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

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Spinal cord injury (SCI) is a condition that causes partial or complete damage to the spinal cord, resulting in persistent changes in bodily functions, such as motor, speech, respiratory, and cognitive disabilities. Every year, between 250,000 to 500,000 new SCIs occur around the world. While living with these disabilities can have a severe negative impact on quality of life, assistive technology and other forms of technological support can have an outsized positive impact on the 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 differ from most other people with disabilities, as they commonly struggle with multiple disabilities simultaneously. These disabilities change over time during their rehabilitation process, which can take a year or even longer post-injury. Moreover, the changes are different for each individual and depend on many other factors. While there is some guidance in the literature for conducting HCI research with disabled people, they focus on participants with one specific type of disability (e.g., motor disability).

This paper reviewed 28 papers published in HCI venues to understand how prior studies reported their research methods while working with people with an SCI. 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 participants' communication abilities. Moreover, they seldom reported any adaptation to these methods they might have required. These observations suggest that a lack of guidance for working with an SCI population leaves a problematic gap in the literature. Further, this indicates that 1) HCI research is excluding participants with severe SCI who have multiple complex disabilities (i.e., they're not represented in HCI research), or 2) they are including these participants without reporting enough details about their methods and relevant adaptations, or 3) the research methods are not being adapted to meet the participants' abilities and the participants' perspectives are not fully captured.

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. In this work, we developed a list of health conditions and environmental factors that contribute to the disabilities of individuals with an SCI, providing a starting point for future researchers to design their research accordingly. 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 the research participation of people with an SCI. The paper concludes with guidelines and challenges for the HCI community to consider when working with an SCI population.

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