Patient-Nominated, Community-Based HIV Treatment Supporters: Patient Perspectives, Feasibility, Challenges, and Factors for Success in HIV-Infected South African Adults

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Abstract

This study aimed to characterize the experience of having a treatment supporter among HIV-infected South African patients enrolled in a randomized controlled trial that compared the efficacy of patient-nominated treatment supporters administering partial directly observed antiretroviral therapy (DOT-ART) versus self-administered ART (Self-ART). Results of the parent study showed no virologic or sustained immunologic differences between groups, but revealed a significant survival benefit among the DOT-ART group. One hypothesis is that this survival benefit may be explained by differences in the training and involvement of the treatment supporters between groups. In the current study, results from a semi-structured exit interview of 172 participants indicate that most participants in both arms maintained a positive, satisfying relationship with a single supporter, typically family member or friend. Most patients (82.6%) perceived supporters as helpful with medication adherence, with no significant difference between groups ($p=0.752$). Additionally, supporters provided emotional, instrumental, and material support. DOT-ART patients were more likely than Self-ART patients to report that their supporter helped to decrease drug or alcohol use ($p=0.03$). Patients identified supporter trustworthiness, availability, good communication and reciprocity of support as factors beneficial to a successful relationship. These results suggest: (1) Patient-nominated peers are feasible candidates for ART supporters in this resource-constrained setting; (2) In addition to assistance with medications, treatment supporters have the capacity to promote healthy behaviors and provide other types of support, which may contribute to improved outcomes, particularly with enhanced training; (3) Trustworthiness, availability, good communication, and reciprocity are key factors in a successful patient-supporter relationship.

Introduction

ADHERENCE TO ANTIRETROVIRAL THERAPY (ART) is vital to successful treatment of HIV. Higher ART adherence is associated with lower rates of morbidity, hospitalization, and mortality,¹ while lower adherence may lead to the development of viral resistance, treatment failure, transmission of drug-resistant HIV, disease progression, and mortality.²⁻⁶

Life-long adherence to ART, however, is a tremendous challenge to persons living with HIV, their family and friends, and care providers. As access to ART increases in resource-poor areas,⁷ there is a growing need for low-cost, high-impact strategies to support medication adherence among HIV-infected persons.

One such strategy is the use of community-based treatment supporters to promote ART adherence, a method that

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is well-suited to low-resource settings with a shortage of healthcare workers and/or facilities. Researchers have studied the delivery of a variety of interventions by treatment supporters, including psychosocial support,⁸ education about ART adherence,⁹ adherence measurement and referral to other providers.¹⁰ Directly observed therapy (DOT) is another potential approach for treatment supporters to promote ART adherence, based on the efficacy of community-based DOT for tuberculosis administered by family members or guardians.^{11–13}

Our collaborative research group conducted a randomized, controlled trial that compared partial DOT administered by trained patient-nominated treatment supporters (DOT-ART) to self-administered ART (Self-ART) in ART-naïve adult patients with treatment supporters in South Africa.¹⁴ There was no significant difference between the groups in the proportion of patients with undetectable viral load or median CD4 cell count increase persisting beyond 6 months. Despite this lack of virologic or sustained immunologic differences between the groups, the DOT-ART group showed a significant survival benefit compared to the Self-ART group (6.6% vs. 15.3% mortality, $p=0.02$). One hypothesis to explain this survival benefit is that treatment supporters trained in the DOT-ART group may have conferred health benefits through pathways unrelated to medication adherence, viral load, and CD4 count.

We conducted a secondary qualitative analysis from the parent trial to characterize patients' experiences with treatment supporters, and how these experiences differed between those participating in DOT-ART versus those who were not. Specifically, we aimed to (1) assess the feasibility of using patient-selected community based supporters for ART assistance in a low-resource setting, (2) evaluate the impact of treatment supporters on patient behaviors, and (3) identify strengths and weaknesses of patient–supporter relationships.

Methods

To explore and compare patients' experiences with treatment supporters in both study arms, we conducted a semi-structured interview with participants at the completion of the parent study. The interview was focused on the nature of the patient–supporter relationship, its role in medication adherence and other behaviors, and the other perceived benefits and challenges of having a treatment supporter.

Study population and setting

The parent study enrolled patients >18 years old with HIV infection and CD4 counts of <250 who were initiating ART at GF Jooste hospital, Cape Town, South Africa, which is a public sector secondary-level hospital serving several peri-urban townships. Government-funded comprehensive ART care, which is free of charge to patients, is provided at primary care clinics and in the hospital clinic.

All study completers were eligible to complete a semi-structured exit interview. As part of the parent study intervention, patients in the DOT-ART arm selected a single treatment supporter by using a personal network inventory instrument.¹⁵ Selected treatment supporters underwent a 90-min baseline training session on ART adherence and support techniques, and were asked to observe and document at least one medication dose daily. Treatment supporters and

patients received 4 additional ART adherence training sessions at baseline, as well as booster education sessions every 3 months for 12 months. These sessions included training on how to fill pill boxes and complete the study adherence chart, as well as discussions on effective communication strategies, the provision of emotional support, and identification of barriers to adherence and potential solutions. Treatment supporters were not provided with any incentives for participation. In the event of relationship dissolution or loss of support from their initially-selected supporters, participants were encouraged to select another treatment supporter. After 12 months, treatment supporter training and partial DOT were tapered at the discretion of the patient and supporter.

As per standard of care, patients in the Self-ART arm were instructed to select a treatment supporter (without the network inventory instrument), and both Self-ART patients and supporters were asked to attend a single 90-min training session describing ART and the importance of adherence without DOT.

Data collection

Study personnel obtained informed consent from all participants. Interviews were conducted face-to-face, and followed a semi-structured format. An interpreter was present for interviews conducted with Xhosa-speaking participants. Personnel fluent in Afrikaans conducted interviews with Afrikaans-speaking participants. Interviewers recorded participants' responses in English during the course of the interview.

Data analysis

Study personnel entered interview responses into a database. We then tabulated all yes/no and quantitative responses blinded to treatment assignment. A single researcher reviewed all open-ended interview responses line-by-line in order to identify main themes and/or categories of responses, and assigned codes to each identified category. The researcher subsequently coded all responses for these categories blinded to treatment assignment. Such an inductive approach is an established method for analyzing qualitative research, and has been used in research analyzing patient experiences of treatment supporters in Tanzania.^{16,17}

Permission for the parent study was obtained from the IRBs of Johns Hopkins University and the University of Cape Town.

Results

Baseline demographics and clinical characteristics

Interview respondents included 89 patients from the DOT-ART group and 83 patients from the Self-ART group. Participants were similar in terms of gender, age, race/ethnicity, and HIV stage. Table 1 shows the demographic and clinical characteristics of the study participants.

Overview of the patient–supporter relationship

The vast majority (91.3%) reported that they were still in touch with the supporter who joined the study with them initially, with no significant difference between the groups ($p=0.175$). Most patients reported that they had either one

TABLE 1. BASELINE CHARACTERISTICS OF STUDY PARTICIPANTS

	DOT-ART	Self-ART	p Value
Sample size (N=173)	N=89	N=83	
Sex (% male)	41.6%	36.1%	0.466
Age (years)	34.6	35.3	0.676
Race			0.840
Black	84.3%	83.1%	
Mixed race	15.7%	16.9%	
Language			0.700
Sotho	0.0%	1.2%	
Xosha	32.6%	35.8%	
English	51.7%	50.6%	
Afrikaans	7.9%	10.8%	
Not recorded	7.9%	2.4%	
WHO Stage			0.213
WHO Stage III	49.4%	45.8%	
WHO Stage IV	46.1%	43.4%	

(80.2%) or two (14.5%) treatment supporters throughout the course of the study. Although DOT-ART patients were slightly more likely to have had two supporters, there was no significant difference between the groups in terms of the proportion reporting one versus more than one supporter ($p=0.303$).

The most common type of treatment supporter was romantic partner (i.e., spouse, boyfriend, or girlfriend), chosen by 19.1% of participants in the DOT-ART and 20.5% in the Self-ART group. Among the DOT-ART group, the next most common type of treatment supporter was either a sister (15.7%) or mother (11.2%); these were also the most common treatment supporters for the Self-ART group (both 14.5%). Other members of the patient's family, including children, cousins, aunts, and sister-in-laws were common choices of supporters. Nonfamilial supporters included friends and neighbors, among others (Table 2).

TABLE 2. PARTICIPANTS' LONGEST SUPPORTER DURING THE STUDY

Response	DOT-ART	Self-ART	Total
Spouse/partner	17 (19.1%)	17 (20.5%)	34 (19.8%)
Sister	14 (15.7%)	12 (14.5%)	26 (15.1%)
Mother	10 (11.2%)	12 (14.5%)	22 (12.8%)
Daughter	5 (5.6%)	5 (6.0%)	10 (5.8%)
Friend	7 (7.9%)	2 (2.4%)	9 (5.2%)
Cousin	2 (2.2%)	5 (6.0%)	7 (4.1%)
Aunt	3 (3.4%)	3 (3.6%)	6 (3.5%)
Sister-in-law	3 (3.4%)	2 (2.4%)	5 (2.9%)
Brother	3 (3.4%)	1 (1.2%)	4 (2.3%)
Neighbor	3 (3.4%)	1 (1.2%)	4 (2.3%)
Son	1 (1.1%)	3 (3.6%)	4 (2.3%)
Niece	1 (1.1%)	2 (2.4%)	3 (1.7%)
Grandmother	1 (1.1%)	1 (1.2%)	2 (1.2%)
Father	1 (1.1%)	-	1 (0.6%)
Nephew	-	1 (1.2%)	1 (0.6%)
Uncle	-	1 (1.2%)	1 (0.6%)
Other/proper name/ no response	18 (20.2%)	15 (18.1%)	33 (19.2%)
Total	89 (100.0%)	83 (100.0%)	172 (100.0%)

Patient perception of treatment supporters and the patient-supporter relationship over time

Most participants viewed the patient-supporter relationship as unchanging throughout the course of the study. When asked about changes in their relationship over time, most participants denied changes in either the first (73.8%) or second (80.2%) year of the study. When asked specifically about changes in the level of support they received from their treatment supporter over time, 90.2% of respondents reported no change, with no statistically significant difference between the groups ($p=0.883$).

Of those respondents who noted changes in the patient-supporter relationship during the first year of the study, most (68.9%) reported changes that reflected improvements or bettering of the relationship. For example, some described a closer, more trusting relationship, for example: "We very close now. I can tell her my secrets." Others reported improved communication and openness: "Our relationship got better. She taught me about life and HIV. We just talked about everything." Only two participants reported negative changes in the relationship, specifically increased number of arguments. Several respondents noted positive changes in the patient-supporter relationship during the second year of the study, which included increased emotional closeness or improved communication. Of the five respondents who reported negative changes during the second year, most described an increased number of arguments; one described the supporter as "bossy;" and another referred to the supporter's drug use.

When asked to describe ways in which the patient-supporter relationship remained the same during the study, most respondents (76.3%) generally referred to positive feature. These included positive attributes of the support person ("she is a good person"), as well as positive attributes of the relationship itself ("good friendship, good understanding."). Several specific themes emerged from their descriptions. Many respondents (9.2%) noted good communication in the relationship: "After every quarrel we will sit and talk things out because we love each other." Others (3.5%) reported supporter acceptance of patient's HIV status: "She still treats me the same—not different because I'm sick."

Another theme was reciprocity between the patient and supporter, described by 6.4% of respondents, "We both had TB then and we both had HIV too, so we helped/ supported each other through our sicknesses." Several (3.5%) respondents also noted instrumental and material support (e.g., "cooked for me," "financial support") from their supporter. Only three participants (1.7%) described specifically negative features: "Our relationship has been difficult. He was very jealous and argumentative."

Most (93.0%) participants denied any specific features that were unhelpful about the treatment supporter. Of those who did identify an unhelpful feature, two patients described irritation with reminders about medication adherence, for example: "...got a bit/ slightly irritated with her constantly asking me if I took my tablets. Telling her again and again yes I did take it."

Other complaints included the lack of availability of a treatment supporter, arguments between the patient and the supporter, feeling like a burden to the supporter, and the supporter acting too controlling.

Most participants (92.4%) denied having any problems or issues with the supporter. Of those who did report problems, issues included family and financial disputes and other arguments, personality conflicts (e.g., “very bossy”), and lack of supporter availability. Two participants described more pervasively dysfunctional relationships:

“He does not give me money; if he has, he buys the food himself. He throw my tablets in my food. He wants to kill me. He scold me out a lot.”
 “...treating me like a child, wanting to choose my friends, disapproval of my boyfriend, over protective.”

The role of treatment supporters in medication adherence

Approximately 80% participants in the DOT-ART group used the adherence chart to record medication doses. Most participants (82.6%) reported that they found it easier to take medications when the treatment supporter was observing, with no significant difference between groups ($p=0.752$). When asked what was most helpful about the treatment supporter, 39.3% of respondents described medication adherence. For example, one participant noted that the supporter “...was always making sure that my treatment was taken at night times—she always made sure of that.”

Approximately 86.6% of respondents reported that their supporter continued to observe them take medication into the second year of the study, with no statistically significant difference between the groups ($p=0.728$).

Other perceived effects of having a treatment supporter

In addition to providing assistance with taking medication, respondents described additional ways in which their treatment supporter was helpful. More than one-quarter (27.2%) of participants cited emotional support (“encourage me and lift me up”). Other participants (15.6%) reported receiving consistent general support: “lots of support when I was not able to help myself.” Some (9.8%) also cited material support (“provides me with food”). Others (4.0%) described the trustworthiness of the supporter as helpful: “I could trust her not to tell anybody that I’m taking HIV medication.” Several participants (1.2%) found having a supporter who was also HIV-infected helpful: “She was HIV positive too so we can do this together.” Only 2.3% of respondents reported that nothing was helpful about the supporter, or made a negative comment about the supporter (e.g., “she disappointed me”).

Many participants also noted that supporters influenced changes in their lives. Specifically, approximately one-third (32.0%) of patients reported a change in their drinking or drug use while enrolled in the study, with no statistically significant difference between the groups ($p=0.177$). Of those who reported a change, 82.5% described a decrease in drinking or drug use (e.g., “I stopped completely.”), with no statistically significant difference between the two groups ($p=0.578$). No participants described an increase in drinking or drug use. DOT-ART participants were more likely to report that the supporter had an effect on this change than the Self-ART group (78.8% vs. 52.0%, $p=0.031$, Table 3).

TABLE 3. PATIENT PERCEPTION THAT SUPPORTER AFFECTED LEVEL OF DRINKING OR DRUG USE

Response category	DOT-ART	Self-ART	p Value
Yes	26 (78.8%)	13 (52.0%)	0.031
No	7 (21.2%)	12 (48.0%)	

Of the 31 (18.0%) respondents who reported a change in employment status during the study, 26.5% reported that the treatment supporter affected this change. There was no significant difference between the two groups ($p=0.855$). Of the 119 (69.2%) respondents who reported a change in their overall health during the study, 78.6% felt the supporter had a role in this change, with no significant difference between groups ($p=0.573$).

Discussion

The feasibility of using community-based treatment supporters in resource-constrained settings

Analysis of this semi-structured interview indicates that most patients in both arms of a randomized, controlled trial comparing the efficacy of DOT-ART versus Self-ART reported enduring, largely positive, beneficial relationships with treatment supporters from their existing social network. These treatment supporters assisted patients in both study arms with medication adherence and provided material, instrumental, and emotional support.

Trained community health workers have been utilized extensively to support persons living with HIV, including the promotion of medication adherence.^{18–20} There have been few randomized trials, however, of lay treatment supporters. The results of the current study suggest that most HIV-infected patients in this peri-urban South African community have supportive family and friends who are able to successfully assume the role of treatment supporter for ART initiation. Further, patients have the motivation and skills to introduce and maintain this new yet compatible role into an existing relationship in their social networks, with minimal or no external assistance. This is consistent with evidence that for many persons living with HIV/AIDS in South Africa and elsewhere, informal caregiving by family, friends, and other community members is often the major source of care.^{21,22} Even without interventions, HIV-infected patients in this community appear to rely on existing social relationships and informal caregivers to obtain the necessary resources and support to adhere to ART. The results of the current study therefore reinforce that the use of community-based treatment supporters to improve the care and treatment of persons living with HIV/AIDS is well-suited to South Africa and potentially other resource-constrained settings.

Community-based treatment supporter: The potential for an expanded role in supporting HIV-positive persons

Many participants noted that medication assistance was the most helpful aspect of having a treatment supporter, and having a supporter made it easier for most participants to adhere to therapy. However, this is only one of many role assumed by treatment supporters.

Patients in the current study frequently mentioned the role of their supporter in providing them a wide range of assistance, from basic material and instrumental aid to emotional support and encouragement. These benefits are consistent with those noted in the recent study by O'Laughlin and colleagues that highlighted the role of treatment supporters in promoting the social health of HIV-infected persons in Tanzania.²³

Further, participation in a formal training program may enhance the benefits of a patient–supporter relationship. In this study, DOT-ART patients were significantly more likely to feel that their supporter affected their alcohol and drug use behavior. This is a promising finding, given that alcohol and other substance abuse is a well-documented barrier to antiretroviral adherence in both developed and developing countries.^{24,25} One explanation is that interventions, such as educational sessions, may provide supporters with new knowledge and strategies to impact health-related behaviors. Another possibility is that participation in a formal DOT-ART program gives supporters greater “moral authority” over patients than informal caregivers.²⁶ Additional research is needed to identify the type and extent of training needed to optimize patients' relationships with informal caregivers and other supporters.

Together, these findings highlight the diverse and highly influential roles of community-based treatment supporters, which may have a profound impact on health. The fulfillment of basic material needs, such as food, is critically important to ART adherence and successful treatment outcomes.^{27,28} Further, it is well-established that emotional and instrumental support is predictive of HAART adherence and virologic outcomes.^{29–31} The current study therefore suggests several specific potential pathways for the survival advantage noted in the parent study and supports the concept that social support impacts physical well-being.³² For example, DOT-ART treatment supporters may promote alcohol and drug cessation, improve nutrition by providing food, or decrease stress by offering emotional support, all factors that may contribute to improved survival independently of medication adherence in the parent study.

Characteristics and relationship dynamics of a successful patient–supporter relationship

Given the potential for treatment supporters to positively impact patients, the choice of appropriate treatment supporter is critical. The results of the present study may help to guide the choice of treatment supporters in future study and practice.

First, a patient's existing social network—namely supportive family and friends to whom a patient has self-disclosed his or her HIV status—are likely to be appropriate candidates for treatment supporters. In this study, it was particularly common for treatment supporters to be from long-lasting familial relationships (e.g., spouses). Targeting existing supportive ties from long-term relationships may help to address the need for sustained adherence promotion.

Trustworthiness is an important characteristic in a treatment supporter. HIV-related stigma is prevalent in South Africa,³³ and persons may fear that disclosure of their HIV-infected status could lead to social isolation and resource deprivation. The majority of patients in this study were able to identify a supporter to whom they had already or to whom they could disclose their HIV status. Supporters' involvement

in the patients' treatment appeared to increase trust, and ultimately improve the relationship.

Patients also frequently described the benefits of a supporter being “always there.” This may include physical proximity, emotional availability, extra material resources, and available time. This suggests it is important to determine individual patient needs, and identify supporters capable of meeting those specific needs.

Certain relationships dynamics and skills may also be important in a successful patient–supporter relationship. In this study, good communication helped patients share their problems and needs with their supporter and also to resolve disagreements. It also appeared to contribute to participants' feelings of acceptance about their disease.

Reciprocity in the patient–supporter relationship may also contribute to the success of the relationship. Forms of reciprocity include shared reminders about medications, the exchange of resources, and emotional support. Such reciprocity may ultimately improve not only a patient's satisfaction with the relationship, but also his or her health. Abbott and Freeth suggest that an unbalanced relationship may lead to short-term and long-term stress, ultimately negatively impacting health.³⁴ They conclude that balanced, reciprocal relationships help to maintain social networks, encourage social participation, and positively impact health. Though this finding is well-established in the literature, it is not addressed by predominant models of adherence intervention.

Despite the largely positive feedback from participants, several referenced negative aspects of their relationship. For example, treatment supporters may be too “controlling” or “bossy”, behavior which the role itself may encourage. Addressing this potential negative relationship dynamic at the onset and during the course of future interventions may be beneficial. In addition, abusive or violent relationships may have a profound negative impact on persons initiating ART. Additional research is needed to explore the extent and impact of this problem in patient–supporter relationships.

Study limitations

There are several limitations to this study. First, the study population lived in peri-urban townships and attended a hospital clinic. The results may not be generalizable to HIV-infected persons attending primary care clinics, or to rural areas of South Africa, or to other countries. Further, the patients in the parent study were recruited during the early stages of ART roll-out in South Africa; this population may be different than the patient population currently on ART. Additionally, only patients who completed the study were eligible to complete the interview; those who withdrew from the study may have had different experiences with their treatment supporters. It is also possible that there was self-selection bias in the sample of participants who chose to complete the exit interview. Last, the use of self-reported data is a significant limitation of the study. For example, participants may be more likely to report positive experiences rather than negative ones if they seek social desirability or if they perceive lack of confidentiality.

Conclusions

In summary, findings from this study suggest that the use of patient-selected community-based treatment supporters

can be a beneficial and satisfying experience for South African adults living with HIV, especially if they receive additional training. Community members with whom patients have an existing long-term supportive relationship, who may already be acting as informal caregivers, are feasible candidates to act as ART treatment supporters. These supporters have the capacity to not only assist patients with medication adherence, but to provide additional material, instrumental and emotional support, as well as to promote other healthy behaviors, such as decreased alcohol and drug use. Enhancing certain aspects of the patient–supporter relationship—trust, supporter availability, communication, reciprocity of support, and medication assistance—in a manner consistent with patients' expectations may help to optimize the relationship, and its positive impact on patient health.

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Author Disclosure Statement

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