The Impact of Spinal Cord Injury on Participation in Human-Centered Research

Kazi Sinthia Kabir
kskabir@cs.utah.edu
PeDEL Group, University of Utah
Salt Lake City, Utah, USA

Ahmad Alsaleem
ahmad.alsaleem@utah.edu
PeDEL Group, University of Utah
Salt Lake City, Utah, USA

Jason Wiese
jason.wiese@utah.edu
PeDEL Group, University of Utah
Salt Lake City, Utah, USA

ABSTRACT

Individuals with spinal cord injuries (SCI) can have multiple cognitive and physical disabilities because of their injury. Appropriately-designed technology can be empowering and transformative for this population. Unfortunately, just like most technologies, user-centered research methods do not directly account for differing motor and communication abilities. This paper synthesizes SCI literature and leverages our own experiences in three research projects spanning five years with SCI users to highlight significant challenges that HCI researchers might face while employing user-centered methods with this population; communication disabilities, motor disabilities, and difficult contextual or environmental factors can make it difficult or impossible to use standard HCI methods when working with SCI users. We conclude with a set of guidelines and challenges for the HCI community to consider, which can be used both when evaluating papers that work with this population, and to fuel development of new methods or approaches that better-serve them.

CCS CONCEPTS

• **Human-centered computing → Accessibility design and evaluation methods**.

KEYWORDS

Spinal cord injury, Research methods, ICF, Multiple disabilities

1 INTRODUCTION

Spinal cord injury (SCI) is partial or complete damage to the spinal cord that results in persistent changes in bodily functions. Individuals with an SCI can have multiple disabilities, such as motor disabilities, speech disabilities, respiratory disabilities, and cognitive disabilities. Every year between 250,000 to 500,000 new SCI

occur around the world [35]. Living with these disabilities can have a severe negative impact on quality of life. However, assistive technology and other forms of technological support can have an outsized positive impact on quality of life for people with an SCI. A wealth of human-centered research aims to support people with disabilities, including some work with an SCI population.

The experiences of individuals with an SCI are different from most other people, including people with a single type of disability. These individuals commonly struggle with multiple disabilities simultaneously, including speech disabilities and motor disabilities. The extent of these disabilities changes with time during their rehabilitation process, which can take a year or even longer post-injury. Working with this population is even more challenging because the changes in their ability are different for each individual and depend on many other factors (e.g., rehabilitation, comorbidities, lifestyle). While one patient might be able to speak after two months of rehabilitation, another patient might need more time to be able to speak, even with the same level and type of injury. These changes are difficult to predict, even for healthcare experts.

While there is some guidance in the literature for conducting HCI research with disabled people [26, 37], they focus on participants with one specific type of disability (e.g., motor disability). There is very little guidance in HCI literature on conducting research with an SCI population. We reviewed 28 papers published in HCI venues to understand how prior studies reported their research methods while working with people with an SCI. In our review, we observed that papers tend to report participants' motor disabilities but rarely report their communication abilities even when they use standard HCI methods (e.g., interviews) that rely heavily on the participants' communication abilities. Moreover, they seldom reported any adaptation to these methods that they might have required. In the worst case, patients with multiple disabilities are screened out of these studies because they cannot participate — a form of ableism — and their perspectives are not represented in research. In the best case, researchers include a diverse participant population, and each reinvents their own approach for adapting their methods to work with this population. These observations suggest that a lack of guidance for working with an SCI population leaves a problematic gap in the literature, making it more challenging to conduct, report, and evaluate HCI work with an SCI population.

This paper takes steps towards addressing that gap through a combined synthesis of the literature review mentioned above, the medical literature on SCI, and reflection on first-hand research experiences by the authors in three studies spanning five years. Based on the information captured from these activities, we developed a list of health conditions and environmental factors that contribute to the disabilities of individuals with an SCI. This list provides a starting point for future researchers to estimate what

they can expect while working with this population and design their research accordingly. Acknowledging that these factors can vary widely for each individual, we then show how HCI researchers might use the International Classification of Functioning, Disability, and Health (ICF) framework to understand the impact of these different factors on research participation of people with an SCI. The paper concludes with a set of guidelines and challenges for the HCI community to consider, which can be used both when evaluating studies that work with this population and fuel development of new methods or approaches that better serve them.

The key contribution of this paper is guidelines on what researchers should expect and what to report while working with a participant who has an SCI, and what reviewers and readers should consider when reading research focusing on this population. We firmly believe this discussion will help the HCI research community carry out more inclusive research and guide the community in reporting studies in a more informative manner.

2 BACKGROUND AND RELATED WORK

SCI is damage to the spinal cord that results in persistent changes in bodily functions. It causes multiple types of disabilities, such as motor, respiratory, and speech disabilities. Human-centered research for people with an SCI, therefore, should consider the combined impact of these disabilities. This paper is particularly interested in how these different disabilities influence HCI research design with this population. First, we discuss the relevant health conditions of this population. Then, we discuss existing literature that guides conducting research with people with disabilities.

2.1 Impact of an SCI on Motor Functions

There are different kinds of SCI based on the location of the injury on the spinal cord and the type of damage. For example, it can be a complete or an incomplete injury at that site. The location typically refers to the number of vertebrae in a vertebral segment, including cervical (top/highest section), thoracic, lumbar, and sacral (bottom/lowest section). While a complete SCI causes permanent damage to the affected areas, an incomplete SCI refers to partial damage to the spinal cord. The motor abilities and amount of sensation a person has after an SCI depend on the severity of injury [14]. The location of the injury can also determine whether it results in paraplegia or tetraplegia. Paraplegia causes paralysis of legs and parts of the trunk. However, people with paraplegia have normal hand function [6]. Tetraplegia (also called quadriplegia) is more severe and affects arms, hands, trunk, legs, and pelvic organs. However, depending on the location of the injury, an individual with tetraplegia might have some control over their upper body [14]. SCI may also impact other organ functions: loss of sensation, disability of movement, loss of bowel or bladder control, and difficulty breathing. Patients might also suffer from spasticity or unusual muscle stiffness that can cause painful muscle spasms and limit motion (i.e., movement around a specific joint or body part).

The recovery process for people with an SCI is highly unpredictable. Though most people with an SCI regain some degree of functioning over time, some never do. Moreover, the duration and level of recovery are different for each patient [43]. Different patients might have different physical complications for the same

level and type of injury even after the same duration post-injury. These factors make it difficult for healthcare experts as well as HCI researchers to make a generalized estimation of participants' capabilities, as there are differences even between two people with the same injury type and the amount of time since the injury occurred. Participants' motor disabilities impact what research methods can be used with this population. For example, motor-impaired participants can struggle with participation in methods like activity diaries, surveys, questionnaires, and trials [3].

2.2 Impact of an SCI on Speech Functions

A wealth of HCI research on people with an SCI focuses on their motor disabilities [12, 16, 38]. While motor capabilities are crucial, many people with an SCI also struggle with respiratory and speech complications that can impact the selection of research methods for HCI researchers. Unfortunately, there are not standard practices in HCI for reporting these factors in the participant population. As we discuss in Section 3.1, these conditions are seldom mentioned in HCI literature when describing participant's health conditions.

People with an SCI can struggle with respiratory complications. The severity of the complications depends on the level of SCI and the degree of motor disability [40]. People with more severe injuries can have trouble breathing, in some cases requiring ventilator support either temporarily or permanently [6]. Mechanical ventilators provide external support with machines to help patients breathe when they cannot breathe independently due to the injury.

We asked a collaborator who is an occupational therapist (OT) at our University Rehabilitation Hospital to further our understanding. He explained that speech capabilities are influenced by whether the person with an SCI is on a mechanical ventilator (common for higher-level cervical injuries) or not. If a patient is on a ventilator, they can only speak when they exhale. These patients have to wait until the ventilator provides them enough air during the inhale period since they cannot maintain the air in their lungs by themselves. As a result, patients require frequent and long pauses (during the inhale period) when they speak, which can be frustrating for them and difficult for the listener to follow. By contrast, a non-injured person does not have to pause at the end of an exhale period and wait for the next one. Patients who are not on a ventilator either use an additional pacemaker that helps time their breathing or they breathe on their own. Speech quality can improve significantly at that stage, but it is still different from typical speech. Moreover, people with SCI fatigue quickly while speaking if they have not spoken for a while due to their injury.

The extent of respiratory muscle impairment depends upon the duration of the injury as well. Though recovery rate varies for each patient, improvement in respiratory muscle performance largely occurs in the first year following an SCI [17]. We also confirmed with the OT that SCI patients often do not speak in the acute phase (the first few months after injury), which significantly inhibits conducting spoken interviews. Their ability to speak depends on whether they can tolerate a speaking cuff, a one-way valve to maintain the air delivered from the mechanical ventilator to the lungs but allows the air to be exhaled outside of the closed-loop of the ventilator. While the recovery rate differs greatly between individuals and

is thus difficult to generalize, most patients recover some speech capabilities during the first year post-injury.

A person's respiratory function impacts speech parameters such as the duration of speech phrases, voice intensity, and quality. People who have higher and more complete SCI tend to have a more limited respiratory function and speech performance and have more frequent voice problems [24]. Individuals with an SCI experience some degree of difficulty sustaining voice and maintaining vocal intensity across long speech tasks [44]. They also tend to get fatigued faster than non-disabled people while having a conversation [24]. Some individuals with an SCI experience difficulties with their voice function in social situations, such as speaking in noisy surroundings, asking for help, and conversing during telephone calls, presentations, and dinner parties [44].

The OT added that therapists often communicate with patients through lip-reading during the early months when patients cannot speak yet, but noted that this process is time-intensive and requires them to develop lip-reading skills and lots of guessing. Based on these realities, he suggested that conducting interviews with these patients would need help from experts. He also mentioned that sometimes patients who can speak have low voice tone or long pauses. As a result, an audio recorder's microphone might fail to pick up their voices unless the recorder is placed right next to their mouth. Finally, he mentioned that while most patients recover some capabilities with time, they might also lose some abilities due to further injuries, health complications, or other factors. Thus, participants in HCI studies who have had an SCI may often have reduced voice and speech function and, as a consequence, limitations in communicative participation. A primary objective of this work is to consider the impact of these disabilities on the participation of people with an SCI in HCI research.

2.3 Conducting Research with Participants with Disabilities

HCI fundamentals tell us that the first and most important step towards designing technology for any population is understanding their needs, and this is certainly true when designing for users with disabilities. The disabled population should be included as active participants in this process to increase the likelihood of project success [25]. Accessibility research in HCI frequently conducts studies with participants with disabilities. Past literature provides some guidance on conducting human-centered research with these participants. Lazar et al. offer guidance for working with participants with disabilities as a monolithic group, including recruiting participants (e.g., typical inclusion criteria, considering different levels of abilities), methodological considerations (e.g., sample sizes, in-depth case studies), and communication with potential participants [26]. This guidance focuses on participants with disabilities in general and does not focus on issues regarding specific disabilities. Understanding the impact of disabilities on the requirement elicitation method requires more in-depth insights into the disabilities. Sears et al. noted that representative participants in accessibility research tend to vary more than the participants in traditional HCI studies in terms of abilities and experiences [37]. They also note that even if numerous participants can be recruited, conventional

statistical techniques might be difficult to apply due to these differences in abilities. Thus, they indicated a need for alternative research designs that focus on maximizing the impact of the results obtained from a limited number of participants.

Antona et al. also discuss requirement elicitation methods for different target research participants with disabilities (e.g., motor-impaired, blind and visually impaired, deaf, cognitive, and communication impaired) and discuss which requirements elicitation methods might apply for each of these disabilities [3]. Guffroy et al. also mentioned that it is challenging to conduct discussion groups, interviews, or surveys and questionnaires with participants with communication disabilities [19]. However, as in the case of SCI, a participant can have multiple disabilities together. For example, people with an SCI commonly experience motor disability and speech disability together, *especially* in the first few months post-injury. It might seem reasonable to exclude these participants due to communication complexities or to include them later after they have at least partially recovered and ask them to share retrospective data. However, there are many flaws and issues with memory-based retrospective data collection, and it is problematic to exclude this population from data collection. This poses a significant challenge for doing user-centered work in this context.

Other health conditions like cerebral palsy, amyotrophic lateral sclerosis (ALS) [10], muscular dystrophy [31], Parkinson's disease [34], multiple sclerosis [11], and Friedreich's ataxia [30] may also cause multiple disabilities like motor disabilities, slurred speech, blurry vision etc. However, the disabilities resulting from these health conditions usually get worse over time or are permanent. In contrast, if the communication abilities of SCI patients change, they often get better over time. For these patients, the presence or severity of the communication disability may be a temporary condition. This is an important difference from participants with the disabilities mentioned above. The combination of disabilities discussed earlier, and these differences from other health conditions make people with an SCI a special target group.

3 HCI RESEARCH WITH PEOPLE WITH SCI

There is very limited guidance on HCI research methods for doing user-centered research with people with an SCI, so we set out to better understand currently used methods. First, we review HCI literature that included people with an SCI as active participants. Then we reflect on our own experience of working with this population across three different research studies spanning five years. Our goal is to understand the health conditions of people with an SCI and the implication of these health conditions for requirement elicitation methods in HCI studies.

3.1 Research with People with an SCI: Reviewing Past Studies

We conducted a literature review of HCI studies focusing on people with an SCI with a goal of understanding how prior HCI research described their methods when working with this population. We searched for papers written in English in ACM Digital Library with the keywords "spinal cord injury," "tetraplegia," "paraplegia," and "quadriplegia," which resulted in 411 papers. We only searched in the ACM Digital Library because HCI research and practice is the

Table 1: HCI studies with people with an SCI as active participants. '-' in columns 3 and 4 means 'not reported' in the paper.

Studies	Data collection methods	Duration of sessions	Time post-SCI	Disabilities reported
Shamekhi et al. (2016) [38]	Interviews, think-aloud sessions	90-120 min	2.5-9 years	Motor disabilities (tetraplegia, paraplegia)
Lin et al. (2014) [27]	Observations, rapid prototyping, brainstorming, sketches, interview	-	≈0 days	Incomplete quadriplegia (lacks certain motor skills)
Malu et al. (2018) [29]	Questionnaires, box-and-block test, think aloud, and interviews	2 hr	-	Upper body motor disabilities
Carrington et al. (2014) [7]	Interviews, design activities, prototyping activity	-	-	Upper body disabilities
Harada et al. (2007) [22]	Interviews, field observations	-	30 years	Limited shoulder movement, no sensation in hand, unimpaired speech, restricted long uninterrupted vocalization
Alsaleem et al. (2019) [1]	Interview, user trial, questionnaires	-	-	Tetraplegia, limited hand motion
Alsaleem et al. (2020) [2]	Interviews, user trials, questionnaires	5-14 min interview, 30 min user trial	-	Tetraplegia, paraplegia, limited hand motion
Robinson et al. (2020) [36]	Interviews, design sessions, contextual inquiry and rapid prototyping	-	-	Tetraplegia, have limited use of upper extremities
Buyuktur et al. (2017) [5]	Interviews, focus group	1-2 hr interviews, 50 min focus group	-	Paraplegia, tetraplegia, or low-level injury (no paralysis)
Hara et al. (2016) [21]	Interview, survey, think aloud, design probe activity	53-119 min	-	Mobility disabilities
Sporka et al. (2011) [39]	Interview, user trial	User trial 30 min	2-30 years	Quadriplegia, Paraplegia, No speech disability to severe motor speech disability
Vandermaesen et al. (2013) [42]	User trial, interview	-	-	Paraplegia (severe dysfunction in both hand and arm), no cognitive dysfunctions)
Naftali et al. (2014) [33]	Online survey, interview, diary entry, contextual inquiry	Interview 30 min, contextual inquiry 3 hours	-	Motor disabilities, May have speech, hearing and visual disabilities
Liu et al. (2016) [28]	Observations, interviews	-	6-38 years	Motor disability
Ramirez et al. (2017) [32]	Interview	1.5 hour	1-23 years	Tetraplegia, Complete and incomplete SCI
Friedman et al. (2019) [15]	Contextual inquiry, interviews, design activities	-	-	Tetraplegia, limited motor ability in legs and arms
Bhattacharjee et al. (2020) [4]	Questionnaire, user trial, interview	-	-	Quadriplegia, Tetraplegia, Complete/incomplete SCI
Buyuktur et al. (2018) [6]	Interviews, focus group	1 hour (at least), focus group 50 min	-	Quadriplegia, paraplegia

focus of this work, and the primary HCI publication venues are published by ACM. We wanted to observe the common practices within the HCI community regarding reporting their participants' disabilities and any adaptations to their research methods to accommodate those disabilities. We did not perform snowballing or source-chaining from the references of those papers since that would take us outside the scope of HCI venues. We did not place any constraint on the year of publication of the potentially relevant studies. The search date was February 01, 2021.

We first ran a preliminary review on the paper abstracts and looked for papers that mention people with an SCI as active participants. This process resulted in 28 papers that included *at least*

one person with an SCI as an active participant. Therefore, the eligibility criteria of this review were articles published in English within the ACM Digital Library that have at least one active participant with an SCI. Our review focused on the research methods and any adaptation to those methods reported in the papers. We summarized these details for each of the 28 papers. A subset of these studies that relied on speech-based communication methods (e.g., interviews) is presented in Table 1 since we wanted to explore how they reported participants' speaking abilities while using speech-based methods. The full table with 28 papers is included in the supplemental materials. Below we report our observation based on our review.

3.1.1 Limited Detail about Adaptations of the Research Methods. We observed that 18 of these papers reported conducting interviews with the participants. While some of these interviews were about an hour-long, others did not report the duration. The only exception is [2], where it was explicitly mentioned that they had to make the interviews relatively short (5-14 minutes) to accommodate the participants' healthcare needs. While [4] described calibrations during user trials to accommodate different levels of mobility disabilities, they did not report any adjustments for administering questionnaires or interviews. [39] and [33] reported one or more participants with speech disabilities; however, they did not note how they conducted the interviews with these participants.

The studies that did not use interviews as requirement elicitation methods used other methods (e.g., questionnaire, think-aloud, user trial, design critiquing). These papers reported little detail about adaptations applied to these methods to accommodate participants' health conditions. Robinson et al. explained that traditional participatory design activities were not appropriate for this population and that they had to combine multiple methods (contextual inquiry and rapid prototyping) to conduct co-designing [36]. They asked participants about their technology preferences, created low-fidelity rapid-prototypes, and collected verbal feedback. These participants were able to engage in verbal conversations; for participants with limited or no speech ability, different methods or adaptations might be needed. Hara et al. also mentioned that some of their participants were uncomfortable with sketching due to limited upper body strength and the interviewer sketched on their behalf [21].

3.1.2 Reporting the Capabilities of Participants. Most of the reviewed literature used methods that rely on participants having speech capabilities. Those that did not use speech-based methods (e.g., [9, 16, 41]) performed a quantitative analysis of participants' performance in user trials. Commonly used speech-based methods are interviews, think-aloud, design critiquing (see Table 1). While some of the papers did not report the session duration, others report an hour or more for each participant. Without adaptations, these methods typically rely on the participants' speech capabilities (e.g., loud utterances, long conversations, speaking in noisy environments). However, as stated in Section 2.2, participants with an SCI can struggle with their speech capabilities in many cases.

Three of these studies reported the speech capabilities of their participants [22, 33, 39]. Harada et al. reported that their participant's speech was unimpaired; however, his long uninterrupted speech was restricted due to limited lung capacity [22]. Sporka et al. and Naftali et al. reported that at least some of their participants had speech disabilities [33, 39]. The other papers only reported the motor disabilities of the participants.

While other papers reported requirement elicitation methods like questionnaires, surveys, and Likert scales, they did not report any adaptations to these methods to accommodate the participants' upper body disabilities. Though people with an SCI struggle with generating text [3], the papers we reviewed did not report the relevant capabilities or any adaptations regarding these methods.

3.1.3 Reporting the Time Since Injury. One key aspect related to participants' capabilities is the amount of time since the SCI occurred. Only eight of the twenty-eight papers we reviewed reported the time since their participants' injury. We also noted that only one study ([27]) had a participant who started participation right after the injury. The other seven studies recruited participants who were at least 1-year post-injury. As the medical literature suggests, peoples' capabilities change differently based on the severity and level of injury, recovery rate. It is useful to consider the three phases of SCI to describe these changes: Phase 1 — immediately following the injury; Phase 2 — during the next one year (acute phase); and Phase 3 — more than one year after injury (chronic phase) [17]. The time since SCI is an important factor while considering the capabilities of the participants; however, most of the papers we reviewed did not report this factor while describing their participants.

3.2 Research with People with an SCI: Our Experiences

Next, we wanted to reflect on our own experience of working with this unique population. Our research team has been working on designing technology for people with an SCI in collaboration with a rehabilitation hospital. We have been conducting multiple studies with people with an SCI as active participants. In this section, we reflect on our own experience while working with this population in three studies that spanned a total of five years.

3.2.1 Study 1 and 2: Outdoor Sports Activities for People with an SCI. Our research team has iteratively designed and developed two different pieces of technology-enabled outdoor sports equipment for people with SCI: skiing equipment [1], and sailing equipment [2]. We have conducted user studies with participants with an SCI throughout this process, from the early days of hardware and software development until the point that we are sending the sports equipment to adaptive recreation programs for regular non-research use. Based on physicians' guidance, we recruited participants who were at least six months or more post-injury for our user trials. However, depending on the injury, some patients require more time to reach a stable health condition and participate in our study.

In addition to the quantitative analysis of participants' performances with our novel sports equipment, we had to rely on interviews and qualitative analysis for useful feedback on our design. However, we found that participants had difficulty speaking and, therefore, we could not collect enough qualitative data before they became fatigued and had to conclude the session. In fact, we had one participant with an SCI in study 1, who was also experiencing 'Locked-in syndrome' (a neurological disorder that can be caused by brain injury). People with this syndrome are conscious and can think, but they have difficulty communicating verbally and performing any physical action [18].

For this patient, we had to adjust the question so that the participant could answer with yes or no (with eye signals and face gestures). In addition, we also used a table with pre-labeled tags (e.g., numbers from 1-9, 'Yes', 'No'), and the participant used one finger to select an option from the table. While this enabled us to collect data from that participant, it also made it difficult to be confident that we were not leading the participant through the questions' selection and framing. For the other participants, we also noticed

that the noisy outdoor environments exacerbated the impacts of their speech disabilities, particularly an inability to produce loud and long utterances.

Our research focuses on the users' physical abilities to participate in outdoor activities. It is crucial to understand and precisely define users' abilities for designing more usable experiences. However, we realized that quantifying the impact of SCI is challenging. As healthcare experts on our team noted, the patients' capabilities can improve or get worse with time, especially in the acute phase. The extent of change in abilities cannot be accurately predicted, even by medical experts who specialize in SCI, since it can vary dramatically from person to person. We realized that our participants could lose or gain new physical abilities each time we engaged them to participate in one of our trials. As a result, we recognized the importance of evaluating each participant's physical abilities at the time of recruitment. This is especially important when recruiting the same participant multiple times or conducting an iterative design process that runs for several months or even years.

3.2.2 Study 3: Smart Hospital Room for SCI Patients.
Our other study involves a different context than outdoor environments: a smart hospital room for SCI patients. The smart hospital room project explores opportunities to introduce new technology for supporting patients during their stay in the rehabilitation hospital. This is an ongoing study, and in the process of collecting data in this project, we have encountered a variety of SCI-specific challenges. In one part of the study, we were working with an SCI patient (P1, age 21) to try a virtual reality (VR) headset, which was an opportunity to guide some of our design decisions around a system to support ventilation weaning (i.e., withdrawing from the mechanical ventilator). P1 sustained a high-level cervical injury from a sledding accident. We met him in the rehabilitation hospital, and he was still on a mechanical ventilator.

Ahead of this trial, we worked with healthcare providers and P1's family members, in addition to P1 himself, to evaluate his suitability and interest in participating in the project. In particular, P1's mother informed us that he had used VR systems before his accident and that he liked those experiences. P1 also confirmed this. It is a common approach in user-centered research with people with an SCI to collect background information from the patients' family members. Healthcare providers also rely on information from the family members to estimate what might be helpful for the patients since the patients cannot easily speak for themselves.

P1 could not speak clearly, in part, because he was still on a ventilator. Before starting the trial, the healthcare provider (who helped to conduct the trial) discussed and agreed with P1 on some signals (e.g., slightly moving the head) that P1 could use to communicate if he felt uncomfortable while wearing the headset. This turned out to be important, as P1 quickly expressed his discomfort. Later, when he was asked if he felt claustrophobic with the headset (an educated guess by the healthcare provider based on his expertise), he responded with affirmative eye signals.

This experience demonstrates two important considerations for working with SCI participants. First, even though family members can provide rich information about the patient before and after the injury, there can be situations where they cannot predict what might happen. For our participant who volunteered to try the VR,

all indications were that this would not be a negative experience. However, during the trial, the patient felt claustrophobic with the VR headset. Later, he indicated that this was due to the experience of the accident that resulted in his SCI. Therefore, while patients' families can provide useful background information, we still need to consider these post-injury uncertainties that might impact the situation. The second important consideration in this instance that prevented the experiment from becoming a more serious problem was establishing an alternative communication mechanism since this patient's primary communication had been through eye signals, and the VR system obstructed his eyes.

In another instance, we wanted to test a novel accessible input device with patients for potential future use in the smart hospital room. In this experience, we relied heavily on our research team's occupational therapist (OT) to determine the best time to conduct the trial. However, on the day of a planned trial, we were frequently told that the patients were feeling fatigued either due to rehabilitation sessions earlier in the day or their general health conditions. Moreover, on three consecutive occasions, one patient had respiratory complications that led to placing him under close observation by the healthcare team. Hospital policy forbids any person outside of the healthcare team from interacting with the patient during this observation phase. The key challenge here is, as the OT indicated: *"no one can predict when this can happen...it happens for acute patients with spinal cord injury"*.

In another case, a scheduled participant experienced a significant improvement in her body functions: she could eat by herself for the first time post-injury. This participant canceled her planned trial because she wanted to celebrate her progress and requested not to be bothered for the day. This patient was also in the rehabilitation hospital and was in the acute phase. Note that, acute phase means the first one year post-injury when changes to health conditions are more frequent and unpredictable.

These experiences with the smart hospital room study lead to two key observations: 1) the patients' health conditions are highly unpredictable, especially in the acute phase, and 2) the changing health conditions make it challenging to recruit these patients in the acute phase for research studies. The literature predicts this, noting that recruiting disabled participants can be difficult due to the unavailability of participants with a specific disability in a certain geographic location [26]. Our experience with the patients in the hospital gives a concrete example of how their unpredictable and frequently changing health conditions further contribute to the challenge.

4 DISCUSSION

Our synthesis of HCI literature and reflections on our own experiences of working with this population for five years across multiple studies and contexts exposes significant challenges that HCI researchers might face while employing user-centered methods with this population. Multiple physical disabilities and environmental factors can make it difficult, or in some cases impossible, to use standard HCI methods while working with this population. This section discusses the challenges that the HCI community needs to consider when conducting research with this population.

4.1 Issues for HCI Researchers: Patient Conditions and Environmental Factors

In the process of understanding the complexities associated with the participation of people with an SCI in HCI research, we reviewed medical literature, analyzed our own experience across multiple studies, and then consulted with an OT for further explanation. Based on information collected through these activities, we compiled a list of physical and environmental factors that might influence user-centered research methods that can be used with this population and whether any modifications might be necessary:

- Patient Health Conditions:
  - Respiratory complications
  - Difficulties maintaining adequate respiratory support to produce a loud voice or long utterances
  - Fatigue faster while speaking for a long time
  - Frequent dry throat
  - Difficulty sustaining voice and maintaining vocal intensity
  - Physical abilities vary over time, sometimes unpredictably
  - Uncertain reactions due to the experience of the accident
  - Different motor disabilities due to the accident (e.g., limited or no hand movement, restricted neck movement)
  - Comorbidities (e.g., locked-in syndrome)
  - Cognitive abilities to follow questions and express thoughts
  - Tolerance to speaking cuff for ventilator support
- Environmental Factors:
  - Noisy surroundings (e.g., social events, outdoor location)
  - Conversation over a phone call
  - Patient on a mechanical ventilator

This list shows important factors that can impact the execution of user-centered research, which we encountered in our research activities. This list is not necessarily exhaustive; there is a long tail of potential conditions that can impact a person with an SCI. However, these provide a preliminary understanding of complications that a researcher might encounter in these contexts. These complications significantly impact the participation of people with an SCI in different standard HCI research methods. For instance, typical disabilities around speech function of people with an SCI limit their participation in interview-heavy research studies, especially during the acute phase. Unfortunately, even when participants have speech capabilities, background noise can make it impossible for a patient to have a conversation (e.g., due to voice intensity issues).

Again, as [36] noted, traditional participatory design methods are not appropriate for this population due to their disabilities. In addition, there can be unpredictable reactions due to the injury, as with one of our VR participants described in Section 3.2.2. While including family members sometimes helps collect background information about the participant [5, 20], unpredictable reactions post-injury make it challenging to anticipate adverse situations. In these cases, researchers should consider the complete ecosystem of complications rather than just a disability factor (i.e., motor disability) when designing the study.

These challenges around conducting user-centered research very likely lead to an under-representation of people with more complex conditions in this research. This comes in part from things that are outside of a researcher's control, such as the fluctuating energy levels and health condition of participants, as described in

Section 3.2.2. However, we suspect that some of these are within the control of the researcher but are disincentivized by the research community. For example, it is simply easier to conduct research with a population with more complete speech capabilities than to do that work with someone who cannot speak. This is very problematic, as this population is already extremely vulnerable. As we describe later in this section, we believe that the responsibility falls in large part on the broader research community to acknowledge the work that goes into conducting research with this population and to adjust reviewing expectations to account for the significant challenges undertaken when researchers expend the considerable effort required to work within these constraints.

4.2 The ICF Framework for Patients' Conditions and Participation Abilities

HCI researchers need to account for the complications described in the previous section when conducting research with people with an SCI. How do these different factors influence the research methods we employ? For a deeper understanding of these impacts, we tie our observations with the International Classification of Functioning, Disability, and Health (ICF) framework. This framework recognizes the role of health conditions and relevant environmental factors in creating disability to perform certain activities. This framework's key goal is to facilitate an understanding of health and health-related states, outcomes, determinants, and changes in health status and functioning [13]. Our aim is to understand the impact of health conditions and functioning on patients' participation in HCI research, and the ICF framework provides a helpful structure towards this goal. We tie the ICF framework to our observations with the help of two example personas.

Patient 1: *Bob (imaginary person) is a 20-year-old male. He sustained a high-level cervical SCI during a skiing accident. It has been three months since his injury. He was initially on a mechanical ventilator, and now he can tolerate the speaking cuff. He could only communicate through lip signals for the first two months while he was on a ventilator. Now he can speak; however, he struggles with long conversations due to ventilatory muscle fatigue and frequent dry throat. It is also challenging for him to speak in noisy environments since he struggles with maintaining voice intensity. In addition, due to the cervical SCI, he has minimal hand movement and sensation.*

An HCI researcher would struggle to collect data using primarily speech-based methods (e.g., interviews) with Bob. During the first two months, when he was on a ventilator, he could only communicate with lip signals. The researchers would have had to be accompanied by an expert (e.g., an occupational therapist) who could also understand lip signals. Moreover, the questions would have to be framed such that Bob could respond with lip signals (e.g., yes/no responses, multiple choices of answers). Now that he is not on a ventilator, he still has restricted speech capabilities. While he might be able to participate in speech-based methods, the interviews would have to be short, and the environment would have to be quiet enough that he would not have to compete with additional noise. While he can communicate better with his limited speaking capabilities than without them, the researcher would still need to prepare very targeted questions to extract relevant information in a short amount of time. Furthermore, the questions should be

prioritized in case the patient needs to end the session early. Since this patient has minimal hand movement, he cannot participate in text-based methods (e.g., surveys) (see Figure 1).

Patient 2: *Trudy (imaginary person) is a 45-year-old female with an SCI. It has been five years since her injury. She has minimal upper-body movements. As a result, she cannot move her fingers to write or type. However, she has no major problem with her speech. Though she tends to fatigue earlier than non-disabled participants during long conversations, she can continue the conversation with pauses.*

For Trudy, an HCI researcher can use speech-based methods with some adaptations (e.g., allowing pauses, having a quiet environment). However, Trudy would not be able to participate in methods that require hand movements or text generation (e.g., surveys). She could answer the survey question orally, and an interviewer could take note of the answers. However, this alternative only works because of her high level of speech abilities (see Figure 2).

These examples reflect how different disability components interact and influence a participant's ability to take part in different HCI research. While these examples do not show additional personal factors beyond the body functions and environmental factors, they can similarly influence participation. As the ICF framework suggests, individual measures must be based on this understanding that there are multiple dimensions of disability and potentially multiple perspectives to consider [13]. Therefore, we propose applying the ICF framework to understand the different dimensions and perspectives of disability when determining which user-centered research methods to use in a particular context.

4.3 Combining Multiple Methods to Extract Rich Data

The combined effect of motor disabilities, communication disabilities, and environmental factors makes it difficult to employ standard user-centered research methods while conducting research with participants with an SCI. The challenge grows bigger with the fact that these factors can significantly vary from person to person. Traditional research design is constituted by selecting one method or a set of methods and applying them for all the recruited participants (e.g., semi-structured interview for everyone, user trial, and survey for everyone). This approach helps with consistency, statistical analysis, detecting themes in thematic analysis, and other analytical methods.

However, as we have already discussed — for participants with an SCI — motor disability, communication disability, environmental factors, and personal factors all contribute to the appropriateness of certain user-centered research methods. Even for the same level and type of injury, the impact of an SCI can vary from person to person depending on other factors (e.g., comorbidities, recovery rate, age). Hofmann et al. also cautions against 'oversimplification of disability' and suggest that even a solution considered to be universally accessible can result in complete inaccessibility for an individual scenario [23]. Therefore, as the ICF framework indicates (discussed in Section 4.2), researchers need to evaluate disabilities for each participant while estimating their ability to participate in research that employs a particular method or set of methods.

HCI studies with participants with disabilities often have fewer participants than a typical HCI study with non-disabled participants

[26]. Participation in the design process can be limited or impossible when disabled people have communication disabilities (spoken and/or written) [19]. On the one hand, if a study defines an eligibility criterion for participants as *"all patients with cervical SCI who can communicate verbally"*, the study would exclude all the participants with speech complications. For instance, Sporka et al. excluded three potential participants from their study due to the severity of their speech disability [39]. It is especially concerning that, even though those participants could provide useful insights about their experience with SCI along with speech complications, their data would not be collected.

Researchers are in a difficult position: they may already be struggling with recruiting enough participants, and excluding participants with speech disabilities might result in losing more data. On the other hand, if a study includes participants with speech disabilities, but the methods are not adapted to their abilities, it might still struggle to collect important data. The HCI community needs to consider how these patients can participate such that they can contribute useful data about their unique experiences — it is an issue of fairness and equity and also a practical issue impacting the validity and importance of the result.

One option is for HCI researchers to consider combining different methods for different participants in a single study design, rather than the traditional one-size-fits-all approach. This is something not reported in any of the papers we reviewed. They can select the applicable research methods for each participant after evaluating their disabilities by combining the different contributing factors using the ICF framework. This might result in using different methods for different participants within the study (e.g., semi-structured interviews for three participants and surveys for two participants). The disadvantage of this approach is intuitive: it requires more work to prepare material using different methods. Furthermore, it would be difficult to analyze the resulting data with consistency and very tricky to analyze quantitative data in a way that ensures internal validity. For qualitative studies, it could be challenging to come up with themes across participants.

However, if we do not adapt our research design to include these participants, we will fail to incorporate their perspectives and to collect useful insights that these participants could provide. This leaves an open question for the community: should we compromise our methods, or should we compromise the potentially rich and important data? We believe this is a case where the right thing, maximizing the number and diversity of relevant perspectives, is not the easy thing. In our opinion, the research community should find a way to recognize the work of researchers who take this additional step, if not to encourage it.

The medical literature and the explanations by the OT suggest that speech capabilities evolve over time for many patients, though there is always a chance that there will be no improvement. From that perspective, HCI researchers might consider including these patients once they are in the chronic phase (starting around one year post-injury) and have improved speech capabilities. However, if the research goals focus on their experience during the initial time post-injury (as was the case for our hospital room study), sharing retrospective insights a year later is problematic for various reasons. In addition to the well-understood issues with retrospective accounts, these patients also deal with many issues post-injury
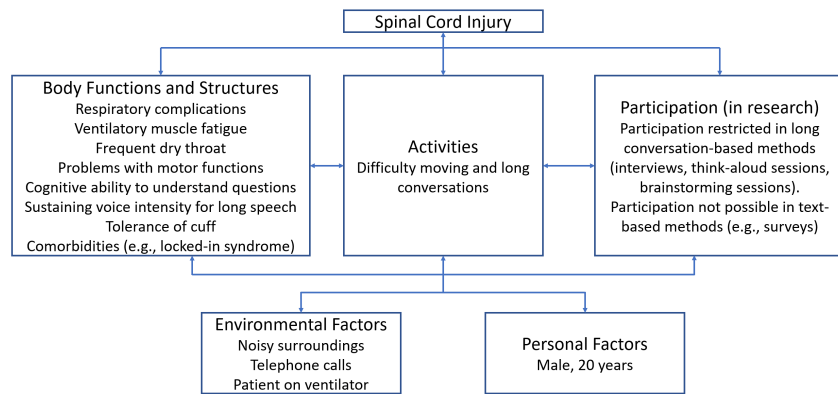
Figure 1: Participant with an SCI with both motor and communication disabilities
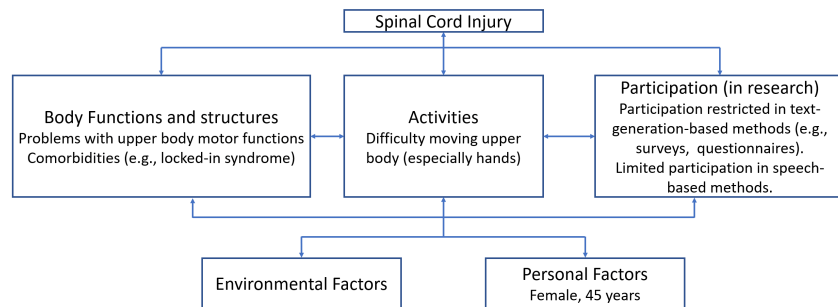

Figure 2: Participant with an SCI with only motor disabilities

(e.g., life changes with disabilities, rehabilitation process, treatment costs), which can further contribute to recall bias.

A researcher might also ask the participants to capture their experience in some form of activity diaries (e.g., written, photo-based, audio recorded) that would help them to recall the experiences later [3]. However, written and photo-based diaries may be difficult for SCI patients with upper-body disabilities, and audio recorded diaries would be difficult due to speech disabilities. Moreover, if a patient never regains his or her speaking capabilities, researchers will never be able to collect their insights without adapting the research design. Designing with the physicians can be a good place to start; however, it will still not completely represent the actual users, and the experiences of the actual users might not be well-captured.

4.4 New Methods for Disabled Participants

An alternative to compromising the consistency of research methods is to come up with new methods. Standard HCI methods implicitly assume participants' abilities (e.g., interviews, think-aloud sessions rely on speech capabilities; surveys rely on writing or typing capabilities). However, these standard methods might be unsuitable to account for the sensory, cognitive, and motor disabilities of people with disabilities [19]. We believe that not having accessible research methods is a form of 'ableism' [23].

The current approach for including participants with disabilities is to adjust the methods based on their capabilities. However, these adjustments might lead to additional complexities for the research design. For instance, if we adjust the interview questions to make them 'yes/no' questions for participants who can neither speak nor write/type, we might end up with leading questions. While one can cautiously design the questions to avoid being leading, they might still fail to collect information that could have been crucial to explain the participant's experiences. The researcher might even fail to capture information with 'yes/no' questions because they could not anticipate it and did not include it in the questions. This is why, for example, semi-structured interviews are so common in HCI literature compared to structured interviews. With the different experiences of each patient, it is challenging to anticipate all possible responses.

One can consider Augmentative and Alternative Communication (AAC) methods to communicate with these patients. A common approach is using sign language when participants have speech disabilities [26]. Of course, sign language requires hand movements, which can be a constraint for SCI patients. Again, patients who are expected to have improved speech capabilities with time might not be interested in learning this new skill for their temporary disability, especially because they already have to learn many things to perform daily activities with their new abilities. Moreover, learning sign language might be considered as a cognitive burden for the participants, requiring additional ethical consideration.

AAC tools may also include symbol boards, choice cards, keyboards, AAC apps, and text-to-speech devices. However, keyboards and text-to-speech devices might require participants to type their intended responses, making it difficult for participants with motor disabilities. Researchers may need to customize tools like symbol boards and choice cards based on the research question and possible responses to be useful and applicable. Another approach for accommodating speech disabilities is using additional assistive input devices (e.g., an eye tracker could be used in situations where a participant cannot speak or write). However, this would still require considering further disabilities (e.g., visual disabilities) or other external factors (e.g., additional time for calibration). Therefore, employing alternative communication methods still requires the researcher to consider the overall context of these participants.

Researchers might consider modifying interview questions to invite shorter responses and use lip-reading to get the answers as noted by the OT (discussed in Section 2.2). However, lip-reading requires an additional level of support from an expert. Moreover, this approach might still be susceptible to the issues regarding 'yes/no' questions of interviews that we mentioned above. However, even the ability to raise a particular topic in just one or two words helps to mitigate this concern — if the participant has something they want to communicate, they can start by raising the topic, and the researcher can work collaboratively with the participant to make sure they are getting to the right points.

Methods that require written input (e.g., questionnaires) from participants have also started exploring alternative input mechanisms. For instance, the NASA Task Load Index (NASA-TLX) questionnaire for measuring subjective workloads is typically administered electronically or by written response, which requires hand function. However, vocal responses can be an acceptable alternative to standard written formats for participants with motor disabilities [8]. While people with an SCI with upper-body disabilities might benefit from this modification, participants with speech disabilities will struggle to complete these questionnaires.

We encourage researchers to explore developing new methods to capture valuable data from participants. To counteract covert ableism [23], we should develop accessible research methods to accommodate disabled people rather than requiring them to act more 'non-disabled'. Developing new methods can be an intensive process and will require considering additional factors like the validity of the method, IRB approval, participants' burden, involving additional experts while designing the methods. Rather than the difficult decision between compromising the design of studies and compromising the rich data that they could gather, researchers have a third option: can the HCI community come up with new methods to collect data from these participants? This question is a challenge and a call to arms for the HCI community; we believe that the community can do better to accommodate diverse disabilities.

4.5 Evaluating Research with People with SCI

As we have discussed throughout this paper, conducting user-centered studies with participants who have an SCI is challenging. Some pioneering researchers have worked hard to include these participants in research by adapting traditional methods. We identified a variety of challenges associated with doing research with

participants who have had an SCI. The HCI community should be mindful of these challenges while evaluating the resulting research.

Unsurprisingly, there are limited participants with a specific type of disability at a specific geographic location (e.g., patients with tetraplegia at the university hospital) [26]. Moreover, in Section 3.2.2, we explained that even with the participants present in the study location, it can still be difficult to complete the study due to myriad factors. A corollary is that studies with people with an SCI as participants involve a substantial amount more work than typical studies with other participant populations, and even so have a smaller number of participants compared to traditional HCI studies. Small sample size also influences the use of standard statistical methods for these studies.

Another important note is the duration of interviews for studies that conduct them. Our literature review (Table 1) shows that eighteen of the reviewed papers conducted interviews while only eight of them report the duration of the interviews. Among those eight papers, six report that an hour or more was required to conduct those interviews. However, [2] showed that interviews can be as short as 5 minutes and still capture valuable information.

Considering that it is very common for a standard HCI study to have hour-long interviews, researchers working with an SCI population might be concerned about being criticized for short interviews. We have already discussed speech limitations and the impact of those limitations on holding a conversation in a research setting. Therefore, when evaluating research, the community should also consider that studies might have a shorter duration of interviews to accommodate users' needs. On the other hand, researchers should report these details about methods (e.g., duration, adaptations required) in the papers for readers' consideration.

One important issue regarding participant interviews is 'leading questions' (a question that subtly prompts the participant to answer in a particular way). In theory, researchers should never ask leading questions. However, as we have discussed earlier, researchers might need to frame their interview questions such that participants can respond with yes/no answers. While researchers should still try to avoid leading questions, this might be challenging at times. Evaluation of the study should therefore consider the context of the participants' limitations.

5 GUIDELINES FOR CONDUCTING HCI RESEARCH WITH PEOPLE WITH AN SCI

The previous sections discuss different challenges that HCI researchers and practitioners might encounter while working with participants who have had an SCI. In this section, we aggregate these discussion points to provide the research community with some guidelines that we believe will be helpful, especially for researchers who are new to this domain. We caution that these guidelines are likely not exhaustive because of the incredible diversity of disabilities that can result from an SCI. However, we still believe that the guidelines can help the HCI research community to engage in more inclusive research design.

5.1 For Researchers and Practitioners

Conducting research with SCI participants can be challenging, which means the most vulnerable participants' perspectives are

less likely to be represented in the design of interactive systems. This makes doing this work especially important. Below, we offer some guidelines to help facilitate working with participants who have an SCI.

5.1.1 Preparing for the Study.

(1) Design the study to recruit participants even if they have more disabilities — such as in the acute phase — rather than avoiding them or asking chronic phase participants to recall the acute phase. Co-designing with caregivers or physicians might still not represent the perspectives of the target population (in Sections 4.3 and 4.1).

(2) Expect that participant recruitment will be challenging, even with carefully planned accommodations to address the difficulties (in Sections 3.2.2 and 4.3).

(3) Consider the different health conditions (in Section 4.1) that your individual participants have and that the disabilities are not all-or-nothing. For example, rather than assuming that participants can either speak or not, remember that they can have different levels of speech abilities (in Section 3.2.1). As a result, adaptations might be different based on individual cases. Try to get information about the abilities of each participant ahead of time so that you can be prepared. Use the ICF framework to understand the impact of these factors on the methods you want to employ (in Section 4.2).

(4) When participants have disabilities limiting their participation in certain research methods, adapt the methods rather than excluding the participants for their disabilities (in Sections 4.1). Any data that you can collect to represent the perspectives of these participants is especially valuable. Researchers can also try to combine different methods to gather as much data as possible (in Section 4.3). These efforts can result in new methods that can be research contributions of their own (in Section 4.4).

(5) Expect additional researcher burdens like more travel since participants may not be able to travel, as well as associated extra time and cost, due to physical limitations (in Sections 3.2.1 and 3.2.2).

5.1.2 During the Study.

(1) Be on the lookout for situations that arise where the participant is unable to fully participate in the research method (in Section 3.2.2). Ideally, adjust the method in response, but if this is not possible, at least make note of this so that you can consider it when you analyze and write up your results.

(2) Be cognizant of the participant's health. You might need multiple sessions due to the participant's fluctuating health condition. They might also suddenly drop out (in Sections 3.2.2 and 3.2.1).

5.1.3 Analyzing the data and writing the paper.

(1) Report all disabilities your participants had and their duration with those disabilities so that readers can understand the context of the study. This can also help the reader understand why adaptations were needed (e.g., shorter interviews, modified questionnaires) (in Sections 3.1.2 and 3.1.3).

(2) Report any adaptations you made so that you communicate what you did as accurately as possible and so that future researchers might be able to apply your adaptations in their own studies. For example, [36] reported that traditional participatory design would not work with their participants, so they used a combination of other methods to accommodate the health conditions. This will also help readers and reviewers to understand the complexities the data collection faced (in Section 3.1.1).

(3) Report your notes from Section 5.1.2 (1) in your paper so that fellow researchers can learn about them (in Section 3.2.2).

5.2 For Readers, Reviewers, and Program Committees

While the rigor of the peer review process must be upheld, we encourage reviewers and program committees to consider the issues raised in this paper and to recognize that the effort required to do research with an SCI population, particularly an acute-phase population, is considerable. Readers should also be aware of this when reading published work. Specific guidelines follow:

(1) Remember that due to health conditions and limited availability, studies might have fewer participants (in Sections 4.3 and 4.5). Rather than asking "should they have had more participants?" consider asking questions such as "Is there value in the data that *was* collected?"

(2) Consider that the methods and tools employed might not appear to be as rigorous as those in the studies with non-disabled participants (e.g., very short interviews). Similarly, for quantitative analysis, the statistical power might not be as strong as would be desired (in Sections 4.3 and 4.5). Reviewers must keep in mind that researchers are tightly constrained and that assuming that additional data could have been easily collected is likely not true.

(3) Recognize that adaptations are an indication of strong work by researchers who are sensitive to the needs of their participants, rather than a weakness, or an aspect that you are "willing to let slide." It would be much easier to ignore the needs and views of these participants. Research that goes to great lengths to make sure they are included ought to be recognized by our research community for that effort.

5.3 Generalizing the Guidelines for Other Health Conditions

As mentioned briefly in Section 2, some other health conditions (e.g., cerebral palsy, ALS, muscular dystrophy, Parkinson's disease, multiple sclerosis) may also result in multiple disabilities like motor disabilities, loss of sensation, slurred speech, blurry vision. Some of our guidelines presented above might apply to these other health conditions as well. For instance, reporting all the disabilities of the participants and any required adjustments to the research methods would be helpful, in general, to future researchers in the community. Accommodating for multiple disabilities at the same time might also require a combination of methods or designing new methods as we listed in Section 5.1. However, as mentioned in Section 2, there are differences in the nature of these health conditions that might impact the adjustments required for these populations (e.g., temporary vs. permanent disabilities, improvement vs. getting worse over time, with vs. without ventilator). To make stronger claims, we

would need first-hand experience with participants with the health conditions mentioned above. As this paper depicts, understanding health conditions like these is a complicated process for researchers that requires studying medical literature, collaboration with experts, and experience with the target population due to limited guidelines in existing HCI literature. Since we do not have such experience, strong guidelines about working with those populations are beyond the scope of this paper.

6 CONCLUSION

Individuals with an SCI are a unique population due to the combined impact of multiple disabilities and additional environmental factors. Their experiences can contribute rich data to user-centered research that aims to support people with disabilities. Unfortunately, user-centered research methods do not directly account for differing motor and communication abilities. This work highlights significant challenges that HCI researchers might face while employing user-centered methods with this population: speech disabilities, motor disabilities, and complicated contextual or environmental factors can make it difficult or impossible to use standard HCI methods when working with people with an SCI.

We argue that the HCI community needs to accommodate creative research designs or develop new methods that maximize the number and richness of research participation for people with an SCI, even at the expense of conventional expectations for research design. Simply put, it is better to collect data from these individuals that might be flawed than it is to continue the covert ableism that results in these perspectives not being represented at all. We propose a set of guidelines that HCI researchers might follow while working with this population. While this paper does not offer a specific solution to the challenges, we believe it prompts our community to engage in more inclusive research.

ACKNOWLEDGMENTS

REFERENCES

[1] Ahmad Alsaleem, Ross Imburgia, Mateo Godinez, Andrew Merryweather, Roger Altizer, Tamara Denning, Jeffery Rosenbluth, Stephen Trapp, and Jason Wiese. 2019. Leveraging Shared Control to Empower People with Tetraplegia to Participate in Extreme Sports. In *The 21st International ACM SIGACCESS Conference on Computers and Accessibility* (Pittsburgh, PA, USA) *(ASSETS '19)*. Association for Computing Machinery, New York, NY, USA, 470–481. https://doi.org/10.1145/3308561.3353775
[2] Ahmad Alsaleem, Ross Imburgia, Andrew Merryweather, Roger Altizer, Jeffrey Rosenbluth, Stephen Trapp, and Jason Wiese. 2020. Experience is Not Required: Designing a Sailing Experience for Individuals with Tetraplegia. In *Proceedings of the 2020 ACM Designing Interactive Systems Conference* (Eindhoven, Netherlands) *(DIS '20)*. Association for Computing Machinery, New York, NY, USA, 35–46. https://doi.org/10.1145/3357236.3395529
[3] Margherita Antona, Stavroula Ntoa, Ilia Adami, and Constantine Stephanidis. 2009. User Requirements Elicitation for Universal Access.
[4] Tapomayukh Bhattacharjee, Ethan K. Gordon, Rosario Scalise, Maria E. Cabrera, Anat Caspi, Maya Cakmak, and Siddhartha S. Srinivasa. 2020. Is More Autonomy Always Better? Exploring Preferences of Users with Mobility Impairments in Robot-Assisted Feeding *(HRI '20)*. Association for Computing Machinery, New York, NY, USA, 181–190. https://doi.org/10.1145/3319502.3374818

[5] Ayşe G. Büyüktür, Mark S. Ackerman, Mark W. Newman, and Pei-Yao Hung. 2017. Design Considerations for Semi-Automated Tracking: Self-Care Plans in Spinal Cord Injury. In *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare* (Barcelona, Spain) *(PervasiveHealth '17)*. Association for Computing Machinery, New York, NY, USA, 183–192. https://doi.org/10.1145/3154862.3154870
[6] Ayse G. Buyuktur, Pei-Yao Hung, Mark W. Newman, and Mark S. Ackerman. 2018. Supporting Collaboratively Constructed Independence: A Study of Spinal Cord Injury. *Proc. ACM Hum.-Comput. Interact.* 2, CSCW, Article 26 (Nov. 2018), 25 pages. https://doi.org/10.1145/3274295
[7] Patrick Carrington, Amy Hurst, and Shaun K. Kane. 2014. Wearables and Chairables: Inclusive Design of Mobile Input and Output Techniques for Power Wheelchair Users. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Toronto, Ontario, Canada) *(CHI '14)*. Association for Computing Machinery, New York, NY, USA, 3103–3112. https://doi.org/10.1145/2556288.2557237
[8] C. Melody Carswell, Cindy H. Lio, Russell Grant, Martina I. Klein, Duncan Clarke, W. Brent Seales, and Stephen Strup. 2010. Hands-free administration of subjective workload scales: Acceptability in a surgical training environment. *Applied Ergonomics* 42, 1 (2010), 138–145. https://doi.org/10.1016/j.apergo.2010.06.003
[9] Shih-Chung Chen, Ching-Yi Chien, Wei-Min Chang, and Shu-Wen Lin. 2008. A New Assistive Communication System for the Serious Disabled. In *Proceedings of the 2nd International Convention on Rehabilitation Engineering & Assistive Technology* (Bangkok, Thailand) *(iCREATe '08)*. Singapore Therapeutic, Assistive & Rehabilitative Technologies (START) Centre, Midview City, SGP, 59–64.
[10] Mayo Clinic. 2019. Amyotrophic lateral sclerosis (ALS). https://www.mayoclinic.org/diseases-conditions/amyotrophic-lateral-sclerosis/symptoms-causes/syc-20354022, Retrieved: 1 February, 2021.
[11] Mayo Clinic. 2020. Multiple sclerosis. https://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/symptoms-causes/syc-20350269, Retrieved: 1 February, 2021.
[12] LTC Tanya Estes, Deborah Backus, and Thad Starner. 2015. A wearable vibration glove for improving hand sensation in persons with Spinal Cord Injury using Passive Haptic Rehabilitation. In *2015 9th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth)*. 37–44. https://doi.org/10.4108/icst.pervasivehealth.2015.259137
[13] Center for Disease Control and Prevention. 2020. The ICF: An Overview. https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf, Retrieved: 31 August, 2020.
[14] Mayo Foundation for Medical Education and Research (MFMER). 2020. Spinal Cord Injury: Symptoms. https://www.mayoclinic.org/diseases-conditions/spinal-cord-injury/symptoms-causes/syc-20377890, Retrieved: 6 August, 2020.
[15] Natalie Friedman, Andrea Cuadra, Ruchi Patel, Shiri Azenkot, Joel Stein, and Wendy Ju. 2019. Voice Assistant Strategies and Opportunities for People with Tetraplegia. In *The 21st International ACM SIGACCESS Conference on Computers and Accessibility* (Pittsburgh, PA, USA) *(ASSETS '19)*. Association for Computing Machinery, New York, NY, USA, 575–577. https://doi.org/10.1145/3308561.3354605
[16] Krzysztof Z. Gajos, Jacob O. Wobbrock, and Daniel S. Weld. 2007. Automatically Generating User Interfaces Adapted to Users' Motor and Vision Capabilities. In *Proceedings of the 20th Annual ACM Symposium on User Interface Software and Technology* (Newport, Rhode Island, USA) *(UIST '07)*. Association for Computing Machinery, New York, NY, USA, 231–240. https://doi.org/10.1145/1294211.1294253
[17] Eric Garshick. 2020. Respiratory physiologic changes following spinal cord injury. https://www.uptodate.com/contents/respiratory-physiologic-changes-following-spinal-cord-injury, Retrieved: 25 August, 2020.
[18] Genetic and Rare Diseases Information Center. 2020. Locked-in syndrome. https://rarediseases.info.nih.gov/diseases/6919/locked-in-syndrome, Retrieved: 31 August, 2020.
[19] Marine Guffroy, Vigouroux Nadine, Christophe Kolski, Frédéric Vella, and Philippe Teutsch. 2017. From human-centered design to disabled user & ecosystem centered design in case of assistive interactive systems. *International Journal of Sociotechnology and Knowledge Development* 9, 4 (2017). https://doi.org/10.4018/IJSKD.2017100103
[20] Kotaro Hara. 2014. Scalable Methods to Collect and Visualize Sidewalk Accessibility Data for People with Mobility Impairments. In *Proceedings of the Adjunct Publication of the 27th Annual ACM Symposium on User Interface Software and Technology* (Honolulu, Hawaii, USA) *(UIST'14 Adjunct)*. Association for Computing Machinery, New York, NY, USA, 1–4. https://doi.org/10.1145/2658779.2661163
[21] Kotaro Hara, Christine Chan, and Jon E. Froehlich. 2016. The Design of Assistive Location-Based Technologies for People with Ambulatory Disabilities: A Formative Study. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (San Jose, California, USA) *(CHI '16)*. Association for Computing Machinery, New York, NY, USA, 1757–1768. https://doi.org/10.1145/2858036.2858315

[22] Susumu Harada, Jacob O. Wobbrock, and James A. Landay. 2007. Voicedraw: A Hands-Free Voice-Driven Drawing Application for People with Motor Impairments. In *Proceedings of the 9th International ACM SIGACCESS Conference on Computers and Accessibility* (Tempe, Arizona, USA) *(Assets '07)*. Association for Computing Machinery, New York, NY, USA, 27–34. https://doi.org/10.1145/1296843.1296850

[23] Megan Hofmann, Devva Kasnitz, Jennifer Mankoff, and Cynthia L Bennett. 2020. Living Disability Theory: Reflections on Access, Research, and Design *(ASSETS '20)*. Association for Computing Machinery, New York, NY, USA, Article 4, 13 pages. https://doi.org/10.1145/3373625.3416996

[24] Kerstin Johansson, Åke Seiger, Malin Forsén, Jeanette Holmgren Nilsson, Lena Hartelius, and Ellika Schalling. 2018. Assessment of voice, speech and communication changes associated with cervical spinal cord injury. *International Journal of Language & Communication Disorders* 53, 4 (2018), 761–775. https://doi.org/10.1111/1460-6984.12380 arXiv:https://onlinelibrary.wiley.com/doi/pdf/10.1111/1460-6984.12380

[25] Shaun K. Kane, Amy Hurst, Erin Buehler, Patrick A. Carrington, and Michele A. Williams. 2014. Collaboratively Designing Assistive Technology. *Interactions* 21, 2 (March 2014), 78–81. https://doi.org/10.1145/2566462

[26] J Lazar, HJ Feng, and H Hochheiser. 2017. Working with research participants with disabilities: Research Methods in Human Computer Interaction.

[27] Henry W.J Lin, Leila Aflatoony, and Ron Wakkary. 2014. Design for One: A Game Controller for a Quadriplegic Gamer. In *CHI '14 Extended Abstracts on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 1243–1248. https://doi.org/10.1145/2559206.2581334

[28] Peng Liu, Xianghua Ding, and Ning Gu. 2016. "Helping Others Makes Me Happy": Social Interaction and Integration of People with Disabilities. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing* (San Francisco, California, USA) *(CSCW '16)*. Association for Computing Machinery, New York, NY, USA, 1596–1608. https://doi.org/10.1145/2818048.2819998

[29] Meethu Malu, Pramod Chundury, and Leah Findlater. 2018. Exploring Accessible Smartwatch Interactions for People with Upper Body Motor Impairments. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (Montreal QC, Canada) *(CHI '18)*. Association for Computing Machinery, New York, NY, USA, 1–12. https://doi.org/10.1145/3173574.3174062

[30] Healthline Media. 2016. Friedreich's Ataxia. https://www.healthline.com/health/friedreichs-ataxia, Retrieved: 1 February, 2021.

[31] Healthline Media. 2019. Muscular Dystrophy: Types, Symptoms, and Treatments. https://www.healthline.com/health/muscular-dystrophy#treatment, Retrieved: 1 February, 2021.

[32] Dafne Zuleima Morgado Ramirez and Catherine Holloway. 2017. "But, I Don't Want/Need a Power Wheelchair": Toward Accessible Power Assistance for Manual Wheelchairs. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility* (Baltimore, Maryland, USA) *(ASSETS '17)*. Association for Computing Machinery, New York, NY, USA, 120–129. https://doi.org/10.1145/3132525.3132529

[33] Maia Naftali and Leah Findlater. 2014. Accessibility in Context: Understanding the Truly Mobile Experience of Smartphone Users with Motor Impairments. In *Proceedings of the 16th International ACM SIGACCESS Conference on Computers & Accessibility* (Rochester, New York, USA) *(ASSETS '14)*. Association for Computing Machinery, New York, NY, USA, 209–216. https://doi.org/10.1145/2661334.2661372

[34] National Institute on Aging. 2017. Parkinson's Disease. https://www.nia.nih.gov/health/parkinsons-disease, Retrieved: 1 February, 2021.

[35] World Health Organization. 2020. Spinal Cord Injury. https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury, Retrieved: 16 September, 2020.

[36] Charlotte Robinson, Emeline Brulé, James Jackson, Alice Torjussen, Joshua Kybett, and Tom Appshaw. 2020. Tricks and Treats: Designing Technology to Support Mobility Assistance Dogs. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems* (Honolulu, HI, USA) *(CHI '20)*. Association for Computing Machinery, New York, NY, USA, 1–14. https://doi.org/10.1145/3313831.3376188

[37] Andrew Sears and Vicki Hanson. 2011. Representing Users in Accessibility Research. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Vancouver, BC, Canada) *(CHI '11)*. Association for Computing Machinery, New York, NY, USA, 2235–2238. https://doi.org/10.1145/1978942.1979268

[38] Ameneh Shamekhi, Ha Trinh, Timothy W. Bickmore, Tamara R. DeAngelis, Theresa Ellis, Bethlyn V. Houlihan, and Nancy K. Latham. 2016. A Virtual Self-Care Coach for Individuals with Spinal Cord Injury. In *Proceedings of the 18th International ACM SIGACCESS Conference on Computers and Accessibility* (Reno, Nevada, USA) *(ASSETS '16)*. Association for Computing Machinery, New York, NY, USA, 327–328. https://doi.org/10.1145/2982142.2982199

[39] Adam J. Sporka, Torsten Felzer, Sri H. Kurniawan, Ondřej Poláček, Paul Haiduk, and I. Scott MacKenzie. 2011. CHANTI: Predictive Text Entry Using Non-Verbal Vocal Input. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Vancouver, BC, Canada) *(CHI '11)*. Association for Computing

Machinery, New York, NY, USA, 2463–2472. https://doi.org/10.1145/1978942.1979302

[40] Elin Tollefsen and Ove Fondenes. 2012. Respiratory complications associated with spinal cord injury. *Tidsskrift for den Norske laegeforening: tidsskrift for praktisk medicin, ny raekke* 132, 9 (2012). https://doi.org/10.4045/tidsskr.10.0922

[41] Ovidiu-Ciprian Ungurean, Radu-Daniel Vatavu, Luis A. Leiva, and Réjean Plamondon. 2018. Gesture Input for Users with Motor Impairments on Touchscreens: Empirical Results Based on the Kinematic Theory. In *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems* (Montreal QC, Canada) *(CHI EA '18)*. Association for Computing Machinery, New York, NY, USA, 1–6. https://doi.org/10.1145/3170427.3188619

[42] Marijke Vandermaesen, Tom De Weyer, Karin Coninx, Kris Luyten, and Richard Geers. 2013. Liftacube: A Prototype for Pervasive Rehabilitation in a Residential Setting. In *Proceedings of the 6th International Conference on PErvasive Technologies Related to Assistive Environments* (Rhodes, Greece) *(PETRA '13)*. Association for Computing Machinery, New York, NY, USA, Article 19, 8 pages. https://doi.org/10.1145/2504335.2504354

[43] Zawn Villines. 2019. Important Milestones in the Spinal Cord Injury Recovery Process. https://www.spinalcord.com/blog/important-milestones-in-the-spinal-cord-injury-recovery-process, Retrieved: 1 September, 2020.

[44] Elizabeth C. Ward, Leigh Jarman, Petrea L. Cornwell, and Delena I. Amsters. 2016. Impact of voice and communication deficits for individuals with cervical spinal cord injury living in the community. *International Journal of Language & Communication Disorders* 51, 5 (2016), 568–580. https://doi.org/10.1111/1460-6984.12232 arXiv:https://onlinelibrary.wiley.com/doi/pdf/10.1111/1460-6984.12232