

Bridging the Gap Between User-Centered Engineering and Clinical Research for Rehabilitation: Reflections & Opportunities

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Abstract

User-centered engineering provides new opportunities to incorporate the needs of multiple stakeholders into the conception, development, and evaluation of rehabilitation technologies. I discuss my reflections on past work, emphasizing considerations for reporting guidelines (clinical measures, eligibility criteria) to ensure compatibility and translation between HCI and clinical research. I also highlight opportunities for future research (digital, at-home, and wearable technologies) and emphasize the importance of user-centered engineering for translating these technologies from the research laboratory into the real-world.

CCS Concepts

• **Applied computing** → **Life and medical sciences**; • **Human-centered computing** → **User studies**; *Accessibility*.

Keywords

User-Centered Engineering, Rehabilitation, Health

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1 Introduction

Rehabilitation technologies (e.g., rehabilitation robots, prostheses, gaming for rehabilitation) are critical tools for motor function, retention, and recovery for many individuals with motor disabilities [10]. However, the translation of these technologies from the laboratory into clinical and at-home care is challenging and requires input from multiple stakeholders (e.g., patients, caregivers, therapists, doctors). I discuss reflections and opportunities for user-centered design, development, and evaluation of rehabilitation technologies in the United States. Much of my prior health work has been published in the clinical domain, and this conference provides an opportunity to integrate the two fields in a unique way. I reflect on my prior work, emphasize the need for reporting guidelines in rehabilitation research, and highlight opportunities for future work toward patient-centered care.

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2 Reflections on Past Work: Considerations for Reporting Guidelines in Rehabilitation Research

My first foray into healthcare research was developing virtual reality tools to support the assessment and rehabilitation of freezing of gait in Parkinson disease [3, 4, 8, 9]. This work has resulted in an ongoing long-term collaboration with Drs. Valerie Kelly and Sujata Pradhan, who are faculty in the Rehabilitation Medicine department at the University of Washington, Seattle. Their mentorship in submitting to clinically focused journals has been invaluable to understanding the reporting guidelines for such submissions. Upon reflecting on my experiences submitting to these journals compared to HCI submissions, I believe that clarity on reporting guidelines for: 1) clinical measures and 2) eligibility criteria is a key first step for producing rehabilitation research that can be translated between HCI and clinical fields.

2.1 Clinical Measures Reporting

When evaluating rehabilitation prototypes with patients, precise clinical measurements of the participants' health (e.g., The Unified Parkinson's Disease Rating Scale (UPDRS) [5], The Freezing of Gait Questionnaire [7], Montreal Cognitive Assessment (MoCA) [6]) are reported to provide greater clarity on the impact of the participants' mental and physical health on outcome measures. Some of these measures (e.g., Freezing of Gait Questionnaire) are self-reported and can be administered in-person or remotely with minimal training, while others (e.g., UPDRS, MoCA) require an in-person evaluation and extensive training to administer. For HCI research, these clinical measures may be difficult (e.g., there is no trained researcher who can administer the tests) or impossible (e.g., the participant is being interviewed remotely so physical evaluations are not possible) to obtain. The lack of reporting of these measures in HCI research can make it challenging to translate the work into the clinical domain.

Self-report measures are one way in which this gap can be bridged. PROMIS (Patient-Reported Outcomes Measurement Information System) are validated self-report questionnaires that provide information about a person's mental and physical health [2]. In the rehabilitation field, Shirley Ryan Ability Lab's Rehabilitation Measures Database [1] provides additional information about how different assessments can be performed to assess health. Greater clarity on which health measures should be reported and for what kinds of research is a critical step towards ensuring that the HCI research can be effectively translated into clinical fields.

A somewhat related challenge is that these health measures are usually reported for each individual participant in clinical fields to provide greater clarity on participant health variability. This is

not always the case in HCI settings, and some papers pool participant information and provide aggregate statistics, rather than participant-specific information. This is because providing such specific mappings between each participant ID and the participants' health conditions can make it possible to guess the person's identity and violate their privacy. One way to bridge this gap could be to clarify in the paper that subject-specific demographics and health information are available upon request to other researchers.

2.2 Eligibility Criteria Reporting

Another area of reporting where there can be a discrepancy between HCI and clinical research is eligibility criteria. In the medical field, eligibility criteria are usually quite specific to test patient population-specific hypotheses. However, this can be a challenge because having stringent inclusion criteria leaves out a large group of individuals who could potentially be end-users of the system. For example, having additional health conditions (e.g., diabetes, heart condition) in addition to what the rehabilitation tool is targeting (e.g., stroke) is often an exclusion criterion. In our work evaluating virtual reality tools for Parkinson disease [3, 9], one of our inclusion criteria was the ability to walk 400 m independently or with an assistive device to ensure participant safety. This meant that we excluded participants who were more affected by freezing of gait and, therefore, unable to walk 400 m. Such participants could also be end-users of our system with different needs than the participants who participated in our study, limiting our work's applicability to end-users.

Conversely, inclusion criteria for HCI work can be quite open and is an opportunity to fill this research gap. In our prior work, we included all individuals with upper-body motor disabilities to develop inclusive and personalized upper-body gestures [11, 12]. Our experience was that having a wider pool of participants resulted in diverse opinions on our proposed system and made participant recruitment easier. However, we cannot make broader claims about specific user groups and their impacts on health due to participant diversity. One way to thread the needle between these two extremes in eligibility criteria is to report on multiple studies. For example, for our virtual reality tool for Parkinson disease [3, 9], we could additionally interview participants who are further along in their motor disability to obtain their perspective while ensuring their safety. Lastly, there are currently few standards on inclusion and exclusion criteria in HCI papers, making it challenging to understand who was included and excluded in the prototype evaluation or interview. Having specific guidelines about what information should be reported is a critical first step toward standardizing reporting.

3 Opportunities for Future Research

Our lab's current and future work aims to integrate user-centered engineering principles into developing new rehabilitation technologies that meet the needs of all stakeholders. A major transition point for myself into HCI research was the desire to integrate participant opinions into rehabilitation technology prototype evaluations and discuss user-centered engineering as part of the research process. Our prior work in user-centered engineering for rehabilitation found that different stakeholders have different needs and design requirements for new rehabilitation technology [10, 13]. This is

particularly relevant in the rehabilitation setting, as patients, parents/caregivers, payers, physical and occupational therapists, and doctors are all potential stakeholders with different needs that must be met. The proposed conference provides a venue to expand on stakeholder needs and develop inclusive engineering principles for rehabilitation engineering to translate research prototypes from the laboratory into the real-world. In our future work, we see: 1) digital and at-home technologies and 2) new and emerging wearables as two promising growth areas.

3.1 Digital and At-Home Technologies for Patient-Centered Care

A significant hurdle for many individuals in the United States receiving rehabilitation care is the limited physical or occupational therapy sessions that are covered by insurance [10, 13]. Oftentimes, patients must show improvement in function or activities of daily living to continue receiving services. This is a challenge because although their physical ability may no longer improve with physical therapy, without it, their health may deteriorate. Digital and at-home technologies can provide a stopgap in such scenarios and also support patients who may not have the time or resources to attend in-person rehabilitation. In our prior work, we found that people with motor disabilities want new rehabilitation technology that centers adaptability, movement tracking, and community building [10]. As we work towards developing patient-centered digital health technology to support rehabilitation, we are investigating research questions such as:

- How can we automatically sense a person's momentary capacity for rehabilitation by measuring fatigue, ability, pain, and other user-specific attributes?
- How can wearable sensors and data-driven methods identify rehabilitation movement quality?
- How can rehabilitation be integrated into existing digital community platforms?

As digital technologies become more ubiquitous, understanding how they can be leveraged to support at-home rehabilitation with user-centered methods is important for impactful and translational work.

3.2 Wearables Technologies for Ubiquitous Rehabilitation and Symptoms Tracking

Wearable technology (smartwatches, computer vision, electromyography) is becoming more ubiquitous and commercially available; this presents new opportunities to study and support rehabilitation. For example, our work in developing virtual reality tools for Parkinson disease enables studying the impacts of diverse environments (e.g., home, movie theater, elevator) on freezing of gait safely and without the need to physically build these environments [3, 4, 8, 9]. Always-on wearable sensors like smartwatches provide opportunities to enable continuous and fine-grained tracking of health symptoms. Such information can be helpful in data-driven tracking and conveying health changes to clinicians and caregivers. Additionally, the development of whole-body tracking for extended reality applications opens new doors to integrate rehabilitation and physical activity into everyday technology interactions [12]. As

our world becomes more digital and more sedentary, providing opportunities for movement and physical activity when interacting with technology is critical for supporting health.

4 Conclusion

The new health-focused HCI conference provides unique opportunities to center the user in rehabilitation research. As we look towards enabling translation between HCI and clinical research, I identify considerations for reporting (clinical measures, eligibility criteria) and opportunities for future research (digital and wearable technologies) for rehabilitation applications. With the large number of stakeholders involved, it is critical to understand and address the needs of all stakeholders when engineering new rehabilitation technologies.

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