HCI Research Challenges in Complex Healthcare Context

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Many health information technology (HIT) researchers and practitioners strive to improve healthcare systems by creating and using engaging and effective technology. However, the challenges researchers face while conducting research in the healthcare context are rarely discussed; HCI researchers who come from non-health-related backgrounds and conduct research with populations with highly complex health scenarios (e.g., chronic conditions, severe/multiple disabilities) encounter situations they are not prepared for. Researchers often handle those situations by adapting various methods "on the fly." Those ad-hoc methods are often unreported in the literature, which can perpetuate the cycle of being unaware of these challenges and leaving future researchers unprepared. This paper presents our experiences during three of our works-in-progress research projects; we report the challenges we encountered and the methods we adapted while working with populations with complex healthcare needs. Finally, we propose preparation guidelines for future researchers and call on the HIT research community to engage in more dialogue about implementing a standard approach to engaging with such populations.

Additional Key Words and Phrases: Research methods, complex healthcare, disabilities, self-tracking

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1 INTRODUCTION

Health information technology (HIT) researchers and practitioners have investigated user-centered technology for healthcare applied to numerous contexts, including self-tracking for chronic condition management, assistive technology, electronic health record management, and delivering health interventions. However, there are challenges to conducting HCI research in a complex healthcare setting that require researchers to adapt their methods, which may impact the quality of their data [6, 7]. For instance, researchers who conduct HCI research with participants in acute or post-traumatic healthcare settings may encounter sensitive scenarios that are unexpected and not well-documented in the HCI literature. These include multiple and multidimensional disabilities (e.g., Spinal cord injury (SCI)), mental trauma caused by chronic or post-acute conditions [2], low self-esteem regarding self-image, and emergency medical conditions. Often, HCI researchers are not prepared or trained to deal with those unexpected scenarios without jeopardizing the integrity of the research process and the quality of the data collected. Additionally, while reporting research findings, researchers likely under-report these unexpected experiences, challenges, and the method adaptations they need to perform — which results in a lack of guidance in conducting future HCI research in such complex environments.

The HCI community has started initiatives on formally documenting these challenges, and adaptations to support current and future researchers in the domain [6]. Following this initiative, we started documenting the challenges we face while conducting HCI studies in different healthcare contexts and our adaptations for overcoming these challenges. While this effort is a work in progress, we discuss some early observations that we documented through three of our own research projects in this workshop paper.

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2 RELATED WORKS

HCI research in complex healthcare contexts can be more difficult than in other domains due to participants' potential vulnerabilities and associated ethical issues. Past literature discusses many such challenges, including researchers' emotions, ethical issues when asking about prior traumatic experiences, access to participants and patient data, patient mental health complications [6], and patients' differing abilities [7]. While conducting HCI research in this context is challenging and requires additional workarounds, the details of these challenges and the adaptations are often unreported in the literature. Reasons for omission may include lack of space in papers, lack of a common platform to discuss these issues [5], and fear of questions that might arise on the validity of the methods [7]. There have been prior efforts to consolidate these observations through several workshops with researchers in this domain (e.g., [5, 10]), however reporting these issues and adjustments in papers remains uncommon. One objective of this work is to explore how we might make it standard practice to report them.

Recent research has reported the challenges encountered during studies where participants have one or multiple disabilities; due to multiple disabilities and comorbidities, participants with disabilities cannot participate in traditional HCI methods [7, 8], hence are often excluded. In addition, people with severe disabilities (e.g., upper body impairments) cannot collect data manually (e.g., diary studies). In such cases, researchers need to adopt multiple strategies and adjust methods so that the data collection is not biased. Currently, there is no structured way to learn about those adjustments and method adaptation; researchers learn them through their experience– mainly "on the fly"— while conducting those studies. This work-in-progress is an attempt to contribute to that knowledge based on three studies we have conducted more recently, and to explore how we might make this kind of reporting standard practice in the field.

3 CASE STUDIES

3.1 Study 1: An Alternative Input Method for People with Tetraplegia

Description: We created a novel directional sip-n-puff (D-SNP) system to address the limited functionality of a traditional single-tube SNP system. D-SNP builds on the advantages of a traditional SNP by introducing an additional tube to the input system. Users can cover one of the SNP tubes with their tongue while they sip/puff from the other tube, expanding the input space from two commands (sip/puff) to six (sip/puff on the left, right, or both) as well as allowing for a continuous input option by applying pressure to only one tube continuously.

Challenges: The best use case for the D-SNP system is as an input method for dynamic adaptive sports like Tetra-Sail or Tetra-Ski [1]. As shown in previous studies, finding participants for this type of research can be difficult; furthermore, finding high-level c-spine participants during a pandemic that are also interested in sailing and skiing is even more difficult.

Adaptations: Though we were already using filters and different tubing for each participant, because of COVID-19 we needed to redesign our prototype to include input tube filters capable of capturing virus particles — this is beyond the standard SNP saliva filters. It required hardware and software modifications to compensate, since a side effect of adding the filters was a dampened pressure signal.

3.2 Study 2: Improving Pressure Relief Adherence among People who Use Powered Wheelchairs

Description: The project identified the factors that impede performing pressure reliefs, one of the most frequent self-care activities for individuals who use a powered wheelchair. We used semi-structured interviews and a needs-validation study (adopted from the Speed Dating method [3]) with seven participants who had spinal cord injuries and used a powered wheelchair.

Challenge 1 (Designing Storyboards): For the need-validation study, we designed nine storyboards with speculative future technology interventions to explore users' need to improve pressure relief adherence [9].

While designing the storyboards, we developed fictional stories around different types of reminders, notifications, and behavioral goals to increase the empathetic connection between participants and our imaginary technology-enabled scenarios. We created stories to accommodate those technical features and converted them into storyboards using license-permissive pictures of individuals in power wheelchairs. We used different filters in Adobe Photoshop to make the images appear more abstract to encourage participants to imagine themselves in those situations. Later, while presenting those storyboards to our expert collaborators — physicians and occupational therapists (OT) of the rehabilitation hospital — for their feedback, they identified multiple concerns. First, one OT pointed out that specific details of the wheelchairs in some pictures we used were not relatable to our target population at all (power wheelchair users). These discrepancies might be offputting to participants. The expert collaborators also indicated that the abstraction we did for the characters by blurring the image or creating some cartoon-like characters might be negatively interpreted by participants. One reason they mentioned is that being in a wheelchair can be associated with self-image crisis for some people; therefore, showing storyboards of wheelchair users with these abstractions may be harmful or uncomfortable for those participants.

Challenge 2 (Tweaking Methods): During the semi-structured interviews, we found two participants had severe speech difficulties and they were answering our questions with one or two words.

Adaptations: We adapted the storyboards to be more representative of the wheelchairs our participants used, and also did not use image filters that abstracted away details of the image. To accommodate speech difficulties, we adjusted questions for those participants to make it easier for them to answer with fewer words. Notably, we had to consider the entire transcript from these participants to infer some answers. We also attempted to email these participants later, during our data analysis phase, to confirm our interpretation of their responses.

3.3 Study 3: Designing Technology for Patients with Disabilities in a Rehabilitation Hospital

Description: This project studies the use of technology in a smart hospital room for patients with an SCI. The study aims to explore new ways to support SCI patients during their rehabilitation hospital stay [4]. During the study, we encountered various SCI-related challenges that are discussed below.

Challenges: In one part of the study, we tested a VR headset with a patient, Abi (pseudonym), who had sustained a high-level cervical injury from a sledding accident and was still on a mechanical ventilator. Before the trial, we consulted with Abi's family members and healthcare providers to determine his suitability and interest in participating in the project. Abi had previously used VR systems and expressed his enjoyment of them. To ensure Abi's comfort during the trial, a healthcare provider in the research team agreed on certain signals that Abi could use to communicate if he felt uncomfortable while wearing the headset. During the trial, Abi quickly expressed discomfort and later responded affirmatively to the healthcare provider's question about feeling claustrophobic with the headset. In this case, due to the past experience and comfort of the user with VR technology, we did not anticipate that they would feel claustrophobic with VR post-injury.

Another challenge imposed by the COVID-19 pandemic, was conducting interviews. Conducting interviews "in the wild" of the hospital room can be challenging to begin with. The increased ambient noise levels from medical equipment can make recording difficult. Beyond the equipment, patients may have common SCI speech complications. On top of the high ambient noise levels and speech complications, everyone was wearing a mask due to COVID-19 precautions. These factors combine to create a research environment that is very difficult for effective communication.

Adaptations: For the VR claustrophobia instance in this project, we realized that irrespective of patients' prior comfort with technology, researchers should plan alternate communication methods when participants have speech limitations to avoid the risk of causing distress like claustrophobia. To improve communication during interviews, we invested in a high-quality microphone setup where the interviewer and the patient use individual microphones. This helped in transcribing since the audio quality had significantly improved.

4 DISCUSSION (TOWARD MAKING A STANDARD PROCESS) AND CONCLUSION

Researchers can face a myriad of unexpected incidents while interacting with participants due to their complex health situations. In the HCI community, there is no standard for what challenges and adaptations to report or how they should be reported, which can raise questions about method validity and the completeness of the methodological descriptions. To mitigate this tension, we describe our experiences in three of our own projects and suggest some steps that future researchers can take while doing HCI research in sensitive areas like complex healthcare. Underpinning the requirement of a more standard process of conducting research with populations with complex healthcare needs, we suggest steps researchers can take that can help them to be well-prepared to conduct research and positively contribute to the reporting of such adaptations:

(1) Work to anticipate challenges that might arise, perhaps by reading other papers where people have reported such challenges. It would be great, but may not be feasible, for these to be consolidated in one place.
(2) If possible, pilot your planned research protocol with someone who has domain expertise (as we did with the OT and physician) so that they might be able to help you identify shortcomings in your plan.
(3) Try to prepare for possible mental distress or trauma that the researcher might experience and have a plan in place to identify if this is occurring and provide support to that individual. If the likelihood of such a situation is high, consider adding another researcher so that there is redundancy and a researcher can tend to their own needs if necessary during the protocol.
(4) During the study, be mindful of issues that arise, adjust the research protocol on-the-fly if necessary.
(5) After the study, try to analyze data soon so you can follow up with participants to seek clarification, ask followup questions, or recognize other issues that may have occurred but you did not realize in the moment.
(6) When reporting your work, take extra care to describe these adjustments in detail so that others can do step 1 better in the future.

In conclusion, while HIT researchers have made significant progress in designing user-centered technology for healthcare, conducting research in complex healthcare settings poses unique challenges requiring researchers to adapt their methods. The lack of guidance on conducting research in such complex environments further exacerbates these challenges. Thus, as an HCI community, it is worthwhile to formally document these challenges and adaptations to support existing and future researchers in the domain. This paper contributes to this initiative by presenting some early observations from three projects in the healthcare context. Overall, this discussion of challenges and adaptations will help researchers to navigate these complex settings better and produce high-quality research that can effectively address the needs of healthcare technology users everywhere.

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