Self-Managing HIV Using Mobiles

Abstract

In order to monitor and improve their mental and physical wellbeing, people living with HIV would like to track and reflect on their personal health data. We investigated the needs and concerns of HIV+ people and present their requirements for mobile application design. Despite the interest in tracking personal health information to improve wellbeing, there are few mobile solutions that support HIV+ users to do so. We describe a current study which evaluates a mobile application, BeYou+, aimed at improving the mental and physical wellbeing for people living with HIV.

Author Keywords

Personal Health Informatics; Mobile Wellbeing; HIV; Self-Management.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

In 2014, nearly 37 million people were living with HIV globally [9]. In England, the majority of people diagnosed with HIV are between the ages of 35-54, with 67% males and 33% females [7]. Medical progress has meant that people living with HIV can live long, healthy lives by taking antiretroviral drugs (ARVs). However, HIV is a complex chronic disease to manage, and is associated with a variety of symptoms, side effects of taking ARVs, co-morbidities, and opportunistic infections [5]. In order to manage their disease, HIV+ people must carefully monitor changes in their mental and physical wellbeing to determine the causes and potential solutions [8].

Personal Health Informatics (PHI) considers the technology and information needs of individuals who collect and reflect on their own health data in order to better understand and self-manage their condition [1]. Previous studies involving chronically ill end-users with diabetes have investigated mobile devices to monitor and track health information [3,6], however, so far little is known about PHI tools for people living with HIV.

There has been little research focused on the use of mobile technology to deliver health services to patients (mHealth) with HIV [8]. Systematic reviews on mHealth

for HIV have found that mobile solutions typically focus on developing countries, or on patients reporting medication adherence to their healthcare provider, which only captures a small aspect of living with HIV [8]. Currently, there are few tools (e.g. TIDES) that leverage mobile technology and offer HIV+ people what they need to self-manage their wellbeing. A recently developed mobile application, BeYou+, provides content and functionality relevant to improving the body, mind and life when living with HIV.

Supporting PHI for people with HIV

We conducted a study focused on HIV+ people who track and manage their health [1]. We interviewed 16 HIV+ adults who had tracked or were currently tracking their personal health information. The aim was to identify the actions, concerns, and challenges of people living with HIV during the stages of the PHI process (Fig. 1). We conducted an inductive qualitative analysis to determine the major themes for each stage. Here we outline the key findings and their impact on designing mobile solutions for supporting wellbeing for people living with HIV.

Intention: Fifteen participants were tracking with the intention of monitoring their well-being, with no plans to take action or make changes, while 7 were also tracking health information to inform what actions should be taken or observe the effects of them. Our results indicate that because people with HIV face continuously fluctuating health, they might continue tracking even when they have learned enough or their life circumstances change [2] and, unlike many other chronic conditions, need support for both monitoring and reflecting [4]. Hence, a mobile solution needs to offer a broad range of functionality that supports

tracking and reflecting at the same time, possibly over a long time period.

Identification: When identifying a suitable PHI tool, only 4 selected a mobile application, mainly due to security and privacy concerns. Participants felt that digital solutions, such as apps, did not provide as much data security as paper notebooks and that data stored in the cloud could be easily hacked. There were also concerns that a mobile app would not protect their privacy; it could be spotted by another person and lead to accidental disclosure. However, participants were still interested in using mobile apps as they felt it would be more convenient for tracking. Thus, mobile tools must provide strong security and privacy through storing the data locally, requiring a password to access the app, and avoiding references to HIV (e.g. red ribbon icons).

Capture: People living with HIV keep track of a variety of information types, which are not always obviously related to HIV. Tracking medication and lab results was common, but a wide range of other information was also important: emotions, food, weight, exercise, side effects, and other conditions. Mobile tools should offer a broad range of information for users to track, possibly leveraging Apple's HealthKit, which already allows the collation and display of activity data (e.g. workouts, calories, heart rate) collected from a variety of apps.

Representation: Mobile apps supported the 4 participants using them by providing visual representations of their data, but did not allow integration of different information. All visualizations were simple graphs which were limited in supporting reflection on a potentially large and complex data set. Further work is warranted to explore visualizations that

are flexible to use, easy to understand and fit within limited screen real estate.

Reflection: Fourteen participants mentioned reflecting on their data to gain a better understanding of their wellbeing, with 11 using their tracked data during healthcare appointments. There is limited work on using PHI data collaboratively with others; this would have ramifications on what data to track (Capture), what to reveal and when (privacy and security in Identification), how to format and visualize information (Representation) and how to share this information, possibly linking to electronic medical records (EMR).

An evaluation of a mobile HIV app

We are conducting a study to evaluate BeYou+ (Fig. 2), a mobile app developed by HIV experts at Chelsea and Westminster Hospital, UK. The app aims to help people with HIV improve their mental and physical wellbeing. It enables users to set and track achievement of wellbeing goals as well as track their lab results (Fig. 3). It also provides detailed information relevant to the body, mind and life when living with HIV (Fig. 4).

On 1 August 2016, we launched anonymous online questionnaires to obtain feedback from both users and non-users of the app. We asked about the app's support for self-management and wellbeing and potential improvements to make. To date, 24 respondents were recruited through social media and HIV+ forums. Our sample consists mainly of gay white males between the ages of 19 and 60, mean age of 33, with year of diagnosis from 1998 to 2016. Twenty-three respondents were non-users, we focus on their responses about required functionality here (Fig. 5).

Tracking and monitoring information is important to people with HIV but currently not well supported by the app. 91% of respondents stated that tracking lab results was important to them, echoing the response from the regular user of BeYou+ who found the *Track my HIV* feature to be 'extremely useful.' 68% of the respondents wanted to record their medication adherence and 36% were interested in setting personal goals. However, currently these functionalities are either not available or only form a small part of the content provided.

In line with our previous research, participants also wanted to track a variety of information related to their wellbeing: 45% of non-users were interested in tracking other health information, including mental wellbeing, and 36% wanted to track daily activities. BeYou+ provides extensive information about living with HIV, which serves 59% of respondents well, but the ability to track a variety of data is lacking. While BeYou+ already presents a simple visualization for lab results, adding more types of tracked information would make representations complex [1].

Many respondents desired to use the app with others: 64% wanted an app that would connect them with other HIV+ people, and 45% specified that they would like to use the app when meeting with healthcare professionals. However, the current *Peer Support* feature was judged as 'Not at all useful;' likely because the feature does not connect users to others, instead provides details on peer support and mentoring. Little is known about patients' use of apps with healthcare professionals [1], but BeYou+ would certainly need to extend the existing functionality, which currently only

allows users to create a list of their physicians (described as 'Not at all useful').

Future Work and Conclusions

Our findings indicate that HIV+ individuals desire a mobile solution to support them in tracking for self-management, and highlight that there is interest in tracking information not obviously connected to their disease; something which few apps support. Future work in PHI should expand on this by developing and evaluating mobile tools for HIV+ individuals, further exploring how they use such applications to track information and benefit their wellbeing.

Our research on BeYou+ will continue with interviews aimed at gathering a deeper understanding of the BeYou+ user experience and unmet user needs, including barriers to adoption. The results will be used to develop a set of design recommendations for mobile applications aimed at supporting HIV+ people in tracking and self-managing.

In this paper we have:
- Described the requirements for a mobile solution that supports HIV+ people in the PHI process
- Presented the early results of an evaluation of the BeYou+ app and desired functionality
- Highlighted opportunities for future work that focus on mobile applications that support HIV+ people in self-managing

Acknowledgements

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