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From HIV diagnosis to initiation of treatment: Social transformation among people starting antiretroviral therapy in Peru

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Abstract

Social support is a key, yet elusive resource for HIV patients living in poverty in Lima, Peru. Despite a greater need for health services and encouragement from others, economic restraints, stigma, and trouble negotiating a fractured health system act as hurdles to accessing support. In this study, 33 people with HIV and 15 of their treatment supporters were interviewed upon initiation of antiretroviral therapy in order to understand changes in social support during this critical time, and how these changes affected their well-being. Everyone's social network underwent dramatic transformation, while some were rejected upon disclosure by people they

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knew, many successfully trimmed their social circles to a few trusted parties. Treatment supporters were most frequently the first to whom they disclosed their HIV status, and most backed the person with HIV, although sometimes out of obligation. HIV peers became a vital new source of strength. Ultimately, people with HIV who successfully reorganized their social network drew personal strength and self-worth from new and old relationships in their lives.

Keywords

Social support; HIV; emotional support; qualitative; ART initiation

Introduction

Social support is an integral component of overall well-being and contributes to favorable health outcomes (Ncama et al., 2008; Vyavaharkar et al., 2007). Among people with HIV, social support has been associated with adherence to antiretroviral therapy (ART) (Cox, 2002; Simoni et al., 2002; Vyavaharkar et al., 2007), improved health behaviors such as healthy diet and exercise, and improved viro-logical outcomes (Burgoyne, 2005). With limited access to resources, people with HIV in extreme poverty struggle to manage the difficulties of a complex disease (Castro, 2005; Mukherjee et al., 2006; Weiser et al., 2003). Research shows that people with HIV living in poverty are better equipped to adhere to antiretroviral treatment when they receive support that bolsters their self-efficacy and motivation to stay healthy (Jones et al., 2013; Shin et al., 2011; Simoni et al., 2002). However, mechanisms that mediate the relationship between social support and medication adherence are still underdescribed, especially in resource-poor settings. Current evidence suggests social support could strengthen coping (Vyavaharkar et al., 2007), encourage self-efficacy and lower depression (Simoni et al., 2002), and increase motivation to stay healthy, such as social responsibility, maintaining relationships, and accepting economic support from loved ones (Ware et al., 2009).

Social support refers to interpersonal exchanges between individuals that foster positive adjustments when confronted with problems and stressful situations (Owens, 2003). The support may include tangible, affectionate, positive social interaction, or emotional–informational support (Burgoyne and Saunders, 2000).

Social support comes through both formal and informal avenues. Formal support refers to support provided by clinical services, mental health services, and social services. Informal support refers to one's social network—friends, family, neighbors, and peers.

This qualitative study explores how people with HIV living in poverty in Lima, Peru use, manage, and structure their social networks and the consequences that follow as they begin treatment. The objectives of this study are: (1) to explore the changes in social support available to people with HIV that occur during the period of diagnosis and initiation of HIV care and (2) to describe how access to social support impacts the individual's overall well-being. In doing so, we seek to deepen our understanding of how social support diminishes negative threats to adherence such as depression and stigma, while improving coping capacity.

Methods

Study setting and standard of care

Peru has a relatively low prevalence of adult HIV with 0.4%, or approximately 65,000 people, in 2013 (UNAIDS, 2013). Despite the Ministry of Health's free provision of ART since 2004, it is estimated that only 60% of those with HIV were receiving ART in 2010 (UNAIDS, 2011). That year, the capital city of Lima and neighboring Callao carried the burden of 77% of the reported cases of HIV in the country (UNAIDS, 2011). Peruvians living in poverty, particularly men engaging in sex with other men (Alarcon et al., 2003; Cohen, 2006; Lama et al., 2006) and their female partners, as well as those with more than two unprotected encounters within the last month (Alarcon et al., 2003), are particularly vulnerable to HIV (Cáceres et al., 2008; Salazar et al., 2005). In a pilot study, only 42% of those enrolled in treatment during a specified time frame in 2005–2006 achieved virologic suppression at 12 months (Muñoz et al., 2010); nonadherence was strongly associated with poverty (Shin et al., 2008).

In Peru, each individual with HIV is expected to identify a treatment supporter—usually a relative, partner, or close friend—upon HIV diagnosis. The treatment supporter is responsible for encouraging the patient to take ART as directed by their doctor and for accompanying the patient to medical visits. The treatment supporter does not receive formal training or compensation and is not responsible for directly observing the individual with HIV's ingestion of antiretrovirals (ARV). The role of the treatment supporter is not enforced after the initial disclosure. Through our research we found that the treatment supporter is often chosen as the person the individual with HIV trusts most, and is often the first person to whom the individual discloses his or her HIV status. Particularly for patients with a limited social network, this person may be the only person the patient trusts with this information, thus making them an important confidant and potential source of social support.

Study design

This cross-sectional and exploratory study sought to identify characteristics of social support for people with HIV from HIV diagnosis to ART initiation. The study is nested in a larger randomized trial, Community-based Accompaniment with Supervised Antiretrovirals (CASA), which assesses the impact of community-based support for people with HIV beginning ART. The CASA cohort includes 356 study participants living in poverty who were interviewed between November 2010 and March 2012 upon enrollment in the study and within 30 days of ART initiation. Institutional Review Board approval was given by Brigham and Women's Hospital in Boston, the National Institute of Health of Peru, Tulane University School of Public Health and Tropical Medicine, and University of Washington in Seattle.

We performed in-depth interviews with people with HIV and treatment supporters selected from the CASA cohort. We used demographic purposeful sampling themed into categories to achieve maximum variation (Sandelowski, 1995). Categories for qualitative interviews were age (18–25 years, 26–35 years, over 35 years) and gender (male and female). In order to ensure participants from a diverse group of social contexts were included, we interviewed

at least three individuals from each of the following six subgroups: individuals with a self-reported history of substance use, participants with previous ART failure, men who have sex with men, immigrants from Peruvian provinces, women who were pregnant or had recently given birth, and sex workers. While individuals from each group faced different challenges, they were included in the study because they shared the common experience of poverty and social vulnerability, which could in turn increase their vulnerability to stigma and social exclusion more than their community counterparts. A total of 33 people with HIV participated in baseline qualitative interviews, all administered within one month of ART initiation. Interviews with 15 treatment supporters provided data to triangulate the findings from the participants and offered additional insight into the relationships between participants and their supporters.

Data collection and analysis

Semi-structured interviews took place in private settings, usually in the participant's home. Interviews continued until data saturation was reached. Semi-structured interviews allowed participants to speak openly about their lived experiences, yet within a framework provided by a set of preestablished questions (Bernard and Ryan, 2010; Miles and Huberman, 1994). The interview guide was developed in Spanish and piloted the previous year in Lima with participants of similar characteristics. Questions focused on how they came to start ART, to whom they disclosed HIV status, who supported them and how, and changes in social network and social roles once treatment began. Questions for the treatment supporters focused on disclosure, how they came to be the treatment supporter, and what their role consisted of. Pairs of study staff trained in qualitative methods conducted the interviews. Interviews with treatment supporters and participants were performed separately. Interviews lasted 45–90 minutes and were audio recorded after obtaining verbal consent.

Members of the study team transcribed interviews verbatim. Interviews were deidentified, reviewed, and edited for errors or omissions. The interviews were then analyzed inductively using open coding to create a codebook (Miles and Huberman, 1994). After multiple iterations of the codebook incorporating feedback from the research team, all the transcripts were coded using the computer software program NVivo version 9. Another researcher coded interviews selected at random for quality assurance. The broad thematic categories used in the analysis include perceptions of what support looks like, extent of current social support network, changes in network with diagnosis, challenges for accessing support, perceived barriers to adherence, strategies for coping, and disclosure of diagnosis. The analysis and write-up followed the 32-item checklist of consolidated criteria for reporting qualitative studies (Tong et al., 2007).

Results

Results are based on the analysis of interviews with people with HIV and treatment supporters, including 48 participants total. Tables 1 and 2 show sociodemographic characteristics of the study population. Overall, treatment supporters were older than people with HIV (39.3 years and 30.5 years, respectively) and more likely to be female (80.0% vs. 33.3% of people with HIV). The average number of children also varied from 1.0 among

people with HIV to 2.6 among treatment supporters. Just less than half of the sample of people with HIV did not complete secondary school, while treatment supporters had slightly more education with only 64.3% with a high school degree. Among people with HIV, two are sex workers, 13 have a history of alcohol abuse or dependence, and 16 are men who have sex with men. Mean CD4 count at the start of ART was 148 cells/mm³, with an interquartile range of 84 and 226. None of the treatment supporters were known HIV carriers—12 had tested negative and 3 did not know their status. Among treatment supporters interviewed, the majority (67%) were female relatives.

Although there was great variation in the narratives of people with HIV, interviews consistently described the time leading up to initiation of ART as a period of significant social upheaval. People with HIV reported a need for increased social support but, simultaneously, encountered great barriers to accessing this support. The social networks of people with HIV during this period underwent transformations, oftentimes abruptly. Ultimately, as people were able to access social support, positive changes ensued, including acceptance of the diagnosis, hope and optimism, and the ability to make healthy choices.

Greater needs yet greater barriers

The journey from HIV diagnosis to starting treatment was a period of intensity, both from clinical and psychosocial standpoints. People with HIV—particularly those who had delayed seeking treatment due to cost or denial—frequently described the need for more frequent medical care, such as screening tests and clinic visits required for starting treatment and hospitalizations for opportunistic infections. Study participants who began treatment after becoming symptomatic were still debilitated by the symptoms at the time of the interview. While the Ministry of Health provides free antiretrovirals, the additional costs associated with certain tests and visits are not covered by the program, which is a great barrier particularly at a time when people with HIV are financially burdened by being too sick to work. In one example, a young woman described the challenge of paying the additional costs for medications to reduce the side effects of the ART.

I have to get injections [to treat side effects] and they're US\$1.80 each—twice a day. Since I don't have money right now, I haven't gotten them in two days, and now the rash is back.

(Female, participant with HIV, age 22)

This young woman struggled with deciding to treat the side effects so that she could continue her ART or stop ART since she could not afford the medicine to treat the side effects. The increased need for health care was stressful for many people with HIV, due to psychological uncertainty about their recovery, but also in terms of depleting any financial reserves of the household. In some cases, the illness made it impossible for people to work for money, and this financial hardship prohibited health improvements. In one case, the treatment supporter provided a much-needed alternative:

I organized two fundraisers to raise money to cover his healthcare costs since he didn't even have one cent for anything. We had borrowed money, since even though some people give you discounts, you still have to pay for each thing especially with his surgery.

(Sister, treatment supporter, age 37)

In this man's case, his HIV was already a financial burden and complications such as this surgery made it even harder to pay for exams and medications for opportunistic infections. Concurrently with increased medical needs, people with HIV expressed the need for greater informal social support, such as emotional support and the need to disclose and trust others to provide that support. Perhaps surprisingly, both formal and informal forms of social support were even more challenging to access for many people with HIV than medical services. Barriers to accessing formal and informal support existed at multiple levels, including structural obstacles related to poverty (e.g., lack of money for transportation or limited childcare options), characteristics of the health care system (e.g., difficulties navigating a complicated, fragmented system), and stigma (e.g., fear of discrimination by providers, family and friends, and the community at large).

Many patients would like to receive more social support, but simply cannot afford transportation costs involved, or have to choose between costly health care and participating in support groups or visiting loved ones. One participant expresses his frustration:

When the doctor told me there would be groups to talk with everyone that is starting ART, they invited us for meetings, but because I didn't have... the truth is I didn't have a way to pay for my bus ticket.

(Male, participant with HIV, age 35)

People with HIV are already isolated due to stigma surrounding their illness and economic hardship and poverty can act as an additional barrier to accessing support and affection. In this case, this woman could not visit her loved ones, although she wanted to:

Because I don't have the resources, I don't travel to see my mother or my younger sisters.

(Female, participant with HIV, age 36)

While structural barriers such as poverty usually made it more difficult for people to access care, in some cases, it obligated people to stay healthy.

In the morning, I look at the time and tell him to take his pill, so that he takes care of himself. I can't have him get sick. If he gets sick, I have no money to help him get better. Where would I have money to care for him?

(Mother, treatment supporter, age 43)

This mother was acutely aware of the economic situation and used it to motivate herself and her son to stay healthy, however, their family still lived fearing an illness may lead to death due to lack of funds.

Even when people were able to make it to the hospital and pay for services, they found they needed help maneuvering around the system productively. This treatment supporter expressed her frustration:

At one point she was barely able to get up, and it's really kind of unjust for people in this state to send them from one place to the next across the hospital.

(Female friend, treatment supporter, age 45)

In this study, treatment supporters helped patient participants access formal support within the hospital system, but also lent informal support by acting as liaisons and patient advocates for them.

It took two months to get the right medicine—first the analysis, then having to return. For those who are sick, they get desperate and start thinking, ‘for what am I going to live? I could kill myself and no one would even notice.’ And so the medical care should be a little bit faster.

(Female friend, treatment supporter, age 45)

The treatment supporters were the most in tune with the patient’s well-being and psychological distress, and therefore well positioned to address additional barriers such as stigma. One person with HIV described the intense fear she experienced in public:

When I leave [home to go to the hospital], the only thing I do is ask God to make me invisible.

(Female, participant with HIV, age 43)

The fear felt by participants was not unfounded. For some, attempts to “act normal” were received with fear and disgust, which deepened their own fear and isolation.

[At the neighborhood restaurant] when they’ve seen me so thin—I feel humiliated. They served my food in a disposable container, seeing me like this.

(Male, participant with HIV, age 35)

Internalized stigma was a prevalent theme among participants interviewed, particularly for those recently diagnosed. A loss of self-worth and sense of shame around their illness was an obstacle to disclosure and contributed negatively to overall well-being. One participant described her acute awareness of how others saw her:

Sometimes I think people just feel grossed out by us. Because I represent the way in which someone behaved. I feel their disgust.

(Female, participant with HIV, age 22)

For many people with HIV, this dilemma of encountering seemingly insurmountable barriers to urgently needed support led to a vicious cycle of prolonged delays in receiving medical attention, worsening health, and growing isolation and despair.

I didn’t tell my mother at first because I knew it would crush her. And when she saw me crying when I returned from the health center—where they had told me my diagnosis—I cried, of course. I didn’t want to see my mom, because my mom is going to find out and is going to get down. ‘What’s going on, daughter, why are you crying? Why are you so sad?’ ‘It’s just that the doctor told me that maybe the baby is going to come early.’ I lied to her like that, and she didn’t even notice. A month went by and I just recently told her why, because I just couldn’t do it anymore, I was very desperate. Despite all the support from the psychologist I received, I, I just couldn’t cope.

(Female, participant with HIV, age 22)

Once this participant shared with her mother her diagnosis, her mother then became a key support in her life. Once she started treatment, she moved back in with her parents because she could no longer tolerate living with her partner, who was in denial about getting tested for HIV.

Transformation of social networks

Throughout this period, participants described an upheaval of their previous social existence. The nature of these changes varied among participants. For about 30% the upheaval was at least in part involuntary, imposed by a partner, friend, or relative who rejected or abandoned them. On the other hand, about 70% of the people with HIV voluntarily withdrew from their prior social networks as a protective precaution against an undesired disclosure or stigma. For a few, the process was gradual while, for the majority, the changes occurred abruptly and even traumatically. Restructuring of social networks was particularly dramatic for participants with prior self-reported substance use, as significant lifestyle changes were necessary to begin treatment. For men who have sex with men, it sometimes meant confirming suspected homosexuality to relatives or friends and risking double stigma if they additionally shared how they contracted HIV. Despite these variations, all participants experienced a transformation in their social network in one form or another, and many found it necessary to draw upon new resources.

When I am sad, I talk to the dog at the factory. I tell him all my problems. I think he is the best friend because unlike others he won't tell anyone ... he has a lot of affection for me.

(Male, participant with HIV, age 39)

Participants expressed loneliness and a sense of abandonment:

Sometimes my friends who are women come, they help me a lot. But my homosexual friends? Nobody comes. Because they know. I haven't been out for four months, but they know where I live.

(Male, participant with HIV, age 35)

Because the Ministry of Health requires disclosure of participants' diagnosis to at least one person (i.e., the treatment supporter), this event became an important calculated risk for many participants. For nearly all of the respondents, the first disclosure took place in order to ask a person to become their treatment supporter. While many people remarked on an initial fear or hesitancy in telling their immediate family, the disclosure process also allowed the patient to identify a person whom they valued and trusted. The act of disclosure revealed whether this was truly the case. Despite fear of stigma and rejection, only 3 of the 33 participants were rejected or abandoned by their closest friends or family, particularly by their partner, and many were able to find the support they needed.

My partner never came to see me—he never believed it was true.

(Female, participant with HIV, age 32)

In some cases telling their diagnosis to their partner was a particular challenge, and in many cases their relationship ended.

For my partner it was a strong blow. I had to distance myself. I had wanted to tell her myself, but someone else told her, she found out. I don't know where she is, her house is closed down, she left. I don't know where she is. Her telephone is turned off, I can't contact her.

(Male, participant with HIV, age 49)

For the great majority, disclosure resulted in greater commitment from the person's nonpartner family members, who served as vital sources of support for the patient. Despite the initial shock, in many cases, the family member stepped up to the needed role to provide support in both emotional and instrumental ways to the patient. In some cases, people with HIV were able to return to their families, or a family member came to live with them.

[My son] and I try to talk to see what we are going to do, [he tells me], '*mamá*, don't worry, you won't have to work, you don't have to work anymore, don't worry we are going to try to help you pay the bills'.

(Female, participant with HIV, age 42)

Nonetheless, even among family members who were able to accept the diagnosis and offer support to the patient, the relationship was often still complex. Treatment supporters and other relatives often struggled with their own stigmatizing attitudes toward HIV, such as a mother not wanting her daughter to share nail clippers or earrings with her other daughter who was HIV positive. In one case, the participant with HIV was abandoned by his wife, and, having nowhere else to turn, he moved in with his elderly parents and his adult niece came by every day to take care of him, despite the fact that she had her own family to care for. Faced with their own fears and uncertainties regarding their relative's diagnosis of HIV, relatives often assumed the role of supporter out of a strong sense of family obligation.

I came to be my father's treatment supporter because who else would take care of him? I am the one because everyone else is too old now, so, it's my turn.

(Daughter, treatment supporter, age 37)

Family members and those close to the person with HIV were often the only people available during the most difficult times and they knew this was the case.

I felt bad. What else can we do? All we can do is tell her everything is going to be fine, that she has to take her medicine and do her part.

(Neighbor, treatment supporter, age 46)

Among wider circles of peers and relatives, about 80% of people with HIV in our study actively cut themselves off for fear of discrimination. Some people pruned their social network down to a few they could trust with their diagnosis. For about 30% of respondents, rather than lose a friendship entirely because of disclosure, they chose not to disclose to family or friends and maintain that relationship, at the cost of keeping their status secret from loved ones. Throughout this adjustment period, all people with HIV were able to assess their existing support networks and intuitively make decisions about whether disclosure was

worth the risk of endangering a friendship. In several cases, involuntary disclosure occurred (e.g., a medical provider disclosed to a family member), but yielded a dedicated supporter after the participant with HIV was confronted and acknowledged his or her HIV status.

In addition to their previous circle of peers, about 60% of participants found social support through new confidants. For instance, engaging with health care services represented a major turning point in terms of psychological and physical recovery. Although still stressful, a handful of participants were able to establish trust with their providers and see hope in the future. Developing relationships with supportive providers started a cycle of acceptance of the diagnosis, as providers reframed the consequences of the diagnosis from what was previously seen as a death sentence to a manageable, chronic disease.

The doctor told me, ‘Look, you just had an operation and you’re healthy. What you are doing is killing yourself because this depression will kill you. The depression will, not the [HIV] disease. There is treatment for this.’

(Female, participant with HIV, age 43)

About 40% of people with HIV also found strength from other people living with HIV, and described getting to know each other in the outdoor waiting areas at the public hospital, perhaps the only place where they felt protected from stigma because they all had HIV in common. Conversations among people with HIV peers took place between once a week and once every two to three weeks mostly in hospitals and clinics. People with HIV who had successfully overcome their initial struggle with HIV and now adhered to treatment often served as informal mentors to those who were less far along in their care. In particular, people with HIV connected vitally with others who had similar life experiences, such as motherhood, migration from the same provinces, and prior substance use.

I talk to the other participants, we talk amongst ourselves, and we tell each other what is going to happen to our bodies, and they tell me, ‘don’t be afraid, this happens to everyone’. Everything they have told me, to have strength in my gut, what will happen to my feet, in my head. I believe them, because everything they said has been true.

(Male, participant with HIV, age 35)

When I talk to other people in the hospital, I tell them, ‘you should be grateful that God has given you this illness, because you could have something worse, like an embolism, or be laid out in bed, or have cancer, that is much more painful. You can walk, you just need to take care of yourself, you need to eat, take your pills on time’, I tell them. ‘And keep going for your children’. I always tell them that.

(Female, participant with HIV, age 22)

These conversations led to alleviation for participants who felt isolated, lonely, shameful, or distrustful of previous relationships, and were of vital importance, especially as they became more accustomed to hospital visits and medication.

Enhanced coping and self-efficacy

All participants with HIV talked about the transformation of their social network however traumatic. If successfully able to access social support, people with HIV, in turn, became more confident in their ability to activate positive change using their own internal resources and strength. For 90%, the process of psychosocial recovery began with receiving support from others as a means of validating one's self-worth and mitigating internalized stigma.

I was crying in the church. Someone came up to me and put his hand on my back. He talked to me. 'Are you feeling badly?' I told him I was. He told me to reflect, he said I was struggling and should ask God for help. We talked for a long time. When I left the church I had a different attitude.

(Male, participant with HIV, age 49)

Despite experiencing waves of emotional distress, many shared a new sense of hope and optimism around staying adherent and returning to a lifestyle closer to what it was before HIV diagnosis.

I decided that I am going to be fine. I am going to care for my daughters for the rest of my life, God willing. I know that I'm not going to die... I've practically accepted [my diagnosis], I'm taking the medications, I'm doing well, thank God, and I can resume my role.

(Female, participant with HIV, age 35)

While participants with HIV recognized that they would continue to fight their own fears for a lifetime, they expressed comfort from compassion lent to them by their treatment supporters, family members, doctors and nurses, and peers with HIV.

I have participated in the group support at the hospital and hope there will be more. They have given me the strength to not back down, to keep going, to not be depressed... Maybe I could lead one of those groups, I think I could be a leader someday.

(Male, participant with HIV, age 27)

Most importantly, perhaps, they felt more capable of managing the logistical and emotional aspects of their illness and, in some cases, drawn to help others like themselves.

Discussion

In the period leading to ART initiation, participants described an urgent need for support from family and health services, while simultaneously encountering new difficulties in accessing support. In every narrative, the social landscape changed dramatically. Almost all patients lost at least one relationship, while new ones developed, as stigma (both internal and external), trustworthiness for disclosure, and need for support were assessed and acted upon by the patient. In almost all cases, this meant that a participants' social network was consolidated to include only the most dependable parties. These results parallel findings in a study in India, where recently diagnosed participants took part in "social pruning," a process by which stigma was "managed" such that disclosure and support were sought from only a few key members of their social network (Van Hollen, 2010). During this period of

social upheaval, new relationships developed as people with HIV successfully identify social spaces in which disclosure is permissible (including health care providers and other people with HIV). In a qualitative study in rural Uganda, Seeley and Russell (2010) found that social support and encouragement facilitate the person with HIV toward a positive social transformation, and that specifically in resource-limited settings, the rebuilt or new social relationships are essential.

These findings contribute to a growing body of research indicating that improved social support for HIV participants can trigger self-care mechanisms and, ultimately, improve health outcomes (Kelly et al., 2014; Kunutsor et al., 2011; Rivera-Rivera et al., 2014). Participants in this study who successfully disclosed and received support were able to overcome internal barriers, which in turn improved their outlook, self-confidence, and motivation to continue seeking care. Not disclosing HIV status has been linked to a negative effect on adherence (Mills et al., 2006), and a recent study has found that community health workers can help create a safe environment for disclosure (Root and Whiteside, 2013). One qualitative study among women with HIV in urban United States found that social support buffers external stressors and serves to restore hope and improve illness adaptation (Andrews, 1995). In turn such buffers can serve as a “shield against depression and stigma” and improve adherence and healthy decision making (Nam et al., 2008). While evidence shows that disclosure can bolster social support, and social support is linked to improved adherence, causation is still unclear (Burgoyne, 2005). The results of this study highlight the importance of facilitating people with HIV the tools and encouragement to disclose to those around them.

One strength of this study is the inclusion of not only people with HIV but also their treatment supporters. Through these dual perspectives, apart from validating the data, we found that the relationship between the people with HIV and the treatment supporter was extremely complex. On the one hand, people with HIV risked rejection at the moment of disclosure, and this disclosure was mandatory—they cannot start ART without a treatment supporter. On the other hand, the treatment supporters assumed additional risks—both real and perceived—when they committed to supporting people with HIV. Supporters often contributed financial and material resources, as well as their time, to assist the person until he or she could resume work. In addition, they may have perceived greater additional risk of HIV infection to themselves and other family members, and may not have received adequate education on HIV and transmission to overcome their own ambivalence and stigma. Programmatic interventions, e.g., targeted education for treatment supporters to understand the needs of people with HIV and their role, that have been used in other HIV treatment programs (Kunutsor et al., 2011; Nachega et al., 2010) could be explored further to cultivate effective and positive relationships in these dyads.

Our findings are in line with Ware et al.’s (2009) ethnographic study that interviewed people with HIV, treatment supporters, and health care providers in Sub-Saharan Africa and describes the strength of social relationships in facilitating sustained adherence.

The practice implications of these results highlight the key role of social engagement in setting people with HIV on a trajectory of acceptance of HIV as part of one’s life and

self-efficacy. Whether it is a provider who reframed the diagnosis, a treatment supporter who normalized the disease, a neighbor who paid frequent visits, or a family member who reminded the people with HIV to take their pill—these social interactions played a pivotal role in improving self-efficacy in managing social networks, and therefore well-being of people with HIV by supporting them to utilize their existing strengths and resources. The framework of social work practice considers each person in the context of their unique social environment, including factors such as socioeconomic status, family history, support systems, addictions, traumas, and health issues. This comprehensive framework is critical for identifying a person's strongest foundation of tools and for identifying opportunities for increased social engagement, which is especially key for people with HIV who are going through a social transformation into a new social network if their previous group is no longer compatible with their life on ART (Seeley and Russel, 2010).

Literature on social support delivered by self-selected treatment supporters suggests that treatment supporters can help improve ART adherence (Kunutsor et al., 2011) and describes the characteristics of the supporter that may lead to successful relationships (Duwell et al., 2013). More research is needed to understand how the treatment supporter model could be optimized in Peru; however, findings suggest a careful selection of a supporter based on personal characteristics and relationship factors (Nachega et al., 2006).

The study had some limitations. It focused on baseline data to understand social support among participants beginning ART. Follow-up interviews as well as more detailed social network analysis could provide more information on the evolving role of the treatment supporter and transformation of social networks over time. Nonetheless, our findings are consistent with evidence from other cultures suggesting that some elements of the process of social transformation may be fairly universal (Seeley and Russel, 2010). Finally, the number of interviews with vulnerable subgroups was not sufficient to identify differences in social support between different groups.

In summary, learning to successfully manage social networks during the period leading to ART initiation is a crucial turning point for many people living with HIV. The ability to access both formal and informal social support is an active process for many participants, demanding a critical appraisal of their existing social supports and the selective pursuit of additional resources. When successful, this process is a catalyst for internal transformation, resulting in reduced internalized stigma, greater optimism, and active engagement in their disease management. Focus on facilitating participants' efforts to restructure their social networks in a protective, supportive manner could result in greater psychosocial well-being and, ultimately, improved long-term health outcomes.

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Table 1.Descriptive statistics of study participants with HIV, $n = 33$.

| Characteristic (<i>n</i> , if not 33) | <i>N</i> (% or std) |
|---|---------------------|
| Female | 11 (33.3) |
| Age | 30.5 [9.4] |
| Single or widowed | 20 (60.0) |
| Number of children | 1.0 [1.0] |
| Did not complete secondary school (32) | 14 (43.8) |
| From Lima | 13 (39.4) |
| History of alcohol abuse or dependence | 13 (39.4) |
| Sex worker | 2 (6.1) |
| Man who has sex with other men | 16 (48.5) |
| Baseline BMI | 22.4 [2.6] |
| Mean CD4 count (at start of ART) ^a | 148 [84, 226] |

^aMedian [interquartile range].

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Table 2.Descriptive statistics of treatment supporters, $n = 15$.

| Characteristic (<i>n</i> , if not 15) | <i>N</i> (%) or [std] |
|---|-----------------------|
| Female | 12 (80.00) |
| Age | 39.26 [12.19] |
| Single or widowed | 9 (60.00) |
| Number of children | 2.60 [1.80] |
| Socioeconomic status | |
| Unemployed, dependent, student or housewife | 8 (53.33) |
| Limited education (14) | 5 (35.71) |
| HIV positive status | 0 |
| Relation to participant with HIV | |
| Friend | 3 (20.0) |
| Partner | 2 (13.33) |
| Parent | 4 (26.67) |
| Brother or sister | 4 (26.67) |
| Other family member | 2 (13.33) |

Note: Numbers within the parenthesis are percentages, numbers within brackets are standard deviation.