
The Role of Reflection and Context in Medication Adherence Tracking for People Living with HIV

Gabrielle M. Salib

Drexel University
Philadelphia, PA, USA
gms79@drexel.edu

Nadia Dowshen

Children's Hospital of
Philadelphia and
University of Pennsylvania
Philadelphia, PA, USA
downshenn@email.chop.edu

Juan Fernando Maestre

Indiana University
Bloomington, IN, USA
jmaestre@indiana.edu

Gabriela Marcu

Drexel University
Philadelphia, PA, USA
gmarcu@drexel.edu

Kenneth B. Nimley

Drexel University
Philadelphia, PA, USA
kbn29@drexel.edu

Abstract

It can be difficult to take time to reflect on healthy habits and goals. For those living with HIV, it is particularly important to have the opportunity to understand when and how their bodies are reacting to certain medications. In this work, we explore how a medication adherence application could help adults with HIV to reflect on their medication tracking behaviors in a way that promotes adherence. We present qualitative data collected through an early design stage activity by means of the Asynchronous Remote Communities (ARC) method, and a survey measuring attitudes toward a prototype application. We discuss two design implications for medication adherence applications: enabling users to record qualitative data that gives context to adherence data, and providing more visual support for reflection on daily medication behaviors.

Author Keywords

health informatics; HIV; medication adherence

ACM Classification Keywords

J.4 [Computer applications]: Social and behavioral sciences; K.4.2 [Computing milieux]: Social issues

Introduction

For people living with HIV, adhering to a required daily medication can be difficult. In prior work, we designed a smart-

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the owner/author(s). Copyright is held by the author/owner(s).

CHI'18 Extended Abstracts, April 21–26, 2018, Montréal, QC, Canada.

ACM ISBN 978-1-4503-5621-3/18/04.

<http://dx.doi.org/10.1145/3170427.3188631>

phone intervention, TreatYourSelf (TYS) ¹, to address medication adherence among individuals living with HIV [8]. The purpose of YYS is to provide reminders and support adherence tracking over time. YYS was designed for and with Philadelphia youth living with HIV. In this work, we explored the potential for YYS to help adults with HIV understand when and how their bodies are reacting to medication, which can only be accurately comprehended through the use of consistent medication adherence data.

We engaged participants in a discussion about YYS, and gathered their attitudes via survey, by means of a closed Facebook group of adults living with HIV, using the Asynchronous Remote Communities (ARC) method. We explored the following research questions:

1. Is the design of YYS appropriate and engaging to a diverse population?
2. How could YYS help people with HIV reflect on the effects of medication on their wellbeing?
3. What other functionality might help people with HIV monitor their medication adherence in motivating ways?

We discuss design implications for exploring new ways to allow reflection on medication adherence data using qualitative data to support the quantitative data collected daily, to promote healthy adherence behavior.

Related Work

Medication Adherence

Managing adherence of daily medications is one of the most difficult adjustments for adults who have recently

been diagnosed with HIV. It is also one of the only ways to continue living well for a normal life expectancy with the disease [4]. Anthropologists have reflected deeply on how communities have built systems of support and resilience to combat this arduous adjustment process [9]. Management of daily medications involves a range of factors, including the relationship between reading and health literacy levels and medication adherence [11]. One study found that nearly one third of patients are not 100% adherent and the patient's literacy level was "associated with more than a three-fold greater likelihood of missed doses" [11]. This indicates the strong need for easily understandable forms of data that has been collected on their patient's adherence [4]. Wolf et al. affirm that "comprehensive interventions are needed that target both patient understanding and self-efficacy through empowering approaches to care" [11].

Reflection on Context of a Behavior

Previously, researchers have found design flaws which could hinder users from regularly utilizing a personal informatics device. One of the main problems was a lack of ease in interpreting and accessing information within the system [2]. Because of the unique needs of persons living with HIV, it is necessary to understand how contextual data collection could influence their experience with the application. Bussone et al. contribute a process model through which people living with HIV inquire on a personal health tracking tool. Having an intention in keeping record of the data they have collected was reported to be specifically important to people living with HIV rather than being generally important to people living with any chronic disease [1].

Methods

The ARC Method

To obtain perspectives on YYS from a diverse range of potential users, we employed the Asynchronous Remote

¹Previously TreatYoSelf: changed per request from funding sources.

Gender	N (%)
Male	11 (58%)
Female	7 (37%)
Gender Queer	1 (5%)
Sexual Orientation	N (%)
Heterosexual	8 (42%)
Homosexual	8 (42%)
Bisexual	3 (16%)
Race/Ethnicity	N (%)
Caucasian	12 (63%)
Latino	4 (21%)
Asian	2 (11%)
African	1 (5%)
Country	N (%)
U.S.	13 (68%)
Philippines	2 (11%)
Kenya	1 (5%)
Mexico	1 (5%)
South Africa	1 (5%)
U.K.	1 (5%)
Education	N (%)
High School	14 (74%)
College	5 (26%)

Table 1: Participant demographics

Communities (ARC) method developed by MacLeod et al. [6, 5]: "An ARC study involves a group of participants in an online environment (typically a private or secret Facebook group) completing periodic activities both individually and as a group. These activities can be anything from lightweight ice-breaker activities to psychometric exercises" [7]. Initially, the ARC method was created to study people living with rare diseases in order to overcome barriers of geographic distribution of participants [5]. More recently, the ARC method has been used to study stigmatized populations who have been traditionally difficult to recruit for studies conducted in face to face settings. In particular, Maestre et al. used the ARC method to study people living with HIV [7] and found that the method "facilitated recruitment and data collection. It registered a high response rate and little delay in completion of activities. It also sustained participant engagement throughout the study" [7]. Thus, ARC has allowed researchers to overcome barriers that make it difficult—or even impossible—to conduct face to face studies with certain hard-to-reach populations².

Procedure

Participant recruitment and data collection was completed via the ARC-based study conducted by Maestre et al [7]. In that study, the ARC method was deployed in a secret Facebook group "in order to compare and validate findings with previous ARC studies that have used the same platform" [7]. During May and June of 2017, the search keywords "HIV support" were entered on Facebook to find HIV support groups from which to recruit potential participants. A request to join the groups was sent to several groups that had at least a thousand members. Administrators from four different groups accepted the membership request, and asked for IRB documentation regarding the

²For a more detailed guideline on how to implement the ARC method for these populations, please refer to [7].

study before adding a researcher to their groups. Participants were recruited via a post on the wall of each of these support groups. Group members who were interested in the study responded to the recruiting post and were asked to send either an e-mail or private Facebook message to the researchers. Questions regarding the consent form were addressed via Facebook Messenger. After participants sent a scan of the signed consent document, they were invited to a secret Facebook group named "Chicken Soup Group". Participants were compensated with \$50 via PayPal at the end of the study, regardless of their level of participation.

During the eight week study, which is explained in more detail in [7], participants were asked to complete weekly activities. Maestre et al. did an overall meta evaluation of the suitability of the ARC method to study a stigmatized population. They discuss their findings in terms of recruitment, data collection, participation, engagement and delay in completion of activities. In this paper, however, our findings are derived from an in-depth analysis of data collected from specific activities that were deployed during the sixth and seventh weeks. These two activities were designed to capture feedback about the TreatYourSelf mobile application. Accordingly, on week six, the activity consisted of a video and an interactive prototype of the TreatYourSelf mobile application. The video had a duration of five minutes and showed animated screens of the application with audio explanations about its main features and functionality. Additionally, participants were provided with a link to an interactive online prototype of the app so that they can interact with its main features more directly. Participants were asked to provide feedback and engage in discussion about the app in the comments area of the activity post. On week seven, participants were asked to fill out an online survey about the app regarding its usability and features.

Survey

A survey composed of about forty questions was administered to the participants, and 16 out of the 19 participants completed it. The survey covered topics such as aesthetics, organization, existing reminders and motivations for medication adherence, impressions of the application's effectiveness for themselves and others, and participants' impression of the various features of the application.

Participants

Participants ranged in age from 18-60 and the number of years living with HIV ranged from 1-30 years. Four participants were employed full time, while the rest were either self-employed, unemployed, or receiving disability payments. All were able to write and speak English fluently. Detailed demographics can be found in Table 1.

Data Analysis

The data from the discussion in the Facebook group and the survey were analyzed together using affinity diagramming [3] and inductive thematic analysis [10]. The research team iteratively discussed emergent themes.

Results

The conceptual model and overall design of TYS were validated by participants. This was particularly interesting seeing as the application was originally designed with and for youth in Philadelphia. The application has now been validated as a medication adherence tracking tool by a diverse group of people, including ethnicity and a wide age group. This could indicate generalizability of the design and the universal need for the concepts incorporated in the design.

75% of participants reported never having attempted monitoring their medication adherence with an application. After seeing the design and functions of our proposed application, 80% of participants reported that they would download



Figure 1: This iteration of the application allowed users to visualize their adherence recorded in weekly, monthly, and daily forms although, without qualitative record keeping.

and use it for their own medication adherence tracking. Participants also indicated perceived ease of use and intuitive navigation: 88% (14/16) agree and strongly agree that "The sections in the app fit well together" and that "The sections in the app appear nice and neatly grouped." These findings suggest an overall validation of the design and organization of the application, allowing us to further investigate more complex facets of the design's implication in participants' lives. We identified two main themes: a need to provide context along with the qualitative data of daily medication adherence, and to easily visualize all the data collected surrounding their daily medication routine.

Need for Context Surrounding Medication Routine

Participants communicated a need for a qualitative data collection of their medication adherence routine. The need arose from several perspectives; from a need for "place for notes to state what may have been going on physically to

make a change i.e. cold, infection etc," to noting "when and why they might have stopped taking a certain medication". This goes back to the uniqueness of the disease and the needs associated with tracking medication habits [1]. When tracking adherence, it is just as important to understand why they might have missed their medication that day and how a new medication might be effecting how they feel and go about their daily routine:

Jacob³: It might be helpful if a med is missed to record a reason why: away from home, ran out, forgot, didn't want people to see, feeling side effects, etc. That way folks could trouble shoot ways to overcome problems.

As Jacob reported, with a space to evaluate the context in which persons living with HIV have reacted to a new medication or missed a medication, there could be a higher likelihood of troubleshooting and overcoming the problem that could be occurring. This design could also provide physicians an increased awareness of their patients' habits and reasons for various side effects of new medications.

Need to Easily Evaluate Data Collected

Participants communicated a need to evaluate data of adherence to medications. Participants reported liking the bar graph included on the application. The graph indicates how many times that month they recorded taking their medication. It can be difficult for those more recently diagnosed to become accustomed to the process of creating habitual adherence to a regular medication routine while maintaining awareness of how a certain medication could be effecting their bodies. Having visuals and a digestible interpretation

of their adherence on the application was reported as encouraging, and could have potential to increase self efficacy in the difficult adjustment to regular medication adherence:

Sarah: I like the bar graph for talking meds. [...] Might be nice to get a % at the end of each month for adherence.

Many participants also felt that medical data tracking their CD-4/8 cell levels and viral loads (indicators of the amount of HIV in the blood) would be useful to have on hand in the application to help them compare the progression of their HIV with their medication adherence.

Conclusion

Overall, we found that it is important for adults living with HIV to understand how their bodies are reacting to certain medication based on qualitative data recorded to provide context to the quantitative data of medication adherence for the day. In addition, with visual graphs that are easy to understand, adults living with HIV can easily reflect on their adherence habits and be encouraged to continue a consistent streak. To this end we have proposed two design considerations when developing applications for persons living with HIV. We propose that by allowing users to visualize their medication adherence track record quantitatively and qualitatively, the application could empower users to take positive steps forward in tracking their health. It is possible that positive reinforcement and context provided in the two design suggestions, could empower those living with HIV to continue consistent habits of medication adherence and communicating with their health care professionals.

Acknowledgements

We thank all of our participants. This work was funded by NSF grant No. 1702243 - a NSF LSAMP BTD fellowship

³All names are pseudonyms to protect anonymity.

awarded to the first author, NIH grant No. K23MH102128-01A1 and Penn Center for AIDS Research (Penn CFAR)/NIH No. P30AI45008.

REFERENCES

1. Adrian Bussone, Simone Stumpf, and George Buchanan. 2016. It Feels Like I'M Managing Myself: HIV+ People Tracking Their Personal Health Information. In *Proceedings of the 9th Nordic Conference on Human-Computer Interaction (NordiCHI '16)*. ACM, New York, NY, USA, Article 55, 10 pages. DOI: <http://dx.doi.org/10.1145/2971485.2971542>
2. Rebecca Gulotta, Jodi Forlizzi, Rayoung Yang, and Mark Wah Newman. 2016. Fostering Engagement with Personal Informatics Systems. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems (DIS '16)*. ACM, New York, NY, USA, 286–300. DOI: <http://dx.doi.org/10.1145/2901790.2901803>
3. Karen Holtzblatt and Hugh Beyer. 1993. Making customer-centered design work for teams. *Commun. ACM* 36, 10 (1993), 92–103.
4. David A Kindig, Allison M Panzer, Lynn Nielsen-Bohlman, and others. 2004. *Health literacy: a prescription to end confusion*. National Academies Press.
5. Haley MacLeod, Ben Jelen, Annu Prabhakar, Lora Oehlberg, Katie Siek, and Kay Connelly. 2016. Asynchronous Remote Communities (ARC) for Researching Distributed Populations. In *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth '16)*. ICST, ICST, Brussels, Belgium, Belgium, 1–8. DOI: <http://dx.doi.org/10.4108/eai.16-5-2016.2263322>
6. Haley MacLeod, Ben Jelen, Annu Prabhakar, Lora Oehlberg, Katie Siek, and Kay Connelly. 2017. A Guide to Using Asynchronous Remote Communities (ARC) for Researching Distributed Populations. *EAI Endorsed Transactions on Pervasive Health and Technology* 17, 11 (7 2017), 1–19. DOI: <http://dx.doi.org/10.4108/eai.18-7-2017.152898>
7. Juan F. Maestre, Haley MacLeod, Ciabhan Connelly, Julia Dunbar, Jordan Beck, Katie A. Siek, and Patrick Shih. 2018. Defining Through Expansion: Conducting Asynchronous Remote Communities (ARC) Research with Stigmatized Groups. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*. ACM, New York, NY, USA. DOI: <http://dx.doi.org/10.1145/3173574.3174131>
8. Gabriela Marcu, Nadia Dowshen, Shuvaditty Saha, Ressa Reneth Sarreal, and Nazanin Andalibi. 2016. TreatYoSelf: empathy-driven behavioral intervention for marginalized youth living with HIV. In *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare*. ICST, 69–76.
9. Laurence Ralph. 2014. *Renegade dreams: Living through injury in gangland Chicago*. University of Chicago Press.
10. Dennis Wixon. 1995. Qualitative Research Methods in Design and Development. *interactions* 2, 4 (Oct. 1995), 19–26. DOI: <http://dx.doi.org/10.1145/225362.225365>
11. Michael S Wolf, Terry C Davis, Chandra Y Osborn, Silvia Skripkauskas, Charles L Bennett, and Gregory Makoul. 2007. Literacy, self-efficacy, and HIV medication adherence. *Patient education and counseling* 65, 2 (2007), 253–260.