Using Online Social Spaces for Information Seeking and Identity Construction for People with Spinal Cord Injuries
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Problem Statement
Individuals who sustain a Spinal Cord Injury (SCI) undergo abrupt changes in their functional abilities. This traumatic incident has a heavy impact on their physical and mental health; it also affects people’s lives and identity due to sudden physical disability and mobility restrictions (due to manual or power wheelchair usage), and challenges people to cope with a wide variety of challenges relating to the differences in their lives from pre- to post-injury. After sustaining an injury, people initially receive treatment, including information on their body, self-care practices, and lifestyle considerations from clinicians, therapists, and patient educators at rehabilitation hospital; however, SCI-specific healthcare and professional support after the rehabilitation period can be difficult and sometimes impossible to access [3].

Online Social Spaces can Facilitate Information Exchange for People with an SCI
Online social spaces often facilitate people’s engagement in seeking information and creating identity after significant life events including job loss [2], pregnancy loss [1], gender transition [6], relation breakups [7], and death of loved ones [9]. Prior research also shows that people with chronic conditions (e.g., cancer, diabetes) have often used online social spaces for health-related discussions [5]. Users benefit from these platforms being free of physical or social status cues [4], and can connect with others easily, obtain necessary health information, and make health-related decisions [8]. Notably, after sustaining an SCI, people’s amount of internet usage increases significantly [10]. For instance, individuals more rely on internet-based educational videos to build their health-management knowledge after an SCI. Therefore, online social spaces might have significant potential to support these people with information seeking which has not been explored yet.

Potential Challenges for Discussion
Through this paper, we aim to facilitate discussion among participants of the workshop regarding the following topics:

• **What:** What types of information do people with an SCI seek in online social spaces? For example, do they seek only health-related information or information related to other post-SCI life-facets? To what extent is there evidence that they are forming new dimensions of their identity?

• **How:** How do the differences in level of injury impact the information-seeking behavior in online social spaces? For example, would the information seeking behavior of a person with a severe SCI (e.g., upper body impairment, power wheelchair user) be different than a person with a less severe SCI?

• **Who:** How do people navigate circumstances where they might really benefit from online social spaces for SCI related information seeking, communication, or information-seeking [10], but they currently rely on someone (e.g., caregiver, family-members) else as a proxy to do these things on their behalf. Are there any privacy concerns in this context?

• **When:** In what ways can the temporal, spatial, and contextual variability of information seeking behavior of a person with an SCI impact their identity management? For example, is the information seeking behavior likely to change as time passes since the injury was sustained?

We hope to leverage insights from the CSCW research community to understand how online social spaces support, and could support, information-seeking and self-identity formation for this population. We also hope to explore the lack, as well as the potential value, of creating more inclusive online social spaces.
References


