TreatYoSelf: Empathy-driven behavioral intervention for marginalized youth living with HIV

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ABSTRACT

Behavioral intervention technologies are well suited to addressing health behavior such as medication adherence, but only if successfully integrated into a user's daily life. Little is known about how to design such technologies to be adoptable, adaptable, useful, and feasible in everyday life. We report on the design process for TreatYoSelf, a smartphone application designed to improve medication adherence among youth living with HIV through reminders and positive reinforcement. Using participatory design, our aim was to understand factors related to adoption and acceptance of behavioral intervention technology as part of daily life. Two challenges of living with HIV led to an empathy-driven approach in our design process: (1) HIV is a stigmatized condition, which (2) disproportionately affects the marginalized populations of young African American men who have sex with men and transgender women. We discuss five empathy-driven design strategies: positive and nonjudgmental tone; minimal, avatar-based gamification; motivational and corny messages; nondisclosure through neutral signifiers; and social support through camaraderie. Our approach enabled us to identify and work through factors, often related to stigma and marginalization, which would lead to rejection of TreatYoSelf use in daily life.

CCS Concepts

• **Human-centered computing**→**HCI design and evaluation methods** • **Applied computing**→**Consumer health.**

Keywords

Behavior change; participatory design; behavioral intervention technologies; ecological momentary intervention; HIV.

1. INTRODUCTION

Treatment for HIV has improved dramatically. Antiretroviral therapy, a combination of three or more medicines, has made HIV a manageable chronic condition with a potentially normal life expectancy. However, antiretroviral therapy requires near perfect adherence for effectiveness [29]. Adherence rates are lowest among youth aged 18-24 [2]. HIV also disproportionately affects youth. Youth between the ages of 13-24 make up 17% of the US population, but account for about 26% of new HIV infections [4]. Few interventions have been developed or tested that target

medication adherence among youth living with HIV, and these interventions are typically based on intensive case management that requires significant resources from a clinic [36]. Mobile devices are pervasive and can enable low cost, tailored interventions in real-time as people go about their daily lives. Interventions delivered via mobile devices are well suited to address factors associated with non-adherence, including: housing instability, forgetting, not having their medications with them, and complications in daily routines [23,28,32].

In this work, we draw from research on behavioral intervention technologies (BITs) and ecological momentary interventions (EMIs). Both of these intervention types aim to change behaviors related to physical health, mental health, and wellness. The common characteristics of these interventions are that they: employ strategies from behavior change theory and psychology; are delivered via personal technologies such as smartphone applications, text messaging, or websites; and enable tailored and context-aware approaches by leveraging sensed and self-reported data streams [31,34].

The effectiveness of BITs and EMIs is dependent on their integration into a user's daily life—a relatively unexplored area of research. The use of personal technologies to deliver interventions has been studied across disciplines including human-computer interaction, psychology, public health, and medical informatics. It is widely acknowledged that little is known about how to design these technologies to be adoptable, adaptable, useful, and feasible for sustained use in everyday life [16,26,34] — especially when it comes to mobile technologies [31].

This paper describes our design process for TreatYoSelf, a smartphone application designed to improve medication adherence among youth living with HIV through reminders and positive reinforcement. Building on the traditions of user-centered design, human-centered design, and empathic methodology in HCI [40], we aimed to understand the experience of living with HIV and engage individuals in participatory design of a technology that would fit into their lives. Our design process addressed two challenges of living with HIV: it is a stigmatized chronic condition [37], and it disproportionately affects the marginalized populations of young African American men who have sex with men and transgender women [5]. Factors related to stigma are known to negatively affect adherence to medication [23,28,32] and adoption of interventions [31].

The contribution of this work is five empathy-driven design strategies that helped us to overcome issues of stigma and marginalization in the design and validation of TreatYoSelf: positive and nonjudgmental tone; minimal, avatar-based gamification; motivational and corny messages; nondisclosure through neutral signifiers; and social support through camaraderie.

Our empathy-driven strategies elicited more enthusiasm toward TreatYoSelf than has been reported from traditional user-centered design for youth living with HIV [10,11,31]. For example, other work focused significantly on participant concerns about privacy and indicated a reluctance to use technology that would require them to report sensitive health information or share it with others [31]. Our design strategies enabled us to move past these barriers and validate the design of TreatYoSelf with end users. These findings have implications for understanding and overcoming rejection of potential features due to stigma and marginalization, which are experienced by many populations that could benefit from pervasive technologies for health and wellness.

2. RELATED WORK

In this section, we describe what is known about designing BITs, the extant literature on EMIs specifically for youth living with HIV, and the role of stigma and disclosure in the acceptance of these interventions. In the rest of the paper, for purposes of clarity and generalizability of our findings to a broader range of interventions, we refer to the broader category of BITs, though TreatYoSelf can be considered an EMI because it is a pervasive mobile technology designed to be incorporated into daily life.

2.1 Behavioral intervention technologies

BITs are personal technologies that address physical health, mental health, and wellbeing [34]. BITs deliver interventions based on behavioral and psychological strategies via technologies such as smartphone applications, text messaging, and websites [26]. Common behavioral strategies used in BITs include goal-setting, rewards, self-monitoring, and feedback [27,34]. Behavioral and psychological strategies can inform the design of BITs, but on their own do not provide clear guidance for development or evaluation of BITs [20,26].

In HCI research, Klasnja et al. argue that the development of novel BITs should aim to improve our understanding of people's experiences with the technology, including why and how an intervention is working [20]. Our work on TreatYoSelf follows this approach, and we contribute to a broader understanding of how to integrate BITs into everyday life, particularly with the added complexity of users living with a stigmatized condition.

Schueller, Mohr, and colleagues note that clinical researchers often develop BITs by translating existing interventions into a digital form, rather than leveraging the affordances and capabilities of technology for novel intervention delivery [26,34]. Clinical researchers developing interventions for youth living with HIV have identified the potential of mobile technologies, but our review of the literature (discussed in the following section) reveals largely SMS-based interventions. In this work, we combined HCI and clinical perspectives in a multidisciplinary team to develop TreatYoSelf, which is to our knowledge the first smartphone application for youth living with HIV.

2.2 Ecological momentary interventions for HIV

As traditional, clinic-based methods of intervention have failed to increase medication adherence among youth living with HIV, EMIs have emerged as a promising approach to reaching youth in their daily lives and providing real-time interventions that are not resource intensive. Studies have used both daily and weekly unidirectional, standardized SMS medication reminders for HIV positive individuals in low-resource settings (e.g., [30]). Recent studies also show promise of interactive SMS medication

reminders among youth living with HIV, including feasibility, initial efficacy, and high satisfaction scores [11,14].

There is growing interest in leveraging smartphone capabilities for interactive, tailored, and context-aware interventions for youth living with HIV, but none have yet been developed. A recent review of the literature on SMS interventions for health behavior change noted that interactivity and tailoring of messages were associated with higher retention rates in multiple studies [7]. Ramanathan et al. elicited the preferences of youth living with HIV toward potential features of smartphone-based interventions; participants voiced interest in interactivity; ability to control the reminder content, timing, and location; limited data sharing; and incentivization to reduce the burden of self-reporting daily health data [31]. Interestingly, their participants showed little interest in two features typically highly valued in EMIs: feedback and social support [31]. Our participatory design process therefore focused on these themes in order to understand their acceptability to youth living with HIV.

2.3 Stigma and disclosure

People living with HIV face significant stigma [37], and as such many keep their diagnosis a secret [32]. The stigma associated with HIV leads to additional problems such as not screening for HIV, not seeking health care, psychosocial health (e.g., depression, self-esteem), and sexual risk behaviors [13]. Some even skip taking their medications due to fears of unwanted disclosure of HIV status and the stigma associated with disclosure; when they do take their medication, many have to hide their medications, plan ahead, and make considerable lifestyle changes [32]. Withholding information about stigmatized identities may also lead to health problems if one is not attending to physical or emotional needs or not adhering to treatment [15].

Disclosure of HIV positive status can be intentional or unintentional [17]. A person living with HIV might intentionally decide to disclose this information with other people, might decide to not disclose it to others and "pass" as someone without the stigmatized condition when it is concealable, or this information could involuntarily be disclosed to other people through other means (e.g., if someone else reveals the diagnosis). Although disclosure of stigmatized identities or significant negative life events could be helpful due to the potential for receiving social support from confidants, many times when these disclosures happen, the responses are not supportive and as such lead to more isolation and reduced wellbeing [3].

Ramanathan et al.'s [31] focus group findings indicated that nondescript wording, anonymized data for sharing, password protection, and control over location tracing were key privacy-related factors for youth living with HIV. In a survey study, Dowshen et al. [10] found that disclosure concerns are more prevalent compared to other forms of HIV-related stigma, such as personalized stigma, public attitudes, and negative self-image.

3. METHODS

We developed TreatYoSelf through participatory design. We applied the patient-clinician-designer framework, involving all three stakeholders in a participatory design process that has been shown to generate a design that is feasible for everyday use and viable for a clinical trial [12,25]. The multidisciplinary research team was comprised of HCI researchers with experience developing pervasive technologies for chronic conditions, and clinical researchers with expertise developing interventions to improve medication adherence of youth living with HIV.

We recruited patients for participatory design workshops through an adolescent clinic that provides care to youth who are HIV positive. The clinic is housed at a large pediatric academic hospital, which commonly involves patients in research studies. Demographic information in Table 1 indicates that our sample is representative of youth living with HIV in the U.S. [4,5].

Table 1. Participant demographics (N=12)

2 formative participatory design workshops (N=10)	
Mean age (SD, range)	21 (1.7, 18-24)
Race	90% African American 10% Bi-racial/Multi-racial
Gender	90% Male 10% Trans woman/girl
Highest level of education completed	10% 10th grade 10% 11th grade 60% High school graduate 20% 2 year Associate's degree
Current housing status	40% Own/share house 50% Parent's/other family's home/apartment 10% Transient
Smartphone type	60% Android 40% iOS
1 final participatory design workshop (N=3)	
Mean age (SD, range)	22.7 (2.08, 21-25)
Race	100% African American
Gender	66.7% Male 33.7% Other
Highest level of education completed	100% High school graduate
Current housing status	33.3% Own/share house 66.7% Own/share apartment
Smartphone type	100% Android

Two formative participatory design workshops engaged 10 youth living with HIV in discussing mockups and initial ideas for features, based on the literature. These workshops were led by clinical researchers on our team, who asked participants about their barriers to medication adherence, and their preferences for the design of a smartphone app to help them with medication adherence. Results from these workshops informed design work over three months, during which the research team met weekly to iterate on design mockups and features by combining their technical and clinical expertise. Clinical researchers involved in this design work also included a young adult living with HIV.

After developing a partially functioning prototype, we held an additional participatory design workshop, with 3 youth living with HIV (one of whom had participated in a formative workshop), to validate the prototype and obtain another round of input for the final design. This workshop was led by HCI researchers on our team, who gave a prototype to each participant to test during the workshop, and described additional functionality that was not yet fully developed. Data from this workshop, including observed usability problems and opinions or feedback expressed by the participants, was discussed by the research team and incorporated using another round of rapid iteration on design mockups that informed development of TreatYoSelf.

All workshops were recorded and transcribed; two members of the research team also took notes. Transcriptions and notes from all workshops were analyzed together. Four members of the research team were involved in inductive thematic analysis of these data, and discussed emergent themes iteratively during data analysis. Participant codes were used during all note taking and data analysis to protect confidentiality; all names in this paper are pseudonyms assigned to participant codes.

4. FINDINGS

The design of TreatYoSelf was validated and finalized when workshop participants could pick up and use TreatYoSelf with no training, and they also indicated an interest in adopting it. Features or aspects that had previously elicited negative, confused, or ambivalent reactions were iterated upon or removed, until the final design had no major issues. Regarding the final design of TreatYoSelf (see Figure 1), participants were enthusiastic and told us they were looking forward to it becoming available. For example, when participants were interacting with their prototypes during the last workshop, their opinions included *"I just wanna know when it's comin' out, for real, because I really would use it"* (Christopher) and *"I wouldn't put it down; I would download it to my phone"* (Gabriel).

We discuss our empathy-driven approach around four themes that emerged during our design process: (1) positive and nonjudgmental tone, (2) minimal, avatar-based gamification, (3) motivational and corny messages, (4) nondisclosure through neutral signifiers, and (5) social support through camaraderie.

4.1 Positive and nonjudgmental tone

Prior work has revealed privacy concerns with EMI collecting or sharing information about sexual behaviors, HIV positive status, or other sensitive health data—such features were found to be a burden to users and a barrier for adoption [31]. Strategies included reducing burden of self-report activities on users and providing financial incentives to promote adoption [31]. In this work, we explored what functionality might be perceived as judgmental in order to find alternate approaches that would be acceptable and engaging to youth living with HIV. We found that an informal tone was preferred to one focused on formality, credibility, and authority, because it resulted in TreatYoSelf being perceived as positive and nonjudgmental.

4.1.1 The stigma and judgment of living with HIV

Formative workshops revealed the types of features that participants felt triggered the stigma and judgment they experience living with HIV. For example, the following discussion resulted from our suggestion that the app could learn what leads a user to have unsafe sex, and then provide context-aware cues to promote practices like condom use (although the primary purpose of the app is medication adherence, we initially explored secondary goals):

Anthony: *"Mm-mm. No, because that's stigmatizing. No. You ain't about to do that."*

Tyler: *"That'd be like you judging me, like no."*

Anthony: *"Because last time you went to this bar, you got a little messy. No."*

Isaiah: *"Yeah, like I don't know, something like reminders of safe sex I think would be great, but just to tell me, like, hey—"*

Jayden: *"Yeah, not asking how many times."*

Isaiah: *"—Yeah, how many times."*

This discussion is an example of the strong reactions that participants sometimes had, collectively, around features that would potentially track their sexual activity or respond to it. This finding is in line with other research on the preferences of youth living with HIV [31], and led us to two implications. First, we highlight that an intervention related to sexual activity and safe sex practices remains very challenging to design for youth living with HIV, and requires further empathy-driven investigation to determine acceptable approaches. Second, we came to understand the importance of ensuring that an app is not perceived as judging the behaviors that it aims to change, especially when it concerns a stigmatized condition like HIV.

4.1.2 The appeal of positivity

In our final design, the positive tone of TreatYoSelf starts with the name itself, which is a play on words meaning both to provide self-treatment and to treat oneself to a reward. The aesthetics of the app also underscore this tone, for example with cartoon-like avatars (see Figure 1). We also used playful, warm colors like purple rather than cooler tones that are used to connote a more serious tone in interfaces when trustworthiness is key (e.g., online banking) [19]. Participants responded well to the name and tone in the final workshop. Without being prompted, they pointed out that they liked the name, its positivity, and its spelling. They immediately picked up on the double meaning.

Some of the most glowing reviews of our final design referenced its positivity. Participants believed our approach in this design would be able to reach a lot of youth. Christopher identified the potential positive impact of TreatYoSelf, saying *"this is a good thing"*. When we asked the group if they knew someone who wouldn't use TreatYoSelf, they admitted that they did, but said *"if you can't reach them through this, because it's positive, then what can you do"* (Christopher). They highlighted the positive tone as likely to appeal to the largest number of youth, and they could not think of any suggestions for how we could increase our likelihood of reaching more. Xavier felt that TreatYoSelf would be adopted by those who were open to behavior change, or as he put it, *"if you actually care about treating yourself"*.

4.1.3 Informal but still credible

Interestingly, participants did not question the credibility of the app nor feel that it trivialized their condition, suggesting that we struck an appropriate level of informality. Participants said they would want the app to provide education and resources such as information about their medication, or myths about HIV. These design ideas suggest that the informal and friendly tone of TreatYoSelf would not hinder its credibility or its effectiveness in delivering important health information.

4.2 Minimal, avatar-based gamification

It is common for BITs to provide useful ways to review data so users can reflect on their progress, and receive informational feedback or rewarding incentives that encourage positive health behaviors. An often used approach to designing these aspects is gamification, with visualizations and metaphors such as a fish tank [22], garden [8], and virtual pet [18,21]. Although this approach has been accepted by users in interventions for physical activity [8,22,33], eating behavior [18], and asthma self-management [21], there is evidence that it is not appropriate for particularly stigmatized conditions. Marcu *et al.* attempted to introduce similar gamification during participatory design with
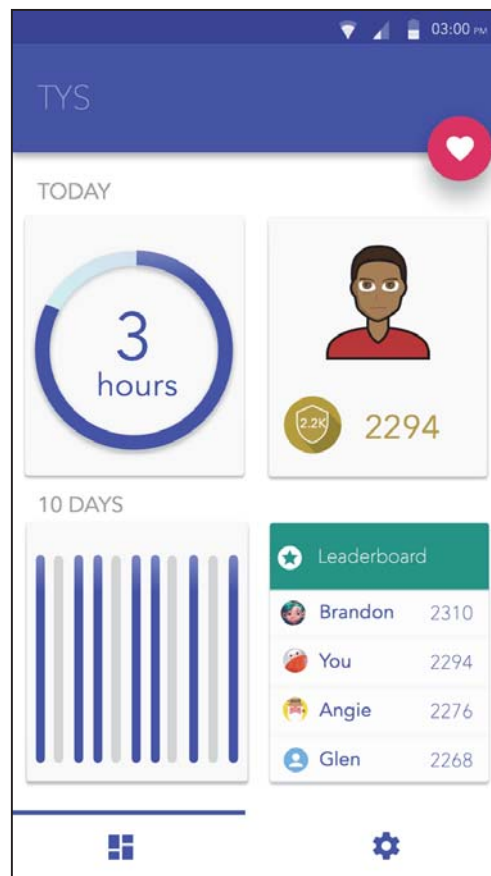

Figure 1. Home screen of the TreatYoSelf Android interface.

individuals receiving outpatient treatment for bipolar disorder, but participants reacted negatively, saying *"I do not want my illness to be reduced to a game"* [25].

4.2.1 Avatar puts focus on the user, not the condition

We aimed to use gamification sparingly and strategically. A customizable, cartoon-like avatar is the primary graphic element, intended to create focus on the user rather than their condition (Figure 1, top right). The avatar is the most engaging and game-like component of the interface. Our design's focus on the avatar was also based on evidence that avatars provide self-representation that can make interventions more effective [9,41].

Formative workshops identified the avatar as a favored potential feature, which aligns with prior research on designing BITs for youth [9]. During final workshop, despite the fact that our prototype was still buggy, participants enjoyed interacting with the avatar by changing its skin color, hair, eyes, mouth, and shirt. Some said they would be likely spend a lot of time playing with the avatar, and requested a wider variety of options for customization, including a full-body avatar to dress. We also proposed that a full-body avatar could be animated, for example to dance, and participants liked the concept.

The positive responses to the avatar, especially compared to negative reactions reported in other work designing BITs for stigmatized conditions [25,31], indicate significant potential for avatar-based gamification. Our findings suggest that avatars should be highly customizable (e.g., skin color, hair, eyes, mouth, clothing), should provide exclusively positive representations of

the user and their progress (e.g., smiling and dancing, rather than sad or suffering), and can be used to deliver rewards and reinforcers (e.g., earning a new clothing item or accessory, watching the avatar wink or dance). Participants did comment, however, on the avatar looking dated and not modern enough—examples of preferred avatars were characters from The Sims video games and the Nintendo Wii console.

4.2.2 Points and streaks as rewards

Rewards, or incentives, have been identified as important aspects of BITs [34], including those for youth living with HIV [31]. However, it was unclear how we could appropriately incorporate rewards while keeping gamification to a minimum. Designers on the team recommended straightforward representations of data for self-monitoring, and patient participants also requested basic graphs of their data. Examples of straightforward data include: the amount of time left until the next dose (Figure 1, top left); a calendar with week, month, and year views of adherence data (Figure 1, bottom left shows 10 days of data).

However, clinicians saw significant potential in providing point-based rewards for medication adherence, particularly to encourage the consistent adherence that makes medication more effective. We built on the success of the avatar to incorporate these rewards. A running point total is shown below the avatar (see Figure 1, top right), and points earned can be exchanged for new clothing or accessory items for the avatar. Users earn points each time they take their medication, and the maximum possible number of points are earned if they report taking the medication on time, at the same time each day. Streaks are also rewarded with additional points, if the users report taking their medication on consecutive days without missing a dose.

Participants responded positively to these rewards. The acceptance of these features indicates that some gamification is appropriate when designing for stigmatized conditions, perhaps as a result of our focus on the user, rather than their condition, through the custom self-representation of an avatar. Further, we believe acceptance of this reward system can also be explained by our approach of designing a positive and nonjudgmental intervention. The reward system applies exclusively positive reinforcement (i.e., points are not taken away), without focusing on undesired behaviors (e.g., missing a dose of medication).

4.3 Motivational and corny messages

Prior work with text message reminders for medication adherence among youth living with HIV showed that allowing users to personalize messages increased their effectiveness in improving self-reported adherence [11]. Our design process elicited additional guidance for designing messages to appeal to youth living with HIV. Whether the content of messages was pre-determined or customizable, participants wanted the tone to be motivational and inspirational—some even used the term "corny".

Initially, participants rejected the idea of notifications that would remind them to take their medication, saying it was unnecessary because they always remember to take their medication: *"I don't want no notification. Wait, notify me about what, what time to take my medicine? Like I should know that by now. Like, I'm grown now"* (Isaiah). However, knowing the statistics on low medication adherence among youth living with HIV, we continued to probe about the acceptability of this feature. When we suggested the idea of a customizable message, for example with a song lyric or inspirational quote, participants found the idea more acceptable, with Anthony saying: *"I could see that. That*

would be cute. But I would probably write profanity to myself, like get your shit together, and I'll remember, like okay".

4.3.1 "Get your stuff together. Keep your head up."

Anthony was expressing a desire for the app to accommodate, and even help him through, difficult times when living with a chronic condition like HIV. It is unclear what functionality might be appropriate and effectively address this need, but we found his articulation of this need important to consider. Anthony continued by suggesting a feature he called a mood swing button:

> *"Because I often go through like mood swings to where I'm just like sometimes it's like I don't want to take this medicine no more, so I should be able to push a button, like I'm going through it. And then it's like a couple hours later, still like the snooze, it's like I really think you should get your stuff together. So that would be cool."*

We interpret this suggestion as indicative of a desire for TreatYoSelf to provide motivational messaging. For Anthony, motivation appears to mean tough love, as evidenced by his repeated use of the phrase *"get your stuff together"*. However, in a different workshop, participants requested inspirational, positive messages such as *"it's going to be okay"* (Christopher); or *"keep your head up"*, *"here's a smile for today"*, *"if nobody told you, you're beautiful"* (Gabriel). These messages proposed by participants—which sounded like their own positive self-talk—provide further evidence supporting our approach of designing TreatYoSelf with a positive tone, and gives further guidance on how an app could be designed to provide the motivation that impacts behavior change. For some users a tough love approach may work whereas others may be more receptive to unconditional love and acceptance. Either way, we found that participants saw messaging from the app as an extension of their own positive self-talk, and therefore TreatYoSelf has the potential to reinforce the motivational messages that users find helpful.

4.3.2 "I'm corny like that"

We were surprised by some of the participants' examples of inspirational messages, because we had attempted to make TreatYoSelf engaging and appealing by avoiding anything that might be interpreted as cheesy. Our design team had eliminated some design concepts containing positive, encouraging imagery and messages when we thought users may find them cheesy.

One design element that we decided to keep and experiment with—despite its high risk of appearing cheesy—was a riddle presented with the medication reminder. When a notification appears to remind the user to take their medication, it displays the riddle "what is the warmest part of any room?". The user must then confirm that they have taken their medication in order to see the answer to the riddle ("the corners, because they're always about 90 degrees"). We expected the riddle to be rejected by participants, and planned to ask for suggestions of alternative messages or graphics that would be motivating.

Unexpectedly, participants liked the riddle, with Gabriel admitting: *"I'm corny like that"*. We interpret this acceptance as relating to the participants' need for positivity. Considering initial rejections of the concept of a medication reminder and claims that participants always take their medication, our findings indicate participants may have felt judgment or pressure, especially in the context of societal pressures on youth. There was an interesting shift in a later workshop, as reactions were very different when the feature was presented to them in the form of a cheesy riddle. A cheesy riddle may have helped to keep the tone light and nonjudgmental, and apparently without participants feeling that it made light of their condition. It was this riddle feature that elicited

the suggestions of inspirational messages discussed above (Section 4.3.1). Participants therefore embraced the concept of corniness, perhaps as a way of adding to the positive, nonjudgmental tone of TreatYoSelf (Section 4.1).

4.3.3 A heart-shaped social support button

The acceptance of a pink heart on the TreatYoSelf interface indicates that users embrace some potentially corny visuals when they promote positivity. Early design discussions included a feature for contacting a close network for social support—a custom list of friends, family members, social workers, or other trusted members of an individual's support system that were easily visible and accessible within the interface, to encourage users to reach out for social support. During initial discussions, we referred to this feature as the "panic button", but as we focused the design more on positivity, the name evolved into the "social support button". Similarly, we avoided a visual design that would represent panic or emergency. We settled on a pink heart icon (see Figure 1, top right) to connote caring and remind the user that they could reach out to a support system that was there to help them. All participants who were shown this feature in the final workshop approved of the design.

4.4 Nondisclosure through neutral signifiers

Similar to other work [31], our formative workshops largely centered around participants ensuring that their condition would not be disclosed. For example, participants discussed what could be seen on their smartphone if someone glanced over at their screen (e.g., the app itself open, the icon on the home screen, a notification), or if someone else was using their phone and might open the app. Participants had diverging concerns about whom exactly they were concerned about disclosing to—friends, family, or strangers. Isaiah said he had a nosy family: *"and then I've got to get into the question game, I hate it. So if they see something, it's going to be a whole different conversation"*. Joshua disagreed, saying it was friends he didn't trust:

> *"Your parents ain't going to do anything to hurt you. If that was the case, they wouldn't have birthed you. Friends are the people that you really need to watch out for. ... They'll turn around and do it right – stab you in the back. So in my eyes, I think it's friends. Everybody's not to be trusted. Your parents, you're gonna trust them regardless."*

Most participants agreed with Jayden's sentiment that *"somebody's going to ask, well, what is this thing? It keeps popping up"*. Formative workshops therefore often involved recommendations for, as Kevin and Cameron put it, *"something that's not going to draw attention"*—for example, a nonmedical appearance, and language that does not unintentionally disclose their HIV status. Icons were rejected for appearing too *"medical"* or not being *"discrete"* enough. The color red was also associated with HIV/AIDS and therefore avoided.

We addressed concerns about nondisclosure by using neutral signifiers in the design of TreatYoSelf. For example, a simple "it's time!" notification reminds the user to take their medication. Pills, plus signs, and other medical imagery were avoided in the visual design. Participants in the final workshop approved of this neutral design. As they interacted with the notifications, avatar, and other features, they had no concerns about disclosure.

Interestingly, despite the concerns in formative workshops about an HIV-related app drawing attention, the engaging aspects of TreatYoSelf were so appealing to participants that disclosure was less of a problem for them. Or, perhaps, they were no longer concerned about the app drawing attention because the neutral signifiers would not lead to unintentional disclosure. They acknowledged that the design might be interesting enough to attract attention, but together they enthusiastically discussed how they could lie to others to avoid disclosure, for example by telling them it was a jogging app:

> Christopher: *"I think even if I'm on it, and I'm like duh, duh, duh, duh, (waves phone around without caring who sees it), you still wouldn't be able to like, know."*
>
> Xavier: *"[They wouldn't] be able to, like, tell. What is that? I'm like, girl I been joggin. Checkin my progress. You know."*
>
> Gabriel: *"Right."*
>
> Xavier: *"What's that 2,000? That's the amount I've been walkin. Okay. I'll be gettin my kilometers on."*
>
> Christopher: *"They'll be like what was that?"*
>
> Gabriel (to himself, pleased): *"TreatYoSelf."*

This spirited conversation suggests that the neutral signifiers provided protection against unintentional disclosure, making participants feel both safe and excited about the app's potential. Gabriel even evoked the name of TreatYoSelf, suggesting that not only would the app help him treat himself, but that he could treat himself openly around others without fear of judgment.

4.5 Social support through camaraderie

Social support from similar individuals has been shown to improve medication adherence among youth living with HIV [24], as well as other health behaviors [6]. However, prior work on BITs for youth living with HIV found that there was little desire to interact with others for peer support [31]. Our findings, on the other hand, suggest that there is a significant sense of camaraderie among youth living with HIV, which can be leveraged for social support by fostering positivity and protecting anonymity.

4.5.1 Constraining social features for positivity

Designers, clinicians, and patients involved in the design of TreatYoSelf all agreed that any social features should include constraints that foster positivity and prevent any negative interactions among users. Clinicians wanted to leverage the health benefits of social support by enabling users of TreatYoSelf to engage with one another through leaderboard showing point standing. Displaying point totals would not reveal any specific personal data, yet a leaderboard could encourage the community to provide positive reinforcement to those doing well, and check in on those appearing to be struggling based on their points.

In contrast to other work [31], participants liked the idea of interacting with peers through the leaderboard. We attribute this finding to the level of anonymity TreatYoSelf provides. The leaderboard (see Figure 1, bottom right) displays avatars, point totals, and customizable usernames. Research suggests that people engage in significantly more support seeking in stigmatized contexts such as sexual abuse if they feel more anonymous [1]. Extant computer-mediated communication research indicates that anonymity and the absence of nonverbal cues in computer-mediated environments facilitates intimate disclosures [38] and increases disinhibition [35]. A major advantage of online support groups compared to offline interactions is the perception that there is less stigma linked to one's status by others in the group because of increased feelings of anonymity [39].

Participants did, however, recommend constraining social features to prevent exploitation and sexual content. All participants agreed with this concern, citing social media sites such as Vine, Tumblr,

and Kick, which have grown to have increasingly explicit content. They identified this as a problem particularly within the gay community: *"Everybody's an at-home porn star now. ... I'm just concerned about gays. Like, gays are going to smudge this all up"* (Xavier). Participants recommended restricting uploaded content to text only, in order to maintain the positive tone of the app: *"Yeah, because this is a good thing. I like it. Yeah, so maybe it can be like a blog, but like no photos, no videos"* (Christopher).

4.5.2 Rewarding and protecting one another
Our workshop findings indicate that the type of social support participants seek is basic motivation and positive reinforcement; that is, they are not necessarily looking for extensive conversation or an exchange of experiences. While discussing ways to constrain social features, we asked participants what type of simple communication channel could enable TreatYoSelf users to reach out to one another, but restrain communication to only positive messaging. We provided the examples of Facebook's "Like" or "Poke" features. Participants referenced earlier discussions of what they considered motivating for themselves—clothing and accessories for their avatar, points, motivational words—and suggested they could give these as gifts to other users. Typically, the design of BITs is focused on the technology providing these reinforcers, but this finding suggests the social aspects of these BITs could facilitate the delivery of behavioral reinforcers among users themselves.

Participants also saw TreatYoSelf as a platform for youth helping one another to engage with care. We observed a sense of camaraderie within the community of youth living with HIV—not only did they want to provide rewards and motivation for one another, but they also wanted to help others get tested, seek out care, and share information about prevention. For example, Anthony said, *"you should also be able to get more points for like taking your friends to like [the clinic] to get tested or whatever, or linking people into care"*. Anthony went on to playfully suggest friendly competition—*"that would be like cool, because I want to be on top, so I'm just letting you know"*—which was in line with the gamification we had incorporated into TreatYoSelf, as well as other work on collaboration for health behavior change [33].

5. CONCLUSION
The effect of BITs on health behaviors is dependent on whether they can be integrated into users' daily lives. However, little is known about what features, content, messages, and tone can help users integrate BITs into their lives for sustainable, long-term use. Moreover, BITs may involve stigmatized conditions or marginalized status, factors that influence users' daily lives and add complexity to designing a user experience. We have addressed these design challenges using an empathy-driven approach in developing TreatYoSelf, a smartphone app aiming to improve medication adherence among youth living with HIV. Our approach helped us overcome initial rejections of potential features, and work with end users to reach a design that was not just acceptable, but comfortable and exciting to participants.

We found that five aspects of our approach to the design of TreatYoSelf elicited positive responses from participants: (1) a positive and informal tone came across as nonjudgmental, helping users feel the technology was a safe space from stigmatization, (2) minimal, avatar-based gamification put focus on the user rather than their condition and formed a good basis for rewards and behavioral reinforcers, (3) motivational and corny messages helped to lighten the tone and replace judgment with an optimistic outlook on living with a chronic condition, (4) neutral signifiers

and visual design protected against unintentional disclosure of their condition, helping the user feel in control and safe while using the app, and (5) a significant sense of camaraderie among the community indicates that social support has significant potential for providing positive reinforcement and motivation, if social features are constrained to protect anonymity and positivity.

Building on the significance of HCI approaches such as human-centered design and participatory design, we assert that an empathy-driven approach is both ethical and effective in designing for everyday life, especially with stigmatized and marginalized populations. Our design process used empathy to not only elicit participant needs and preferences, but also give participants agency and consider their emotional wellbeing. For example, we posit that an emphasis on positivity may help to alleviate concerns around burden and privacy by helping users to cope with the stigma of HIV and therefore perceive the BIT to be nonjudgmental, including as a platform for connecting users to clinicians and peers.

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