



Published in final edited form as:

J Int Assoc Provid AIDS Care. 2015 November ; 14(6): 471–475. doi:10.1177/2325957415601505.

Development of an mHealth Intervention (iSTEP) to Promote Physical Activity among People Living with HIV

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Abstract

A randomized controlled trial is being conducted in the United States to test the efficacy of a personalized interactive mobile health intervention (iSTEP) designed to increase physical activity (PA) and improve neurocognitive functioning among HIV-positive persons. This article describes an initial qualitative study performed to develop iSTEP for the HIV-positive population, including assessment of PA barriers and facilitators. Two focus groups, with 9 and 12 unique HIV-positive individuals, respectively, were administered to evaluate barriers limiting PA and potential iSTEP content created to encourage greater PA. Group discussions revealed prominent PA barriers, including HIV symptoms (neuropathy, lipoatrophy), antiretroviral medication effects, and fatigue; significant PA facilitators included self-monitoring and family support. Participants provided feedback on strategies to increase PA and expressed positive support for a mobile intervention adapted to personal priorities. These findings will assist the development of novel PA interventions focused on treating the epidemic of HIV-associated neurocognitive disorders.

Keywords

focus groups; physical activity; HIV; mHealth; neurocognition

Introduction

Although combination antiretroviral therapy (cART) has dramatically reduced AIDS-related morbidity,¹ HIV-associated neurocognitive disorders (HAND) remain prevalent.² HIV-associated neurocognitive disorders, which may involve deficits in executive function, attention, and memory, continue to represent a significant public health concern linked to

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

impaired everyday functioning and poor quality of life among persons with HIV infection.² Despite the widespread incidence of neurocognitive deficits in the HIV-positive population, few studies have evaluated methods to compensate for this phenomenon, and there are no currently validated therapies to effectively treat HAND symptoms.³

Physical activity (PA) has been utilized as an effective non-pharmacological method to improve cognitive performance among elderly individuals and patients with dementia.^{4,5} Observational studies reveal a similar positive association between active lifestyle factors, including PA, and neurocognitive outcomes among HIV-positive persons.⁶⁻⁸ Although interventions to promote PA among HIV-positive persons have reported improvement in cardiopulmonary fitness,^{9,10} the effects of PA interventions on HAND have not been characterized.

Recent short message service (SMS) interventions have successfully increased moderate PA associated with significant health benefits.¹¹ The aim of the parent project is to conduct a randomized controlled trial that utilizes a personalized interactive text messaging intervention to increase PA and subsequently improve neurocognitive functioning in HIV-positive participants with HAND. The purpose of this qualitative study was (1) to identify key PA barriers and facilitators for HIV-positive persons and (2) to obtain feedback for the development of a PA mHealth intervention (iSTEP) addressing the specific needs of the HIV-positive population. These findings will provide a foundation for the future refinement of mobile PA interventions dedicated to treating HAND.

Methods

Participants

Two focus groups, one with 9 and the other with 12 unique HIV-positive individuals, were conducted in fall 2013 for a total of 21 participants. Participants were recruited from ongoing studies of HIV infection at the HIV Neurobehavioral Research Program (HNRP) that receive referrals from HIV clinics. Participants had a confirmed HIV diagnosis, and half (10/21) met criteria for HAND based on comprehensive neuropsychological testing at the HNRP, following established guidelines²; no other inclusion/exclusion criteria were applied. HIV-associated neurocognitive disorder is characterized by periods of remission as well as decline, and PA interventions may prevent or slow the development or reoccurrence of HAND in cognitively intact individuals. Therefore, the inclusion of participants with and without HAND allowed us to capture a broad range of perspectives to inform intervention development. Study approval was obtained from the local institutional review board. Each participant provided written informed consent for the study and received monetary compensation (US\$35).

Intervention

The objective of the focus groups was to inform a 4-month SMS/multimedia message service (MMS) intervention (iSTEP) designed to increase moderate PA in HIV-positive persons with HAND. The iSTEP intervention, based on control theory principles of self-regulation,¹² uses SMS text prompts and MMS images to promote PA self-monitoring,

facilitate personalized PA goal setting, and provide feedback on progress toward increasing PA.

Focus Group Procedure

We conducted 2 focus groups, each 1.5 hours, with semioverlapping content to increase the number of perspectives. Group moderators initiated discussion with a series of predetermined nonleading open-ended questions and asked follow-up questions to elicit additional opinions from the group. Group 1 acquired information about PA barriers and facilitators for people with HIV, and group 2 solicited feedback on potential intervention content (eg, text message topics, SMS frequency and timing). Group discussion was audiotaped and subsequently transcribed verbatim and blinded for review, that is, deidentified participants were assigned coded labels.

Data Analysis

Transcripts were independently coded at a general level by 2 investigators based on emergent themes. The description or assignment of codes was determined by consensus among all study investigators. The selected code list consisted of themes related to PA barriers and facilitators and discussion content related to iSTEP. Interrater reliability of the coded statements had a kappa value of 0.87, indicating high rater concordance. Data analysis was performed using QSR International NVivo9 data analysis software.

Results

The participants were middle aged (47.5 years, $SD = 5.6$), predominantly male (95%) and Caucasian (67%), with some college education (13.2 years; $SD = 3.0$). The open-ended questions used to guide the focus group discussions elicited a variety of responses from participants, and our qualitative analysis uncovered an assortment of main themes for each question. These are outlined in Tables 1 and 2, including representative participant statements. Below we present the findings regarding PA barriers and facilitators and preferences for iSTEP content.

Physical Activity Barriers

Analysis of the focus group transcripts identified 9 thematic barriers to PA among HIV-positive persons: (1) HIV-related symptoms and medications, (2) decreased motivation, (3) general medical conditions, (4) depression, (5) aging, (6) financial concerns, (7) competing priorities, (8) screen time, and (9) exercise concerns. *HIV symptoms* limiting PA included peripheral neuropathy and leg fat lipoatrophy as well as negative side effects of medications (eg, nausea, dizziness, and diarrhea). *Decreased motivation* included continuously putting off exercise until tomorrow, feeling unmotivated due to self-doubt, being comfortable with an inactive lifestyle (ie, “a body at rest stays at rest”), allowing boredom to forestall activity, and not feeling up for, or wanting to, exercise. Other *medical conditions* that inhibited PA included comorbidities such as Parkinson disease, hip replacements, respiratory problems, and the belief that exercise is ineffective at lowering cholesterol and triglyceride levels. *Depression* served as a barrier for PA in regard to not wanting to do anything (eg, not leaving one’s house). *Aging* encompassed “listening to the body” (eg, “if the body hurts,

why push it?”), self-doubt about getting older and “having a belly,” and regarding “working out” as a thing of the past. *Financial concerns* were a prominent PA deterrent, with many members disclosing difficulty affording gym memberships or being too busy trying to find a job. *Competing priorities* (ie, busy schedules and life demands) suggested that PA was a secondary concern and thus neglected. *Screen time* referred to the overuse of recreational electronic media, including excessive time watching television or using the Internet. *Exercise concerns* included lack of knowledge of how to use gym equipment and fear of sustaining an exercise-related injury.

Physical Activity Facilitators

Seven themes emerged as PA facilitators in the focus groups: (1) self-motivation, (2) daily routine and life circumstances, (3) self-care, (4) self-monitoring fitness/activity, (5) social support, (6) animal care, and (7) incentives. *Self-motivation* entailed making an effort to exercise (eg, using stairs instead of elevator); wanting to reinvent oneself; setting personal fitness goals; wanting to get out of the house; and walking to avoid medical complications, to improve quality of life or self-esteem. Physical activity was encouraged by *daily routine or life circumstances* (walking in lieu of owning a car, choosing to walk instead of taking public transit, and maintaining a daily routine outside the house). *Self-care* involved walking to soothe neuropathy, preventing health conditions by performing PA, and exercising to stabilize mood. *Self-monitoring* via phone apps and pedometers encouraged PA. *Social support* from peers, family, and physicians entailed having walking/exercise buddies, caring for children, having active friends, competing with others, and listening to physician health advice. *Animal care* provided an avenue for PA engagement (ie, walking a dog). *Incentives* were regarded as effective motivators to encourage participant effort to win a competition or prize.

Text Messaging Intervention Content to Promote Physical Activity

Several iSTEP intervention components were considered in the groups. Of note, participants held various views about SMS content to support PA, with some advocating for directive messages (eg, “Get your butt in gear!” and “Get outside!”), others encouraging the use of inspirational messages (“You can do it!,” “Your life is worth it!”), whereas a few simply wanted to be asked if they had engaged in PA rather than receiving encouragement to do so. Participants unanimously encouraged the use of messages to set PA goals based on step counts recorded via a pedometer and supported walking as a feasible option. There was a discrepancy about whether text messages related to HIV disease status were helpful. Participants requested that messages be unique for each person, as some did not mind receiving messages asking about HIV-related issues (eg, neuropathy), whereas others did not want to be asked if HIV symptoms prevented them from achieving PA goals. Discussion of personalized or generic messages revealed individual differences (eg, “I want personalized messages” versus “generic messages are fine”). Some participants supported receiving MMS graphs that charted PA progress, whereas others did not like the idea of receiving picture messages. In regard to confidentiality, many indicated that having sole access to their phone was sufficient, whereas others requested generic messages to provide additional privacy. Participants indicated varied preferences for message frequency (1 to 4 times a day) and further reported that a higher number of daily texts would lose impact. Varied preferences

for text message timing were also reported (ie, messages at a specific time everyday compared to a variable range), although participants uniformly liked 2-way communications (ie, receiving and sending messages). Some advocated for additional components to help with PA adherence, such as incentives and interparticipant interaction (eg, participant competition or receiving feedback when other participants achieved goals).

Discussion

Focus group discussion yielded identification of prominent PA barriers and facilitators, informing the development of a novel SMS/MMS intervention to promote PA among HIV-positive individuals with HAND. A myriad of preferences regarding SMS/MMS delivery and iSTEP content illustrated the benefits of adopting a personalized approach to promote the acceptability and scalability of mHealth interventions.

Physical activity may represent an effective strategy to address the significant health challenges faced by an aging HIV-positive population, including the widespread incidence of cardiovascular disease, metabolic syndrome, and neurocognitive deficits that persist in the cART era.¹³ Few studies have examined free-living PA (ie, performed around the home environment), although one report confirms that HIV-positive persons engage in less exercise than is recommended by the US Centers for Disease Control and Prevention.¹⁴ Previous PA interventions with HIV-positive persons have involved rigorous PA (eg, running on a treadmill)¹⁵ and significant participant resources (eg, supervised exercise requiring weekly travel to a gym)¹⁶ that the focus group discussions indicated may be impractical for many persons with this disease. For example, several participants voiced concerns about the potential for exercise-related injuries and described feeling unfamiliar with gym equipment. Many participants described a lack of transportation as a barrier to “formal” PA but noted that they can and do walk to conduct errands or appointments, sometimes in lieu of public transportation. Of note, previous studies indicate that relatively small PA increases (adding 500 pedometer step counts per day) are associated with improved neurocognitive functioning,¹⁷ which may be feasible even with physical limitations noted by the focus group participants (eg, peripheral neuropathy, hip replacements, and Parkinson disease). Thus, the aim of the iSTEP intervention will be to provide support via SMS/MMS to encourage participants to increase moderate PA (eg, the number of steps they walk).

The current study demonstrates a content development approach for promising mHealth interventions; however, several limitations deserve mention. Multiple focus groups are preferable to identify themes until saturation is reached. Our relatively small sample may not have covered additional relevant themes, and/or additional theme modifications may not have been revealed. Demographic factors may have influenced response variability in our predominately male Caucasian sample; thus, future observational and intervention studies with greater minority and female representation would help to address the needs of the diverse HIV-positive population. Although our focus group members were amenable to an mHealth intervention promoting PA, a prospective clinical trial is needed to determine actual acceptance and compliance. Despite these limitations, the perspectives of persons

living with HIV remain important for developing interventions, and several thematic approaches for targeting PA engagement were explored in these focus groups.

This qualitative study demonstrates the feasibility of using focus groups to derive patient-centric intervention content to address health challenges. The study identified PA barriers and facilitators for people living with HIV and lends support to tailored intervention strategies adapted for this population. Further research may aim to (1) investigate the usefulness of SMS/MMS technology to promote PA and (2) explore the efficacy of user-controlled settings (eg, controlling message timing). Such research is strongly warranted in an effort to develop validated methods that effectively treat symptoms of HAND.

Acknowledgments

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: supported by NIMH grants R21 MH100968, R01 MH099987-02S1, and P30 MH062512.

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Table 1

Barriers and Facilitators of Physical Activity for HIV-Positive Persons.

1. What are the barriers to physical activity?	
HIV-related symptoms and medications	<p>“Medications, depression, changing doctors, and doctors changing your meds. Dizziness from meds, so having to constantly change what you’re doing.”</p> <p>“Well you have good days, and you have bad days, you know. I have an AIDS diagnosis, so my body tells me when I have to take it easy.”</p>
Motivation	<p>“I know I should exercise, but it’s like uhhh I’ll do it tomorrow, but then tomorrow, it’s the same mindset all over again.”</p>
Medical (non-HIV specific)	<p>“I was on a donor list for a right hip replacement, and then now I’m on a list for the left. It’s medication management, and now, I have to do all this stuff with my hip. And, to exercise I have to get through that, and to get there I have to get passed that. So, with managing pain, along with medications that have me sedated, I am not going to want to exercise.”</p>
Depression	<p>“Two years ago I went into a depression and then the whole eating thing came along, then all of a sudden where did the exercise go?”</p>
Aging	<p>“When I was younger, I was always doing something, but I’ll be 45 next week, so I listen to my body, and it tells me I need to lay down and sleep. So, I listen to my body, and I lay down and sleep, or my body will say, “No, that part hurts,” and if it hurts, why would I push it?”</p> <p>“To me, working out is now a thing of the past. I think it has to do with my age. I used to be that guy who would wake up each day at five in the morning and go for a jog for about 10 to 15 miles and then go do gymnastics for three to four hours, and now, I don’t do that anymore.”</p>
Financial	<p>“Well, it’s just that with the financial thing, if I could afford it, I would be at the gym everyday.”</p>
Competing priorities	<p>“I just don’t see where I would have any time to exercise with this whole busy schedule”.</p>
Screen time	<p>“That’s a good point about the whole thing about the computer and the Internet. It’s really become more of a recreational thing, whereas in the past, I would have thought maybe, ‘oh maybe I should go swimming,’ but now I just want to get online.”</p>
Exercise concerns	<p>“I don’t know about you guys, but I tend to have a fear of exercising because it seems that everything goes wrong. I went to walk my dog and then something went wrong, and I was hurt and then the doctor said I have to get surgery on it.”</p>
2. What are the facilitators of physical activity?	
Self-motivation	<p>“Yeah, motivation really does have a lot to do with it, and the more you do something, the better you get at it. Things I haven’t done in a while will start to come back. It’s kind of like when you first start lifting weights. You watch yourself improve and start feeling better about yourself and all the positive reinforcements.”</p>
Daily routine and life circumstances	<p>“I work at the senior living center, and every time I get a call to go do something there, I walk there, so that is my daily activity.”</p> <p>“I walk a lot. Part of the reason I walk a lot is because I don’t have a car, but I do like to walk. I wouldn’t say I go out to walk, say for 40 or 45 minutes, but I would say that on average, I walk quite a bit during the week. I would say it’s my primary form of exercise.</p>
Self-care	<p>“You know I also have neuropathy, and walking soothes the neuropathy, so I generally walk throughout the day. I wake up in the morning, and I’m on my feet.”</p>
Self-tracking	<p>“You know, being able to track it on your iPhone or on your computer—I think that really works and just setting daily goals for yourself.”</p>
Support from peers, family, and physicians	<p>“Yeah, I think another thing is having a good relationship with family members, and that they can keep you moving from time to time when you stop caring about stuff. They can pull you out. Good friends can do that, too.”</p>

“It depends on who you hang out with, too. If you hang out with people who like to sit around and watch movies, then we will just sit around and watch movies. If we like to ride bikes, then we ride bikes. It’s all about friends. If someone calls me up and says, “Hey, let’s go do this today,” then I’m out the door.”

Caring for an animal

“I have a dog. It’s really been helpful in making me get up and going and doing something. I got a dog in March, which is really making me more active. When you have a dog you have to go out with your dog. I live close to a dog park, so I go out there a lot.”

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Table 2**Focus Group Feedback on the Delivery and Content of an mHealth Intervention to Promote Physical Activity.**

1. What should the message content look like for a physical activity intervention?	
Physical activity messages	<p>“[The text should be] something inspirational. I try to go through life being positive.”</p> <p>“[I would prefer] a text asking if I worked out instead of telling me to go workout. I would much rather get a text asking than telling. That would motivate me.”</p>
HIV-related messages	<p>“I don’t want it [the text] saying, ‘How’s your HIV?’ Maybe just ask if I took my meds.”</p> <p>“I like the positive messages. I don’t need messages asking about how my HIV is.”</p>
Personalization of message content	<p>“For me, I want personalized messages during the day and then report my stats each night.”</p> <p>“I like the idea of generic messages sprinkled with a little bit of trivia, like if you walk a few blocks this way, it’s approximately 1000 more steps. It might give me a little inspiration.”</p>
Text versus picture messages	<p>“Yes, graphs are really good. I could use some graphs right now.”</p> <p>“I don’t like the idea of picture messages; I like text messages but not picture messages.”</p>
Message confidentiality	<p>“You can give me any type of text message you want because no one has access to my phone.”</p> <p>“I think the more generic the better.”</p>
2. What are other features of the text messages that might be helpful?	
Two-way communication	<p>“[Include] an option to respond to the text message, reporting back how much walking you did for the day or something like that.”</p> <p>“It might be helpful for me to report my feelings via text like, ‘Hey, I’m feeling like a 3 today,’ and then he might respond back in a text message saying, ‘Okay, why don’t you take a walk to [the park]^a?’”</p>
Frequency and timing of messages	<p>“If you were to send me 6 messages a day, I think it might lose some impact.”</p> <p>“For me, I want texts once a day for motivation and then stats once a week.”</p>
Incentives and Interparticipant interaction	<p>“If there is an incentive at the end of the trail, then obviously I am going to try a little harder all the way through.”</p> <p>“Well, that sounds helpful, and it would be cool if the texts and the program could go even further because, for example, P8 and I know each other, so it would be cool if we could have subdiscussions on Facebook reporting to one another, ‘Hey, I have done like 500 steps today,’ and the other person can say, ‘That’s great! Keep on going.’”</p>

^a Name of park redacted for participant confidentiality.