

Designing Technology for Complex Self-care: Considerations for people with Spinal Cord Injury

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ABSTRACT

We aim to represent the complex nature of health perspectives for individuals with spinal cord injuries (SCI) during this workshop, and to explore the circumstances in which health needs typically differ. Health needs can be complex for individuals with SCI who develop a range of impairments and motor disabilities [1]. Managing those needs can also be a significant challenge. These impairments may include limited sensation in hands, arms, elbows, and upper body functions that necessitate the use of power-operated wheelchairs (PWC). In addition to that, this population needs to follow multiple life-long self-care routines [2], including pressure relief (PR), respiratory care, bladder and bowel management which are highly frequent and complex for individuals with SCI and often require additional assistance. For instance, individuals are expected to perform 30 to 50 PRs per day – every 20 minutes – to prevent pressure ulcers by changing their sitting positions in wheelchairs manually or with the tilt function of the power wheelchairs to redistribute the tissue load. Performing this high-frequency self-care activity can be situationally difficult for social or practical reasons [3, 4, 5]. In addition, the severity of the complications resulting from SCI highly depends on the level of SCI [6] – can have breathing trouble, use a ventilator and/or an additional pacemaker, and/or have speech difficulties and other comorbidities. Recent research [7] also pointed out that the complexity of their health and disability conditions can increase or decrease over time, further complicating this landscape. Further, because of their complex and fluctuating health needs, engaging with this population in user-centered research is challenging and their ability to participate in different HCI research methods is uncertain [7]. Therefore, designing technological interventions for this target population requires consideration of their level of disability, additional comorbidities, social, and psychological concerns, in addition to health outcomes.

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