

Peers Keep It Real: Re-engaging Adults in HIV Care

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Abstract

Background: After diagnosis, a substantial number of people with HIV disease fall out of care. Effective interventions are needed for this priority population. **Methods:** The “Peers Keep It Real” study aimed to help adults who were disengaged from HIV treatment. Peers, lay individuals living with HIV, facilitated intervention sessions. Participants were randomized to immediately receive the peer-facilitated intervention or were wait-listed. **Results:** Considerable attrition occurred in the control group. Pre-/postanalyses showed that among participants ($n = 23$) who received the intervention, 65% had viral load suppression and 100% remained in care at 12 months postintervention. Impact on viral load was significant ($P = .0326$), suggesting that peers are effective change agents who positively impacted outcomes for individuals struggling with adherence to HIV treatment. **Conclusion:** Future endeavors should consider providing all individuals from this priority population with an active peer intervention from the onset to enhance retention and adherence.

Keywords

HIV, out of care, medication adherence, intervention

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Introduction

Efforts to end the HIV epidemic include identifying undiagnosed individuals through HIV testing, linking them to medical care, and engaging them in lifelong HIV care and treatment with antiretroviral (ARV) medications.^{1,2} After diagnosis and linkage, a portion of the HIV population does not fully engage in HIV care and struggles with medication adherence.³ This subgroup does not benefit from sustained viral load suppression, fuels HIV transmission, experiences higher rates of morbidity and mortality, and often falls out of care.⁴⁻⁷ Lack of virologic suppression due to disengagement from HIV treatment is costly not only at the individual but also at the population level. A person living with HIV disease who does not have a suppressed viral load is risking his or her individual health while also being much more likely to transmit HIV infection to another individual. Hence, suppression of HIV viral load is a matter of public health. Moreover, suboptimal medication adherence can cause HIV drug resistance and can often increase the need

for more complex, and more expensive, treatment regimens to ultimately suppress viral load.⁸

Effective strategies are needed that can reach individuals who have been diagnosed with HIV but are not engaged in care and thereby are not taking ARV medications and do not have a suppressed viral load. The purpose of this article is to describe

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What Do We Already Know About This Topic?

Individuals living with HIV who struggle with medication adherence and therefore do not have a sustained, suppressed HIV viral load are at high risk for poor health outcomes.

How Does This Research Contribute to the Field?

This research contributes further evidence that peer-facilitated adherence interventions help people who are struggling to take life-saving HIV medications as prescribed.

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

This research has implications for practice and recommends that peers be part of all HIV medical care teams to enhance engagement in care and adherence to antiretroviral medications.

the development and testing of the Peers Keep It Real program, a theory-based, tailored, behavioral intervention. The peer-delivered program specifically aimed to reach individuals who were struggling with medication adherence and were disengaged from HIV care.

Intervention Program Development

The Peers Keep It Real program was developed and tested in a 3-phase process that included planning, implementation, and evaluation.⁹ A cohesive group of academic and community partners worked together as a team throughout all phases of the project. The study team met biweekly during the planning phase of the project. An advisory group, consisting of community members and health care professionals, was formed to provide input about recruitment strategies, design of materials, and intervention procedures. The 1-year planning phase focused on expanding a peer-led intervention, which had been tested in one setting,¹⁰ to 4 HIV medical care settings. In addition, preparation of project materials, development of recruitment materials, submission of institutional review board (IRB) applications, and recruitment and training of peer interventionists occurred during this year.

Peer Interventionist Selection Process

To be considered as an intervention facilitator, an individual must have been (1) living with HIV for at least 1 year, (2) taking HIV medications as prescribed, and (3) sustaining a suppressed HIV viral load. Additional criteria included: (1) minimum of 6 months' recent experience working or volunteering as an educator in an HIV health care setting or an HIV service organization, (2) ability to complete training

and participate in project team meetings regularly, (3) ready access to transportation to study sites to deliver the intervention, (4) letter of recommendation, preferably from current/recent employer, and (5) a desire to participate.

Eight peers, lay individuals living with HIV, were selected as intervention facilitators. Peers were compensated hourly for their time during all phases of the project, including training. The curriculum for training consisted of a variety of learning activities including readings, didactic presentations, interactive discussions, and role-playing. Five vignettes for role-playing were developed from qualitative data that had been collected in a formative study involving individuals who had experienced repeated challenges with engagement in HIV treatment.¹⁰ Vignettes have been used successfully in social science research to address sensitive topics.^{11,12} In this study, vignettes provided a safe environment where peers gained experience about how to communicate and respond to study participants' behaviors, attitudes, and emotions.

Of peers selected as interventionists, 7 completed the training as 1 person felt uncomfortable by the responsibility of the research procedures and chose to leave the study team. A second peer interventionist left the team for a different employment opportunity, and a third peer was motivated by the research experience to apply for graduate school and became a full-time student. Hence, in the end, 4 peers stayed on throughout the entire project.

Study Intervention

The Peers Keep It Real program built on an HIV medication adherence intervention called "Ready" that was originally developed in a nurse-led format¹³ and then transformed to a peer-led format and tested in one HIV medical care setting.¹⁰ Peers Keep It Real aimed to address the multifaceted problem of nonadherence to HIV medications and lack of engagement in HIV care. Two theoretical frameworks, Social Cognitive Theory¹⁴ and the readiness stage of Wellness Motivation Theory,¹⁵ guided the Peers Keep it Real intervention program.

Peer intervention facilitators delivered the intervention in an effort to enhance cultural relevance and effectiveness.^{16,17} Other researchers have reported that incorporating ethnocentric and culturally relevant components within HIV interventions enhances receptivity by the priority population.¹⁸ Intervention activities focused initially on identifying individual, community, and system barriers to achieving the desired goals of engagement in care, medication adherence, and sustained suppression of HIV viral load. The identification of perceived barriers was explored via a dialogue between the peer and the participant. A detailed checklist guided the dialogue (Table 1). The checklist was developed for this intervention by the study team and informed by an exhaustive review of the HIV literature. In addition to the checklist, participant's responses to 4 questionnaires (ie, readiness for healthful behavior change, depression symptoms, perceived social support, and confidence/self-efficacy to take ARV medications as prescribed) were used to guide the dialogue.¹⁹⁻²²

Table 1. Checklist to Guide Exploration of Perceived Barriers.

Topic	Past Barrier	Current Barrier	Notes/Details
Housing issues			
Not enough/right food			
No experience with anyone living with HIV			
Cultural issues			
Substance use/alcohol use			
Fear of disclosure of HIV status			
Denial of HIV diagnosis			
Stigma			
Isolation/loneliness/lack of support			
Depression/emotional distress			
Forgetfulness			
Lack of a "routine"			
Lack of trust in HIV medications and/or health care system			
Medication regimen too complicated/too many pills			
Side effects or perceived side effects			
Sleeping through medication dosing time(s)			
Decreased quality of life			
Family responsibilities			
Work responsibilities			
Problems getting HIV medications			
Does not think can be adherent			
Problems getting to medical appointments/transportation issues			

A unique list of individualized barriers to engagement in HIV care and treatment was then created and ranked by the participants, from those perceived as most to least difficult to address. Then, beginning with the barriers perceived least difficult to address, strategies were created to overcome the identified barriers. The intervention focused on developing tailored strategies based on the identified needs of the participant.²³ Strategies were developed by the peers and study participants, in partnership, during the study sessions. The peer in this program served as a role model who provided positive reinforcement to help the participant create practical plans to reach desired health outcomes.²⁴ The peer worked closely with a nurse liaison throughout the intervention period. The primary objectives of Peers Keep It Real were to help participants reach, and sustain, viral load suppression and attend HIV medical care appointments on a regular basis.

In addition to the intervention activities described above, the intervention provided a knowledge- and skill-building component. At the intervention sessions, peers provided health information or taught a skill that was tailored to the unique needs of the participant. Included in the knowledge/skills component were learning about participant's own ARV medication regimen, recognizing desired laboratory test results, enhancing medication adherence skills (eg, how to use a pill organizer), and incorporating healthy lifestyle behaviors (eg, smoking cessation).

Methods

Study Design, Setting, and Population

A pilot study was undertaken to examine the feasibility of implementing the peer-facilitated intervention with multiple peers and recruiting participants from a variety of health care settings. A mixed-methods approach was used to evaluate the Peers Keep It Real program. Qualitative methods (ie, detailed field notes, observation, individual interviews) were utilized to examine acceptability and the workings of the intervention. Quantitative methods with a pretest/postdesign were used to examine the impact of Peers Keep It Real on participants' engagement in HIV care and adherence to ARV medications. This article reports the quantitative study findings and addresses the following research question: What is the impact of a peer-led intervention on engagement in HIV care (ie, attendance at HIV medical care appointments) and on medication adherence (ie, HIV viral load suppression)?

The Peers Keep It Real program was slated to be implemented in 1 metropolitan area at 4 sites: (1) an infectious disease specialty physician group who practiced at several area hospitals, (2) a safety net public hospital, (3) a freestanding community clinic that was part of a federally qualified health center, and (4) an academic medical center. However, there were substantial delays in obtaining IRB approval at the academic medical center. Peers did not meet historical criteria (ie, research or health care professional) as members of traditional research study teams. In the end, participants from the academic medical center were referred to the *Peers Keep It Real* program but had to receive the intervention at one of the other study sites.

Inclusion criteria for participation in the study were (1) age 18 years or older, (2) ability to speak English or Spanish, (3) documentation of nonadherence to ARV medications and/or being out of medical care >6 months, (4) HIV-1 RNA by polymerase chain reaction (PCR) not suppressed (ie, >1000 copies), and (5) community-dwelling individual with access to ARV medications. Individuals who were newly diagnosed with HIV or who were naive to ARV therapy were excluded. Recruitment occurred via flyers and brochures distributed to potential participants by case managers, health care providers, and social workers.

The recruitment materials briefly described the study and directed potential participants to call a study coordinator for more details. Most participants (75%) were referred to the study after presenting to outpatient HIV or infectious disease clinics with an acute illness or during hospitalization. Other participants learned about the study from case managers or health care providers who reached out to their eligible clients. There was one participant who was referred by an individual who had enrolled in the study. Individuals who expressed interest in the study were scheduled to meet with a study coordinator who provided more information and, if desired, set up a study enrollment visit. Of those who agreed to participate in the study, 5 did not show up for the enrollment visit.

At the enrollment visit, participants signed consents, completed baseline questionnaires, and were randomized to receive

the Peers Keep It Real intervention immediately or were wait-listed. Participants in the wait-listed control group were to receive the standard of care for 6 months after enrollment into the study and then receive the active Peers Keep It Real intervention. Both groups received the same compensation for visits with a study coordinator (ie, a US \$25.00 gift card at enrollment and again at 3 and 6 months postenrollment). In addition, participants received a US \$10.00 gasoline card, or 2 bus passes valued at US \$6.00, to assist with transportation to intervention visits with peers. The first 7 of 10 participants randomized to the wait-listed control group were lost to follow-up prior to the 3-month follow-up time point. Based on input from the advisory board, the remaining study participants were assigned to receive the active intervention immediately. Participants who received the Peers Keep It Real intervention ($n = 23$) were followed for 1 year.

Procedures

The Peers Keep It Real intervention program consisted of 7 individual sessions: 1 session per week for 6 consecutive weeks with a booster session 6 weeks later. Each session, facilitated by a peer interventionist, lasted approximately 60 minutes. Sessions occurred, ideally, at the health care setting where the participant would obtain his or her HIV care and, if an option, were scheduled on the same day as appointments with HIV medical care providers. However, some participants chose to meet their peer initially at a neutral location, such as the public library. Peers met participants for study sessions at mutually agreed-upon dates/times. Permission was obtained from each participant to send reminders about study session dates/times via phone call or text message. Participants were given the peer and the study coordinator's contact information and could call, between study sessions, with questions or concerns.

Measures/Data Collection

Using the web-based software program Qualtrics, participants provided self-report data at baseline. Demographic and health characteristics that included age, gender, ethnicity, education level, year of HIV diagnosis, and number of previous HIV medication regimens were collected. Participants also completed the following Likert scale surveys at baseline: Index of Readiness scale to assess readiness for healthful behavior change (9 items); Medical Outcomes Study *Social Support Survey* (19 items) to assess social support; and the Center for Epidemiologic Studies Depression Scale (20 items) to assess depressive symptoms.¹⁹⁻²¹ A questionnaire about self-efficacy for medication adherence, developed for this study based on Bandura's guide for constructing self-efficacy scales,²² was also administered at baseline. Responses to the 4 surveys were utilized as part of the intervention. The peer facilitator reviewed responses with the participant and then integrated the information into the intervention sessions in an effort to tailor strategies for each individual.

The main outcomes of interest were sustained HIV viral load suppression and engagement in HIV care. Laboratory results (HIV viral load, CD4 count) from each participant's electronic health record were collected at enrollment, 6-month, and 1-year follow-up time points. Study personnel also tracked kept/missed clinic visit dates by examining participants' electronic health records. Data from the 2 academic medical center participants were provided to the principal investigator (PI) via password-protected e-mail in a deidentified Excel document.

Medication Adherence. HIV viral load suppression (ie, HIV-1 RNA by PCR) was used as the proxy measure of medication adherence. A viral load of <200 copies was used as the cutoff point for suppression based on the US Department of Health and Human Resources HIV/AIDS Bureau Performance Measures for HIV viral load suppression.²⁵

Engagement in HIV Care. Attendance at clinic visit appointments scheduled with the participant's HIV health care provider was used as the proxy measure of engagement in care. If a participant rescheduled a clinic appointment, this was not documented as a missed visit.

Data Analysis

The evaluation of intervention impact on engagement in care and suppression of viral load used a pre-/postdesign and all participants who received the *Peers Keep It Real* intervention ($n = 23$) were included in the analysis. There was essentially equal enrollment at 3 of the recruitment sites: physician group practice, safety net hospital, and federally qualified health center. Only 2 participants were enrolled in the program from the academic medical center. The 2 participants referred from the academic medical center met with peers at the federally qualified health center due to inability to obtain timely IRB approval from the academic medical center. Due to the small number of participants, analysis of differences among outcomes by study site/setting could not be done.

Descriptive statistics and t tests were used to examine differences between the intervention and wait-listed control group with regard to demographic and health data, readiness, social support, depressive symptoms, and self-efficacy for medication adherence at enrollment. A mixed-model analysis was used to determine intervention effect on viral load suppression, while taking into account the repeated measures at the time points of baseline, 6 months, and 1 year postintervention.

Ethics Statement

The IRB of the University of Missouri–Kansas City (protocol number 14-215) approved this study. All participants signed a written informed consent to participate in the study as well as an additional consent giving permission to collect laboratory data (ie, HIV viral loads and CD4 counts) from their medical record and to obtain information about dates of kept/missed

Table 2. Characteristics of Study Sample by Group.

	Immediate Peer Intervention, n = 20	Wait-Listed, n = 10
Age (years)		
55 and older	0	0
45-54	10 (50%)	6 (60%)
35-44	3 (15%)	4 (40%)
25-34	6 (30%)	0
18-24	1 (5%)	0
Gender		
Female	9 (45%)	2 (20%)
Male	11 (55%)	6 (60%)
Transgender	0	2 (20%)
Ethnicity		
African American/black	12 (60%)	8 (80%)
Latino/Hispanic	1 (5%)	1 (10%)
Caucasian	6 (30%)	1 (10%)
Other	1 (5%)	0
Education level		
Did not complete high school	5 (25%)	0
Completed high school/GED	7 (35%)	8 (80%)
College graduate	8 (40%)	2 (20%)
Years living with HIV		
Mean (SD)	13.75 (10.34)	15 (7.3)
Range	1-32	3-28
Baseline viral load		
Mean (SD)	72 206 (114 155)	35 386 (24 983)
Range	1000-376 210	3603-88 822
Baseline CD4 count		
Mean	290 (204)	217 (262)
Range	1-657	1-627
Number of previous HIV medication regimens		
Mean (SD)	3 (2.52)	3 (1.85)
Range	1-10	1-5

Abbreviations: GED, general educational development; SD, standard deviation.

HIV health care provider visits. Participants received a US \$25 department store gift and assistance with transportation (ie, gasoline card or bus passes) at enrollment, 3 months, and 6 months postenrollment time points. In addition, participants received the US \$10.00 gasoline card or bus passes (ie, US \$6.00 value) for assistance with transportation to each study visit.

Results

Demographic and Health Characteristics of Participants

The baseline demographic characteristics of adults who enrolled (n = 30) in the study are shown in Table 2. With regard to gender, there were 17 males, 11 females, and 2 transgender individuals. Most participants identified as African American/black, were between the ages of 25 and 54, and had a high school education. Participants reported having been prescribed between 1 and 10 previous ARV medication regimens and living with HIV from 1 to 32 years.

Table 3. Viral Load Suppression by Time Point.

Time Point	VL Suppression
Baseline	0/23 (0%)
6 months	9/10 (90%) ^a
12 months	15/23 (65%)

Abbreviation: VL, viral load.

^aSmaller n due to missing data and wait-listed participants had not rotated to intervention group yet.

With regard to immune system status, based on HIV 1 RNA by PCR (viral load) and CD4 count, individuals randomized to the wait-list group (n = 10) were similar at baseline to those who received the intervention immediately (n = 20). There were no significant differences between the 2 groups at baseline on viral load ($P = .228$) or CD4 count ($P = .149$). In addition, no significant differences were found between groups on the responses to baseline questionnaires that peers used to guide intervention study sessions (ie, depression symptoms, $P = .277$; perceived social support, $P = .257$; readiness for healthful behavior change, $P = .858$; or self-efficacy for medication adherence, $P = .536$). Differences between groups at baseline were examined using the independent t test, equal variances not assumed.

Engagement in HIV Care and Medication Adherence

At enrollment, all participants were struggling with ARV medication adherence or had stopped taking ARV medications and did not have a suppressed HIV viral load. Participants in both groups received identical compensation for study participation (ie, a gift card at enrollment and 3 months postenrollment). However, 7 of 10 wait-listed participants were lost to follow-up by 3 months postenrollment. Conversely, all participants randomized to immediately receive the Peers Keep It Real intervention (n = 20) were still engaged in care at the 6-month postenrollment time point. Three additional wait-listed participants received the intervention, after the wait period.

A mixed model using SAS software was employed to analyze data from the participants (n = 23) who received the Peers Keep It Real Intervention. A mixed model was used due to its flexibility in accounting for repeated-measures response and/or intervention effect. The analysis was conducted with baseline, 6-month postintervention, and 1-year postintervention viral load suppression data. When wait-listed control group participants received the Peers Keep It Real intervention at 6 months, they were then labeled as intervention group and included in the analysis. The mixed model showed significant intervention effect ($P = .0326$) with odds ratio equals to 6.213 (95% confidence interval, 1.173-32.916). The intervention increased the chance of viral load suppression by 5.2-fold. Among the participants who received the Peers Keep It Real intervention, the majority (90%) were adherent at 6 months postintervention, that is, they had a suppressed HIV viral load. At the 1-year postintervention time point, 65% remained virologically suppressed (Table 3). Participants' log₁₀ HIV PCR from baseline

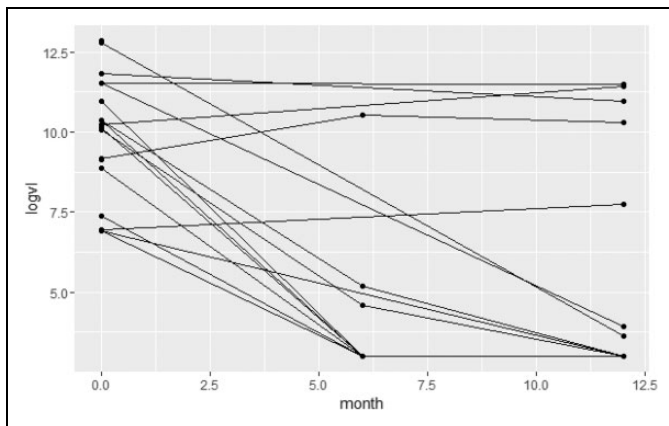


Figure 1. Log₁₀ HIV PCR from baseline to 1 year postintervention. PCR indicates polymerase chain reaction.

to 1 year postintervention is shown in Figure 1. Of note, 100% of those who received the Peers Keep It Real intervention remained in HIV care at the 1-year postintervention time point.

Discussion

Identifying strategies to help people who are struggling with engagement in HIV care and treatment is important for individual and public health. In this study, adults who were disengaged from HIV care and did not have a suppressed HIV viral load were invited to participate in a peer-led intervention program named Peers Keep It Real. Recruitment sites for this study that were located in the community were more amenable to having peers (ie, lay individuals living with HIV) deliver an intervention, than was an academic medical center. This acceptance by the community settings was perhaps due to the very nature of community-based health care. Of note, individual HIV health care providers in all the study settings welcomed peers as intervention facilitators who could potentially help their patients who were not engaged in HIV care.

The current study demonstrated significantly improved long-term medication adherence and engagement in HIV medical care among the participants who received the Peers Keep It Real intervention. Peer-facilitated interventions, that is an intervention led by a person who is living with the same disease, that have addressed a variety of other chronic health conditions have shown success.^{26,27} The current study and our formative study that was conducted in one care setting¹⁰ have shown the ability of peers to act successfully as change agents in HIV disease and, as other researchers have demonstrated, to deliver complex behavioral interventions.²⁸ However, it is important to consider that peer interventionists themselves are a vulnerable population who experience challenges and are living with HIV as a chronic health condition. In this study, half of the 8 peers who trained initially as interventionists left the study team for a variety of reasons. Hence, training twice the needed number of peer facilitators upfront salvaged the ability to conduct the research project.

The participants in this study were adults living with HIV who had experienced previous virologic failures to HIV medication regimens, were not engaged in care, and did not have a suppressed HIV viral load at the time of study enrollment. Most participants had dropped out of routine HIV medical care and were told about the study when they interacted with the health care system (eg, urgent care, hospitalization,) due to an acute health care need/illness. The fact that many participants in this study were experiencing an acute health issue may have triggered their desire to enroll in a study that focused on reengagement in HIV care and treatment.²⁹ However, this desire alone, coupled with the standard of care but without peer engagement, did not appear to be enough, as evidenced by the sizeable attrition that occurred among individuals randomized to the wait-listed control group. In contrast, all participants who were randomized to the immediate intervention group were still in care at the 6-month follow-up time point. The fact that participants in the active intervention group received a US \$10 gasoline card, or US \$6 worth of bus passes, could have been construed as a factor that enhanced retention in the intervention group. However, 2 of the 3 recruitment sites provided transportation assistance in the form of bus passes or taxi voucher to HIV medical care visits for the control group. Hence, we believe these findings suggest that the interaction with the peer interventionist, a lay individual living with HIV, contributed to the ability to stay engaged in HIV care. Interventions or programs that provide interaction with peers in venues that are not associated with health care (eg, social organizations) may also be a viable strategy for reaching individuals who have fallen out of HIV care.

Limitations

Results were significant with regard to sustained virologic suppression at 1 year post-intervention among participants who received the Peers Keep It Real intervention. Moreover, 100% of those who received the intervention remained in care at the 1-year postintervention time point. Although the results of this study and the formative study that preceded it¹⁰ are encouraging, there were limitations that must be considered when interpreting the findings. Recruitment occurred in one city located in the Midwestern United States with a small sample of adults. All participants had access to HIV medications and were prescribed a once-daily dosing regimen. The pre-/postevaluation of impact in the current study was essentially an as-treated analysis that included all participants who received the intervention. The authors acknowledge the weaknesses of a 1-group pre/postdesign, which was ultimately used by the study, and the small sample size. Hence, the findings of this study may not be generalizable to other communities and health care settings or to individuals who may not have ready access to HIV medications. In addition, a larger study would be needed prior to widespread implementation of the intervention approach.

Furthermore, attrition among adults who were wait-listed was concerning. Future studies should focus on strategies to

minimize attrition of the control group, such as providing a valuable comparison intervention during the wait-list period or shortening the wait-list period. Another consideration for extremely vulnerable priority populations, such as the one in this study, would be to instead use a matched historical control group and deliver the active intervention to all participants. Although there were limitations in the current study, the peer-facilitated intervention appears to have merit as a strategy that may help individuals who struggle with medication adherence, are not taking life-saving HIV medications, or have fallen out of HIV care.

Conclusion

Despite effective, tolerable, and simple HIV medication regimens, lack of retention in HIV care and nonadherence to ARV medications resulting in nonsuppressed HIV viral load persist as a formidable challenge in the fight to eradicate HIV disease. Effective and practical interventions are needed that can reach people with HIV who are out of care so that they may achieve the maximum benefit from available treatment. The Peers Keep It Real intervention, with its culturally relevant, tailored, and peer-led format, shows promise as a strategy to help individuals struggling with adherence to HIV care and treatment. Our work suggests that a peer-led format increases receptivity by the subgroup of individuals living with HIV who are not in care or who may not have responded to previous strategies to enhance ARV medication adherence. Although this study demonstrated that a peer-led intervention format was acceptable in community-based health care settings, more work is needed to enhance promotion of peers as facilitators of healthful behaviors overall. All types of HIV care settings should consider incorporating peers as part of the HIV care team, not only in an educator role³⁰ but as change agents to enhance engagement in care and sustain adherence to HIV treatment.

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