Development of a theory-based relational realistic talking human embodied agent mobile phone intervention to promote HIV medication adherence and retention in care in young HIV-positive African American MSM

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Abstract

Background: Avatars and embodied agents are a promising innovation for human health intervention because they may serve as a relational agent that might augment user engagement in a behavior change intervention and motivate behavior change such as antiretroviral adherence and retention in care.

Objective: To develop a theory-driven talking avatar-like embodied agent mobile phone intervention to promote HIV medication adherence and retention in care in young African American MSM (AAMSM).

Methods: We performed 5 iterative focus groups in Chicago, guided by the Information Motivation Behavioral Skills Model, with young HIV-positive AAMSM to inform ongoing development of the mobile phone app.

Results: Acceptability for an embodied agent app was universal in all five focus groups. The app included embodied agent response to questions and antiretroviral regimen information, adherence tracking, CD4 count and viral load tracking, motivational spoken messages, and customizability. Concerns that were identified and responded to in the development process included privacy, stigma, avoiding harsh or commanding tone of voice, avoiding negative motivational statements, and making reminder functions for a variety of healthcare interactions.

Conclusions: An avatar-like embodied agent mHealth approach was acceptable to young HIV-positive AAMSM. Its relational nature may make it an effective method of informing, motivating, and promoting health behavioral skills.
Introduction

An avatar is an animated computer character designed to look like a person. They may be cartoonish and simplistic or remarkably realistic in their resemblance to an actual person. While avatars are commonly employed in computer games, their application to the promotion of human health is new and actively emerging [1,22-25]. Whereas an avatar is most often employed as an embodiment of an online user (as in a computer game), the term embodied agent (or embodied conversational agent) refers to a computer-generated character that provides a feeling of human verbal or nonverbal interaction to the user. Avatars and embodied agents are promising innovative tools for human health intervention because they may serve as a relational agent, a computerized image to which a person may react as if they are in a relationship. This relational aspect might augment user engagement in a behavior change intervention and motivate behavior change [26].

Avatars and embodied agents can be customized to a user’s preferences, engaging the user in a personal way. They can engage the user with multiple modalities such as audio, graphics, text, and interactivity that may motivate behavior, educate, and encourage repeated use. They also can raise the user’s health literacy by explaining terminology and improve their understanding of the rationale for healthy behavior. Encouraging the user with simple engaging speech, hand gestures, facial cues, and other nonverbal behaviors may augment comprehension and impact [2].

Young HIV-positive men who have sex with men (MSM) are an important population who may benefit from an avatar-based health intervention. MSM account
for 82 percent of new HIV diagnoses among men [3]. The largest subgroup within this population are African American MSM (AAMSM). In a national study of HIV-positive MSM reported by the CDC, both young MSM (ages 18-34 years) and African American MSM had the lowest viral suppression and retention in care compared to MSM in other age or racial/ethnic groups [4]. Although African Americans represent 13% of the United States (US) population, they account for more than 50% of deaths from HIV/AIDS [5]. African Americans have lower proficient health literacy than Caucasians [27], which is especially important since health literacy is associated with antiretroviral adherence [28].

There is evidence that a mobile Avatar health intervention might be effective in African American MSM. African Americans (72%) have high smartphone ownership.[6] A national survey reported a higher odds of smartphone use by lesbian, gay and bisexual persons than heterosexuals [7]. A randomized controlled trial (RCT) examined a virtual agent nurse providing discharge instructions in 764 hospital patients among whom approximately half were minorities and half had low health literacy [8,9]. The nurse was randomly provided as either an African American or a White avatar. Patients had very high satisfaction with the agent. A larger number of patients stated that they preferred to talking to the agent compared to a human. Patients with lower health literacy reported feeling more cared for by the agent than those with higher health literacy.

Since low health literacy is a factor associated with ART adherence and retention in care [10-15], avatar-based technologies may be a useful vehicle to promote healthy HIV-related behaviors. However, to our knowledge, this is the first
study to develop a mobile-delivered, avatar-based intervention addressing retention in HIV care.

We developed a theory-driven avatar-based embodied agent mobile phone intervention (hereafter referred to as an avatar) to promote HIV medication adherence and retention in care in young AAMSM. This embodied agent was created using an avatar framework from the image of a young African American male volunteer. This mobile phone application was informed by an iterative process of focus groups with young AAMSM that provided feedback on serial versions. We describe here the development of this application and lessons learned.

Methods
Participants

Five focus groups with 3 to 4 participants in each group were conducted in Chicago during January through May 2016. Participants for the focus groups were recruited from four University of Illinois at Chicago Community Outreach Intervention Project (COIP) sites located in different high HIV incidence areas of the city and the University of Illinois at Chicago HIV clinic using fliers and word of mouth. Three of the men who participated in the first group returned for the second group, and the other 13 participants were present only one time (N = total 16 participants).

Inclusion criteria for the study were self reported age 18-34 years, African American race, HIV-positive, on ART for at least 3 months by self-report, and owning a smartphone.
Procedures

All procedures were approved by the University of Illinois at Chicago School of Public Health Institutional Review Board. Before each focus group began, informed consent was obtained and subjects were provided a short questionnaire to determine their age, number of ART doses missed in the past 2 weeks, and, if relevant, the main reason they miss doses. Focus groups were performed in a confidential setting led by one of the investigators (Dr. Dworkin) and an experienced focus group moderator. Subjects were encouraged not to share what was discussed within the room or disclose anyone else’s participation and their names were not used. Focus groups lasted approximately 90 minutes. Feedback from subjects was immediately transcribed for review by the research team and discussion with the computer scientist as developmental drafts emerged.

Focus group questions and the proposed mobile phone application were developed by the investigators and guided by the Information Motivation Behavioral Skills Model that focuses on feedback between information and motivation that affect one’s behavioral skills, behaviors, and desired health outcomes [16]. This model was selected for this population because of the intent to target health literacy (Information), promote self-efficacy which is a factor associated with adherence (Motivation), and utilize existing phone functions (e.g., alerts and calendar functions) that can promote adherence (Behavioral Skills). Focus group topics included barriers for care engagement and preferences for an avatar-based app to address this. This included review of avatar features (e.g., look and sound) as well as content of the intervention (e.g., role of racism, homophobia, and social isolation on
retention in care). As dialogue for the avatar was developed, subjects were read the dialogue (such as questions that the avatar might say and answer) and then asked about the relevance of the question, comprehension and reaction to the response. They were also asked if there were other questions they wanted addressed.

Relational language (i.e., language that may promote a social-emotional relationship with the user) was purposively inserted into dialogue. New components and content that augmented the avatar’s functionality were developed based on participants’ input and shared with the next focus group for feedback in an iterative way. Initially, subjects were shown storyboard images of planned functions and graphics (Figure 1). By the third focus group, subjects were shown the evolving application on a mobile phone, which included both visual and audio.

Focus group feedback was categorized as follows to inform development of the application: acceptability of the intervention (including issues related to stigma and privacy), avatar customization and content preferences, information, motivation, and behavioral skills that impact HIV care retention. Since the purpose of these focus groups was to primarily guide real-time image and function app edits, the data did not require formal qualitative analysis.

Figure 1. Proposed initial appearance of the Avatar shown to focus group participants at the first focus group.
The Proposed Mobile Phone Application

The initial proposed mobile phone application included two major functions: Let Me Explain and Medicine Manager. The Let Me Explain function displays the Avatar and a scroll bar of questions. Tapping on the question causes the Avatar to read and respond. Planned content included some illustrations such as an animation.
of an x-ray developing an infiltrate while the avatar explains Pneumocystis pneumonia in response to the question, “What can happen if I get AIDS?” The Medication Manager function includes several components. A screen displaying images of current antiretroviral therapy (ART) regimens (Enter Medicine) allows user’s to select which regimen they are currently taking. Additional ART information, including generic and commercial names, common side effects, doses per day, and food restrictions is available. Each day the app is opened, the user is prompted to record whether they took their ART doses that day. If they respond no, the app asks the reason for the missing dose by providing a list of common reasons to check which applied. If none of the listed responses is applicable, the user can enter a free text response as Other. These data results are available to view in a calendar screen that shows the image of a pill on the dates with medication taken and an “X” for dates they responded no. The app also features the ability to enter current and past viral load and CD4 counts to populate a trends curve. Users can create multiple simultaneous personalized reminders for medication and care or lab appointments, which can be set as recurring reminders. Finally, users may customize their Avatar appearance (such as, hair, glasses, clothes, background), enter phone numbers for key contacts (healthcare provider, case manager, and pharmacy) for touch and click calling, and read the Let Me Explain and ART information without activating the avatar audio. Users also may pause and silence the Avatar with a button located on all screens. When the pause screen is not used, the Avatar has slight head motion and blinking to appear lifelike. Entry into the app is password protected.
As the app development progressed, participants in the last three focus groups were shown app demonstration in a phone. The avatar’s dialogue included both motivational and empathetic statements (to promote the relationship with the avatar), and phrasing derived from focus group discussions. Avatar dialogue was recorded, not synthetic. The avatar’s animation included minimal head movement, eye blinking, and mouth movement. By the final focus group, the app offered the user to make a few interactive choices by responding to questions such as if they wanted to hear the avatar’s (or his friend’s) thoughts on a subject (e.g., depression) which would allow the avatar (or his friends in the form of audio recordings) to provide additional motivational dialogue that were derived from focus group participant thoughts or recommendations.

Results

The reported ages of the 16 participants ranged from 21 to 34 years (median: 29.5 years). As per the inclusion criteria, all were AAMSM. Seven had missed at least three ART doses, four had missed two, four had missed one and only one participant did not miss any ART doses in the past 2 weeks. The main reason for missing a dose was forgetting (8), being away from home (4), avoiding side effects (2) and both being away from home and forgetting (2).
Acceptability for the concept was universal in all five focus groups. Participants affirmed that the idea of a talking instructional avatar was a welcome innovation:

“He looks so real and he’s a nice attractive man and I’m going to ask him a lot of questions about medication! This is genius idea! Thank you! People can go on their phone. People say, I’m afraid to take my meds. This thing can talk back to say, ‘It’s okay. Here’s why to take your meds.’” [Focus group 1]

“I think it will work. I’m sure it will.” [Focus group 2]

“It’s good that it can explain the side effects. It’s a good idea that there’s a picture of the medicine.” [Focus group 3]

Participants also provided feedback about content, suggesting on which dialogue should be changed to facilitate greater understanding. This informed changes that were tested in a subsequent group that were much better received. For example, although participants accepted the use of the word AIDS in a question such as “Is AIDS the same thing as HIV?” participants reacted negatively to its use as an explanation of the CD4 count that stated, “It’s pretty low if it’s under 200. That’s AIDS if it’s under 200.” A participant asserted that if he had a CD4 count below 200 and was told by the app that he had AIDS, it would make him not want to use the app. He stated,

“Like I’m gonna keep it real, like if my doctor told me that, I’m not going back to the doctor.” [Focus group 4]

Another participant said, in response,
“I think that in the black community, we are not comfortable with that word, AIDS. Instead, don’t have it say below 200 you got AIDS. Have it say if you less than 200, you got to see the doctor. Don’t say, ‘That’s AIDS!’ Say, ‘That means your risk of infection is much higher and it’s so important to take your medication to get healthy.’” [Focus group 4]

While participants generally welcomed the use of images to complement the dialogue, images portraying sickness or negative consequences of having HIV were less well received. Originally, an illustration of an avatar on a ventilator appeared during the explanation of the complications of AIDS in part to provide a rationale and motivation for healthy behavior. Some participants felt that negative images were upsetting and not motivating. However, illustrations that explained the body and HIV were welcomed such as an image of an x-ray that revealed and explained Pneumocystis pneumonia as a complication for AIDS that required taking an antibiotic to prevent it when the CD4 count is low. One participant stated,

“It’s interesting to know what’s going on in the body.” [Focus group 5]

Stigma and Privacy

Stigma emerged as an important issue in the first four focus groups. Participants voiced no concerns related to the app by the fifth group, after it had been edited in response to previously voiced issues. Participants sought privacy features that protected anonymity concerning their MSM identity, HIV-status, and their health in general. For example, they wanted to minimize unwanted attention from alerts or reminders to take medicine. They also expressed reluctance to ask
questions of healthcare providers or to disclose problems when not asked about them. They also suggested a feature that would allow them to instantly change the app screen image to an image that hides their activity to mislead people who are trying to figure out what they are looking at. Images of a game, Facebook, or other culturally appropriate graphics were suggested. A screen hiding function was added by the fourth focus group.

“*What would be nice, they trying to be nosy and he can change into a game image. Only we know that he’s a puzzle now.*” [Focus group 1]

“I wouldn’t want it to pop up saying take your meds.” [Focus group 1]

“The ‘Did you take your medicine notification’ is a problem. ‘Did you take your medication?’ Anybody in their right mind is going be, ‘What do you mean you take medication?’ It lets them know you’re sick. You could be hiding it from your family.” [Focus group 3]

Customizability

Nearly all the participants found the male avatar acceptable but four participants stated they would like to be able to choose a female version (specifically a White nurse). Changing the avatar’s clothing, accessorizing him (such as with glasses or a stethoscope), and adding or subtracting hair were built into the app in response to requests. They enjoyed the concept of the avatar and desired customization that sometimes reached beyond the budget and timeline for the project. For example, in the fifth focus group a participant recommended that the avatar have his (the user’s) own face and voice.
“Make him functionable like I can brush his hair or take his medicine, drink water, get rest. Have the alarm clock to be aware of his medicine.” [Focus group 1]

“Have everybody create the avatar that they like. That way everybody’s can be distinct. They don’t say, ‘Hey you got that thing on your phone.’” [Focus group 3]

“Throw a lady in there as a choice.” [Focus group 4]

Information

Participants were read dialogue from the “Let Me Explain” component and provided feedback that led to the development of additional content (e.g. signs and symptoms of syphilis, taking ART with alcohol, ART side effects, and additional basic HIV and ART adherence information) as well as overall improvements in dialogue to improve comprehension and relevance. Participants suggested that avatar dialogue be combined with imagery to reinforce complicated topics (e.g., the meaning of an elevated versus undetectable viral load and affirmed or offered ideas for images that were added to the app (Figure 2).

“The illustrations are a better way of explaining it. Sometimes I still get confused, the CD4 confused with the viral load.” [Focus group 2]
Figure 2. An illustration that appears during the answer to “What is a viral load?” Responding to the question, the Avatar explains in a relational way, “You can think of the viral load as the load of virus you’re carrying around. You don’t want to carry around a big load of this virus. Right? So you want the doctor to tell you that your viral load is low.”
Motivation

Participants were enthusiastic about the inclusion of motivational messages that appeared throughout the application, which addressed ART adherence, retention in care, advocating for their needs during appointments, and app function use, including in the Let Me Explain function’s questions and answers. However, they varied on their preference for positive versus negative encouragement. Some felt that talking of HIV “like a dog that is barking at you” and can be locked up in a cage by taking medication regularly was a good way to motivate adherence and retention in care. However, others rejected it and favored positive imagery. One participant recommended that medication taking be thought of like keeping one’s hands on a steering wheel to maintain control and this language was adopted and found acceptable to the subsequent focus group. Participants also discouraged any intonation in the avatar’s voice that sounded harsh or commanding. They welcomed that the avatar acknowledged their concerns and used “straight talk” to motivate like a friend or relative would. These concerns included advocating for their needs during a medical visit, struggling with adherence, being afraid to take medication, getting help with depression, asking for reexplanation of health information they did not understand. One participant gave an example of having gotten clarification about his neuropathy that led to his doctor addressing his problem.

“I have neuropathy too. I asked the doctor. He said it come from the disease, not the medicine. If I wouldn’t have asked, I kept going along like it’s ok…I advocated for myself.” [Focus group 1]
“Some people need that push from your parent.” My “mother said, boy if you don’t take your medicine I’m not coming to your funeral.” [Focus Group 1]

“Have Avatar tell to take a walk in the park or other motivating language” when depressed. “Some people shuts down.” “See a family member, tell somebody that’s on the same level as me.” [Focus group 1]

“When I get any depression, I don’t want to take any medicine.” Regarding avatar dialogue recommending avoiding isolation and activities to try when depressed: “That'll keep me more motivated. I like that.” [Focus group 2]

“When someone jumps on my back about something, I get rebellious. Better with a smooth voice, as if they have love for you.” “My doctor at first irritated me too bad so we almost got in a fist fight. I got up and left.” [Focus group 4]

“Keep your hand on the steering wheel. You got to go straight. You can control your own choice.” “Its gonna eventually turn. But if you keep your hand on the wheel, you got control.” [Focus group 4]

In the fifth focus group, participants approved of avatar-spoken motivational statements that would initiate upon entering the app (after its first time use). The avatar would greet the user with a question such as, “Do you know what I think?” or “Do you want to hear me talk about depression?” If the user clicked yes, the avatar provided a brief statement that derived from focus group discussion such as how social support from a trusted person can help with adherence. In the fifth group, users supported the concept of adding audio recordings of real people (young HIV-positive AAMSM and health professionals) giving a brief motivational message. We
recorded 11 people (5 young AAMSM and 6 healthcare professionals including two doctors, a nurse, a nurse assistant, a pharmacist, and a mental health provider) who spoke for 1-2 minutes each. To hear one of these real people recordings, the user would respond to the avatar asking, “Do you want to hear what a friend of mine says?”

Behavioral Skills

Participants provided suggestions for how the app could address needed behavioral skills to adhere to ART and stay in care. Some participants thought that the ability to track and observe trends in CD4 counts and viral load was “a good idea” but advised that the avatar should “explain how to read the graph.”

Participants also approved of reminder functions. However, they encouraged that reminders should be available for other healthcare events such as blood draws. In response to their feedback, explanatory dialogue concerning the trends and reminder functions for medication taking, appointments, and blood draws were added to the app as choices on a scroll bar as well as an option of “Other” to accommodate other potential events. A participant recommended a dictation-like function to record concerns to be shared at future healthcare appointments. This capability was placed on a list for future work because it was not accomplishable within the 1-year timeframe available for development.

“Alarm is a good thing to alert – or to pick up medication too – or to make your appointments, like getting blood work. Have avatar ask about ‘I'm wondering what's causing my low platelets.’ It could take notes and tell to ask the doctor about this.”

[Focus Group 1]
Discussion

Principal Findings

These focus group data demonstrate the value of iterative development of technology-based health interventions. Enthusiasm for a theory-based mobile phone app that employed a talking realistic human avatar-like embodied agent was strong across all five focus groups conducted with young African American MSM. Their feedback helped to design and refine the app to more closely align with their preferences for receipt of app-based information, motivation and skills. By the final focus group, much of the discussion was affirmation of the more fully-developed app and a unanimous request to download the app onto their personal phones. These findings help to move the field of adherence research forward. For example, young AAMSM living with HIV liked the idea of a mobile phone avatar-based app approach to adherence and retention in care. Negative messages and images were not welcome by some young AAMSM but positive messages and images were welcome by all. In addition, our study revealed that design of a health app for this population must consider stigma at many levels of interaction (e.g. icon, tab appearance, reminders, and password protection).

Many participants described the role that HIV and sexual identity related stigma plays in their lives and how an app-based intervention must not contribute to this problem. They explained how having an HIV-related app on their phone could place them in situations that could inadvertently result in disclosure of their HIV
status or sexuality. They stated that it was common to have someone looking at or holding their phone. App features such as an HIV-related icon, reminders, and notifications for ART use may draw unwelcome attention. Similarly, if they were to store private information such as viral load, CD4 count, and medication data, access to the app must be password protected and time out features after a period of nonuse were expected. Participant input helped to modify the app and strengthen its acceptability as the icon was made uninteresting in appearance, reminders and notifications were designed to be customizable, password entry was required for use and password entry required for reentry after the app automatically closes when nonuse time reaches 5 minutes. The avatar tells the user about these privacy features at the time of initial use while acknowledging to the user an understanding of these privacy concerns in a relational statement. “People are always getting up in my business. How about you?” Relational dialogue such as this example may help build trust and credibility as it introduces the avatar as an ally who has some understanding of their world. Goldberg et al performed focus groups to help develop an app for HIV prevention in MSM [17]. Similar to our study, they found that an app for MSM needed to feel safe and trustworthy. Liu, in a focus group study of patients with chronic diseases in Beijing, reported that worrying about privacy of personal information was the main reason for not using a health related app [17,18]. These studies support the prioritization of privacy when designing a mobile phone health app for young AAMSM living with HIV.

A critical part of the development of an Avatar or embodied agent intervention is the dialogue. Participants expressed universal enthusiasm for
positive motivational statements while the use of negative motivational statements was controversial. In order to maximize acceptability, we chose to edit dialogue to remove negative statements and images that participants could not all agree were acceptable. We replaced these statements with participant suggested language and images. Whereas all participants found educational images of disease acceptable to view (such as a tongue with thrush or an x-ray with pneumonia), images of an ill avatar or statements that allowed one to be directly reminded that they have AIDS were strongly rejected by several participants. Negative images can overwhelm users and make then want to turn-off the app and not return to it.

An advantage of our approach is that motivational language can be inserted throughout the app. In the context of the IMB model, motivation is a key component that can drive behavior change, especially ART adherence [16,26]. Similar to the practice of motivational interviewing, the avatar’s dialogue is intended to move the users away from indecision and towards adherence and retention in care [19]. For example, responding to a question about viral load can include a statement affirming self-efficacy about ART adherence. The response to a question about how often to see a healthcare provider can emphasize the importance of keeping appointments. Similarly, in the final version an explanation of the benefit of taking HIV medication expresses that “you can handle” the twists and turns of the road of life “by keeping your hands on the wheel” and an optimistic closing statement follows: “Good luck with your personal goals. Enjoy that full life! You’ll get there.” This kind of language contributes to the relational aspect of the Avatar and may allow users to feel that the avatar cares about them.
Among the behavioral skills that mobile phone apps can promote are reminder and notification functions, especially when combined with other interventions and when delivered weekly rather than daily [20,21]. Such functions are typically available on Smartphones such as calendar alerts. However, while such capability was already in their phones, participants did not report common use and welcomed these functions in this app. Although the avatar announces that such functions are available during the initial interaction, it is uncertain if having the functions in the app will lead to their use or if they will be effective. It is possible that encouragement to use reminders in persons who are receptive to them might be most effective if coming from the healthcare provider or case manager who may introduce the app to them. Such an interaction might include setting the reminders as part of the appointment where the app is used as an intervention. Future research piloting the app will determine frequency of use of this function independent from such human assistance. While notification by itself may be insufficient at producing ART adherence change, this app allows for user customization of the message and this function is integrated into a broader experience.

Low health literacy has been associated with poor ART adherence and retention in care [10-15]. A talking Avatar may help overcome this barrier by providing information in an audiovisual format allowing for instruction that goes beyond usual practice in outpatient settings where providers may have limited time for instruction, patients may be reluctant to ask for explanation, and medical jargon may be used that the patient does not understand. Another advantage of a mobile phone avatar app is that information may be replayed to overcome distraction or
emotional impact as when a provider says something upsetting and the patient cannot concentrate on information provided immediately after. The participants in the focus groups were eager to learn new information and acknowledged that they had learned from the avatar dialogue.

The avatar’s appearance was important to them to ensure he appeared credible. Although they welcomed customizability with casual clothing, they expected him to be dressed in a professional manner as a default. There was a white racial preference by some participants for a female dressed as a nurse. Future app development will offer this option.

Limitations

Limitations of this study include generalizability. The focus groups included only 16 persons and were performed in one city. We focused on young African American MSM because of their relatively high HIV incidence and poorer adherence and retention in care [3,4]. In addition, participants had to own a Smartphone. While the intervention could be modified for delivery on a computer, we do not know if this broadening of the audience would influence preferences.

Conclusions

We developed a theory-based relational realistic talking human Avatar-like embodied agent mobile phone intervention to promote HIV medication adherence and retention in care in young HIV-positive AAMSM. We employed an iterative approach that helped to ensure that app development considered the desires and concerns of users. An avatar mHealth approach was acceptable to this population
and its relational nature may make it an effective method of informing, motivating, and promoting health behavioral skills. We propose that this app may be especially helpful if recommended and initially overseen by a case manager or healthcare provider as when a patient is initiating ART or is recognized to be struggling with adherence or retention in care. Future research piloting this app to determine preliminary efficacy is currently being performed.

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