



Physical and psychosocial impact on peers with HIV co-leading an HIV intervention: A pilot theory-guided case-study

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ARTICLE INFO

Keywords:

Peer coaches

HIV

Social Learning Theory

Safety-net

ABSTRACT

Objective: To examine longitudinal changes in activation, HIV health outcomes, and social and psychological determinants of adherence to antiretroviral therapy (ART) among peer trainers with HIV.

Methods: A multi-method case study. The study population included peers ($n = 4$) from a randomized controlled trial about peers training patients with HIV ($n = 359$) to better manage their health. Each peer completed a semi-structured interview that we analyzed using Social Learning Theory (SLT) as a guiding framework. The peers also completed longitudinal surveys about their health after each training cohort ($n = 5$) over 3-years.

Results: Peers reported personal benefits from training others with HIV in self-management. Their self-reported activation, self-efficacy and some health outcomes increased overtime. The peers mentioned SLT principles during their interviews. Generally, the peers enjoyed and benefited from training others with HIV in a group-based learning environment.

Conclusion: Our findings suggest peer leadership can serve as a means for empowerment that is effective at both supporting improvements in health outcomes for patients and for themselves, which may be both scalable and sustainable.

Innovation: To our knowledge, this is the first mixed-methods study to show reciprocal long-term improvement in health behaviors in a diverse group of peers training others with HIV to self-manage their care.

1. Introduction

Research studies increasingly include people with lived experiences relevant to the condition (e.g. HIV or cancer) to serve as peer supporters and educators [1-4]. The growing involvement of peers has offered ways for them to reduce health disparities, particularly in HIV [2,5-7]. A systematic review by Boucher *et al* found 390 experimental studies from 1996 to 2018 reporting on peer-led HIV self-management interventions [8]. HIV interventions that include peers are associated with better rates of HIV testing, medication adherence, health literacy and prevention among the participants [8-11]. Despite the vital roles that peers play in improving the health of others, the long-term impact (positive or negative) of participation on the peers themselves has not been systematically evaluated.

According to Social Learning Theory (SLT), people learn social roles and expectations from others and in turn become role models themselves. The social learning process is based on four principles: attention (focusing on

the relevant behavior), retention (committing information to memory), reproduction (being able to rehearse the behavior), and motivation (a reason for wanting to engage in the behavior) [12]. SLT has been proposed as a theory that might explain the effectiveness of peer education [13]. SLT suggests, those that socially model (or rehearse) a behavior using those principles are more likely to perform that action themselves [14]. This learning through role modeling provides learners with both the skills and confidence that underlie patient activation [15]. A qualitative study by Raker *et al.* found that people with HIV who served as peers for others with HIV described acquiring HIV-related knowledge as a benefit of this work. This knowledge not only enabled them to support their trainees, but also helped them with their own care. One participant in the study reported that their work as a peer led to achieving the highest T-cell count they had ever had [16]. Other studies found peers benefited from an increased sense of empowerment, self-esteem, employment skills, and a network of social support [17-21]. However, the literature to date has lacked theoretical explanation

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and longitudinal measures. There is a paucity of subjective evidence on how working as a peer affects one's own physical and psychosocial health over time [1]. Adding to this evidence can maximize our ability to plan, train, support, and sustain peers during their work.

The goal of this pilot theory-guided case study was to examine longitudinal changes in peers' activation, HIV health outcomes, and social and psychological determinants of adherence to antiretroviral therapy (ART). A central research question guided the study: Does peers' long-term co-leadership of training sessions around HIV-related health behaviors affect their own HIV-related health behaviors?

1.1. Conceptual framework

We used a theory guided small case-study design [22]. We collected quantitative and qualitative data from a group of peer trainers from the Get Ready and Empowered About Treatment (GREAT) study from 2014 to 2017 [6,23]. We drew on SLT theory as it was a part of the theoretical underpinnings of GREAT [6]. To the extent the SLT played a role in the peers' participation in the study, we expected to observe an improvement in their HIV health-related behaviors over time.

2. Methods

2.1. Description of parent study

The GREAT study was a pragmatic randomized controlled trial (ClinicalTrials.gov Identifier: NCT02165735). The primary outcome and the protocol have been previously reported [6,24]. Briefly, the primary purpose of GREAT was to evaluate the impact of a peer-led intervention on patient activation among people living with HIV (PWH). Three hundred fifty-nine PWH participants from safety-net primary care practices in Rochester, NY (ROC) and Clinical Directors Network (www.CDNetwork.org) a primary care practice-based research network (PBRN) headquartered in New York City (NYC), took part in the study. Participants were randomized 1:1 to either an intervention ($n = 180$) or control condition ($n = 179$). The study took place from 2014 to 2017.

Participants randomized to the intervention condition participated in six weekly training sessions with a cohort of 6–8 other PWH. The 90-min training sessions focused on: (1) use a handheld smart-device (Apple iPod Touch™), (2) basics of navigating the internet and email, (3) use an HIV personal health record app, and (4) promoting shared learning among their cohort. Those in the control condition did not have contact with the peers or have any study-related intervention. Participants in both arms completed self-reported surveys at baseline, approximately 3-months and then 8-months post baseline with research assistants. Participants in both conditions received an iPod Touch device as an incentive for their participation. The intervention group received their device during their first training session and the control condition received it after completing their final follow-up survey.

A total of $n = 7$ peers participated. Certain peers were recruited from our previous pilot study, while others first participated in the study and, thereafter, served as a peer educator for a subsequent site [25]. On average, three peers jointly co-led each training session. The actual number of peers per session depended on their availability. The peers were not required to attend all of the sessions. They had the opportunity to participate in weekly research team meetings and professional development opportunities during the course of the study, as they desired.

2.2. Case study population

Four peers consented to complete the peer assessments. The other three peers only facilitated one training cohort and were not included in the study. The study team executed an IRB amendment and began collecting peer assessments approximately 3 months after the first participant training session in GREAT. Peers completed surveys at baseline and after a subsequent training cohort (5 training cohorts) was complete.

2.3. Measures

2.3.1. Debriefing sessions

After the last cohort completed their final training session, the peers met individually with a study coordinator to complete a 1:1 debriefing session. The study coordinator used a semi-structured interview guide to ensure consistency. The interview began by asking the peer to broadly “Focus on a high point of your time working with participants – a time when you were at your best, and you were really able to be helpful, or a time when you felt good about the work you were doing.” The peers were also asked to reflect on their experiences participating in the study including barriers and facilitators to co-leading the training sessions, how they spent their time, their motivation for participating in the study, and the impact of participation on their personal life [26]. The interview sessions were audio-recorded and the coordinator took notes (e.g. points of clarification, notable periods of silence and deviations from the original questions) during the sessions. The audio-recordings were transcribed verbatim and de-identified.

2.3.2. Demographics

The demographic questions asked about age, gender, race, ethnicity, and highest level of education completed.

2.3.3. Patient Activation Measure (PAM)

The PAM is a reliable and validated 13-item scale used to assess self-management empowerment [15]. An example item included “I am confident that I can tell a doctor concerns I have even when he or she does not ask.” Response options were on a 4-point Likert scale, 1 (disagree strongly) to 4 (agree strongly). We summed all of the items and normalized them to a 100-point scale, with higher scores reflecting higher levels of activation. Scores ≤ 47 indicate individuals do not feel they have an active role in their own health and healthcare; 47.1–55.1 indicate increasing awareness and confidence in self-management tasks; 55.2–67 indicate readiness to take action; scores ≥ 67.1 indicate individuals have adopted necessary behavior changes for activation, but may not be able to maintain them over time or during periods of stress.

2.3.4. HIV Treatment Adherence Self-Efficacy Scale (HIV-ASES)

HIV-ASES is validated 12-item scale used to measure patient confidence to HIV treatment-related behaviors (such as medication regimen adherence) in the face of barriers [27]. A sample question included: “In the past month, how confident are you that you can get something positive out of your participation in treatment, even if the medication you are taking does not improve your health?” Responses options were on a 10-point Likert scale ranging from 0 (cannot do it at all) to 9 (certain can do it). We summed all items for a total possible score of 0–120, with higher scores indicating higher self-efficacy.

Three HIV health questions were developed *de novo* by the physicians on the study team.

Two questions asked peers to self-report their most recent CD4+ and viral load: (1) “What is your most recent CD4/T-Cell count?” (Under 200, 201–349, 350–499, over 500 and don't know) and (2) “What is your most recent viral load?” (Undetectable, 50–999, 1000–9999, 10,000–99,999, 100,000 or above, and don't know). The third question was “Can you name all the HIV medications you are taking?” (yes or no).

SLT Codes

2.4. Analyses

We used the rigorous and accelerated data reduction (RADaR) technique to analyze the qualitative data from the debriefing session [28]. Specifically, we created an Excel table (our RADaR table) with column headers for each question asked during the debrief. Each coder ($n = 5$ research staff) used the transcripts to independently insert rows that contained each peer's response to each question (if a response was provided). This resulted in 25 rows (5 rows from each coder for each of the 5 transcripts). The team then worked to reduce data from the table that they felt did not directly relate to the

question. The team iteratively discussed and condensed the data in the RADar table. The final RADar table was reached by group consensus. We then used SLT as a guiding framework to map and understand the data in the table. For example, the data were thematically organized based on how they related to the four SLT principles: attention, retention, reproduction or motivation. Data that did not fit the principles were not used in these analyses. The table underwent 4 phases of reduction before the final list of exemplar SLT related quotes were selected for the study.

We carried out our quantitative data analysis in STATA 12.0 (Stata Corporation, College Station, Texas, USA). We performed descriptive analyses to report demographics, mean PAM, HIV-ASES, HIV outcomes over time. We did not test for statistical differences within or across the peers due to the small sample size.

Fig. 1 depicts how we used our qualitative findings to contextualize the results of our quantitative findings.

The study was approved by the University of Rochester and Clinical Directors Network Institutional Review Boards.

3. Results

3.1. Demographics

Three out of the four peers self-identified as male and one self-identified as female. Their mean age was 54 (SD 12.6). Two self-identified as Black (50%), one as White (25%) and one as Non-white Hispanic (25%). One peer had an associate degree (25%), two had a high school diploma (50%) and one had less than a high school diploma (25%).

3.2. Social Learning Theory

The peers reported examples of the four SLT principles (attention, retention, reproduction, and motivation) as they reflected on their experience conducting the training sessions.

Principle 1. Attention

All of the peers noted the importance of paying attention and learning the material. Several raised concerns about study participants not paying attention during the training sessions. They saw paying attention and staying on task, as central to the mission of the study. One peer noted a strategy for redirecting participants who were distracting to others. The sessions were only 90-min and the peers wanted the participants to get all they could out of each session.

“You do not want tell people to be quiet or nothing like that. So you just start talking louder then grab their attention.”

[—Peer-#1]

Principle 2. Retention

Peers recalled their strategies for helping the participants commit the training material to memory. One strategy was the use of cues. For example, one peer used hand gestures to facilitate participants' recall around the importance of open vs. close-ended questions when trying to get more information about one's health.

“I would do things like open my hands and close my hands...cause... sometimes it would take them some time to come up with the answers, but you're supposed to allow them their time”

[—Peer-#2]

Principle 3. Reproduction

There was implicit mention of role-modeling behavior. They wanted to make sure they were exemplifying what it meant to be healthy for the participants. This sometimes meant going beyond HIV-related treatment. For example, although smoking cessation was not a primary focus of GREAT, one peer quit during the course of the study. They were partly motivated by the desire to not have the participants see them smoking (i.e. being seen as a hypocrite).

“So (insert name) was like ‘you still smoke so why (are) you telling me that?’ ... and they are right! I am more adherent to my medicine (and) my numbers have been way better.”

[—Peer-#3]

Principle 4. Motivation

The peers often developed motivation from helping the study participants. They noted it felt good to be able to give back to those in their community that presumably needed the most help. They each shared stories around being proud to help participants who were struggling with using the technology and or struggling to keep up with the material.

“When one person does not understand and the rest of the crowd is like ‘we are already way past this.’ [I step in like]... let me ... get this person up to speed.”

[—Peer-#3]

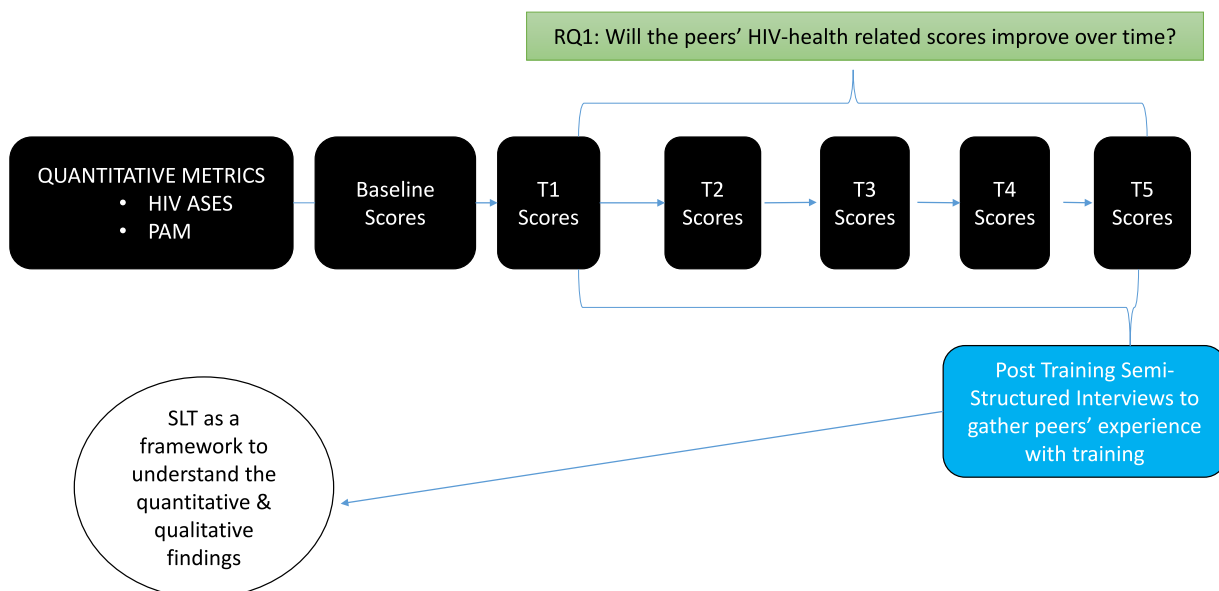


Fig. 1. Conceptual model.

However, there were also examples shared of being motivated to fill social voids for participants, such as that of a family member.

“He does not have any family here. So we celebrated his birthday ... with the group. He hugged everyone in the group and said that we really made his day ... they become like family!”

[—Peer-#4]

3.3. HIV health outcomes

Fig. 2 shows the mean changes PAM and HIV ASES scores over time.

The overall mean PAM score was 81.6 (SD 12.8). The mean baseline PAM score was 76.7 (SD 9) and increased to 87.5 (SD 15) at the end of the study. The overall mean HIV ASES score was 110.6 (SD 8.23). The baseline mean HIV ASES was 112.7 (SD 6.8) and decreased to 108.3 (SD 13.9) at the end of the study.

Three out of four (75%) peers reported they could name all of their HIV medications at baseline and all four (100%) reported they could by the end of the study. The HIV viral loads of all of the peers were undetectable throughout the entire study period.

3.4. Mixed methods outcome

Our qualitative findings from the semi-structured interviews suggest SLT may explain changes in peers' HIV related health behaviors over time. We propose the peers' HIV self-management behaviors improved

given their ability to model SLT and rehearse the intervention over the course of the five training sessions, Fig. 2.

4. Discussion and conclusion

4.1. Discussion

The purpose of this study was to understand if the peers' long-term involvement in training sessions around HIV-related health behaviors affected their own HIV-related health behaviors. We found that the key principles of SLT were readily applicable to peers' functions over a three year period and that SLT was associated with mixed findings-activation (PAM) improved, but treatment adherence self-efficacy (ASES) did not. Mentions of all four SLT principles emerged during the debriefing sessions. Generally, the peers enjoyed their social learning environment. They commented on the benefit of both working with the other peers and helping the participants in the parent study. They wanted to be exemplars for the study participants and so they practiced role-modeling healthy behaviors. These findings are similar to what have been reported in other studies on peer education and role development [13].

There appeared to be an increasing trend in peer activation based on the PAM scores among the peers over time (from 76.7 to 87.5). Although there was an increase in mean scores, the level of activation did not change due to ceiling effects, i.e. peers scored in the highest level at baseline. HIV ASES declined slightly (from 112.7 to 108.3). We are unable to comment on the clinical significance of the decrease. However, all of the peers reported viral suppression at the end of the study.

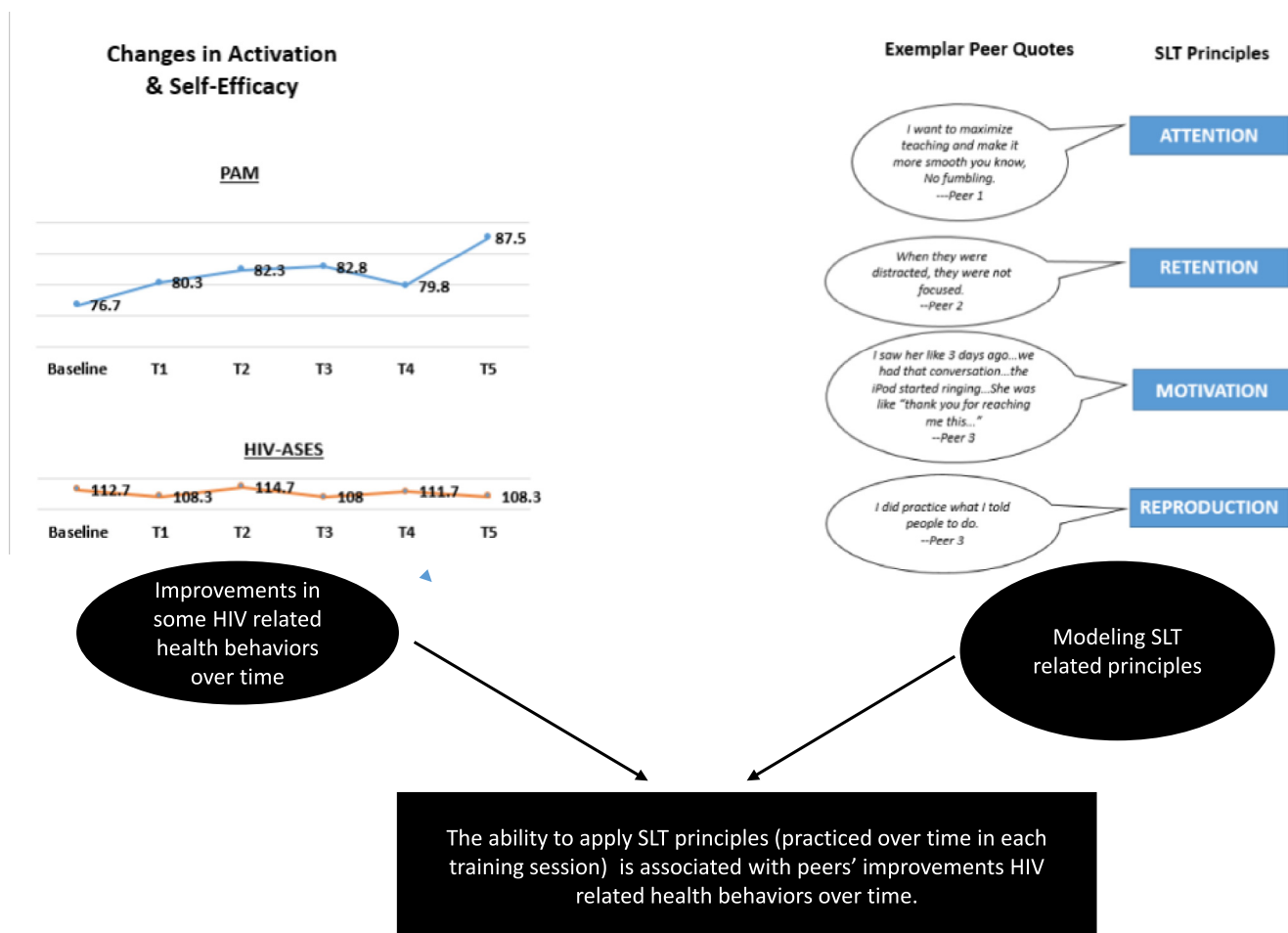


Fig. 2. Mixed method findings.

The peers had higher PAM and HIV-ASES scores than the participants in the GREAT study. The final mean PAM scores for participants in the intervention and control condition were 73.35 and 70.53, respectively [24]. This is not surprising as the literature shows that peers tend to be more motivated than a typical patient [29], which is likely why they choose to be peers. The higher scores from peers at baseline may also signal a possible social desirability bias. They were aware of the purpose of the study and had a desire to be a peer in the study. Therefore, they may have over-reported their scores on the PAM in order to appear qualified for their role. We also cannot rule out the Hawthorne Effect as an explanation for the upward trend in the PAM scores over time. However, the peers were not privy to which survey questions were linked to which scales and their mean scores in the HIV-ASES decreased overtime. Given this, we are doubtful that the Hawthorne Effect played much of a role.

The study has implications for practitioners working in psychosocial HIV interventions. The peers in our study remained for the life of the study. This allowed for increasing exposure to social connection and the opportunity to build comradery with the other peers over the course of the three years. This may signal a dose response. The peers had the opportunity to practice the four SLT principles over a 3-year period. Perhaps more exposure led to greater effect. Future studies should test this assumption in larger peer sample sizes.

4.2. Innovation

Prior qualitative studies have reported peers' improvement in health behaviors and expanded networks of social support [16,17,20]. Our mixed-methods study was innovative in its ability to support these observations quantitatively and with longitudinal data.

Another strength of our study is the sociodemographic diversity of the peers. There was heterogeneity in terms of race, ethnicity, education, and gender. They were all able to successfully co-lead the training sessions for participants; whilst improving the same psychosocial and physical health metrics we were hoping to improve in participants, as well as in themselves. To our knowledge, our study is the first to demonstrate this type of reciprocal effect. Moreover, we were able to retain all of our peers throughout the study period.

Our study highlights the importance of identifying potential interventional approaches that allow more roles for peers to be exposed to interventions for longer periods of time and group-based peer training models.

Despite the strengths and innovation of this study, we do have a few limitations to note. First, our analysis is based on a cohort of only four peers. Therefore, we were unable to test for statistical significance across training sessions. Second, this is only one case-study and we are not able to speak to the generalizability of our findings in other settings. Third, we did not have a true baseline measure of the HIV outcomes for the peers. We began collecting data 3 months into the study.

5. Conclusion

Peers living with HIV reported personal benefits from training others living with HIV in self-management. If confirmed, these findings suggest that peer leadership can serve as a means for empowerment that is effective at both supporting improvements in health outcomes for patients and for themselves, which may be both scalable and sustainable.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Kevin Fiscella, MD MPH reports financial support was provided by Patient-Centered Outcomes Research Institute.

Acknowledgments

This work was supported with a grant from the Patient-Centered Outcomes Research Institute (AD-1306-03104). We would like to thank Michele Boyd, MPA and the GREAT peer coaches for their hard work and dedication to this project. We would also like to acknowledge the Federally Qualified Health Centers and health systems for their support with recruiting participants: Family Health Centers at NYU Langone, Brooklyn, NY; Horizon Health Center (Alliance Community Healthcare), Jersey City, NJ; Metropolitan Family Health Network, Jersey City, NJ; Morris Heights Health Center, Bronx, NY; Anthony Jordan Health Center, Rochester, NY; Strong Memorial Hospital/Infectious Diseases, Rochester, NY; Trillium Health, Rochester, NY; and Rochester Regional Health/Unity Hospital, Rochester, NY.

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