) |
| **Mental health**                     |         |
| Received mental health services       |         |
| No                                    | 40 (17.1) |
| Yes                                   | 194 (82.9) |
| Mean BSI (SD)                         |         |
| Global index                          | 0.7 (0.6) |
| Anxiety                               | 0.7 (0.7) |
| Depression                            | 0.8 (0.7) |
| **HIV-transmission risk behaviors**   |         |
| Abstained from sex previous 6 months  | 103 (44.0) |
| 1 Sex partner, previous 6 months      | 122 (52.1) |
| Used alcohol, previous 6 months       | 61 (26.1) |
| Used hard drugs, previous 6 months    | 38 (16.2) |
but the significance was lost in the multivariable models shown in Table 4.

Turning to the multivariable model presented on Table 4, containing only individual-level variables, disclosure-averse attitudes was associated with a 46% reduction (OR = .64 [.50–.84], \( t = -3.31, \ df = 196, \ P < .01 \)) and each logged CD4 count was associated with a 36% increase (OR = 1.36 [1.13–1.63], \( t = 3.33, \ df = 196, \ P < .01 \)) in the odds of disclosure; odds of disclosure changed little with the addition of network-level measures. While the effect was slightly attenuated in the presence of network-level measures, the odds of disclosure was almost three times as likely for WLH receiving mental health services (OR = 2.95 [1.01–8.65], \( t = 1.97, \ df = 196, \ P = .05 \)).

Both disclosure-averse attitudes and CD4 counts reflect the propensity to disclose to any relationship in their network. Characteristics of those relationships, however, were significantly associated with the propensity women have to disclose to those relations. In particular, controlling for all other individual and network-level variable, the odds of a woman disclosing to a given network member were 2.5 times more likely if that target provided the woman with social support (OR = 2.53 [1.10–5.82], \( t = 2.18, \ df = 196, \ P < .05 \)). Odds of disclosure were more than 10 times as likely for social network members whom women believed to be HIV-positive (OR = 10.52 [3.76–29.42], \( t = 4.49, \ df = 196, \ P < .01 \)). Finally, relative to all other types of relationships, spouses/romantic partners had four times the odds of being the targets of disclosure (OR = 4.06 [1.28–12.83], \( t = 2.38, \ df = 196, \ P < .05 \)).

Discussion

By using individual-level and network-level data simultaneously, this study provides a complex understanding of what factors are associated with women’s disclosure practices to members of their social networks. There are several important findings that emerge from this analysis, some in keeping with previous studies and others that are
contradictory. Turning first to individual-level results, in keeping with recent work that has assessed women’s fears surrounding disclosure (e.g., Chin and Kroesen 1999; Clark et al. 2003; Gielen et al. 1997, 2000a; Sowell et al. 1997; Wolitski et al. 2008), these data show that women with disclosure-averse attitudes were less likely to disclose, regardless of the particular target. Women in the United States continue to worry about the negative outcomes of disclosure and such fears become real barriers in the process of disclosing to network members. Second, these data revealed that women who had higher CD4 counts were more likely to disclose. This finding contributes to the jumble of inconsistent findings with respect to disease progression and disclosure among women (e.g., Kirshenbaum and Nevid 2002; Rotheram-Borus et al. 1997; Serovich et al. 2007; Simoni et al. 1995). Perhaps for these women, being physically healthier enables them to have a greater capacity to manage the social and psychological challenges of sharing the secret of their disease with important people in their lives.

There were also three important negative findings that are worth mentioning. Previous research has often linked disclosure to length of time since diagnosis (Kirshenbaum and Nevid 2002; Rotheram-Borus et al. 1997; Serovich et al. 2008; Simoni et al. 1995, 2000), emotional distress (Armistead et al. 1999; Comer et al. 2000; Kalichman et al. 2003; Rotheram-Borus et al. 1997), and race/ethnicity (Comer et al. 2000; Simoni et al. 1995). None of these factors were significantly associated with disclosure in networks in the final multivariable model, whereas disclosure-averse attitudes, history of counseling, CD4+ count, and several social network-level variables were significantly associated.

A woman’s disclosure within her social network is largely related to network-level factors influencing her decision. First, network members who provide social support were more likely to be the targets of women’s disclosures, which supports other recent work on the importance of social support in facilitating disclosure for women (e.g., Kalichman et al. 2003; Simoni et al. 2000). Second, for women living with HIV/AIDS, spouses/romantic partners were the relationship to which women were most likely to have disclosed, relative to all other relationships. Several other researchers have found the highest rates of disclosure to sex partners (e.g., Simoni et al. 1995; Sowell et al. 1997), while other studies have highlighted the importance other social relationships (Armistead et al. 1999; Kalichman et al. 2003; Serovich et al. 2007; Sowell et al. 2003). Finally, for the women in this sample, network members who are known to be HIV-positive were much more likely to be the targets of disclosure relative to members known to be HIV-negative. This last result has been demonstrated repeatedly in samples of men who have sex with men, but rarely in samples of women (Arnold et al. 2008). Although many of these results are in keeping with previous literature, this study shows that even controlling for the more typically researched individual-level variables, these network-level variables are strongly associated with disclosure practices within networks.

It has been well established that women are selective in their decisions about to whom, how, and when to disclose (e.g., Armistead et al. 1999; Kalichman et al. 2003; Serovich et al. 2007; Simoni et al. 1995, 2000; Sowell et al. 1997, 2003). These network-level results provide insights into why women choose to disclose to certain members of
their networks over others. In a recent review article, it was proposed that social roles and social identities both play an important function in the whys and wherefores of disclosure (Arnold et al. 2008). Viewing the present results through the lens of social roles and social identities imbues these data with added meaning.

Social roles, as conceptualized by many social psychologists, refer to ongoing relational identities, such as mother, sexual partner, child, or friend (Burke 1980; McCall and Simmons 1978; Stryker 1968; Turner 1978). In one's social network, the social role occupied by a given member dictates a set of socially shared, taken-for-granted expectations for behaviors, values, and beliefs that are conferred to that respective member; these expectations, based on social role, are above and beyond the expectations that accompany that network member based on their history of support. Being a spouse/romantic partner is a social role laden with social expectations of trust, support, and honesty. For HIV-positive women there are additional expectations that incumbents of these roles need to be protected from disease; that they have a “right” to know about potential exposure to the disease. For a woman considering disclosing to an occupant of the “partner” role, these social expectations come into play, increasing the odds of disclosure, despite the well documented fears women have regarding disclosure to their partners.

Social identity, likewise, helps to bring clarity to these results. Most social psychologists conceptualize social identities as large social categories, which people occupy, such as African American, woman, and HIV-positive person (Hogg and Abrams 1988; Tajfel and Turner 1979; Turner 1982, 1985, Turner et al. 1987). Like social roles, social identities are also associated with a set of expectations for behaviors. In the disclosure process, perhaps the most salient social identity is “HIV-positive person”. Particularly, in the United States where HIV/AIDS has long since been a highly politicized disease, there is a host of socially agreed upon expectations attached to “HIV-positive person” as a social identity. Perhaps part of why women were more likely to disclose to other HIV-positive persons was because of the socially shared expectations for others who share the HIV-positive identity. Paramount among these expectations may be an assumption that another HIV-positive person will share the burden of stigma, will not reject one based on fears of disease, and will likely be a reliable source of continued support.

Despite the strengths of the social network data for the modeling of the disclosure process, there are a few limitations to the current data that must be acknowledged. First, this study uses cross-sectional data. As such, the results are inherently associational and not causal. Second, the data are not exhaustive of disclosure events in the lives of the women under study. These data come from questions that begin with asking women to delineate network ties (couched as friends and others), followed by questions regarding having disclosed status or not to those network members. It is likely that past network members to whom women disclosed but who reacted negatively to the disclosure were no longer within the domain of relations under study here. Thus, these results should be interpreted within the domain of disclosure practices with ongoing social relationships with important network members only. Third, the measure of disclosure used here is defined somewhat differently from other studies. Here women reported on whether or not network members “know your HIV status,” which allows for the possibility of a third party having made the disclosure. Thus, in some cases, disclosure may be more properly interpreted at HIV status “awareness.” Fourth, because disclosure practices were investigated for women who delineated network ties, there was no disclosure information collected on the minority of women who did not specify their network. Additional analyses not reported here showed that women who did not delineate a network perceived less social support in general. Given the link between disclosure and receipt of social support (e.g., Chin and Kroesen 1999), it is entirely possible that women who did not delineate their networks were among the least likely to disclose their status to anyone.

These data have important implications for future research on the disclosure practices of women living with HIV. First, research on disclosure would benefit greatly from increased attention to disclosure within relationships and within social networks. Disclosure is inherently a social process, including at least two persons. If work on disclosure is to progress it must move beyond the typical focus on the disclosing individual and move toward an examination of relationships and networks. In depth qualitative interviews with women about their relationships and how, when, and why they disclosed or not to key persons would inform research on this topic. Moreover, detailed qualitative examinations of women’s social networks may help to uncover social factors that encourage and discourage disclosure. For example being a part of a network of religious persons (as many Latinas and African America women are) may facilitate or inhibit disclosure. Traditional values held dear in such a network may discourage disclosure. The social support, however, that women derive from these communities may encourage disclosure. The data presented here suggest both processes will likely be in play. Networks impact behaviors in powerful ways and there is a dearth of research documenting these phenomena and the implications such social forces may have on disclosure practices and subsequent secondary prevention efforts directed at HIV-positive women.
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