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[Extended Abstract]

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ABSTRACT

The purpose of this research is to evaluate issues with current recruitment and data collection methods that are scene through-out face-to-face and online studies that evaluate support exchange among individuals living with HIV. These issues will be addressed through the adaptation of remote participatory design principles and the Asynchronous Remote Community (ARC) method. Our adaptations to the ARC method include online support group activities that promote user participation and provide intricate data [3]. We found that blabla. In conclusion blabla. This opens new doors to further explore bla and bla.

Categories and Subject Descriptors

H.4 [Information Systems Applications]: Miscellaneous; D.2.8 [Software Engineering]: Metrics—*complexity measures, performance measures*

General Terms

Theory

Keywords

ACM proceedings, L^AT_EX, text tagging

1. INTRODUCTION

People living with HIV often feel withdrawn from others and, therefore, have difficulty getting the support they need [6]. Finding participants for face-to-face studies has proven to be a major hurdle in past research because stigmatized individuals do not often want to expose the nature of their medical conditions in fear of social or professional backlash [10]. Some success has been had with anonymous surveys, yet there are limitations to the richness of the data that can be gathered.

It has been suggested that individuals living with stigmatized diseases are more responsive to online studies [1]. This fact has rarely been exploited besides for the purpose of survey distribution. There has been some success with online outreach (see related work), because patients feel their confidentiality is more

protected, yet there has been very little actual technology designed as a result of this online research.

In our research on patients with stigmatizing diseases, more specifically those living with HIV, we identify holes in support exchange systems that can be filled by technology. The Asynchronous Remote Community (ARC) method has been applied successfully in a study conducted with people living with rare diseases as well as a study with pregnant women. The first ARC study was successful in the collection of rich qualitative data [3]. MacLeod et al. note in their paper, however, that there are aspects of their methods that warrant further exploration [3]. The second ARC paper made some modifications to the ARC method as a whole, including splitting the population into multiple groups based on shared experiences, and the introduction of a few new activities [8].

The researchers provided evidence supporting many of the speculations from the original ARC paper, but many questions still remain open, or warrant further confirmation. In particular, the second study did not attempt to incorporate some of the community building suggestions of the first. Walsh et al. demonstrate the advantages of participatory design in an online platform by using the process to iteratively develop an online design tool [11]. We will be adapting the ARC method and remote participatory design principles to be used on populations of individuals living with HIV, with an end goal to design technology to support the given populations.

2. RELATED WORK

2.1 Recruitment and Data Collection Methods

Face to Face Studies

Participants for qualitative studies are often recruited through physically distributed materials [e.g. [8]], or contact with organizations (such as hospitals or support network in the case of people living with HIV) who then distribute the study information to potential participants [e.g. [7], [9]].

Face to face qualitative studies frequently employ surveys [e.g. [7]], interviews [e.g. [9], [7]], and focus groups [2] in order to obtain their data. The advantage of surveys is that, after informed consent is obtained, they do not require input from the researcher. This means they can be distributed to a large number of participants, increasing the statistical significance of the data. Beyond surveys there are two other main face-to-face methods of gathering qualitative data, which include interviews and focus groups. Interviews require a lot of work on the part of the researcher, but

can be used to gather rich data about experiences and opinions. The advantage of focus groups is that they encourage interactivity and generation of ideas.

Approaching HIV positive populations in person is difficult because the stigma makes much of the population wary of revealing their status to anyone [6][5][9]. Reeves notes that her data may be skewed by the fact that the only people likely to volunteer for an interview are educated and eager to help research surrounding their condition. This means that the results will be biased towards a particular background. Peterson explains that there are large subsections of the HIV positive community that are understudied and do not have access to the same resources as the more visible sections [7]. This reinforces the necessity for recruitment that transcends demographic barriers.

Online Studies

The most notable advantage of conducting research online is that more potential participants can be reached with recruitment material. Brenda Curtis notes this in her paper on the ethical challenges involved with reaching HIV positive patients online. She also explains that it is easier to reach a wider range of demographics than through traditional methods [1]. These advantages have led to face-to-face studies frequently recruiting through online means. Benjamin Eveslage demonstrates this in his paper on reaching sexual minorities for interview in Ghana [2]. He did this by searching Facebook for 'men interested in men', joining Facebook groups for gay men, and adding friends of those encountered by the other two methods. Eveslage managed to recruit 64 members of sexual minorities (compared to the 49 that he managed to recruit through traditional methods) for interviews, observation, and focus groups in a country where homosexuality is criminalized. While his research did not specifically target HIV positive individuals, it did demonstrate the benefit of such an approach on a stigmatized group.

Online data collection methods are often similar to face-to-face approaches. Researchers frequently exploit the additional reach of online recruitment methods in order to more widely distribute traditional surveys [e.g. [4]].

2.2 The ARC Method

MacLeod et al., introduced the ARC method to facilitate conducting rich qualitative research on geographically distributed populations [3]. They conducted their research on patients living with rare diseases by inviting them to join an online community and asking them to participate in a series of activities from which data were gathered. In addition to their findings, the authors listed the challenges they encountered and encouraged other researchers to replicate and modify their work. Prabhakar et al., adapted this approach to the population of pregnant mothers, showing the value in iterating on and tailoring the method based on past challenges and circumstances specific to the study [8]. Table 1 contains a list of the lessons and recommendations from previous iterations of the ARC method that we intend to build on.

3. METHODOLOGY

In this section we cover our process for gathering our data including recruitment, study activities, and entry and exit surveys. We will also discuss the changes that had to be made to previous iterations of the ARC method in order to protect and cater to an HIV positive population.

Study	Challenge	Lessons Learned
Rare Diseases	Participation	Build a relationship with the participants.
Rare Diseases	Ethics	Explore alternate methods of receiving informed consent.
Rare Diseases	Participation	Encourage participants to build on each others' work.
Rare Diseases	Participation	Encourage participants to post their work to the group.
Rare Diseases	Activity Design	Consider activities carefully before implementing them.
Rare Diseases	Participation	Examine behavior of participants to inform study design.
Rare Diseases	Participation	Use multiple avenues to inform participants of activities.
Rare Diseases	Activity Design	Keep activities from relying on chronological participation.
Rare Diseases	Participation	Provide opportunities for participants to socialize.
Rare Diseases	Recruitment	Try to recruit a homogeneous population.
Rare Diseases	Activity Design	Be mindful of the number of ways participants submit data.
New Mothers	Activity Design	Be mindful of the number of steps to complete an activity.
New Mothers	Activity Design	Consider participants' technology preferences.
New Mothers	Activity Design	Strike a balance between ease of use for participants and usefulness of data.
New Mothers	Activity Design	Adapt data capturing methods from focus groups to the ARC method.
New Mothers	Ethics	Intervene to help participants who are struggling outside of data collection.
New Mothers	Data Collection	Be proactive about designing methods to make data collection and overhead easier.

Table 1: Recommendations

3.1 Recruitment

Participants were recruited from two different sources: Positive Link and Facebook. Positive Link is an organization in Indiana dedicated to helping people living with HIV in a variety of ways. They aid those under their care with navigating bureaucracy to get medication and services, as well as helping patients adjust back to normal daily life with their disease. Positive Link agreed to give our recruitment materials to people in their service in order to help us obtain participants.

The administrators of large Facebook groups for people living with HIV were also contacted with a request to post our recruitment information. [List how many groups were contacted and how many groups accepted]. In both cases, when someone interested in participating contacted us, we provided them with materials for informed consent. [x] participants from Positive Link expressed interest, and [x] completed the informed consent form, as opposed to [x] who expressed interest from the Facebook groups, and [x] who sent in a consent form. Following the suggestions of MacLeod et al. regarding homogeneous populations, we separated the recruited Facebook participants and Positive Link participants into two separate online groups in which to conduct the ARC method [3].

3.2 Participants

Of the [x] participants recruited through Positive Link, [x] lived in [list the numbers in the most common cities], and the rest were scattered throughout Indiana [... and other states if applicable]. [Other relevant demographic information about Positive Link participants].

The participants recruited through Facebook groups were largely located in the U.S., with the biggest clusters around [areas]. There were also participants from [other countries?]. [Other relevant info]

3.3 Outline of HCI Research Methods

Interviews

Face-to-face interviews were held with either one subject or a few subjects (2-3 subjects). Interviews consisted of question and answer sessions that were recorded with audio or visual and audio and were later transcribed.

Online Surveys

Standard rating surveys were distributed to the two online groups asking participants different questions that ranged from social implications, to medical treatments, and more. A debrief survey about the FB group activities and TreatYoSelf application were also distributed.

ARC

The ARC method is focused on targeting recruitment and participation for online research. ARC takes inspiration from focus groups while also taking advantage of the unique characteristics of an online platform. Researchers are able to analyze the experiences of participants from multiple angles by using varying data collection methods that help establish an environment that is more easily moderated and open for all participants. The ARC method has the additional advantage of taking place over an extended time span without requiring a high level of investment on the part of the participants.

FB Group Activities

In this section we will be addressing the online group Facebook activities used in our research, which are an adaptation of the ARC method [3]. We will only be thoroughly addressing the activities in which we made significant changes to the ARC model or which are completely new activities to the study. ***State which ones they can reference in other paper(s)***

Introductions

The introductions will be kicked off by the researchers introducing themselves and a general template for introductions will be provided so that no personal information of the participants will be given out about the individuals.

Template:

- Introduce Name: Hi my name is Julia!
- One reason you are excited to Participate in the FB Group: I am excited to be in the FB group to gather more information and create a helpful technology.
- Two/Three things you enjoy doing: I enjoy playing tennis, reading, and hanging out with friends.

Beginning Questionnaire

This questionnaire will include demographic questions, as well as questions regarding living with HIV, and getting to know you questions.

Ice Breakers

Ice breaker activities will be distributed to the Facebook group to elicit conversations. There will be three main Ice Breaker activities which will be described in more detail below:

- 1) Re-Vamped 20 Questions: This activity will require participants to think of an object that represents who the participant is or something they like. After they have thought of this object other participants will have to ask this individual questions about what there object is until someone guesses the individuals object.
- 2) Create a Story: Participants will be asked to create a story as a team in this activity. A researcher or participant will be asked to begin the story with a phrase, such as "Once upon a time in a land far far away...". After the first sentence of the story is posted participants will be asked to reply to it with a sentence to continue the story. This activity continues until the participants are done or the story is complete.
- 3) GIF activity: Participants will choose and post a GIF that they feel represents them. After they have posted their GIF other group members will guess the key word(s) the participant used to search for the GIF they selected for themselves.

Ranking of Problems

-Different problems associated with HIV will be contrived from interviews, questionnaire(s), etc. from those living with HIV and caregivers. -Some sort of Ranking Game will be created. -This activity is meant to be entertaining and informal.

Photo elicitation

Participants will be informed what type of photos are appropriate to submit for this activity (not eligible photos: drugs, sexual acts, etc.). Then they were instructed to take photos that represent two themes from the Ranking of Problems activity. After they selected their themes participants were told to take photos and describe their meaning(s). Afterwards the photos will be submitted to the research team privately all at once. The researchers screened photos and descriptions to ensure they do not contain

any elicit activities. After the screening was completed the photos were posted to the Facebook Group with the short description and participants were asked to comment on each photo. -If conversation is slow researchers may ask a few questions to get the ball rolling.Ex: How do these photos make you feel? or do you feel like you can relate to anyone else's photos?

Circles

A circle diagram template (made more colorful and inviting) will be uploaded to the Facebook group and participants will be asked to print out the template and fill it out accordingly. Participants will be informed to think of different technologies they use or find the most helpful in living with their HIV and to put the name(s) of these technologies into the different circles. The distance to the center circle will represent how important that type of technology is for the participant. The closer to the center the more important the technology is to that individual, the farther from the center the amount of importance of the technology decreases.

TreatYoSelf

-A quick blurb on what the TreatYoSelf Application is will be given to the Facebook group and they will also be directed to look at the TreatYoSelf video and guidebook that will be linked to the post. -Quick blurb: The TreatYoSelf application is an interactive application designed to help users discretely and seamlessly keep track of their medications, doctor's appointments, prescription refills, and interact with other people living with HIV. -Link to video and guidebook will be provided. -We will ask participants to comment on what they think of the application in the group and also fill out a quick evaluation of it.

Solutions

-From the problems in ranking of problems and after viewing the TreatYoSelf Application (a Solution example) participants will discuss different strategies or solutions they have used in the past or have ideas for solutions that can be developed. -These solutions can be conceptual or they can sketch out ideas.

4. RESULTS AND DISCUSSIONS

4.1 Results

This is a rough bullet point outline of what will be addressed in this section... -We will hopefully launch the Facebook group this week and if the group is launched we will then discuss the activities within this section. -Information gathered from the Facebook group will reveal common problems/issues that those living with HIV often deal with. -We will discuss how participants stay engaged throughout the process.

4.2 Discussions

This is a rough bullet point outline of what will be addressed in this section... -Discuss trouble of recruitment of this stigmatized community and how it has effected our research and may effect others research as well. -Our adaption of the ARC method, more specifically the activities for the Facebook group. -What people can take away and further from our research.

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