



Published in final edited form as:

*AIDS Behav.* 2011 July ; 15(5): 992–1002. doi:10.1007/s10461-010-9707-y.

## Social networks of PLHAs in Uganda: Implications for mobilizing PLHA as Agents for Prevention

Harold D. Green Jr.<sup>1</sup>, Lynn Atuyambe<sup>2</sup>, Sarah Ssali<sup>2</sup>, Gery Ryan<sup>1</sup>, Eric Sseguja<sup>2</sup>, Nicolante Nekesa<sup>2</sup>, and Glenn Wagner<sup>1</sup>

<sup>1</sup>RAND Corporation, Santa Monica, CA <sup>2</sup>Makarere University, Kampala, Uganda

### Abstract

The objective of this study was to describe the social networks of people living with HIV/AIDS (PLHA) and explore the implications social network characteristics might have for mobilizing PLHA as prevention agents. Thirty-nine PLHA attending an HIV clinic in Kampala, Uganda provided information on themselves and on 20 network members. Based on these data, descriptive statistics for social network composition and structure were calculated. Research questions relating these network characteristics to treatment-related variables such as time since diagnosis, ART status, and time on ART were investigated. Analyses reveal that, in general, network members know the PLHA's status, are trusted, provide advice and support, and are well-connected to each other. Network features (e.g., proportion of individuals who know the PLHA's status) are related to the previously mentioned treatment variables. Findings suggest that PLHA surround themselves with a social context that enables PLHA to feel fairly protected and supported if they choose to discuss HIV and prevention. With respect to treatment, those on ART may be better prepared to act as prevention advocates.

### Introduction

People living with HIV/AIDS (PLHA) have a crucial role to play in preventing further spread of the HIV virus. Prevention programs increasingly target PLHA, but these efforts focus almost solely on their individual risk behaviors, rather than tapping the potential for this population to promote HIV prevention and behavior change in their social networks. If HIV clients in care advocated for HIV prevention to those in their social networks, prevention messages could diffuse through those networks to reach a larger number of individuals, broadening the impact of prevention activities. However, to design successful programs that empower PLHA to advocate for prevention in their social networks, it is important to first have a greater understanding of these networks and how prevention advocacy might function within them.

Research on the social networks of PLHA has been limited largely to studies of HIV transmission and risk behaviors, many of them focused on networks of injection drug users (IDUs), though some recent studies have focused on social support.<sup>1</sup> HIV risk studies have found that IDUs with more interconnected networks are more likely to share needles, as are drug users with larger drug-using subgroups in their networks, thus increasing the risk of HIV transmission.<sup>2–4</sup> A study by el-Bassel et al.<sup>5</sup> indicated that HIV-positive women on methadone were more likely to associate with HIV-positive network members than their

HIV-negative counterparts. This study recommended that HIV prevention programs should extend beyond individual attributes to address contextual dynamics of social networks.<sup>6</sup> Knowlton et al.'s study of the support networks of HIV+ injection drug users also suggests that interventions target social networks to improve social support and utilization of medical services.<sup>1</sup> Based on these findings, network-based interventions have been developed to reduce risk behaviors among IDUs by focusing on social contexts beyond those of individuals or dyads, and have resulted in promising outcomes.<sup>2, 7</sup> While the above cited studies generally apply social network analysis in HIV prevention, these study findings are not readily generalizable to non-IDUs or other groups among PLHA.<sup>1, 8, 9</sup>

Furthermore, nearly all of these network studies have focused on populations in the United States. Little is known about the networks of PLHA living in Africa. A study in KwaZulu-Natal established that the number of close friends and family members in an individual's support network was significantly correlated with a greater sense of social support for adherence in HIV disease.<sup>10</sup> Another study in South Africa provided richer descriptive information on the individuals who provide treatment support and how they might affect health outcomes,<sup>11</sup> with family and close friends identified most often as treatment support providers.

Though not focused on African populations, Campero et al.<sup>12</sup> also found that more family and self-help group members in an individual's support network increased the likelihood of PLHAs being able to access and adhere to ART. Knowlton et al.<sup>1</sup> found, on the contrary, that having a supportive spouse or more supportive kin did not increase medical services utilization, though more sources of support did. However, these studies, including those in Africa, applied "social networks" as a metaphor to describe the social support context rather than as a structure that may be more or less capable of providing necessary support. That is, these studies asked respondents questions such as "How many friends can provide you with X resource?" to elicit information on network composition. These studies did not ask the questions required to elicit social structure.

An in-depth assessment of social networks allows the examination of how structural and compositional network characteristics may influence information exchange and both protective and risky behaviors.<sup>13</sup> Studies outside the context of HIV suggest that individuals are embedded in networks of social relationships and systems of support that influence their health behavior and decisions.<sup>14</sup> Individuals may be influenced through a number of mechanisms operating in their social networks, such as social influence,<sup>15</sup> social norms,<sup>16</sup> social modeling,<sup>17</sup> social monitoring,<sup>18</sup> social support<sup>19</sup> or sanctions<sup>20</sup> working singly or interdependently. Thus, understanding the social network characteristics of PLHA is a critical first step for developing network-based interventions to reduce risk and improve health behaviors among PLHAs and their social network members.

There is much to discover about the social network characteristics of PLHA in Africa. This study uses innovative personal network methods to examine the social networks of persons receiving HIV care with respect to composition (What type of people do PLHA interact with?); structure (How interconnected are the members of PLHA's networks and how strong are the ties between them?); and the nature of the relationships between the respondent and the members of their network with regard to trust, support, and HIV disclosure. Network composition and structure may not only influence trust and social support, but also information exchange, perceived norms, and the process by which behavior change among network members can be facilitated. It is unknown whether these network features vary depending on length of time since HIV diagnosis, whether or not someone is on HIV antiretroviral therapy (ART), and, if so, for how long they have been on ART. Thus, the study also assesses whether network characteristics differ depending on time since HIV

diagnosis, ART status and length of time on ART. Due to small sample sizes and very little previous research on the personal networks of PLHA in Africa and even less on how features of HIV treatment might relate to network structural and compositional features, we focus on investigating these research questions:

1. To what extent does time since diagnosis affect personal network structure and composition?
2. To what extent does being on ART affect personal network structure and composition?
3. To what extent does time on ART affect personal network structure and composition?

This is, to our knowledge, one of the few studies to apply personal network methods in the study of social support and HIV care and perhaps the only study to apply these methods in Uganda, if not in all of Africa. The findings will inform interventions that target the interrelated concepts of trust, stigma, social support and HIV prevention advocacy.

## Methods

### Study Participants

Participants in this preliminary, cross-sectional study included a convenience sample of 39 HIV-positive adult clients attending an HIV clinic (The Infectious Diseases Institute) in Kampala. The sample was stratified based on ART status and length of time on ART, consisting of 19 non-ART clients in care for variable amounts of time, 10 clients on ART for 6 months or less, and 10 clients on ART for 12 months or more. Over the course of one month, a clinic staff member identified clients in attendance at the clinic by announcing the study to the clients in the waiting room, screening those who were interested to determine whether they fit the selection criteria. Selection was based purely on meeting sampling criteria: equal numbers of men and women and equal numbers of those on ART and not on ART. Eligible clients were referred to the study interviewers for further description of the study and consent procedures including assurance of confidentiality. Though no direct data on refusals were collected, the study interviewers report that very few (less than five) respondents refused to participate, with no evidence of systematic refusal that might have biased our results. The research protocol was approved by the Higher Degrees, Research and Ethics committees of the Faculty of Medicine at Makerere University and the Human Subjects Protection Committee at RAND.

### Measures

Data were collected between February and March 2009. Computer assisted, in-person, structured interviews were conducted by trained social science graduate students in the respondent's language of choice, usually English, Luganda or Lunyankole though other tribal languages were used when necessary. The study team reported no incidents for which item translation was problematic or potentially confusing for participants. We believe that the statements were straightforward enough for easy translation into any of the primary languages and simple enough to be easily understood. Participants received 10,000 Uganda Shillings (~ \$6 USD) after the interview to compensate for transportation costs.

Demographic (age, sex, marital status, education level, occupation) and HIV medical (date of HIV diagnosis, CD4 count, ART treatment status, and ART start date) characteristics of the respondent were collected.

Perceptions of general social support, peer community support, HIV discrimination, and internalized HIV stigma were assessed with single items from previously developed and tested scales. General social support was assessed using, “I can count on my family and friends to give me the support I need”, and a 4-point rating scale with higher scores representing greater support.<sup>21</sup> Community support amongst fellow HIV clients or peers was assessed with, “I feel a sense of community when I am with other HIV clients here at the clinic,” rated from 1 “strongly disagree” to 4 “strongly agree.” HIV discrimination was measured using a single item from an 8-item scale developed by Berger and colleagues.<sup>22</sup> Participants were asked to rate their level of agreement with the statement, “My friends and family stopped visiting me when they found out I was HIV positive” using a 4-point scale; higher scores represent greater discrimination. Internalized HIV stigma was assessed with a single item from an 8-item scale developed by Kalichman et al.<sup>23</sup> Participants were asked to rate their level of agreement with the statement, “I am ashamed that I am HIV-positive” using a 4-point rating scale with higher scores representing greater stigma. Single items, rather than complete scales, were used to limit respondent burden and because of the pilot nature of the study. The specific items were selected because the concepts they probed were most relevant to our research questions.

To assess the respondent's social network, we used a personal, egocentric network approach, which focuses on the network of ties that surround the respondent. Established procedures for conducting personal network interviews were employed,<sup>24–26</sup> through which network information is collected from one individual about their network (the participant, or ego) rather than from each member in the network. The personal network approach is designed to identify the wide range of network members individuals interact with in their lives (“alters”) and to measure participants' understanding of the connections among those alters. The interview included the three following sections to elicit social network information:

In the Alter Generation section, participants list the first and last initials of 20 individuals with whom they have been in communication in the past 6 months (by phone, email, in person, etc.), starting with those most important to them. These individuals could include kin (immediate and extended family), friends, acquaintances, neighbors, or people in service/helping positions (e.g., health care workers, counselors). While there is likely a large amount of variation in individuals' personal network sizes, research has demonstrated that 20 alters can reliably capture the variability in most network characteristics.<sup>27</sup> Thus, all respondents named 20 and only 20 alters.

In the Alter Composition section, the following data are collected from each network alter: demographic and background information (age, gender, HIV status, and if HIV-positive, whether or not they are in HIV care and on ART); information about the nature of the relationship to the respondent, including type of relation (e.g., family member, friend, sex partner, service provider), whether the person knows the respondent's HIV status, ratings of closeness and trust, and how much the respondent talks to, seeks advice from and receives and provides support to the alter.

To assess Network Structure, respondents indicate if each unique pair of alters knows each other and how often they interact. Each affirmative response corresponds to a link in a network diagram between two alters. The level of interaction represents how well the two individuals know each other in general. Based on this information one can determine, for instance, who the most important individuals are, and how interconnected the network is overall. Because this pilot study was focused on understanding general patterns of interaction, no further information about supportive (sharing resources) or risky (sexual contact, drug use) behaviors was collected.

The following network structural measures were calculated and used in subsequent analyses. Network density is calculated as the ratio of ties that are reported to the total number of possible ties. Maximum degree is the number of relationships reported with the most popular network member, providing information on how many other network members that individual could contact directly. Average degree indicates how well-connected all network members are, on average. Components are groups of three or more individuals completely separated from others, which, when combined with the size of the largest component, provides information on how fragmented a network might be. A clique is a group of individuals all connected to each other, another indicator of network interconnectivity. The number of isolates in a network indicates the level of fragmentation in a network.<sup>28</sup>

## Analysis

Because the primary goal of this paper is to describe the personal networks of PLHA, we present descriptive statistics for the measures described above. For investigations of the relationships between network characteristics and time since HIV diagnosis, ART status, and time on ART, ANOVAs and bivariate correlations were calculated.

## Results

### Socio-Demographic Characteristics of Respondents

The mean age of the 39 respondents was 34 years (SD=9; range: 18 to 52), the average level of education was 9.8 years (SD=3.1), and a large proportion (67%; n=26) reported current occupations that provided household income. As in most HIV clinics throughout Uganda and Sub-Saharan Africa, the majority of the respondents were women (67%; n=26); nearly half the sample was married (49%) and another 31% were either divorced or had a spouse who had died. Mean self-reported CD4 count was 332 (SD = 174), and mean length of time since HIV diagnosis was 48 months (SD = 52.6; range: 2 to 224 months, about 18.5 years).

### Demographic Characteristics of Network Members

With respect to network composition, PLHA's network members were an average of 34 years old, half were female (52%, about 10 network members), and most were either family members (including spouses) (45%, 9 network members) or friends (33%, about 7 network members). Seven percent of alters were co-workers (about 1 network member), but all other types of network members (e.g., non-spousal sex partners, church members, HIV clinic patients, healthcare providers) represented less than 2% of the alters elicited, less than one network member on average. These results are also presented in Table 1.

### Social Support, Stigma, Discrimination

Over two thirds of our respondents (69%) felt supported by their social networks in general. Most (69%) felt a strong sense of community when at the clinic. Specific support behaviors between respondents and their network members were expressed in terms frequency of contact, degree of trust, and likelihood of receiving advice or tangible support such as food and clothing. Respondents reported having more than occasional contact with 98% of their alters (nearly all 20 network members) in the past six months and trusting 76% (about 15 network member) of those alters. Respondents received advice from 67% (13) of alters and received tangible support from 55% (11) of their alters. Only 10% of respondents expressed feeling ashamed because they were HIV positive. However, 25% agreed that people they knew stopped calling them or visiting them when they learned that they were HIV positive. These results are also presented in Table 1.

## Social Network Structure

Structural analyses revealed that most networks were well-connected. Network density averaged 47% in our respondents' networks, when we consider interactions between network members defined as 'sometimes' or 'often'. When we only consider the most frequent interaction, 'often', network density remains fairly high at 20%. Keeping our focus on the most frequent level of interaction, these networks showed an average of 1.5 completely separated components, with the largest component containing, on average, 65% (13) of network members. Networks averaged only 3 isolates revealing that 85% (17) of alters are connected and interact 'often'. On average, the most popular member of our respondents' networks was directly connected to 43%, or 9, of all other network members, while the 'average' network member was connected to 20%, or 4, of all other network members. These results are presented in Table 1.

### Relationships between knowledge of HIV status and social support

Bivariate correlations indicate that those who have a higher proportion of network members who are aware of the respondent's HIV status also report higher proportions of network members who they trust ( $r=0.44$ ,  $p=0.005$ ), and, more importantly, higher proportions of network members who they trust 'a lot' ( $r=0.67$ ,  $p<0.001$ ). Furthermore, a greater level of awareness of the respondent's HIV status in their network also is associated with having a higher proportion of network members from whom they ever receive advice ( $r=0.47$ ,  $p=0.002$ ), receive advice from 'often' ( $r=0.43$ ,  $p=0.006$ ), and receive more tangible support from ( $r=0.36$ ,  $p=0.023$ ).

### Relationships between network characteristics and length of time since HIV diagnosis

Bivariate correlations indicate that respondents who report having been diagnosed longer were more likely to report having more service providers ( $r=0.33$ ,  $p=0.042$ ) and clinic patients ( $r=0.48$ ,  $p=0.002$ ) in their networks, a greater proportion of network members who were aware of the respondent's HIV status ( $r=0.36$ ,  $p=0.024$ ), having more HIV-positive network members ( $r=0.34$ ,  $p=0.036$ ), and contrary to expectations, reported greater feelings of internalized stigma ( $r=0.56$ ,  $p<0.001$ ).

### Relationships between Network Characteristics and ART Status

ANOVAs reveal significant differences between the PLHAs on ART and those that were not, independent of length of time in HIV care (see Table 2). Respondents on ART were older (38.26 compared to 29.80;  $F=10.91$ ;  $df=1, 37$ ;  $p=0.002$ ) and better educated (11.21 years compared to 8.40 years;  $F=9.96$ ;  $df=1, 37$ ;  $p=0.003$ ), with lower CD4 counts (230.77 v. 433.08;  $F=12.98$ ;  $df=1, 24$ ;  $p=0.001$ ). Respondents on ART also had older network members (35.94 compared to 32.13;  $F=6.38$ ;  $df=1, 37$ ;  $p=0.016$ ), went to more of them for advice (74.47% compared to 60.00%;  $F=4.38$ ;  $df=1, 37$ ;  $p=0.043$ ), had a greater proportion of network members who were aware of the respondent's HIV status (68.68% compared to 30.25%;  $F=15.19$ ;  $df=1, 37$ ;  $p<0.001$ ), felt less shame associated with being HIV+ (1.00 v. 1.50 average scale response;  $F=4.29$ ;  $df=1, 37$ ;  $p=0.045$ ), and reported a greater proportion of network members in whom they trusted 'a lot' (42.11% compared to 21.00%,  $F=7.51$ ;  $df=1, 37$ ;  $p=0.009$ ). Respondents on ART also showed a trend toward fewer separate network components (1.30 components compared to 1.70 components;  $F=2.91$ ,  $df=1, 37$ ,  $p=0.097$ ).

Examples of these results are also represented visually as personal network diagrams in Figures 1a and 1b. Figure 1a is of a 34 year old, married, employed female with 9.8 years of education who has been on ART for 15 months. Figure 1b is of a 31 year old married, employed female with 9 years of education who is not on ART. These diagrams present the

personal networks of individuals matched (approximately) on age, gender, marital status, employment, and education, different only on ART status. The respondents themselves do not appear in these diagrams, as they would be connected to all other network members. These diagrams focus only on the interconnections among the network alters. Each network alter is represented by a node; relationships among them are represented as lines. Alters who know a respondent's HIV status are squares; those that do not are circles. Alters who respondents report receiving advice from are black; those who respondents report trusting a lot are larger than those they do not. Each network has approximately the same network density (0.26 for figure 1a and 0.25 for figure 1b). That is, each of these women report the same number of ties among their network alters. These networks are arranged using the Kamada-Kawai layout algorithm,<sup>29</sup> the positions of each node in the diagram are chosen analytically based on network structure rather than researcher decisions. We chose to present these diagrams because figure 1a provides a fair representation of the typical ART patient in our sample. Figure 1b provides a non-ART counterpoint matched as closely as possible to our standard ART patient. Key differences are that the non-ART patient has two, rather than one, network components, seeks advice from few network alters, has an entire component in which no one knows their HIV status, and has disclosed, in general, only to a few very trusted network alters. In contrast, the ART patient has only one primary component, seeks advice from all network alters, has twice as many network alters who are aware of the respondent's HIV status, and seems less likely to require high degrees of trust be associated with status disclosure.

### Relationships between Network Characteristics and Number of Months on ART

Correlations reveal that those who had been on ART for more months reported very frequent contact with more of their network members ( $r=0.68$ ,  $p=0.002$ ), report often receiving tangible support from more alters ( $r=0.62$ ,  $p=0.008$ ), and have more groups of network members who all know each other (known as cliques,  $r=0.51$ ,  $p=0.037$ ).

### Discussion

This may be perhaps the first study to describe the composition and structure of the social networks of PLHA in Africa and how those features might relate to treatment related variables like time since diagnosis and time on ART. Previous studies have reported only network composition,<sup>1-12</sup> not structural or functional characteristics. Using an egocentric, personal network approach, we sought to explore these networks with an emphasis on identifying patterns with regard to makeup of the network members, the extent to which alters are aware of the individual's HIV status, internalized stigma, discrimination and social support received by the individual from those in their network, and the degree of connectedness among network members. In addition, we explored whether these network characteristics are associated with the amount of time that someone has been aware of their HIV status, whether a respondent was on ART, and the duration of ART treatment (the latter of which is a proxy for exposure to the HIV clinic environment and support). Greater understanding of the social network characteristics of PLHA may provide key insights into how HIV clients could be effective agents for positive behavioural change and HIV prevention in their social networks through network-and relationship-based interventions that take advantage of social influence mechanisms.<sup>13-20</sup>

With regard to composition, network members were on average the same age as the index participant, reflecting the predominance of peers rather than parents or children. Men and women were equally represented in these networks regardless of whether the respondent was a male or a female. Nearly half of the elicited members were described as family or relatives and another quarter were described as friends. This finding runs counter to Latkin et al., who found that while respondents may name at least one family member, family was

not the primary component of their social networks.<sup>2, 9</sup> They also run counter to el-Bassel et al's findings among HIV+ men and women.<sup>5, 6</sup> However, these studies focus largely on drug using HIV+ populations in the United States. Thus, it is unknown whether the differences are because of geographic location (United States v. Africa) or behavioral differences (drug use). The high proportion of family in these networks, we believe, is indicative of the larger average size of extended families in Uganda, but these findings also suggest that family and friends remain the core of the social life of these PLHA, despite changes that may have been caused by the epidemic.<sup>30</sup> Ncama and colleagues noted that high proportions of family members are correlated with higher levels of social support, but argue that a more diverse network (such as one that contains family, friends and coworkers as we have found among our sample) may be more effective in the long run.<sup>10</sup> The fact that most individuals report gender-balanced networks composed of similarly-aged friends and family (likely brothers, sisters, and cousins given similar age measures) suggests that in this context peer-based interventions will likely reach a range of individuals who share similar patterns of HIV risk behaviors with the advocate. Homophily within these networks also suggests that peer influence mechanisms may encourage behavioral change within these networks.

Other known HIV-infected individuals represented just over 10% of the network members of the study participants, though there may be others whose status is unknown. This suggests that prevention advocates will likely reach an appropriate (though diverse) audience, comprised of those who are HIV positive and may need encouragement to enter care, those who are HIV- and may need information on prevention activities, and those who do not know their status who may need encouragement to be tested. However, the diversity in respondents' networks vis-à-vis HIV status suggests that a range of prevention advocacy activities should be built into any network-based intervention.

While relatively few network members were thought to be HIV+, participants believed that nearly half of their alters (on average) knew the participant's HIV status. We believe this finding indicates a fair amount of active HIV status disclosure to non-HIV+ network members, though we recognize that people may become aware of a person's HIV status without that person directly telling them, such as through indirect disclosure or deduction.<sup>31</sup> Having more network members aware of the respondent's HIV status was generally related to having more trusted network alters who provided advice and tangible support. Roughly 70% of the sample found their personal networks to be supportive overall, and an equal proportion found the clinic environment and other clinic patients to be supportive. Furthermore, very few expressed feeling shameful about their HIV disease. In general, these data indicate a supportive social environment surrounding PLHA in Uganda, or at least in urban Kampala.<sup>32</sup> This supportive environment suggests that network members, due to their trust of the advocate, may be more likely to listen and adopt new behaviors than they would if those behaviors were suggested by an unknown individual. Trust-based peer influence mechanisms may prove to be powerful vectors for behavioral change within these networks.

However, it is noteworthy that one quarter of the sample reported that at least some of their former network members stopped calling or visiting once they became aware of the respondent's HIV status, and a sizeable minority (30%) described their social network of family and friends, and fellow HIV clients at the clinic, as unsupportive. These latter findings highlight the continued presence of HIV discrimination and its potential as a barrier to disclosure of HIV and prevention advocacy behaviors. This finding underscores the importance of developing specific guidelines for determining the risks associated with disclosing HIV status in the context of network-based prevention advocacy behaviors. Given the same network composition, prevention advocacy may be safe for some and not for others. Interventions should be designed to help educate PLHA on the risks associated with prevention advocacy.



The network structures of study participants can be characterized as well-connected (fairly high density), with few isolated members and a high proportion of interactions among network members. On average, approximately half of the network members interact at least sometimes with each other, and roughly two-thirds of the alters typically make up a single network component, meaning that they are connected to each other either directly or indirectly through relations to other alters. The vast majority of participants had networks with only one or two components, and only 20% of alters were isolates. With the high level of density observed in these networks, and just under half of the network members knowing the respondent's HIV status, it was rare to observe networks in which a person had isolated those who were aware of their HIV status from those who were not aware. While there is little evidence of individuals being rejected by or isolating themselves from those closest to them (based on the density and isolates measures in our study), it is possible that an individual could have been rejected by some of his or her family members (data that were not collected in this study) yet still maintain a high proportion of family members in their network. Because we would be able to see whether family members left or joined the network and would know how frequently a respondent interacted with his or her network members over time, a longitudinal study would shed more light on this phenomenon.

With respect to interventions, few isolates and fairly dense networks suggest that information exchanged through peer advocacy has the opportunity to diffuse through these networks fairly easily and efficiently, and that others will have the opportunity to reinforce that information as it flows to and through them. The presence of behavioral 'feedback loops' among connected individuals further strengthens direct peer influence mechanisms.

Analysis of how time since HIV diagnosis and ART status were associated with social network characteristics revealed that both greater time since diagnosis and being on ART were generally associated with an increase in the proportion of network members who were also HIV-positive, greater awareness of the respondent's HIV status among their network members, and greater perceived social support from the network. This finding could be explained by the increased amount of exposure to HIV peers and opportunities to make friendships as a result of being part of and possibly more exposed to the HIV community and associated organizations, support services and prevention messages at the clinic (e.g., posters, dramas or educational videos), and the more frequent clinic visits associated with ART. Contrary to these findings, and contrary to each other, greater time since HIV diagnosis was associated with a greater likelihood of feeling shameful about one's HIV status, while being on ART was associated with a lower likelihood of feeling shameful. We did not capture the date of entry into HIV care, so it is possible that these findings reflect circumstances in which considerable time had passed between testing HIV-positive and entering HIV care. It could also reflect a cohort effect, in which those who have been diagnosed for longer are from a group that feels more HIV-related shame and internal stigma. However, the increased exposure to the HIV clinic environment and support associated with being on ART may help individuals feel less internal stigma related to being HIV positive. These opposing findings also underscore how little is known about how the availability of treatment resources and the visibility of PLWHA in treatment affect stigma (both internal and external) and discrimination, further evidenced by the conflicting results found in Maman et al.<sup>33</sup> and Maughan-Brown.<sup>34</sup>

The network diagrams in Figure 1, while merely descriptive, when combined with these analyses, suggest that the ART process may reduce stigma associated with HIV status disclosure. That is, perhaps the frequency or periodicity of clinic attendance or the amount of time spent at the clinic each visit or some other care-related variable works in some way to reduce internalized stigma. One possible factor may be that this clinic site, like most HIV clinics in Sub-Saharan Africa, requires that at least someone in the client's network be aware

of the client's HIV status and is able to act as a treatment supporter. Also, the improved health associated with ART can motivate and empower clients to reveal their status. In addition, needing to take antiretroviral medication may encourage clients to disclose their status rather than needing to explain the presence of medications.

These findings have implications relative to how PLHA might expect their networks to change as they become more involved in treatment. That is, as treatment progresses, PLHA may find their network composition changing to include more trusted individuals who know the PLHA's status and who provide advice. The PLHA may also find that their networks become more interconnected, with fewer separate components. Further exploration of network structure and content, through an intervention that uses a network diagram to facilitate discussion, might be useful in exploring who might be an appropriate treatment buddy, who it may be appropriate to disclose HIV status to, who might be able to act as a network 'coordinator' to facilitate provision of support (e.g., transportation, food, etc.), or who might be a potential source of problems with respect to disclosure or treatment. This approach has been used in other health contexts with positive results.<sup>35, 36</sup>

These findings also have implications relative to HIV clients' potential for being advocates for HIV prevention in their social networks. In general, respondents report that a considerable proportion of their current network members are aware of their HIV status and are supportive and trustworthy. This suggests that HIV clients are fairly comfortable disclosing their HIV status and thus may also be comfortable discussing HIV and advocating for prevention and protective behaviors (e.g., HIV testing, condom use) with members of their network without the concern of losing social ties. Alternatively, HIV clients may have lost or eliminated network members who are unsupportive or to whom they would feel uncomfortable disclosing their status or discussing HIV prevention and protective behaviors. The mechanisms leading to our respondents' network composition can only be determined with further longitudinal study. The density and interconnectedness of the networks, however, indicate that information and attitudes can rapidly travel through these networks; hence, messages encouraging HIV prevention and testing could be highly effective in promoting behavioral change throughout the network. Higher network interconnectivity, more advice seeking (communication), less need for high levels of trust to disclose HIV status, and less maintenance of a component of individuals ignorant of their HIV status are features that would facilitate discussion of HIV and HIV related behaviors and attitudes. Interconnectivity may also suggest that prevention advocacy behaviors may extend to other network members via 'ripple effects'.

Network-based interventions<sup>35, 36</sup> may also be effective, though rather than focusing on how PLHA might modify or activate their networks to improve treatment adherence and long-term health outcomes, these interventions might focus on whether the network is one that enables an individual to advocate for prevention safely (perhaps outside the core network elicited in our study but with the support of the core) and which individuals in the core might be effective targets for prevention messages or useful partners for prevention advocacy behaviors in the larger social context. That the most popular network member (the alter most connected to other alters in terms of frequency of contact) is connected to nearly half of all network members should not be overlooked. The extent to which this alter could be encouraged to further promote prevention or serve as a role model for prevention behaviours could have significant impact on improving the perceived norms in the network regarding the use of condoms and HIV testing. Research by Kelly et al.<sup>37</sup> involving popular opinion leaders as agents for prevention in other parts of the world have demonstrated the effectiveness of this strategy in promoting HIV prevention. The persistence of discrimination in some circumstances, does, however, argue for the importance of training to

help PLHA determine when and with whom it is appropriate to advocate for risk reduction behaviors.

Beyond the implications for encouraging all PLHA to advocate for HIV prevention behaviors, findings may, ultimately, indicate that ART patients are more probable prevention advocates than non-ART patients. Our findings suggest that those on ART may have more heterogeneous networks, which means they may have access to a wider variety of individuals for prevention advocacy. Further, because they are on ART, they are likely to have been exposed to or have experienced all the possible changes in social network composition, structure, stigma and social support that might occur. Thus, they are better prepared to speak to the kind of experiences PLHA may have to withstand in the course of the disease. Finally, those on ART have likely already achieved some level of network equilibrium, with drastic changes in their own networks less likely as they increase their prevention advocacy behaviors.

There are several limitations to be considered in interpreting these findings. The study was designed to be exploratory, not to generate population level parameter estimates; thus, sample size is small, limiting generalizability. We are not able to generalize to all PLHA in Uganda and the region because those attending clinics (who comprise our convenience sample) are likely to be less stigmatized and more comfortable disclosing their HIV status and may have greater social support since they must have a treatment supporter to be eligible for ART. We elicited only 20 alters per respondent, which we expect to be sufficient to establish basic information about the networks of this population, but a larger number of alters may have allowed us to capture a more complete range of the members of these networks, particularly non-family network members such as co-workers. The cross-sectional nature of the study limits the ability to capture the effects of the duration of ART and HIV care on social network dynamics; longitudinal prospective studies are needed to assess the impact of time, HIV care and ART on the composition and structure of social networks more fully.

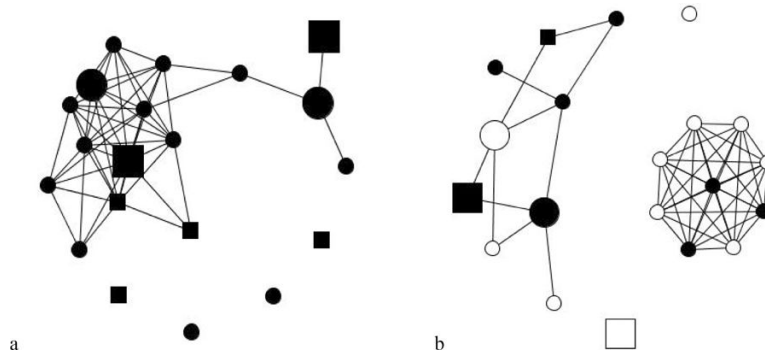
In summary, we have learned that for this group of PLHA, network members know their HIV status, are trusted, provide advice and support, and are well-connected to each other. Network features (e.g., proportion of individuals who know the PLHA's status) are related to being on ART and time on ART. These findings suggest that PLHA surround themselves with a social context that enables PLHA to feel fairly protected and supported if they choose to discuss HIV and prevention. With respect to treatment, those on ART may be better prepared to act as prevention advocates. More research is needed, however, to delineate and define the social network characteristics of this population and explore how PLHA can be empowered to act as agents for change for HIV prevention within these networks. Further research should investigate how treatment-related variables such as time since diagnosis, being on ART, and time on ART might directly affect prevention advocacy behaviors in more detail. Longitudinal studies will also allow us to explore the dynamics of PLHA's social networks, providing even more insight into how the treatment process may affect the social context surrounding PLHA. This paper, however, presents a first step in that direction.

## References

1. Knowlton AR, Hua W, Latkin C. Social support networks and medical service use among HIV-positive injection drug users: implications to intervention. *AIDS Care*. 2005; 17(4):479–92. [PubMed: 16036234]
2. Latkin C, Mandell W, Oziemkowska M, Celentano D, Vlahov D, Ensminger M, et al. Using social network analysis to study patterns of drug use among urban drug users at high risk for HIV/AIDS. *Drug and alcohol dependence*. Apr; 1995 38(1):1–9. [PubMed: 7648991]

3. Potterat JJ, Rothenberg RB, Muth SQ. Network Structural Dynamics and Infectious Disease Propagation. *Int J STD AIDS*. 1999; 10(3):182–85. [PubMed: 10340199]
4. Rothenberg RB, Potterat JJ, Woodhouse DE, et al. Social Network dynamics and HIV transmission. *AIDS*. 1998; 12(12):1529–36. [PubMed: 9727575]
5. el-Bassel N, Chen DR, Cooper D. Social support and social network profiles among women on methadone. *Soc Serv Rev*. 1998; 72:379–401.
6. el-Bassel N, Cooper DK, Chen DR, Schilling RF. Personal social networks and HIV status among women on methadone. *AIDS care*. Dec; 1998 10(6):735–49. [PubMed: 9924528]
7. Latkin CA, Mandell W, Vlahov D, Oziemkowska M, Celentano DD. The long-term outcome of a personal network-oriented HIV prevention intervention for injection drug users: the SAFE study. *Am J Community Psychol*. 2006; 24(3):341–64. [PubMed: 8864208]
8. Montgomery SB, Hyde J, De Rosa CJ, Rohrbach LA, Ennett S, Harvey SM, et al. Gender differences in HIV risk behaviors among young injectors and their social network members. *Am J Drug Alcohol Abuse*. 2002; 28(3):453–75. [PubMed: 12211360]
9. Latkin CA, Forman V, Knowlton A, Sherman S. Norms, social networks, and HIV-related risk behaviors among urban disadvantaged drug users. *Soc Sci Med*. 2003; 56:465–76. [PubMed: 12570967]
10. Ncama BP, McInerney PA, Bhengu BR, Corless IB, Wantland DJ, Nicholas PK, et al. Social support and medication adherence in HIV disease in KwaZulu-Natal, South Africa. *International journal of nursing studies*. Dec; 2008 45(12):1757–63. [PubMed: 18653188]
11. Nachega JB, Knowlton AR, Deluca A, Schoeman JH, Watkinson L, Efron A, et al. Treatment supporter to improve adherence to antiretroviral therapy in HIV-infected South African adults. A qualitative study. *J Acquir Immune Defic Syndr*. 2006; 1(43 Suppl 1):S127–33. [PubMed: 17133196]
12. Campero L, Herrera C, Kendall T, Caballero M. Bridging the gap between antiretroviral access and adherence in Mexico. *Qual Health Res*. 2007; 17(5):599–611. [PubMed: 17478643]
13. Heaney, CA.; Israel, BA. Social Networks and Social Support. In: Glanz, K.; Lewis, FM.; Rimer, BK., editors. *Social Networks and Social Support in Health Behavior And Health Education Theory, Research, and Practice*. Jossey-Bass; San Francisco, CA: 2002.
14. Valente TW, Fosados R. Diffusion of innovations and network segmentation: The part played by people in promoting health. *Sex Transm Dis*. 2006; 33(7 Suppl):S23–31. [PubMed: 16794552]
15. Cialdini, RB.; Trost, MR. Social influence: Social norms, conformity, and compliance. In: Gilbert, DT.; Fiske, ST.; Lindzey, G., editors. *The handbook of social psychology*. 4th ed. McGraw-Hill; Boston, MA: 1998. p. 151-92.
16. Ajzen I, Fishbein M. Attitudes and normative beliefs as factors influencing behavioral intentions in hypothetical situations involving risk. *J Pers Soc Psychol*. 1972; 21:1–9.
17. Bandura, A.; Walters, RH. *Social learning and personality development*; New York, NY. Holt, Rinehart & Winston; 1963.
18. Pickett, CL.; Gardner, WL. The social monitoring system: Enhanced sensitivity to social cues and information as an adaptive response to social exclusion and belonging need. In: Williams, K.; Forgas, J.; von Hippel, W., editors. *The social outcast: Ostracism, social exclusion, rejection, and bullying*. Psychology Press; New York, NY: 2005. p. 213-26.
19. Kelly RB, Zyzanski SJ, Alemagno SA. Prediction of motivation and behavior change following health promotion: role of health beliefs, social support, and self-efficacy. *Soc Sci Med*. 1991; 32(3):311–20. [PubMed: 2024141]
20. Burns TR, Dietz T. Cultural evolution: Social rule systems, selection and human agency. *Int Soc*. 1992; 7(3):259–83.
21. Ware JE, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36): I. Conceptual framework and item selection. *Med Care*. 1992; 30(6):473–83. [PubMed: 1593914]
22. Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Research in nursing & health*. Dec; 2001 24(6):518–29. [PubMed: 11746080]

23. Kalichman SC, Simbayi LC, Jooste S, Toefy Y, Cain D, Cherry C, et al. Development of a brief scale to measure AIDS-related stigma in South Africa. *AIDS and behavior*. Jun; 2005 9(2):135–43. [PubMed: 15933833]
24. Campbell K, Lee B. Name generators in surveys of personal networks. *Soc Networks*. 1991; 13:203–21.
25. McCarty C. Measuring structure in personal networks. *J Soc Struct*. 2002; 3:1.
26. McCarty C, Bernard H, Killworth P, Shelley GA, Johnsen EC. Eliciting representative samples of personal networks. *Soc Networks*. 1997; 19:303–23.
27. McCarty C, Kilworth PD, Rennell J. Impact of methods for reducing respondent burden on personal network structural measures. *Soc Networks*. 2007; 29(2):300–15.
28. Wasserman, S.; Faust, KB. *Social Network Analysis: Methods and Applications*; New York, NY. Cambridge University Press; 1994.
29. Kamada T, Kawai S. An algorithm for drawing general, undirected graphs. *Information Processing Letters*. 1989; 31(1):7–15.
30. Ntozi, JPM.; Nakayiwa, S. AIDS in Uganda: How Has the Household Coped With the Epidemic?. In: Caldwell, JC.; Orubuloye, IO.; Ntozi, JPM., editors. *The Continuing African HIV/AIDS Epidemic*. Health Transition Centre, National Centre for Epidemiology and Population Health, Australian National University; Canberra, Australia: 1999. p. 155-81.
31. King R, Katuntu D, Lifshay J, Packel L, Batamwita R, Nakayiwa S, et al. Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda. *AIDS Behav*. 2008; 12(2):232–43. [PubMed: 17828450]
32. Kaleeba N, Kalibala S, Kaseje M, Ssebhanja P, Anderson S, van Praag E, et al. Participatory evaluation of counseling, medical and social services of the AIDS support organization (TASO) in Uganda. *AIDS Care*. 1997; 9(1):13–26. [PubMed: 9155910]
33. Maman S, Ablert L, Parker L, Lane T, Chirowodza A, Ntogwisangu J, et al. A comparison of HIV stigma and discrimination in five international sites: The influence of care and treatment resources in high prevalence settings. *Soc Sci Med*. 2009; 68:2271–78. [PubMed: 19394121]
34. Maughan-Brown B. Stigma Rises despite antiretroviral roll-out: A longitudinal analysis in South Africa. *Soc Sci Med*. Nov.2009 3 [Epub ahead of print].
35. Tracy EM, Whittaker JK. The Social Network Map: Assessing Social Support In Clinical Practice. *Fam Soc*. 1990; 71(8):461–70.
36. Rempel GR, Neufeld A, Kushner KE. Interactive use of genograms and ecomaps in family caregiving research. *J Fam Nurs*. 2007; 13(4):403–19. [PubMed: 18180467]
37. Kelly JA. Popular opinion leaders and HIV prevention peer education: resolving discrepant findings, and implications for the development of effective community programs. *AIDS Care*. 2004; 16:139–50. [PubMed: 14676020]



**Figure 1.**  
HIV disclosure and advice seeking. ART (a) and Non-ART (b) PLHA

**Table I**

## Measures of Personal Network Composition and Structure and of Support and Stigma

	<b>Variable</b>	<b>Percent/Mean</b>	<b>Average Frequency in Network</b>
<b>Network Characteristics</b>	Average Age of Alters	34	
	Female Alters	52%	10.4
	Family/Spouse	45%	9
	Friend	33%	6.6
	Coworkers	7%	1.4
	Other community member types	<2%	0.4
<b>Support and Stigma</b>	Respondents who feel support from their network	70%	27.3
	Respondents who feel a strong sense of community at the clinic	69%	26.91
	Respondents who feel ashamed because they were HIV+	10%	3.9
	Respondents who feel people stopped calling or visiting when they learned they were HIV+	26%	10.14
	Network alters respondents interact with more than occasionally	98%	19.6
	Network alters respondents trust	76%	15.2
	Network alters respondents receive advice from	67%	13.4
	Network alters respondents receive tangible support from	55%	11
<b>Network Structure</b>	Network Density (Sometimes/Often)	47%	
	Network Density (Often)	20%	
	Average Number of Components	1.5	
	Network Members in Largest Component	65%	13
	Network Members Who are Isolates	17%	3.4
	Network Directly Connected to Most Popular Network Member	43%	8.6
	Network Directly Connected to Any Network Member	20%	4

**Table II**

Differences between PLHAs on ART (n=19) and not on ART (n=20)

	No ART Mean (SD)	On ART Mean (SD)	F
Respondent Age	29.80 (7.63)	38.26 (8.37)	10.910**
Respondent Years of Education	8.40 (2.46)	11.21 (3.08)	9.959**
Respondent CD4 Count	433.08 (190.72)	230.77 (68.01)	12.977***
Average Age of Network Alters	32.13 (4.21)	35.94 (5.20)	6.375*
Percentage of Network Alters Respondent Reports Trusting At All	68.25% (25.72)	84.05% (24.73)	3.820
Percentage of Network Alters Respondent Ever Gets Advice From	60.00% (18.99)	74.47% (24.03)	4.379*
Percentage of Network Alters Who Know Respondent's HIV Status	30.25% (27.46)	68.68% (33.95)	15.187***
Respondent Score on `Shame Associated with HIV' Scale	1.50 (1.05)	1.00 (0.00)	4.292*
Percentage of Network Alters Respondent Trusts `A Lot'	21.00% (19.97)	42.11% (27.71)	7.505**
Number of Network Components	1.7 (0.73)	1.3 (0.67)	2.907

\*  
, p < .05;\*\*  
, p < .01;\*\*\*  
, p < 0.001