TreatYoSelf: A Condition-Sensitive Medication Adherence Tool for HIV-Positive Youth

Ressa Reneth Sarreal
University of Maryland,
Baltimore County
Baltimore, MD
Saressa1@umbc.edu

Gabriela Marcu
Drexel University
Philadelphia, PA
Gm472@drexel.edu

ABSTRACT

Youth are disproportionately affected by HIV, and have the lowest rates of adherence to the medication regimen that is critical for treatment. TreatYoSelf is a smartphone application designed to improve medication adherence among HIV positive youth using four forms of persuasion: tailoring, conditioning, self-monitoring and social influence. We describe the design of TreatYoSelf based on psychological theory of persuasion and via co-design with patients and clinicians. This work contributes to our understanding of the role of persuasive and pervasive personal monitoring systems that are designed to fit into the everyday life of a patient in order to support treatment. We discuss how TreatYoSelf was designed and validated as a smartphone application that can be adopted and accepted by patients, and meet the approval of clinicians in its approach to addressing medication adherence rates. TreatYoSelf is currently being evaluated in a pilot study, in preparation for a clinical trial.

INTRODUCTION

Adolescents are less likely to adhere to medication when compared to older adults (Becker et al., 2002). Their medication adherence ranges between 27% to 41% (Flynn et al., 2004; Hosek et al., 2005; Martinez et al., 2000; Murphy et al., 2001) Apps that address a lower medication adherence exist; the most effective, based on app rating are MyMedSchedule, MyMeds and Rxmind Me (Bangsberg,2000). These are good for normal medication however there is the issue of HIV-positive youth. These apps are in no way sensitive about taking medication. They are not subtle. Tools to help this population need to be more discrete to provide more privacy and to avoid stigma. We are developing an app that will help medication adherence, increase support groups and inform the user about their illness. This tool will be an app on a smart phone. There will be medication reminders, personal monitoring system through calendar, avatar customization and a support button. All of these features will function while remaining sensitive about the user's condition. Medication reminders are designed to be discrete about what they are reminding the user about. The push notification on the user's smart phone appear in the form of a customizable message that the user can set so that they understand what the notification is for and the message does not have to express any relation to HIV. The Calendar will be a personal monitoring system that is a glancable visualization of medication adherence. Clinicians will also be able to explore the data that they receive through the server that the app connects to. Avatar Customization acts as reinforcement. The basic avatars have customizable hair, eyes, skin tone, and clothes. The user will be able to customize their avatar the more they take their medication. The avatar's mood will become more positive as the user takes their medication more often. The support button is a feature that not many health apps have. This allows quick-access to help if the user needs it. The purpose of this button is to allow the user to contact anyone very quickly and easily when they feel under the weather or if their situation is more urgent. Stigma has always been an issue when discussing of different bodily conditions. Stigma is the mark of disgrace associated with a particular circumstance, quality or person. Stigma is inevitable; what mankind can do is set up precautions to avoid it. Stigma associated specifically with HIV and AIDS is especially intensified. HIV is treated with daily medication; furthermore it is very easy to forget to take medication until it is completely a part of one's daily routine. If irregularities in that routine occur, there is a higher likelihood that medication consumption will be forgotten. These irregularities in routine are more frequent in younger people's lives. Also, living with HIV as an adolescent can be especially difficult and confusing. Having a support is very important at this time in one's life. This app overall will be created to tackle these issues at hand.

RELATED WORK

HIV is a fairly large issue on its own. Countless research projects have been done on HIV and studies show that even though the youth the youth only are about 21% of the population, they account for 39% of new infections (Centers for Disease Control, 2011).

Medication reminders

Other studies show that the aforementioned apps like MyMedSchedule, MyMeds and RxmindMe are very popular and highly rated because of medication reminders (Dayer, 2013). RxmindMe is a reminder app for medication, vitamins and supplements. It allows users to enter all your dosage information, set up reminders and keep track of when they take them. MyMedSchedule manages medication, sets reminders, and make it easier to communicate with healthcare providers in a portable

manner. It also allows users to record their medical data on the app. MyMeds is a secure cloud-based web and mobile application that helps manage medication.

Avatars

When given the option, 60% of people create or select avatars that resemble their race/ethnicity (Kalyanaraman, 2008), and since there have been findings that if avatars on a system resemble the user, they will have more positive attitudes towards the avatar and the system (Suh, 2011). Understanding this, a customizable avatar would be a good approach since the goal is to get the user to want to use the app.

Monitoring Progress

These types of systems help users by enabling them to monitor and visualize their behaviors, keeping them informed of their physical states, reminding them to perform tasks, providing feedback on the effectiveness of their behaviors, and recommending healthier behaviors or actions (Marcu, 2011).

METHODS

To approach these issues and create a functional, modern app, searches through existing literatures and frequent meetings with expert clinicians were held.

User Centered Design Process & Agile Development

Development of a feature is generally straightforward; however, our approach maximized creating the best features for this target population. The current iteration of the app was developed through agile development. This form of development is when the programing is laid out to be more flexible and adaptable instead of being static and difficult to change in later iterations. At each weekly meeting, an iteration of the app would be presented to the clinicians and they would provide us with feedback on what they thought was effectively done and what they thought could be removed or revised. This is the User Centered Design process. The process consists of collaboration between developers and field experts communicating face-to-face to increase efficiency and comprehension. (Web Accessibility Initiative, 2004) With each iteration of the app, it slowly becomes what this demographic desires and what the clinicians and statistics lead us to believe as an improved tool for HIV-positive adolescents.

Discussion with Expert Clinicians

To understand HIV, clinicians have described the background of the virus and advice us throughout the development process. Dr. Nadia Dowshen led the discussions and she had three assistants with her at the meetings. Discussion lasted between an hour and two hours. Each week, new mockups of the app are presented to her and her team, and they would tell us what they liked or didn't like about the mock ups. This feedback would be used to further develop the app.

Focus Groups

Two focus groups were held by the Children's Hospital of Philadelphia to fully understand what the target population would want in an app. They have recorded the discussion of the app and I will directly quote these groups by referencing the recorded conversations. In this paper, the focus groups will be referred as Group1 and Group2.

RESULTS

The original app the clinicians provided the lab with consisted of a very basic push notification reminder system, a contact list and a list of links the users could easily access to obtain more information about being HIV-positive. In addition to their original design, a support button, medication-tracking calendar, avatar customization system and a more intuitive interface have been developed.

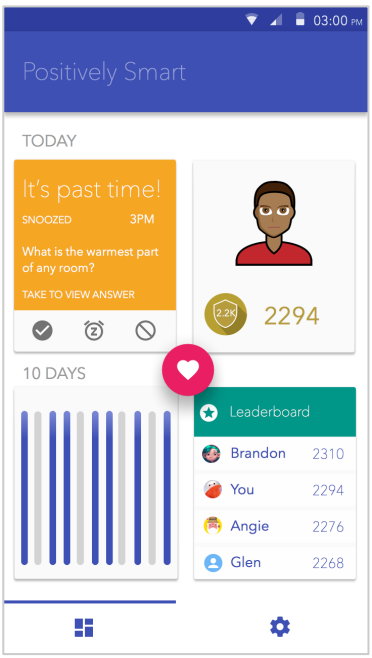

Figure 1: Home page interface with the support button in the center

Medication Adherence

Medication adherence has been found to be especially low in users who are between the ages of 13 and 29 years old (Ruyter, 2010). Through discussion with expert clinicians, and their experience with having focus groups, customizable avatars seem to be a good way to motivate users to take their medication. However, some people in focus groups do not find this form of motivation effective. Other forms of reinforcement like simple riddles that reveal their solutions only after taking a medication dosage or a simple, positive visualization of success like a rocket blasting off or fireworks can be used. During a discussion with a focus group, which was recorded by the clinicians who led them,

A more concrete solution that has already been developed in the app is a calendar that shows the medication adherence progress of the user, which is shown in Figure 2.

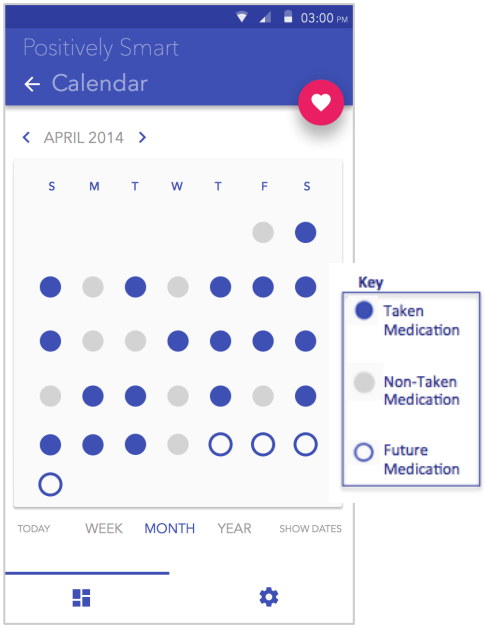

Figure 2: Monthly view of calendar and medication usage

Creating and Maintaining Support Groups

The contact list is meant to keep together the names of people that will always be available to the user. In addition to the contact list, development of a support button became a main priority. Past focus groups felt a strong need for a button, originally called a "panic button". Through discussion with expert clinicians, the button is not only meant to be used in times of critical distress; the button is meant to be used whenever the users is concerned for their wellbeing. The button is placed on every page, at the top corner so that the users are constantly reminded that they have access to caregivers or supporters. If they do forget that it is there, the button will occasionally pulse like a human heart would. The button will be programmed to travel throughout the main page whenever medication is skipped, eventually reaching the center of the page to make the user completely aware that if something is not right, they can talk to someone and get help if they need it.

Privacy and Avoiding Stigma

Privacy is always an issue, despite whoever the user is. While meeting with the focus groups, they have made several requests and have made the desire for other privacy features clear. This app is made to improve the user's lifestyle and habits; however, it was also made to collect data so that improvement in the app can be made. The users have agreed that they "need [their] pictures and [their] contacts to be private" (Group1), so the clinicians have made sure that the developments made on the app cannot collect data other than what is necessary, like medication adherence progress and feature usage. Sometimes the issue is not that the person using the app will be mistreated if someone found out about their HIV-positive condition, but that this person does not want to deal with the situation. Specifically, one person during a focus group has said "if they see something, it's going to be a whole different conversation. It's like I've got to deal with that and I don't – that's what I just don't have time for" (`Group1). This person is just expressing somewhat indifference for if the person found out about their condition, but would rather not go through the trouble being questioned and making these people concerned. A clinician asked the group further about their privacy issues, discussion if they "want the icon to be flashy" or if they would rather it be "kind of in the background" and the group responded with "in the background because if it's too flashy, somebody might pick up your phone like oh, what's this?" (Group1). This further supports how the group would rather this group desires a nice app but not too attention-attracting.

These comments about the app have led to an ultimately minimalistic design to the app, which can be seen through Figures 1 and 2. The app's icon, which is how the app will be displayed on the user's list of apps, does not include the app's current full name, TreatYoSelf, but only contains the acronym TY, which can be seen in Figure 3.

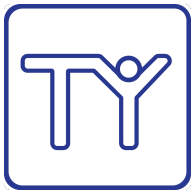

Figure 3: The app's logo

Figure 3 is one of the most recent iterations of the app's logo. During one of the meetings with the expert cinicians, they have agreed that this design would probably not collect much attention from the public. Future testing will determine if this design will be changed.

Another issue arose when discussing medication reminders. Using medication reminders can be tricky because if they appear as any other notification, they are more likely to be ignored and are very easy to swipe away. Also, if users decide to label the alert with "medication" or anything of that manner to differentiate these alerts from the others, if they were around other people that they would prefer not to discuss HIV-related topics with, this label may cause an awkward encounter. The solution to this is to create a very minimalistic, but stylish and official-looking design that did not make clear to the public people that this app is meant for HIV-positive youth; moreover, the app cannot even be

identified as a medication adherence app. In addition to medication reminders, the app allows users to create a separate contacts list for caregivers, so that in case people try to look up someone in your contacts, the user will not feel anxious knowing that this person is scrolling past countless doctors; however, the contact list is not only meant for doctors; any form of caregiver should be included in this list.

DISCUSSION

The support button has gone through several iterations. It began as a concept formed by a member of the first focus group held by the clinicians. This person originally wanted a "panic button". They described it as "a button where it's like pressing it, and then it automatically dials you to someone that's on call or whatever. If you're having an emergency, like oh, I'm having an emotional breakdown or something like that" (Group 1). Their rational behind wanting a panic button was just to have someone that they would be able to contact immediately whenever they are upset or in some kind of critical state. The first group unanimously voted that this feature was a critical necessity on the app, so the idea was carried over and asked about to a second focus group. The second focus group decided this was a good feature but only for certain types of people and that they would not necessarily see themselves using it. They ranked it below a HIV-related information resource, and a calendar. After the focus groups were held, the clinicians met with the developers and discussed their findings with us; ultimately, the discussion led to changing the name of the button from a panic button to the support button. The app is created to have a positive and safe environment, and having a red button labeled with "HELP" or "PANIC" would not support this goal. Associating this app with less negatively based features would result in more effective conditioning. Since the support button's design has changed to a heart, and is pink, it will be seen as more of feature with the purpose of having its user reach out to their community and caregivers whenever they are in any upsetting situation, critical or otherwise. This also results in an increase in social support and outreach.

The concept of an additional avatar customization feature was not brought up by the focus groups, but by the clinicians. Clinicians asked the focus groups if they would enjoy the feature and they agreed. Discussion with the clinician led to the understanding that the population of users enjoy 'House and Ball' which is another term for groups of people who are LGBTQ or people who participate in drag. House and Ball involves dancing and dressing up in colorful, extreme costumes of different themes and styles. The mention of House and Ball has led to the development of not only making an avatar that represents the user, but it also encompasses the idea of House and Ball by acting as a reward system as well. Expert clinicians thought that reinforcement through high medication usage streaks and being able to add accessories to the avatars would really encourage the youth to use the app and to take their medication. Clinicians have also found that it would be useful for the avatar to smile when medication dosages are taken. Users would also be able to manually set the avatar to reflect their own mood and be able to share it with other users using the app. The purpose of this is so that the user can see the avatar be happy and want to keep taking the medication for the avatar. Other rational behind this is so that if other users see that another user has posted a negative mood to the group, they know that something is wrong and can take action to help the upset user. The goal of this feature is to tailor to the user and connect them to other HIV-positive youth, while immediately reinforcing good medication adherence habits.

Privacy

Privacy is an important issue to HIV infected youth for obvious reasons. Privacy management is not a static set of rules and instead it is a dynamic response to the situation (Palen, 2003). A number of needs requires to be satisfied a number of tensions need to be balanced for privacy management (Palen, 2003). Therefore, privacy management measures need to be defined based on a given context and it may vary different circumstances. While deploying privacy management it is also important to remember that, it is more a cultural issue. Therefore, privacy management solution needs to fit into cultural practice (Palen, 2003). In case of using mobile technology privacy issue is more important. The public use of mobile phone involves various norms and conventions, but proper use of mobile phones respecting privacy is often violated (Palen, 2000), (Palen, 2003). In order to ensure privacy management for a given technology, we need to consider all possibilities that can be triggered by that technology in a given culture (Palen, 2003)

CONCLUSION & FUTURE WORK

A basic calendar, avatar customization, and the reminder system have been developed. In the future, the leaderboard displayed in Figure 1 will be functional and will allow for communication between the HIV-positive youth. This will be an optional feature, but by default, it will be active so that the users are aware this is available to them. The purpose of this feature is to try to get these individuals who are in a similar situation together and to discuss and support each other. This leaderboard will also include a "kudos" function that allows users to commend other users on their medication adherence status. Future focus groups will he held to see if what has been developed so far is to their liking.

The app is connected to a server and this will allow administrators to do further research on the existing features of the app. While Empathic Design Laboratory works with the Children's Hospital of Philadelphia, to improve the app, data will be collected to understand several hypotheses. A few of these hypotheses may include:

- If app usage increases then medication adherence will increase

- If users customize and interact with their avatars more, their medication adherence will increase
- If the support button is used, then the user's avatar will express a positive mood more frequently
- If a leaderboard is available to a group of users, the group's average medication adherence will increase

These hypotheses can be tested through the data collected through the server. The data collected will include timestamps of these basic interactions the users have with the app. This will make quantitative data analysis easier. The first group can also be called in so that more data can be collected about what they like and dislike about the app and how their progress is going.

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