

Dynamics of Treatment Supporters and Patients Starting HIV Therapy in Lima, Peru

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Abstract

As per the National HIV Program in Peru, the designation of a patient-elected treatment supporter is a requisite for starting antiretroviral therapy (ART). These individuals are expected to aid the patient in medical and social support. This qualitative study examines the interaction between treatment supporters and people living with HIV/AIDS (PLWHA) to elucidate key dynamics contributing to care. Twenty individual interviews with treatment supporters were analyzed alongside 5 group interviews: 2 groups of treatment supporters, 2 groups of PLWHA, and 1 group of community health workers. Findings characterized formal means of treatment support and informal emotional and instrumental support. Gradual transfer of treatment responsibilities from supporters to PLWHA was found to foster a sense of self-efficacy among PLWHA, and when paired with open communication and committed emotional support, created an ideal reciprocal relationship. However, lack of HIV-related knowledge among treatment supporters was detrimental. More training and systemic support for treatment supporters may optimize their role as informed participants in the care of PLWHA.

Keywords

HIV, treatment supporters, community health workers, biopsychosocial

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Introduction

Daily adherence to medication can be a powerful treatment barrier for patients initiating antiretroviral therapy (ART). Accordingly, several means of support for people living with HIV/AIDS (PLWHA) have been developed to address this problem, in hopes of improving therapeutic outcomes. These supports have taken various forms, including community-based adherence clubs, community home-based care, and treatment partners.¹⁻³ Beyond the impact on treatment adherence, the intervention of a patient-designated treatment supporter has been shown to reverse the isolating effects of an HIV diagnosis and strengthen ties to social systems.⁴ The ability of a treatment supporter to help a PLWHA in accessing social networks, from which ties may have been severed upon diagnosis with HIV, has been suggested to depend on such interpersonal qualities as trustworthiness, availability, good communication, and

reciprocity.⁵ These findings appear to be in accordance with the biopsychosocial framework of health, which posits “to

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What Do We Already Know about This Topic?

Prior studies have described community-based interventions to support the care of people living with HIV/AIDS (PLWHA), including the introduction of treatment supporters.

How Does Your Research Contribute to the Field?

This study describes the role of treatment supporters from multiple perspectives, detailing both beneficial and detrimental aspects of their interactions with PLWHA, as well as their unique relationship to community health workers in Lima, Peru.

What Are Your Research's Implications toward Theory, Practice, or Policy?

The findings of this study may inform policy changes within the treatment supporter program in Peru, and encourage codification of this role in programs globally.

provide a basis for understanding the determinants of disease and arrive at rational treatments and patterns of health care, a medical model must also take into account the patient, the social context in which he lives, and the complementary system devised by society to deal with the disruptive effects of illness.”⁶ However, few studies have described the specific mechanisms by which treatment supporters interact with PLWHA within the biopsychosocial framework. It is necessary to detail these techniques, as well as describe the trials and triumphs of treatment supporters, as these narratives may contribute to the successful treatment of individual PLWHA and enable a more nuanced assessment of the societal impact of HIV. Therefore, this study proposes to examine the role of the patient-designated treatment supporter as practiced in Peru, placing emphasis on the interaction between the treatment supporter and PLWHA. In describing the biopsychosocial mechanisms evidenced in this relationship, we aim to identify the qualities and methods employed by the treatment supporter that both contribute to a PLWHA's success with ART and fortify social networks.

A rigorous characterization of the role of the treatment supporter must consider the social and historical context in which this person must work, as well as the intersectionality of these factors with modern medicine. Though the prevalence of HIV in Peru is relatively low, cited at 0.4% or 72 000 individuals in 2014, the true burden of disease is better characterized by the intense social stigma surrounding this illness, paired with barriers to accessing care due to poverty.⁷ Recognizing these challenges, the Peruvian Ministry of Health began free provision of ART in 2004. As a criterion for receiving this treatment, PLWHA in Peru are required to select an *agente de soporte*,

or patient-designated treatment supporter, to ensure the PLWHA's care during the process of undertaking ART.

In Peru, the intervention of a patient-designated treatment supporter is an innovation both distinct from and placed alongside a history of community-based health care provided by community health workers (CHWs) who have long provided directly observed therapy (DOT) to patients, primarily those affected by tuberculosis and HIV.⁸ While the role of the CHW is well defined, the description of the treatment supporter relies largely on individual practice, in the absence of programmatic structure or specific training surrounding the position at this time. Due to this individualized nature, factors such as the supporter's interpersonal relationship with the PLWHA, as well as level of education and socioeconomic means to undertake this uncompensated position, also necessarily influence the enactment of this position. We carried out a qualitative study in Lima, Peru to better understand the qualities and roles of treatment supporters, as well as the dynamics of PLWHA–supporter relationships.

Methods

This was a nested study in the randomized-control trial community-based accompaniment with supervised antiretrovirals (CASA), which applied the community-based intervention of DOT to support PLWHA beginning ART.⁹ The CASA cohort was composed of 356 participants living in poverty, who were enrolled between November 2010 and March 2012, within 30 days of ART initiation. Participants were at least 18 years of age, starting a new combined ART regimen, residing and receiving HIV care within 10 defined districts in Lima (selected from a total of 45 districts based on high prevalence of HIV), and amenable to receiving CHW visits for DOT. Exclusion criteria included inability to give informed consent (ie, due to neuropsychiatric comorbidities) and incarceration. Enrolled participants were followed through July 2014, and received care at 90 health centers or posts, as well as 2 tertiary care hospitals in Lima. Facilities were designated to the control or intervention group based on a computer-based randomization sequence.

Through CASA, each PLWHA in the intervention group was paired with a community health worker, who provided daily assistance with medication for 8 months, and transitional support that was gradually withdrawn until the completion of 12 months. The primary role of the CHW was to facilitate ART adherence, but by means of their dedication to patient-centered care, CHWs also impacted the relationship between PLWHA and treatment supporters, as well as perceptions of both parties regarding HIV.

About half of the CASA study's participants (200) received the support of a CHW as well as that of a treatment supporter, while the remainder (156) interacted with the treatment supporter alone. Institutional Review Board approval for this study was given by Partners Healthcare Institutional Review Board in Boston and the National Institute of Health of Peru. Study procedures were approved by Partners HealthCare Human Research Committee and the Ethics Committee of the Peru National Institute of Health.

People living with HIV/AIDS enrolled in the study were interviewed at baseline as well as at 12 months. In addition, individual interviews were concurrently performed with all treatment supporters of PLWHA within the CASA study group at the same intervals. Questions asked of treatment supporters provided a framework for these individuals to describe their experiences within their role, including their process of being designated a treatment supporter, the tasks that comprise this designation, and the characteristics that best describe their relationship with the PLWHA. Interviews were conducted in a semistructured style so as to also allow treatment supporters to narrate their experiences freely. Pairs of staff members trained in qualitative methods conducted all interviews in Spanish. Interviews were recorded after obtaining verbal consent and transcribed by members of the study team. A random sampling of 20 interviews conducted with treatment supporters at 12 months was selected for this qualitative analysis. Of the 20 selected, 13 treatment supporters had interacted with a community health worker (intervention group) while 7 had not (control group). Thematic saturation was achieved. Themes identified were used to inform the scope of group interviews. Individual interviews with PLWHA were not included in this qualitative study, as they were not primarily focused on the interaction between PLWHA and treatment supporters.

In order to gain perspective on the role of a treatment supporter from multiple participants in the PLWHA's care team, 5 group interviews were conducted. Two group interviews composed of 14 individuals were conducted with PLWHA, separating individuals according to intervention and control, and 2 group interviews (intervention and control) were similarly conducted with 12 treatment supporters. Finally, 1 group interview was conducted with 9 community health workers, so as to obtain a third-party perspective regarding the interactions between PLWHA and treatment supporters. Group interview size was designed to facilitate collective conversation that would identify trends without obscuring individual perspectives, and was also impacted by the availability and willingness of participants. Group interview participants were selected through convenience sampling from the CASA study cohort. All group interviews took place in an office setting, and participants were provided with transportation as needed. Participants were interviewed according to a pre-established framework of questions meant to clarify or probe themes identified in individual interviews, such as key qualities, motivations, and challenges of the treatment supporter; knowledge and training regarding HIV; as well as interactions between the PLWHA, treatment supporter, and CHW. The interview guide was developed in Spanish and a pair of facilitators from the research team used this structure to direct group interviews, while also providing opportunity for open response, including the ability to share personal stories and ask care-related questions. Group interviews lasted about 2 hours each, and were audio recorded with verbal consent at the start of each group. Two members of the study team not involved in the interview setting transcribed the recordings verbatim, and deidentified transcripts were then reviewed by interview facilitators to verify accuracy and tone.

Qualitative design and analysis employed a case study approach, with the treatment supporters' role and relationship with PLWHA as the primary focus of analysis.¹⁰ Group interviews and individual interviews were analyzed using a codebook developed through open coding. The codebook was finalized after incorporating the feedback of 5 team members of diverse professional and social backgrounds (K.H., M.W., O.S., M.M., and A.N.), including a team member from the United States, who cofacilitated group interviews over 12 weeks spent living in Peru, then coded these transcripts using the computer software program Dedoose. Major themes identified included: types of support provided by the treatment supporter (distinguishing formal versus informal and emotional versus instrumental support, which we will detail further), qualities of the treatment supporter and knowledge regarding HIV, relationship between the PLWHA and treatment supporter, interactions with the CHW, and stigma in social networks. Recommendations to improve the existing system of support were also elicited.

Ethics and Informed Consent

"Institutional Review Board approval for this study was given by Partners Healthcare Institutional Review Board in Boston (2009-P-000815/1) and the National Institute of Health of Peru (HNU-0006611-2010-CN, DIPRO 2009-406). Study procedures were approved by Partners HealthCare Human Research Committee and the Ethics Committee of the Peru National Institute of Health (28853-09, 24195-09). Participants provided written consent prior to enrollment in the CASA study and reiterated verbal consent prior to interviews and focus groups."

Results

In total, the results below comprise the analysis of 5 group interviews (2 groups of treatment supporters, 2 groups of PLWHA, and 1 group of CHWs) as well as 20 individual interviews (Figure 1). These represent a total of 54 unique participants: 31 treatment supporters, 14 PLWHA on ART, and 9 CHWs. Tables 1 to 3 summarize sociodemographic data from each participant group. Group interviews were interpreted as a collective dynamic composed of individual parts.¹¹

Characteristics of Treatment Supporters

Because a treatment supporter must be designated in order to initiate ART, PLWHA frequently reported asking whoever accompanied them to the hospital on the day of initial diagnosis to serve as a treatment supporter, so as to begin treatment immediately. Accordingly, many PLWHA initially chose family members, with parents representing the most significant proportion. Of the 353 individuals identifying as treatment supporters in the CASA study as a whole, mothers and fathers comprised the most frequent selection at 26.7%. Parents also represented the majority of treatment supporters in this qualitative study, though by a greater percentage at 48.2% (Table 1). Other supporters within the CASA study were partners/spouses (25.0%), siblings

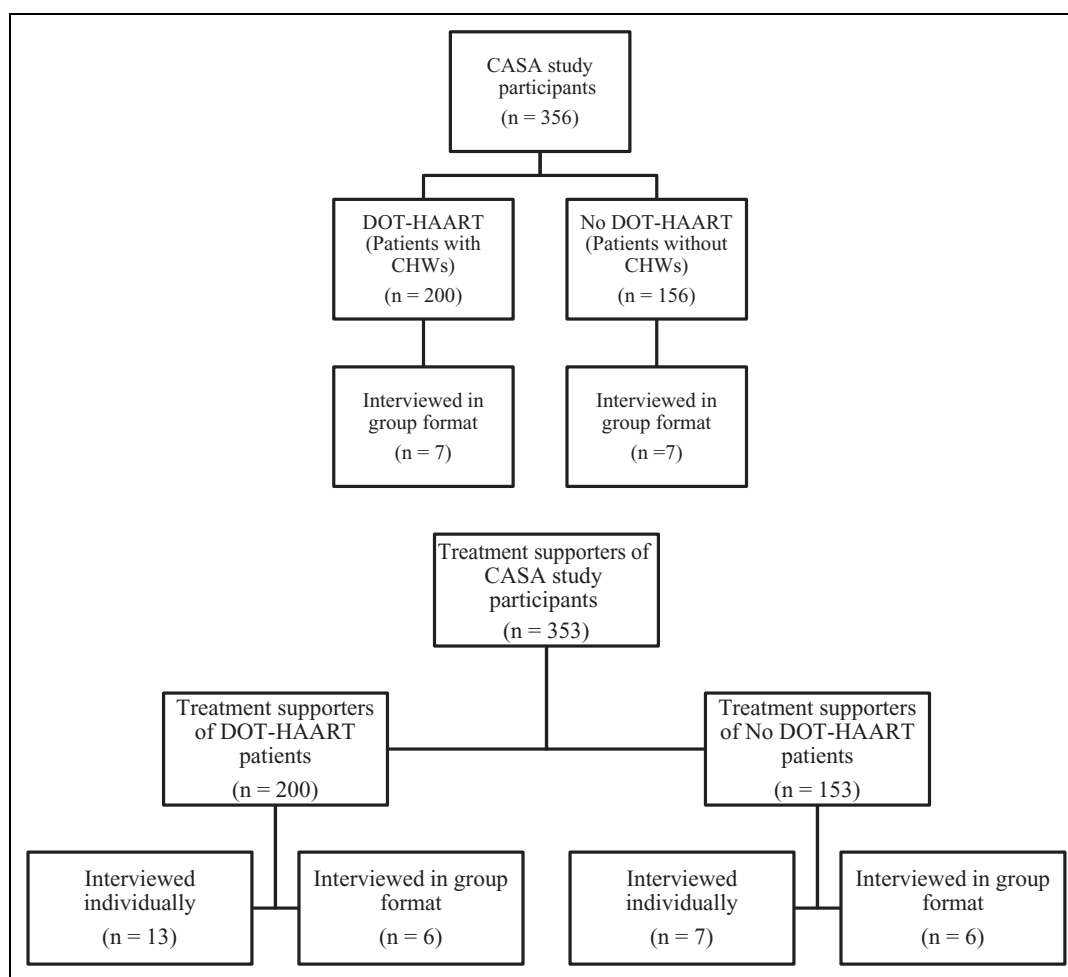


Figure 1. Interviews per total participants.

(17.9%), adult children (7.1%), other family members (8.2%), friends (11.1%), health personnel (1.7%) and counselors (0.6%), and unspecified others (1.7%), a distribution comparable to that found in this study (Table 1). People living with HIV/AIDS and community health workers later reflected on their varied experiences with these treatment supporters, and were able to identify initial misconceptions on the part of supporters, as well as positive qualities contributing to PLWHA-treatment supporter relationships that succeeded in bolstering social support.

Despite the common assumption that a parent-child bond would provide a strong basis for support, PLWHA, CHWs, and supporters themselves indicated that parents were more likely to question aspects of the PLWHA's lifestyle that may have led to an HIV diagnosis. Perhaps especially noted by group interview members who self-identified as homosexual, but also voiced by heterosexual participants, was the difficulty parents faced in coming to terms with sexual practices of their children that had been unknown prior.

How is it that she got sick? Because she never listened, went to parties, hung out here and there—why else? One is always to blame, and she doesn't know who infected her.

Female treatment supporter, mother

CHW1: Like many people of the older generation, because they are conservative, as I said they still have this [belief] . . .

CHW2: They are very old-fashioned.

CHW1: Racism, and things like that, the old ways . . .

CHW2: No, they aren't accepting.

CHW1: They aren't accepting.

Female community health workers

Treatment supporters who were parents of the PLWHA therefore often had difficulty accepting the diagnosis. Mothers especially struggled to let go of the perception that immoral acts contributed to contracting HIV, as well as the expectation that their child would take care of them in old age. When instead faced with the prospect of becoming caretaker for a grown son or daughter, some responded with blame and criticism.

He's been out with bad women and gets involved with them, and it's his fault. He made the mistake, and on top of that he still behaves badly. If I were any other mother, I would have thrown him out a long time ago, would have beaten him, and he would have made his life, I don't know where, dead or alive.

Female treatment supporter, mother

Table 1. Socio-Demographic Characteristics of Treatment Supporter Participants.

Characteristic	N	N (%) or mean (SD)
Socio-demographic characteristics		
Female	31	27 (87.1)
Age (years)	31	43.00 (11.81)
Did not complete high school	31	20 (64.5)
Poverty score ^a	31	42.70 (12.85)
No full time employment ^b	31	17 (54.8)
HIV positive	31	4 (12.9)
Relationship to patient ^c		
Parent (mother or father)	29	14 (48.2)
Child (son or daughter)	29	2 (6.9)
Sibling	29	2 (6.9)
Other Family	29	1 (3.5)
Partner or Spouse	29	6 (20.7)
Friend	29	4 (13.8)

^aPoverty was assessed by the Simple Poverty Scorecard, a Peru-specific tool employing Schreiner Poverty Probability Index. The PPI is a set of 10 simple questions answered by a household member and scored based on a country-specific scorecard. The scored answers provide the likelihood that the survey respondent's household is living below the national poverty line. A score of 35 to 39 would indicate a greater than 60% likelihood of living below the poverty line.

^bThe following responses were classified as no full-time employment: housewife/homemaker, dependent, or unemployed.

^cN = 29 as 2 treatment supporter participants did not identify their relationship with the patient.

What can I do with a sick man who will never be able to help me with anything?

Female treatment supporter, mother

Such conservative beliefs augmented stigma and placed tension on the relationship between supporter and PLWHA. Therefore, a treatment supporter characterized as more of an equal or peer to the PLWHA was noted to be preferable.

However, no PLWHA–supporter relationship could be expected to proceed entirely without difficulty, as both individuals were forced to accept a life-altering diagnosis. People living with HIV/AIDS noted that although every relationship included some disagreement, this did not necessarily indicate a negative relationship. The determining factor in resolving conflict and building an authentic support system was open communication. A treatment supporter with strong skills in conversation and mediation was desirable because the treatment supporter was often required to initiate compromise. This demonstrated to the PLWHA that the supporter would sustain their relationship in spite of strife.

Because I am her treatment supporter, I leave my anger aside. But it has happened that we've argued, and I've had to put aside misunderstandings and have approached her again; and so, as they say, I have reconciled with my mother.

Female treatment supporter, daughter

Table 2. Socio-Demographic Characteristics of Patient Participants.

Characteristic	N	N (%) or mean (SD)
Socio-demographic characteristics		
Female	14	8 (57.1)
Age (years)	14	38.28 (12.34)
Did not complete high school	14	5 (35.7)
Poverty score ^a	14	35.35 (7.83)
Food Insecurity ^b	14	13 (92.9)
No full-time employment	14	10 (71.4)
Psychosocial variables		
Social support score ^c	14	8.64 (1.15)
Perceived HIV-related stigma ^d	14	28.00 (7.23)
Depression ^e	13	2 (15.4)

^aPoverty was assessed by the Simple Poverty Scorecard, a Peru-specific tool employing Schreiner Poverty Probability Index. The PPI is a set of 10 simple questions answered by a household member and scored based on a country-specific scorecard. The scored answers provide the likelihood that the survey respondent's household is living below the national poverty line. A score of 35 to 39 would indicate a greater than 60% likelihood of living below the poverty line.

^bFood insecurity was calculated and categorized using the Household Food Insecurity Access Scale and is defined here as Categories 3 and 4, indicating moderate and severe food insecurity. The following responses were classified as no full-time employment: housewife/homemaker, dependent, or unemployed.

^cSocial support score was calculated using the Duke-UNC Social Support Questionnaire. A total of 40 points are possible, with a higher score indicating greater social support.

^dPerceived HIV-related stigma was calculated using the Berger HIV Stigma Scale, composed of 21 items evaluated along a 4-point Likert-type scale (from 1 = strongly disagree to 4 = strongly agree). The sum of these items yields a total score with higher scores representing a greater degree of perception of stigma.

^eDepression was assessed using the Hopkins Symptoms Checklist, a trans-culturally validated self-report symptom inventory consisting of 25 items, the first 10 pertaining to anxiety and the latter 15 pertaining to depression. Items are ranked on a 4-point Likert-type scale, with higher overall scores correlated to greater psychological distress and high depression scores correlated to the DSM diagnosis of major depression. A score of >1.85 on average per question is often used as a cutoff.

By contrast, treatment supporters who experienced more fraught relationships with their PLWHA described moments of anger evolving into larger roadblocks; accordingly, PLWHA in such relationships did not trust their supporters and feared that anything they might confide could later be turned against them. From their observations of various PLWHA and treatment supporters, CHWs recommended that the treatment supporters should, above all, be loving, patient, and trustworthy, practicing control of anger or frustration in their interactions with the PLWHA.

In my case, with my mother, things are almost always good, but there are moments, as we have said, when she loses control and I've tried to bring her out of that feeling. I try to make sure that she keeps talking, keeps talking. And I stay, I try not to leave her.

Female treatment supporter, daughter

When they start to feel better, sometimes they don't need as much support, only with a few things that have fallen by the

Table 3. Socio-Demographic Characteristics of Community Health Worker (CHW) Participants.

Characteristic	N	N (%) or mean (SD)
Socio-demographic characteristics		
Female	9	9 (100.0)
Age (years)	9	52.03 (5.37)
Did not complete high school	9	2 (22.2)
Poverty score ^a	9	58.44 (14.28)
No full-time employment ^b	9	7 (77.8)
Total number of years as a CHW	9	12.84 (8.90)
HIV positive	9	0 (0.0)

^aPoverty was assessed by the Simple Poverty Scorecard, a Peru-specific tool employing Schreiner Poverty Probability Index. The PPI is a set of 10 simple questions answered by a household member and scored based on a country-specific scorecard. The scored answers provide the likelihood that the survey respondent's household is living below the national poverty line. A score of 35 to 39 would indicate a greater than 60% likelihood of living below the poverty line.

^bThe following responses were classified as not full-time employed: housewife/homemaker, dependent, or unemployed.

wayside, or if they are sick, or feel worse again; but they do need friendship.

Female community health worker

The ideal treatment supporter practiced open communication and commitment over time, building confidence through long-term dedication to the PLWHA. This continuation of emotional support was often also marked by a sense of reciprocity between the treatment supporter and PLWHA.

Like I've said, she and I, we're family. She's a friend of mine, we've grown up together in the same neighborhood, and we've always looked out for each other. Between the two of us, we've always helped each other out.

Female treatment supporter, friend

My partner, no one else—we're a pair. We support each other. Yes, sometimes he gets down but I raise his spirits. And he, just the same, says to me "Get up, let's go," the two of us.

Male treatment supporter, partner

The promise of long-term, reciprocated emotional support on the part of an equal to the PLWHA created more even footing between PLWHA and treatment supporters. This perception of equality served to destigmatize HIV and reestablish faith in community support that may have been severely compromised upon diagnosis.

Treatment Supporter Roles

Prior studies have described treatment supporters providing *formal support* within the hospital system and *informal support* as PLWHA advocates in the community.¹² Treatment supporters in this study exemplified formal support by identifying specific means by which they provided treatment-centered aid, such as reminding the PLWHA to take medication, accompanying the

PLWHA to appointments, and retrieving medication from the hospital. Treatment supporters further elaborated on the model of informal support by describing *emotional* and *instrumental* aid of the PLWHA. These terms have also been described in the literature.¹² The former encompasses encouragement in times of need, while the latter includes the provision of support in tasks that a PLWHA may be unable to perform due to their illness, such as cooking meals or seeking shelter. Described in all interviews, a combination of formal and informal support was a common means of lessening the burden felt by PLWHA.

Thirteen treatment supporters who were comprehensive in their care and close to their PLWHA also practiced a unique strategy based on the gradual transfer of formal responsibility to the PLWHA. This pattern involved slowly giving the PLWHA more agency and control in their own care. Treatment supporters described this practice with respect to: asking questions of the doctor if the PLWHA is initially too nervous, but then encouraging the PLWHA to do so on their own; accompanying the PLWHA to all appointments for a time and then tapering; or reminding the PLWHA to take their pills at first and then suggesting the PLWHA set their own reminder. Supporters noted watching the PLWHA become more comfortable with treatment and aiding according to need.

She listened when I asked questions and I told her, "You have to ask questions, you have to speak so that the doctor explains everything to you," so now she asks questions. Because at first I was the only one who asked questions, who asked the doctor questions, and that was how we conversed with the doctor because she felt a little ashamed. But now, she's more open.

Female treatment supporter, friend

I tell her, "God bless you, my daughter," and I give her a hug, and I've distanced myself a little from her so that she can take responsibility for herself.

Female treatment supporter, mother

Transfer of treatment responsibility was not marked by total disinvolvement or a break in the relationship; rather, the treatment supporters who employed this strategy remained attuned to the PLWHA's progress, so as to discern their present needs. This slow transfer of treatment responsibility, when paired with the promise of long-term reciprocal emotional availability, engendered a sense of supported self-efficacy in the PLWHA. Together, these qualities and actions of the treatment supporter contributed to the PLWHA's confidence, and created a mutually beneficial relationship for PLWHA and treatment supporter both.

Treatment Supporter Needs

In addition to espousing a positive interpersonal relationship, it was helpful for the treatment supporter to have a foundational understanding of HIV. Many treatment supporters had not encountered substantive information regarding the virus or illness in the past, in large part due to the marginalization of

people living with HIV. Accordingly, supporters voiced many questions regarding the illness.

I don't understand, how are there 2 classes of HIV—do you say HIV, or AIDS? . . . Herpes, what is that?

Female treatment supporter, mother

Carrier, carrier, carrier, what's that, I mean now that a patient is taking their medications, are they a carrier or what? What does that word mean, carrier?

Female treatment supporter, mother

Of note, about 50% of the study population received the help of a CHW who interacted with the PLWHA and treatment supporter, while the approximately 50% remaining did not receive this intervention. However, treatment supporters whose PLWHA had access to a CHW paradoxically voiced *more* basic questions and/or misperceptions regarding HIV, with 4 of 6 treatment supporters in one of the group interviews voicing 11 distinct comments that conveyed incorrect information or rudimentary questions regarding HIV. By comparison, among treatment supporters who had no access to a CHW, only 1 misperception was voiced among numerous comments made with regard to the illness in the group interview setting; moreover, treatment supporters without access to a CHW were more likely to describe initial misperceptions from which they had since learned. This trend perhaps indicates the perceived lack of urgency in learning about the illness on the part of some treatment supporters, due to the presence of a CHW, and illuminates a missed opportunity in education. Notably, PLWHA in both groups lamented that their supporters lacked information regarding HIV, which prevented greater utilization of the supporter as a resource.

PLWHA 1: They aren't trained to help you 100 percent.

PLWHA 2: They should receive a training session.

PLWHA 1: Absolutely.

PLWHA 2: Absolutely, because they can raise your spirits, they can tell you "do this," but they can't help you with everything.

PLWHA 1: They need to have more knowledge.

PLWHA 2: But what would you do if all of a sudden you feel bad or you get sick or you get one of those things, like a bad cold—and they don't know which medication to give you. I mean, some of them self-medicate, like my mom, for example, buys medications in the pharmacy. I'm scared of self-medicating, but my mother is supposedly my supporter, and out of innocence, she wants to give me a pill—and what if I take it? I'm afraid it might cross react (with my other medications), and something could happen. Or there could be a rash, I don't know. So, for these reasons, I don't even ask my mom for help.

Female and male PLWHA

People living with HIV/AIDS and CHWs suggested organizing more periodic training sessions and conversations meant specifically for treatment supporters. Community health workers also suggested orienting PLWHA to the qualities of a successful treatment supporter before making a selection, and interviewing the chosen supporter with the help of a psychologist. In relation, while treatment supporters remembered the shock of learning the diagnosis and subsequently signing on to their roles, none recalled specific advice from a medical professional, beyond simply supporting the PLWHA. However, PLWHA were not certain these additional measures would ensure treatment supporters would truly understand their experience and also suggested building a network of peer supporters among people living with HIV/AIDS. People living with HIV/AIDS described informal conversations with other PLWHA when going to pick up medication, or during doctor's visits, and noted having gained much support and information from these interactions. They wished to formalize this network, so that these fellow PLWHA individuals could serve as their treatment supporters.

Essentially yes, I believe that people with the diagnosis would help more . . . like I said, the people who have helped us have been very kind, but you have to admit that they lack the preparation. Better to have the lived experience. Because when you go to the hospital and talk a lot with the others (PLWHA) about everything related to the illness, you take that in, and it's true—not something they've made up. They've lived it, right, that's real.

Male PLWHA

It's better if the support agent is a person who has the diagnosis, because, for example, that person has already known the pros and cons for some time, the lifestyles that we should lead, what food we should eat, what emotional state we should be in. So it's a lot more practical than a person who doesn't understand—for a person, for example, like the siblings with whom others here have shared their diagnoses, it's shocking. They aren't prepared. They don't know how to support those who are emotionally unwell. So, for this role, that person isn't a good supporter.

Male PLWHA

Current treatment supporters voiced their own need for training and psychological support, suggesting periodic meetings or therapy groups for supporters to come together and discuss common challenges.

Treatment supporter 1: We would like it if every month, or two months, or whatever is possible, we could have something like this where each of us could express our feelings and our needs.

Treatment supporter 2: Yes.

Treatment supporter 3: I don't know, in some way, unburden ourselves and talk or express our feelings, what we are carrying—that would be good.

Female treatment supporters, mothers and daughter

Absolutely, it would be nice if there were more trainings. There is no question of whether I'd do it, we have to be well trained.

Female treatment supporter, mother

Overall, the consensus between PLWHA, supporters, and CHWs showed a need for greater codification in the selection of a supporter, as well as thorough training regarding HIV to bring a strong knowledge base to the PLWHA–supporter relationship. It must be noted that general community talks and workshops are indeed conducted by hospitals, and exemplify an important overture to create a connection between the hospital system and treatment supporters; however, few *agentes de soporte* interviewed endorsed having participated in such sessions, though it remains unclear whether this trend may be attributed lack of awareness of these events or logistical inability to attend.

Discussion

Treatment supporters play an important role in HIV care, not only for medication adherence but also for psychosocial support to PLWHA during their early period of engagement in care. In agreement with prior studies, we find the restoration of social networks can counteract the isolating effect of an HIV diagnosis and strengthen access to community resources.⁴ Additionally, we demonstrate these important connections can be facilitated with the help of a treatment supporter. Our findings suggest that the degree to which the treatment supporter is able to fulfill this potential depend on the individual qualities of the supporter, which come to bear upon the PLWHA–supporter relationship.

As the nature of this relationship is variable based on interpersonal factors, our findings may be limited by the sample of 20 individual interviews included in this study. However, the process of randomly selecting a small number of interviews to thematic saturation facilitated the ability to draw out poignant patterns that could be further probed or placed in contrast with those attitudes stemming from group interviews. The process of group interviews may also encourage individual participants to reinforce ideas held in common with other members rather than to voice strongly differing experiences. This serves to identify themes that may be most applicable to the study sample but also risks the exclusion of outlier opinions.

Conversely, some commonalities intrinsic to the study population, such as the struggles of accessing care in an under-resourced setting, may have been too normalized to elicit elaborate commentary. However, the formal and informal help described by treatment supporters, such as waiting in line for the dispensation of medications on behalf of a PLWHA or simply sharing a meal, convey an underlying lack of basic resources. Though not often explicitly described as such, we recognize the difficulties of providing such aid as derivatives of poverty.

In this context, individual characteristics shown to foster a strong PLWHA–supporter relationship include open communication, long-term commitment, and reciprocal support. These qualities were observed among lasting PLWHA–supporter relationships in our study sample and are consistent with prior studies that have shown such qualities in treatment supporters may promote healthy behaviors and contribute to improved

medical outcomes in PLWHA.⁵ Studies directed towards measures of adherence have also shown improvement with the help of a treatment supporter.¹³ However, our findings are unique in demonstrating particular mechanisms within the biopsychosocial framework that may contribute to these improved outcomes, such as the efficacy of remaining emotionally available, but gradually transferring formal treatment responsibilities from supporters to the PLWHA themselves. We posit these actions honor self-efficacy, and thereby build the confidence of PLWHA in their ability to manage their personal health within the hospital system and society at large.

The nature of the pre-existing relationships between PLWHA and treatment supporters also necessarily impacted the degree to which treatment supporters were able to fulfill their roles. Though established care-giving connections, such as those between parents and children, might appear ideal for treatment support, stigma and conservative beliefs also prevailed in these relationships and impeded true treatment support. Supporters perceived as peers or equals of the PLWHA may be better able to foster a sense of partnership in care. In the course of group interviews, PLWHA described receiving informal support from other PLWHA during hospital or community encounters, suggesting a unique understanding shared by peers with HIV. People living with HIV/AIDS emphasized the added benefit of experience on the part of individuals who had already been through the early difficulties of diagnosis and were assimilated to various lifestyle changes.

All participants suggested strengthening the role of treatment supporters through initial guidance of PLWHA in the selection process, as well the formal orientation, training, and community resources for supporters. The Peruvian health-care system may consider programmatic modifications that offer newly diagnosed PLWHA the opportunity to more fully consider whom they might prefer in the treatment supporter role, both by incorporating the experiences of those who have already been through treatment and allowing a greater period of time to make a decision. At present, those who cannot choose such an individual not only feel a compounded social isolation but also face an immense barrier to care. Potential supporters may also benefit from the chance to consider the qualities and responsibilities required of this role. A formalized orientation may create greater codification of the role of a treatment supporter, which often varies by individual characteristics and interpersonal relationships. Periodic training sessions may reinforce the commitment of the treatment supporter once this individual has been selected, and further, provide the opportunity to dispel common misconceptions regarding HIV as well as provide practical knowledge. In Peru, community health workers act as conduits of medical knowledge to PLWHA and wider society, and their work has been shown to improve care.⁸ Fluent in both medical knowledge and local culture, CHWs may be the ideal leaders of such training sessions, and perhaps better able to impart their expertise in the context of formalized sessions. Calling upon CHWs to perform this role may also reinforce the connection between treatment supporters and the robust hospital system. Finally, structured

groups directed toward treatment supporters may create a space for shared experiences, and improve their ability to continue caring for PLWHA and themselves. These additional resources sought to bolster the supporter role are notable in the narratives of PLWHA, community health workers, and treatment supporters alike. These shared desires reflect the importance of the PLWHA–supporter relationship, and provide testament to both the personal necessity and programmatic strength of treatment supporter programs such as that established in Lima, Peru.

Conclusion

This study highlights the inherent value and the even greater potential of treatment supporters in the Peruvian HIV Program. While the success of PLWHA–supporter relationships depends in part on the characteristics of the supporter and the dynamics of their pre-existing relationship, a number of programmatic changes designed to better support treatment supporters—health education, training on supporter roles including responsibility transfer, and ongoing emotional support—could improve their efficacy.

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