AI-driven Personal Informatics for Individuals with Severe Spinal Cord Injury

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1 INTRODUCTION AND BACKGROUND

Although Personal Informatics (PI) research continues to expand in the breadth of domains and individual user contexts it covers, there is a paucity of work examining users with motor disabilities. In particular, individuals who sustain a traumatic spinal cord injury (SCI) undergo an abrupt and dramatic change that disrupts their lives and impacts how they might use PI tools [2]. AI-driven systems [9] that mediate consequential sense-making, decision-making, coordination, and many other aspects of personal and social lives can enrich the domain of PI with the utility of interactions, personal preferences, contexts, and goals of this population and empower them with control over their own life and reduced cognitive workload. In this position paper, we discuss opportunities and challenges for using AI-driven personal informatics to support this population.

In the US, 17,730 people sustain SCI each year on average [7], and worldwide between 250,000 and 500,000 people acquire an SCI every year [17]. SCIs can occur to anyone, and they are most commonly caused by motor vehicle accidents, catastrophic falls, or sports injuries [8]; these typically result in loss of physical ability and sensation. In contrast to other progressive reasons for motor disabilities, SCI causes an immediate loss of motor functions and abruptly changes an individual's life [18]. These traumatic incidents and resulting disabilities can be severe, and can force previously independent people into becoming dependent on others for basic daily activities.

Individuals with severe spinal cord injuries (SCI) develop a range of impairments and motor disabilities [2], including limited sensation in hands, arms, elbows, and upper body functions that can necessitate the use of power-operated wheelchairs (PWC). Additionally, they need to adopt several new self-care routines they will need to complete for the rest of their live [1], including pressure relief (PR), respiratory care, bladder and bowel management. They must carry out these self-care routines frequently throughout the day; they are also particularly complex for PWC users, and often require additional assistance. For instance, individuals need to perform between 30 and 50 PRs each day – every 20 minutes – to prevent pressure ulcers. They can perform a PR by changing their sitting position in PWC manually or with the tilt function of the PWC to redistribute the tissue load. Performing this high-frequency self-care activity can be difficult for both social and practical reasons.

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2 THE POTENTIAL FOR AI TO SUPPORT PI FOR PEOPLE WITH MOTOR DISABILITIES

Our recent study [15] found that individuals with severe SCI desire the support of personalized, ability-based, and context-appropriate technology that will support them to improve their PR adherence. Notably, our findings indicate that these users would both benefit from and be interested in employing a PI lens – monitoring, reflecting, and acting. However, living with an SCI comes with many privacy and social concerns when around others. Thus, an errant reminder notification, or other technology that draws attention to them, can cause more harm than good. Perhaps AI can provide some support for reducing the occurrence of these negative impacts, and for facilitating PI systems that serve this population. For instance, the concept of context-aware just-in-time [16] reminders could provide users with dynamic control to routinize and sustain PR behaviors while accommodating contextual constraints and appropriate opportunities to act [12]. We envision a future PR reminder system that leverages AI to facilitate personalized assistance and reflection for this population and helps them achieve their health goals with minimal additional cognitive load. Additionally, AI can help to accommodate individual levels of disability, where the severity of complications and other comorbidities resulting from SCI can vary broadly [13]. Recent research [11] has also pointed out that individual abilities can fluctuate over time, further complicating this landscape – AI-driven personal informatics could help monitor these fluctuations in users' ability levels and dynamically adjust to support the required adjustment in the self-care routines.

3 CHALLENGES OF INTEGRATING AI INTO PI SYSTEMS FOR PEOPLE WITH SEVERE SCI

Introducing AI has the potential to improve PI systems for people with SCI, but these opportunities also come with new challenges. We describe some foreseeable challenges to integrating AI into PI for people with severe SCI and possible approaches for managing these challenges.

3.1 Challenges of collecting research data can make it hard to use AI approaches

The lives of some individuals with motor disabilities can be unpredictable. Their basic needs, medical conditions, and physical abilities can all have a negative impact on their ability to participate in HCI research at all, and on the extent to which they can engage in data collection methods [11]. This has implications for how researchers can possibly collect the data necessary to enable the types of AI-powered systems we are envisioning. One approach to this challenge is to innovate on the AI side to develop approaches that work even with small or sparse data-sets. Another approach is to explore opportunities to improve the mechanisms for collecting data such that they are unaffected by these limitations. For example, automated data collection, or collaborative tracking with a family member or caregiver, are both ways that we can reduce the data collection burden on these individuals.

3.2 Barriers to interaction affect how AI might interpret usage data

Our recent work [15] has brought into sharp relief the fact that for many individuals who use PWCs, using a mobile device like a smartphone is typically challenging; it's sometimes inconvenient and other times completely impossible. The challenges can include situational issues — for example if the user is actively in transport it is even harder to pay attention to their device than it would be for somebody who is walking and can easily pull their phone out of their pocket — but it can also include basic interaction challenges that stem directly from the motor disability. Thus, even if we successfully create AI-powered systems that are targeted at the needs of this population, we must also be careful with how AI interprets usage data. A notification that appears to have been ignored may have less to do with overall adherence and more to do with systematic differences in how these users interact with their technology. Thus, collected data will likely need to be interpreted differently. One approach to this is for AI to be more explicit in the interpretations it has, and to provide opportunities to adjust those interpretations.

3.3 Individual differences between- and within-individuals can further complicate the data

There can be many differences in physical abilities among individuals who have sustained severe SCI — strength, sensation, and dexterity are examples of some dimensions that can vary dramatically and are not necessarily symmetric between right and left sides. Individual abilities differ so much that describing them is often qualitative. Thus, collecting data from these individuals for AI-based model in training purpose and incorporating them into PI technology will not be straightforward. For instance, people with severe SCI may have a different level of hand/arm functionally and upper-body or lower-body sensation that may introduce several interaction challenges in data collection. Further complicating this landscape is the fact that even for the same individual, individual abilities can change and vary over time, both situationally and as they improve or recover. Being robust to these individual differences. One approach to addressing the uncertain nature of automated data collection in the face of individual differences is employing multiple methods and sources (e.g., multiple body locations for sensor data) for AI-based decision-making. This could help the AI decision-making process to be more adaptive and less biased by capturing more data points per individual.

3.4 PI systems without an explicit focus on people with severe SCI and other motor disabilities are likely to miss important factors that limit their utility for this population

To support people with severe SCI with their unique health needs, designing AI-based PI technology requires an explicit focus on their unique requirements. For instance, assistive mobility tools differ widely according to the severity of SCI –people may use a use cane, walker, crutches, or manual wheelchair for less severe SCI whereas individuals with severe SCI mostly use PWCs [4]. Thus, AI-based PI system designs need to consider specific interactions paradigms for this population. Notably, Epstein et al.'s mapping review on PI literature [10] identified only four works that involved wheelchair users [3, 5, 6, 14] and none of those deployed PI systems to their participants. Additionally, three of them [3, 5, 6] focused almost exclusively on manual wheelchair users — except for one participant in [3] who used a power wheelchair. Despite participants across all of these four works being interested in PI, they acknowledge that the existing PI technologies are not explicitly designed for them, thus excluding them from getting value from PI systems. If we hope for people with motor disabilities to be able to get value from PI systems — even ones that do not specifically target motor disability issues — these systems must be designed and examined with these target users. It is not a safe assumption that PI systems that are designed for a non-disabled population — for example, financial tracking — will necessarily work for this population. Thus, explicit focus on the people with severe SCI is needed to design the AI-based PI systems to support their unique needs.

4 CONCLUSION

PI systems have the potential for serious positive impact on the lives of people with SCI, and other motor disabilities, and AI plays a significant role in that potential. Yet, there are numerous challenges and pitfalls in realizing this potential. It is easy to gloss over these concerns and instead focus on "PI for the masses." However, if PI researchers would like for these systems to be accessible and useful by all, we must figure out as a community how to value contributions that support these and other marginalized or underrepresented populations in a way that is proportional to the effort it takes to do that work.

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