

Before, During, and After: Research with Older Adults with Vision Impairments

Robin N. Brewer

Northwestern University

Evanston, IL, USA

rnbrewer@u.northwestern.edu

ABSTRACT

This paper is a reflection on conducting design interventions for older adults with vision impairments. This underserved group faces unique barriers to technology use such as lack of internet access, low socioeconomic status, and disability, which researchers need to consider when including this population in the design process. Through discussion of a ten-week design intervention, tensions before, during, and after such research studies are raised.

Author Keywords

Older adults; vision impairments

ACM Classification Keywords

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

INTRODUCTION

There is a lack of research for underserved communities within the broader CSCW space. Yet, there are many practical challenges that minority or underrepresented populations face which affect how they are able to use technology such as access to the internet, low socioeconomic status, and disability [6]. Specifically, I discuss my work with older adults (people over the age of 65) with vision impairments as an underserved community who may face access and financial challenges. In addition to their vision impairment, which may progressively worsen as they age, they are also at risk for developing multiple disabilities such as memory and hearing challenges [7]. I continue by reflecting on the successes and tensions I have faced before, during, and after designing research studies for older adults with vision impairments and invite discussion as to how the research community can ease these tensions.

CONTEXT

This paper is situated in the context of my work examining how to build online communities to better address the needs

of people without mainstream forms of internet access. Previously, I conducted formative research through observations, interviews, and prototype testing with older adults. Participants emphasized the value they place on voice-based interactions and use of the phone to communicate [1]. Through a case study to understand ways older adults were already communicating and expressing themselves online through blogging, participants described the important role of blogging post-retirement for providing an outlet for meaningful expression and community [2]. Using these findings, I developed an IVR (interactive voice response) blogging system and in this paper, I reflect on my experiences deploying this system to visually impaired seniors for 10 weeks.

BEFORE: RECRUITING UNDERSERVED GROUPS

To begin the study, I sought to recruit a small group of ten to fifteen older adults with vision impairments. Because this system was developed to address communication and expression needs of seniors without computer and internet access, I had to carefully consider my recruitment technique to attract people who were potentially offline. Also, since members of this population were either blind or had low vision, standard offline recruiting practices such as posting flyers or mailing letters would have been ineffective.

Although the medical school at my university has a curated list of older adults who are interested in participating in research studies, only two people on this list indicated being visually impaired. In this case, it was crucial to be able to reach out to organizations that were not closely linked with the university. Therefore, I decided to partner with organizations that people with vision impairments frequent and share details about the study with people who coordinate in-person support groups. Although this method of convenience introduced sampling bias, I decided it would be the most effective approach. To minimize sampling bias, I recruited from multiple organizations supporting people with vision impairments in the Chicagoland area including larger, national organizations (e.g. the National Federation for the Blind) and more local organizations and communities (e.g. Second Sense and the Hadley Institute for the Blind and Visually Impaired). I had no prior connection with these organizations so it took nearly four weeks to initiate contact with the appropriate representative, explain the study to them, and share the materials. Further, speaking with members of the blind community who either worked at or used the services of

these organizations was useful in learning how to conduct value-sensitive recruitment. Inspired by value-sensitive design, an approach to designing technologies by carefully considering human needs and values [3], value-sensitive recruitment enabled me to use new techniques to capture the attention of people with vision impairments. For example, one person with low vision who worked at an organization I recruited from suggested I create a voice advertisement that they could play for people to explain the details of the study. Another person who worked with members of the blind and low vision communities proofread the recruitment materials and indicated areas to remove jargon that their members would not understand. These interactions were key to improving my recruitment techniques so that they would be presented in a way that was easy to understand to people with vision impairments.

Tensions

Although I was successful in recruiting seven participants, this approach does come with its limitations. While contacting organizations can reach a large number of people, it can be very time consuming to establish partnerships. It took four weeks to establish contact and secure the organizations, but may take longer particularly for older people and people with disabilities, as HIPAA regulations may require the institution to review university-approved recruitment material and research protocols through their internal ethics boards (e.g. Institution Review Board). Also the organizations themselves serve as an IRB-protected population and were concerned about the validity of the study for the sake of the older adults as they often receive spam phone calls and emails. Therefore, this length of time to establish a partnership served as a way to establish trust between me as the researcher, my sponsoring entity (the university), and the organizations. But, ***are there quicker or more efficient ways to establish this trust between the researcher and the organization, particularly organizations with which the university or company has no existing partnership? Does a shorter recruitment timeline negatively affect trust?***

As with any special population, one limitation of this work is the generalizability. While I was able to engage several communities that support the needs of visually impaired seniors, a tension in communicating this work is how much I am able to generalize to other populations. The major difficulty is the ability to recruit participants. It took four months to recruit seven older adults with vision impairments from different communities. The small sample size is a weakness from a statistical perspective, but a strength when considering the richness of qualitative data that can be analyzed from this group. Considering the opportunities for generalizability and the sample size, ***what is the best way to communicate the value of such research to communities that are unfamiliar with recruiting underserved populations?***

DURING: ROLES OF THE RESEARCHER DURING A DEPLOYMENT

After recruiting participants, I conducted a pre-deployment interview to learn about their existing communication routines with and without technology. I also used this interview to give participants a tutorial of how the system worked and allowed them to try the three main features of the IVR blogging system – listening to a post, recording a comment, and recording a post. During these interviews, I instructed participants that there was no minimum or maximum frequency for which they needed to blog by phone and that I would check in on them weekly to get feedback on their use or non-use. Also, I gave them my phone number and asked them to contact me if they had experienced any errors during the week.

While the phone check-ins were included to capture a richer account of what participants did that week and why (as opposed to waiting until the end of the 10-week study when it may have been more difficult to recall such information) the phone check-ins unexpectedly served two purposes. First, I was able to assess participants' mental models for how the system worked and how they should interact. For example, several participants thought they needed to post new content only when others had posted something new as well. When P2 was asked if he created his own posts, he replied, "*No I have 3 there from driving and nobody has responded.*" Similarly, I observed how participants confused new posts with new comments because the system, indicated how many posts had been created since they last dialed in but did not indicate how many comments had been created since their last call. Also, two participants had difficulty understanding that pressing option 1 in the main menu would only let them listen to other participants' posts, not their own. Because of this confusion, one participant recorded a variation of the same post nine times. Without the weekly phone calls, I would not have been able to recognize participants' confusion and provide guidance as to how the system worked.

Second, although I invited participants to call at any time to report system errors, many participants did not do so for the first half of the deployment. Participants were not proactive in their reporting, rather they reported errors during the weekly phone check-ins. Often, these errors prevented participants from being able to dial in and use the blogging IVR system. Therefore, it was important that they be fixed immediately. After three to four phone check-ins per person, participants began to report errors on their own. While it is difficult to speculate why this was the case, perhaps it is related to whom they assigned blame for the errors as research has shown that older adults blame themselves for technology failures more than younger adults [5]. During the pre-deployment interviews, I assessed participant's levels of anxiety towards technology according to the Computer Anxiety Rating Scale (CARS) [4]. Potential CARS scores range from 19 (low anxiety) to 95 (high anxiety). The average score for participants in the

deployment is 60.42 (SD = 6.16), indicating a sense of anxiety towards using computers. Perhaps participants' mid to high anxiety levels towards technology contributed to the level of blame they placed upon themselves when the system did not work how they expected. Therefore, it is important to further understand how participants' self-efficacy and perception toward technology use may affect not only how they participate in a design intervention, but how they report use of the system.

Tensions

While the phone check-ins worked well for providing rich feedback, they also presented two challenges. First, several participants discussed information not pertaining to the research study during the phone calls. P5, who frequently described being lonely in her blog posts, always started the phone calls discussing weather and current events. To establish rapport, I continued this conversation as briefly as I could. Yet, these conversations soon evolved into talking about family and loved ones. Because perceived social support was a dependent variable being measured in the design intervention, I had to carefully consider the boundary between researcher and confidant throughout the phone check-ins and pre- and post-deployment interviews. ***How does the researcher establish and manage such boundaries when considering the need to establish trust and rapport with the participant, particularly for participants who are seeking social support?***

Also, the phone check-ins may pressure participants to using the system more than they would have otherwise. For example, P4 said “*nobody pressured me. Nobody said, “Hey, how you doing?” I mean, you did it, and when you said that, I immediately looked for the phone number and called and said something*”. Although this was an unintended consequence, it may have biased the results. On one hand, I could correlate the frequency of posting with the date of the phone check-ins to observe spikes in posting. On the other, it is difficult for me to know whether this is by chance because the calls were typically conducted towards the beginning of the week and could be due to the small sample size. Therefore, ***how can researchers analyze the bias their involvement may produce in their data?***

AFTER: RESPONSIBILITIES OF THE RESEARCHER POST-DEPLOYMENT

Participants used the blogging IVR system for 10 weeks. After the 10-week intervention, users participated in a post-deployment interview. In these interviews, I asked questions to understand what they liked and disliked about the system and the process of blogging, and to investigate how use may have fostered new forms of expression and communication not available to them before the study. While the data has not been fully analyzed, several participants described how they valued the community aspect of being able to conveniently meet and hear from other people with vision impairments without leaving their homes. All participants wanted to continue using the system though the study had ended and after being told they

wouldn't be receiving compensation for their participation after the post-deployment interview. Thus, all researchers of technology interventions should consider the role that the technology had in the lives of participants and if use could be extended beyond the study.

Tensions

Yet, the above point raises a unique challenge. Should systems in design interventions be developed to be temporary or permanent? Using free, open-source software or low-cost software, or partnering with organizations that have funding could help to make systems more sustainable. The blogging system requires weekly attention to ensure the servers are running and costs \$5-10 per month, although the service is offered at no charge to participants. I recognize this is a minimal effort and other systems likely require more upkeep, ***but how can researchers develop sustainable interventions if it interests the participant to continue using?***

In this case, participants wanted to use the system post-deployment because it provided some value to their lives. Importantly, if the system has an impact on the lives of participants, researchers need to consider what will happen after the technology is removed. If participants stopped using their computers or became dependent on this system for contacting family or friends, it would negatively impact their communication routines if the system were no longer available. Therefore, I ask researchers to consider the question – ***to remove or not remove? Also, should researchers minimize dependency on design interventions to minimize potential consequences of future removal?***

CONCLUSION

In this paper, I presented a reflection on my experiences conducting design interventions for one underserved population – older adults with vision impairments. I have described what worked well during the recruitment process, deployment, and post-deployment. Though establishing new partnerships were vital to recruiting the appropriate group of people, this process took time and led to a small sample size. During the 10-week study, I conducted weekly phone calls with participants to gather rich feedback, but this may have unintentionally affected how often participants used the system. And, after the deployment, I allowed participants to continue using the system but this may not always be possible or to the benefit of the participant. At each step of the research process – before, during, and after, I invite researchers to think critically on how to best incorporate the needs of underserved groups.

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