

# Breaking the “Inescapable” Cycle of Pain: Supporting Wheelchair Users’ Upper Extremity Health Awareness and Management with Tracking Technologies

Yunzhi Li  
Carnegie Mellon University  
Pittsburgh, Pennsylvania, USA  
yunzhi@cs.cmu.edu

Franklin Mingzhe Li  
Carnegie Mellon University  
Pittsburgh, Pennsylvania, USA  
mingzhe2@cs.cmu.edu

Patrick Carrington  
Carnegie Mellon University  
Pittsburgh, Pennsylvania, USA  
pcarrington@cmu.edu

## ABSTRACT

Upper extremity (UE) health issues are a common concern among wheelchair users and have a large impact on their independence, social participation, and quality of life. However, despite the well-documented prevalence and negative impacts, these issues remain unresolved. Existing solutions (e.g. surgical repair, conservative treatments) often fail to promote sustained UE health improvement in wheelchair users’ day-to-day lives. Recent HCI research has shown the effectiveness of health tracking technologies in supporting patients’ self-care for different health conditions (e.g. chronic diseases, mental health). In this work, we explore how health tracking technologies could support wheelchair users’ UE health self-care. We conducted semi-structured interviews with 12 wheelchair users and 5 therapists to understand their practices and challenges in UE health management, as well as the potential benefits of integrating health tracking technologies into self-care routines. We discuss design implications for UE health tracking technologies and outline opportunities for future investigation.

## CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**.

## KEYWORDS

upper extremity health, wheelchair users, health tracking technologies

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## 1 INTRODUCTION

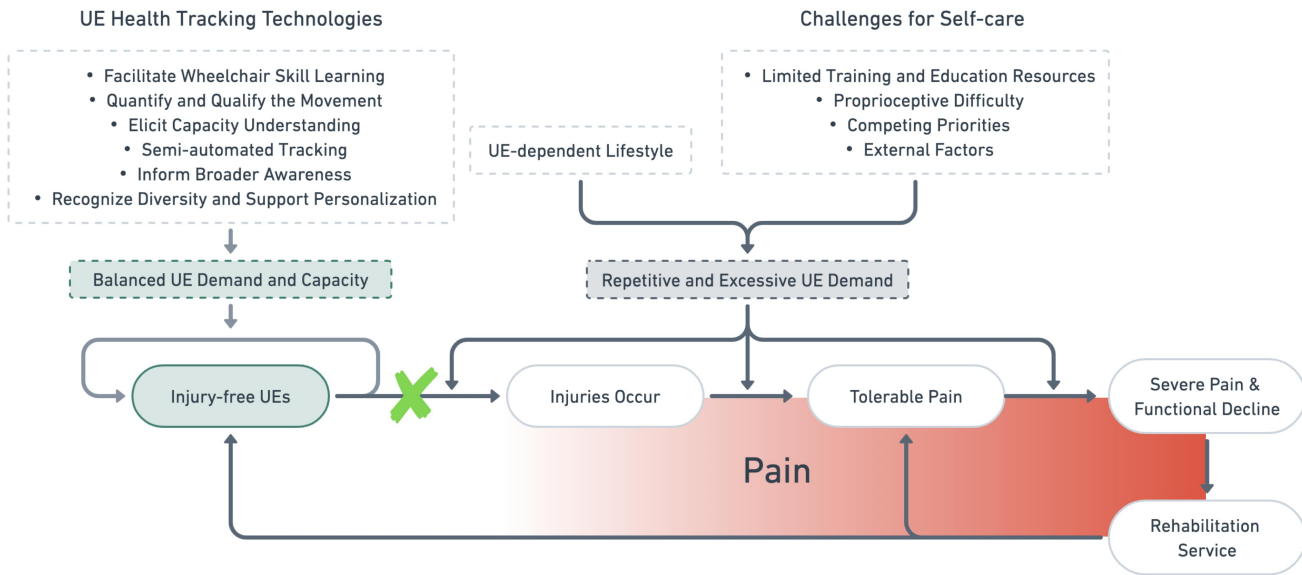
Upper extremity (UE) health is critical for wheelchair users. Previous studies have shown that the integrity of wheelchair users’ UEs is highly correlated not only with their physical wellness, but

also with independence [36], mental well-being [56, 93], and social participation [47]. However, due to wheelchair usage and the corresponding lifestyle, wheelchair users tend to put increased load and repetitive stress on their UEs, especially shoulder joints, for many essential activities (e.g. wheelchair propulsion [71], transfer [54], pressure relief [72, 99]), which violate the non-weight-bearing nature of human upper limbs and significantly increase their risk of acquiring a wide range of acute and overuse injuries [1, 4, 5, 20, 21, 40, 45, 92]. Although the increased prevalence of UE issues and their negative impacts have been documented for decades, these issues remain unresolved. Existing solutions under the traditional provider-patient relationship, including surgical repairs and conservative treatments (e.g. medication, manual therapy), may bring temporary relief to wheelchair users’ UE health conditions, yet none of them has led to sustained health improvement. More importantly, given the chronic nature of most UE health issues, supporting wheelchair users’ day-to-day self-care of UE health is therefore particularly crucial.

Recent progress in Human-Computer Interaction (HCI) shows that patient’s self-care can be effectively supported by health tracking technologies, often based on emerging sensing techniques combined with personal informatics, across different health conditions, such as mental health [58, 61], diabetes [69], and multiple sclerosis [9]. Prior work also identified the potential of health tracking technologies in facilitating wheelchair users’ self-care on chronic health conditions such as bladder dysfunction [22] and pressure ulcers [22, 73]. However, for UE health, a vast majority of existing work is medical research which often adopts a mechanistic and quantitative approach to study injury causality and clinical treatments. Very little research has explored how tracking technologies can contribute to wheelchair users’ UE health self-care. Furthermore, understanding user needs is crucial to the development of any health tracking system [75], yet little is known about the practices and challenges of wheelchair users’ UE health management. We use “UE health management” to broadly refer to both the individual and collaborative activities involved in monitoring, maintaining, and maximizing one’s UE health.

In this work, we aim to build insights into *how tracking technologies can support wheelchair users’ upper extremity health self-care* by understanding their current UE health management practices and the obstacles they encounter throughout the process. Specifically, we conducted 12 semi-structured interviews with wheelchair users to understand their attitudes, practices, and challenges in UE health management, as well as their perceptions of the benefits and desirable features of health tracking technologies.

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**Figure 1: The process of managing UE health for wheelchair users involves a continuous cycle of pain and injury due to a UE-dependent lifestyle and several challenges for UE health self-care, including limited training and education resources, competing priorities, etc. UE health tracking technologies have the potential to break this cycle of pain by augmenting wheelchair users’ health awareness, as well as supporting informed decision-making on balancing UE demand and capacity.**

In addition, considering the critical role of therapists in supporting wheelchair users maintain UE health, we also interviewed 5 therapists to draw insights from their clinical experience for the tracking technology design by both understanding their current therapy practices as well as their perceived practices and challenges of wheelchair users in UE health self-care.

As a result, these viewpoints collectively contribute to a foundational understanding of the current state of wheelchair users’ UE health management. We found that despite the widely acknowledged importance of UE health, wheelchair users tend to have a binary understanding of their UE health through pain or functional declines. This paper emphasizes two central concepts of upper extremity **capacity**, which is a person’s inherent ability to perform physical tasks without experiencing pain, and upper extremity **demand**, which refers to the required actions or motions to perform a particular task. Beyond the UE-dependent lifestyle, wheelchair users’ expectation of acquiring UE issues and challenges like competing priorities, limited health education resources, and proprioceptive difficulty aggravate the excessive demands placed over their UEs and further lead to a recurring cycle of pain, injury, and rehabilitation, as illustrated in Fig 1. These findings illuminate the opportunity for health tracking technologies to augment wheelchair users’ UE health awareness as well as support informed decision-making on balancing UE demand and capacity to achieve better injury prevention and adequate recovery. We further discuss design implications and highlight relevant open research questions for future investigations.

To summarize, our work makes the following contributions:

- Characterizations of the attitudes, practices, and challenges regarding wheelchair users’ UE health management from both wheelchair users’ and therapists’ perspectives.
- Identification of the opportunities in integrating tracking technologies for UE health self-care.
- Design implications and future research effort for health tracking technologies that support wheelchair users’ UE health self-care, especially with regard to health awareness and injury prevention.

In the rest of this paper, we first briefly summarize related work (Sec. 2), followed by a description of our research methodology, including recruitment, interview protocol, and data analysis (Sec. 3). Then we report, in detail, findings from our semi-structured interviews (Sec. 4&5). We conclude by discussing the design implications and future research directions derived from our findings (Sec. 6).

## 2 RELATED WORK

To provide background to this research, we begin by introducing the prevalence and pathology of UE health issues, as well as their documented negative impacts towards wheelchair users. We then describe emerging research on self-care with health tracking technologies and outline existing tracking technologies for wheelchair users and people with physical impairments in general. In the remaining sections, if not specified, the term “wheelchair users” represents both manual and power wheelchair users.

## 2.1 Upper Extremity Health Issues: Prevalence, Impact, and Prevention

There are two types of UE injuries that a wheelchair user may experience: acute and overuse injuries. Acute injuries are defined as traumas resulting from very specific and identifiable events, such as fractures [107]. Whereas overuse injuries are caused by the accumulation of many micro-traumas over time, for instance impingement syndrome [20], chronic rotator cuff tears [1, 20, 40], carpal tunnel syndrome [4, 21, 45], etc. Both types of injuries can be conceptualized as the result of demands placed over one’s UEs exceeding their capacity, either drastically or over time without sufficient recovery, and can cause pain of varying degrees affecting multiple parts of the upper body. Previous studies have shown that approximately 35% to 78% of paraplegic individuals suffer from chronic shoulder pains [1, 5, 20, 40, 92, 103]. One prior study with 130 spinal cord injury (SCI) patients also identified that the prevalence rate of elbow pain, hand pain, and wrist pain were 35%, 43%, and 53%, respectively [36].

The negative impact of these issues on wheelchair users’ ability to perform daily activities and quality of life has also been documented over the years [63, 81, 88, 89]. For example, Dalyan et al. [36] reported that wheelchair users with UE pain had a higher unemployment rate than those without and 28% of them reported limitations in independent living. And Giulia and Holloway’s investigation [11, 12] illustrated how UE pain negatively affects wheelchair users’ independent transfer capability and how the necessity of those tasks further puts wheelchair users’ UEs at higher risk. Silvestri et al. [93] also recently investigated the lived experience of manual wheelchair users with chronic shoulder pain where negative feelings including fear, anger, and loss, as well as negative impact of shoulder pain on their occupational engagement were reported by the participants.

It is widely believed by the rehabilitation science community that wheelchair usage and its corresponding lifestyle put wheelchair users’ UEs at higher risk of acquiring UE overuse injuries. More specifically, because of the kinematic changes and essential activities due to wheelchair use, including wheelchair propulsion [71], transfer [54], pressure relief [72, 99], overhead reach [100], wheelchair users are more likely to overuse their UEs beyond their capacity and to a point of injury. In terms of existing treatments, surgical repairs are often saved for extreme situations due to their cost and stringent post-surgical procedures. Further, the chronic nature of most overuse UE injuries makes them especially challenging to diagnose and completely treat in clinical settings, therefore injury prevention and self-management are believed crucial in wheelchair users’ day-to-day life. To this end, a new wheelchair user is recommended to receive training on proper wheelchair skills, such as efficient propulsion techniques [19]. Previous studies also suggested that home exercise programs are useful for reducing pain and improving UE functions. However, it is unknown how well existing techniques are adopted in wheelchair users’ everyday lives and the significantly lower adherence rate of exercise programs among manual wheelchair users who experience UE pain than those without [50] suggests a serious limitation of exercise-based injury prevention strategies.

To summarize, wheelchair users’ UE health issues have been recognized and studied by the rehabilitation science community for years with a primary emphasis on their pathology and injury mechanism. Only a few prior studies investigated wheelchair users’ lived experience with UE pain, but focused on clinical implications for improving the therapy experience and specific assistive tools (e.g. transfer boards). Within the HCI community, wheelchair users’ UE health has often been overlooked despite its importance. In this work, we aim to fill such a gap by characterizing the overall landscape regarding wheelchair users’ attitudes, practices, and challenges for managing their UE health from a potential technology and interaction standpoint.

## 2.2 Health Tracking Technologies for Self-care

Barlow et al. define “self-care” as the ability to manage symptoms, treatment, emotions, and lifestyle changes as part of living with a chronic condition [16]. Recent progress in HCI has demonstrated that health tracking technologies, ranging from pure medical devices, web applications to mobile technologies can greatly support patients in their self-care by making health and contextual information accessible, suggesting care activities, and fostering collaboration between patients, caregivers, and clinicians [79]. Prior work has paid significant attention to common chronic health conditions, such as diabetes [27, 69], mental health issues [15, 58, 61], and multiple sclerosis [9]. With regard to the UE health of people with physical disabilities, existing work has mainly focused on developing tracking technologies to facilitate stroke patients’ rehabilitation process. The goal of such technologies is usually to motivate exercise and help restore body functionality by quantifying user movement and providing rehabilitation feedback. For example, existing console games with motion tracking devices, such as Nintendo Wii [3, 37] and Playstation 2 EyeToy [41], have been identified as effective in upper limb therapy. Beursgens et al. developed Us’em [18], a wristband-like activity monitor, for stroke patients to monitor impaired arm usage in relation to their non-damaged arm. Previous studies also have investigated using depth cameras [6, 7] or wearable sensors [84] to capture a patient’s upper limb movement data and present it to care specialists in meaningful ways to enhance their collaborations with clinicians. Akinsiku et al. further identified that not only do therapists need movement data from patients, but also experiential information, such as a stroke survivor’s motivation, stress, and frustration [2].

Regarding study approaches, traditional self-care technologies have been mostly medically oriented and prioritizing medical measurements [96]. More recently, designers of self-care technologies started to recognize and prioritize patients’ lived experience in order to better integrate technologies into patients’ self-care routines. For instance, Büyüktür et al. investigated SCI patients’ self-care routines on issues including bladder dysfunction, pressure ulcers, and respiratory issues, and further proposed that semi-automated tracking as a desirable approach to support relevant activities [22].

In line with prior work, we adopt an HCI lens to ensure technologies are designed with a deep understanding of wheelchair users’ current practices and challenges in UE health self-care. We move beyond stroke patients to the wheelchair user population and address a more complete UE health management cycle which is

Reference	Purpose	Tracking Target	Sensor Placement	Sensor Type	Tracked Information
[86]	Wheelchair Sports Tracking	MW	Wheelchair	R	Location, speed
[26]	Wheelchair Sports Tracking	MW	Wheelchair	I, M	Speed zone, orientation change, contextual clues
[98]	Wheelchair Sports Tracking	MW	Wheelchair	I	Location, speed, orientation, rotational speed
[17]	Wheelchair Sports Tracking	MWU	Body + Wheelchair	I	Propulsion frequency, progression force, coordination
[60]	Physical Activity Tracking	MWU	Body	I	Energy expenditure
[77]	Physical Activity Tracking	MWU	Body	I	Energy expenditure
[44]	Physical Activity Tracking	MWU	Body	I	Sedentary, locomotion, deskwork, transfers, moderate physical activity
[52]	Physical Activity Tracking	MWU	Body + Wheelchair	I, G, T	Energy expenditure
[53]	Physical Activity Tracking	MWU	Body + Wheelchair	I	Resting, household activities, propulsion, external pushing, basketball
[46]	Physical Activity Tracking	MWU	Body + Wheelchair	I, H, S	Resting, desk work, propulsion, external pushing, energy expenditure
[66]	Physical Activity Tracking	WU	Wheelchair	P	Sitting posture
[65]	Physical Activity Tracking	WU	Body + Wheelchair	I, P	Sitting posture
[28]	Propulsion Monitoring	MWU	Body	I	Propulsion pattern, propel uphill/downhill
[43]	Propulsion Monitoring	MWU	Body	I	Propulsion pattern
[51]	Propulsion Monitoring	MWU	Body	I	Propulsion pattern
[85]	Propulsion Monitoring	MWU	Body + Wheelchair	I	Propulsion distance, propulsion speed, propulsion, external pushing
[80]	Propulsion Monitoring	MWU	Body + Wheelchair	I, SW	Propulsion frequency, stroke number
[38]	Propulsion Monitoring	MWU	Body + Wheelchair	I, W	Propulsion, external pushing, sedentary
[12]	Transfer Assessment	WU	Body	I	Proper and improper wheelchair transfers
[105]	Transfer Assessment	WU	Environment	D	Proper and improper wheelchair transfers

<sup>1</sup> "MW" - manual wheelchairs, "MWU" - manual wheelchair users, "WU" - wheelchair users.  
<sup>2</sup> R - radio frequency-based indoor positioning system, I - inertial sensor, M - microphone, G - galvanic skin response sensor, T - temperature sensor, H - heart rate sensor, S - strain gauge, P - pressure sensor, SW - SmartWheel [32], W - wheel rotation datalogger, D - depth camera

**Table 1: Tracking technologies for wheelchair users.**

not only concerned about functional recovery, but also day-to-day injury prevention and the general UE health awareness it entails.

### 2.3 Tracking Technologies for Wheelchair Users

There are two major topics when it comes to existing tracking technologies for wheelchair users: tracking the manual wheelchair kinematics and the physical activities of wheelchair users themselves. For example, Rhedoes et al. [86] developed a radio-frequency based indoor localization system for measuring manual wheelchair sports players' field position. SpokeSense [26] is a more complex sensing system which collects manual wheelchair motion data (speed zone, orientation change) and contextual information (dribbling sound, game buzzer, etc) for wheelchair basketball performance analysis. Slikker et al. [98] also examined the feasibility of using wheelchair-mounted inertial measurement units (IMU) to measure the motion metrics such as frame speed, frame rotation, and rotational speed during manual wheelchair sports.

With regard to wheelchair users' physical activity, most of the work being done is on fitness tracking. For example, there is a large body of work on quantifying manual wheelchair users' energy expenditure [46, 52, 60, 77]. And several design-focused studies have explored the current practice and preference of wheelchair users for fitness devices [23–25, 67]. More recently, commercially available fitness tracker - Apple Watch [8] has integrated wheelchair settings to measure wheelchair users' calories burned, active minutes, etc. Prior studies also investigated ways to track several specific physical activities of wheelchair users, such as sedentary [44, 53], deskwork [44], household activities [53], and sitting posture [65, 66]. Among them, two activities associated with wheelchair users' UE health, namely wheelchair propulsion and transfer, have also been studied. More specifically, researchers have examined the feasibility

of tracking propulsion frequency [17, 80], detecting external pushing [38, 85], and classifying propulsion patterns [28, 43, 51]. And a few other works investigated the feasibility of tracking wheelchair transfers and their qualities based on depth cameras [105] and IMUs [13]. More details about each tracking technology are summarized in Table 1, including sensor placement, sensor type, tracked information, etc.

While these data logging techniques have been developed for fitness applications, it is unclear how well these existing approaches address the management of UE Health. Thus, we examine how wheelchair users may adopt existing tracking technologies to facilitate their UE health self-care.

## 3 METHODOLOGY

We conducted a semi-structured interview study with 12 wheelchair users and 5 therapists to understand wheelchair users' current engagement as well as therapists' expert perspectives on UE health assessment and management. The study was conducted in the United States, and all participants were voluntarily recruited through online advertising, word of mouth, and local health organizations. To participate in the study, participants must be 18 years or older and be able to communicate in English. Specifically, we only recruited therapists who had experience in working with wheelchair users. Wheelchair users who use wheelchairs on a daily basis are eligible to participate in our study, and there were no specific exclusion criteria. The therapists we recruited had an average age of 37.6 (SD = 3.65) and an average 9.2 years of practice (SD = 2.68). The wheelchair users we recruited had an average age of 43.8 (SD = 12.48) and an average 20.8 years of using wheelchairs (SD = 13.62). More details about the participants are shown in Table 2 and 3. Participants who completed the interview were compensated with

ID	Age	Gender	Type of Therapist	Years of Practice
T1	38	Female	Physical therapist	8
T2	40	Non-binary	Physical therapist	14
T3	35	Female	Physical therapist	8
T4	42	Female	Occupational therapist	8
T5	33	Female	Physical therapist	8

Table 2: Demographics of therapists

ID	Age	Gender	Wheelchair Type	Use Power Assist	Diagnosed Medical Condition	Years of Using Wheelchairs	Reported UE Issues
W1	39	Female	Power wheelchair	N/A	Arthrogyrosis	37	None
W2	40	Female	Manual & power wheelchair	No	Ehlers-Danlos syndrome	5	1, 2, 3
W3	64	Female	Power wheelchair	N/A	Spina bifida	40	1
W4	54	Male	Manual wheelchair	No	T12-L1 paraplegia	25	1, 4
W5	35	Male	Power wheelchair	N/A	C5 spinal cord injury	12	1
W6	39	Female	Power wheelchair	N/A	C5 spinal cord injury	18	1, 2, 3, 5
W7	47	Male	Power wheelchair	N/A	Muscular dystrophy	16	5
W8	64	Male	Manual wheelchair	Yes	T4 complete paraplegia	41	1, 4
W9	44	Female	Manual wheelchair	Yes	G9-11 complete paraplegia	23	1, 2, 3, 4
W10	35	Male	Manual wheelchair	No	L1-7 spinal cord injury	2	2, 4
W11	20	Male	Manual wheelchair	Yes	C6-7 spinal cord injury	5	1
W12	44	Male	Manual wheelchair	No	T1 spinal cord injury	25	1, 2, 3, 4, 5

<sup>1</sup> A power assist device is a motorized accessory that can be coupled to a manual wheelchair  
<sup>2</sup> 1 - shoulder pain/injuries, 2 - arm pain/injuries, 3 - wrist pain/injuries, 4 - overuse injuries, 5 - fatigue.

Table 3: Demographics of wheelchair users

a \$20 Amazon gift card. The entire recruitment and study procedure was approved by the institutional review board (IRB).

### 3.1 Interview with Wheelchair Users

These semi-structured interviews were 1-hour long and focused on wheelchair users’ attitudes, practices, and challenges in UE health management, as well as potential opportunities of integrating health tracking technologies into their self-care routines.

**3.1.1 Background (~5 minutes).** This section covered demographic information about wheelchair users, their diagnosed medical conditions, and their histories of wheelchair usage.

**3.1.2 Attitudes about Upper Extremity Health (~10 minutes).** We asked wheelchair users about their attitudes towards UE health management, including their definition of healthy UE, importance of maintaining UE functions, previous experience with UE issues, their awareness of UE health risks, etc.

**3.1.3 Practices and Challenges in Managing Upper Extremity Health (~20 minutes).** We asked wheelchair users about their practices and challenges in managing UE health, including if and how they assess their UE health, how they keep track of and maintain their UE functions, current injury prevention strategies, etc. We also asked

wheelchair users about their history and experience with therapy sessions and wheelchair skill training programs.

**3.1.4 Ideal Upper Extremity Health Tracking Solutions (~20 minutes).** In this section, we started with understanding wheelchair users’ experience with existing health tracking technologies. Then we asked them to describe their desired features of an ideal UE health tracking solution and the potential benefits. We adopted Apple’s Health Application as the design probe to introduce the concept of health tracking to those unfamiliar with it and inspire design ideas, as the application covers basic functionalities including manual/automatic data logging, notifications, health analytics, data sharing, etc.

### 3.2 Interview with Therapists

These semi-structured interviews were also 1-hour long and focused on therapists’ perceived practices and challenges of wheelchair users in UE health self-care, their clinical therapy procedures, and the potential role of tracked health information in facilitating their practices.

**3.2.1 Background (~5 minutes).** This section covered demographic information about the therapists, their professional experience, the types of patients they treat and the usual frequency.

**3.2.2 Practices and Challenges in Clinical Therapy (~15 minutes).** We first asked therapists about the definition of wheelchair users' UE health as well as the UE issues they encounter and treat in clinic. We then asked about their current practices in assessing patients' UE health and designing therapy strategies. We also asked about the challenges encountered in their clinical practices.

**3.2.3 Perceived Practices and Challenges in Managing Upper Extremity Health (~20 minutes).** We asked therapists about their perceived practices and challenges of wheelchair users in UE health self-care, including their perceived health awareness, practices in assessing and maintaining upper limb functions, injury prevention strategies, as well as challenges encountered in each of the above processes.

**3.2.4 Opportunities of Upper Extremity Health Tracking Technologies (~20 minutes).** Similarly, in this section, we explored the value that health tracking applications could bring to UE health management. We asked therapists about their desired tracking features, including desired physical activity data, relevant contextual information, etc., as well as potential benefits for both wheelchair users and therapists. Again, Apple's Health Application was used as the design probe here to explore the values of similar applications.

### 3.3 Data Analysis

The semi-structured interviews were conducted through Zoom [83], and all interviews were audio-recorded and transcribed. In total, we obtained 10.23 hours of wheelchair users' interviews and 6.12 hours of therapists' interviews. We analyzed the wheelchair users' and therapists' interviews separately after we finished both sets of interviews using Google Sheets [106]. More specifically, two authors redundantly coded three wheelchair user interviews, and the first author coded two therapist interviews before all three authors met to review and reconcile each codebook. The first author then finished coding the remaining interviews using the respective codebooks before all authors met again to review all codes. After reaching consensus, we performed a bottom-up affinity diagramming process [49] on a Miro board [42] to group the codes into successive higher-level themes. We first identified 30 themes from the unique 315 codes from wheelchair users' interviews and 18 themes from the unique 214 codes from therapists' interviews. Then the 48 first-level themes were merged together and clustered into 4 second-level themes.

In the next two sections, we first describe findings related to the process of UE health management. Then we discuss the participants' expected benefits and desired features of tracking technologies that integrate into their UE health self-care routines. Throughout the remaining sections, wheelchair users are identified with a "W", and therapists are identified with a "T".

## 4 FINDINGS: PRACTICES AND CHALLENGES IN UPPER EXTREMITY HEALTH MANAGEMENT

Here, we present our findings across three subsections, each of which corresponds to one second-level theme emerged through our analysis. We first present the identified wheelchair users' current engagement in their UE health management (Sec. 4.1). Then, we discuss therapists' reported clinical practices for assessing wheelchair

users' UE health (Sec. 4.2). Finally, we present the challenges reported by the participants in their UE health management processes (Sec. 4.3).

As a starting note, we confirmed the previously reported prevalence of UE issues among wheelchair users, as the issues appeared in our study include shoulder pain, rotator cuff injuries, overuse injuries, etc (details in Table 3). All therapists also acknowledged the widespread presence of UE issues among wheelchair users based on their clinical experience. For instance, T2 reported that UE issues are "*the number one reason*" for wheelchair users to seek therapy services from them. And T1 mentioned that wheelchair users can start developing UE issues "*even from the hospital*" when they first acquire a wheelchair. Regarding the significance of UE health, all of the wheelchair user participants believe their UE health is critical to their physical and mental well-being, as it is directly connected with their mobility (W1, W2, W4, W8, W11, W12), independence (W1, W3, W5, W6, W8, W9, W11), quality of life (W2, W3, W7, W10, W12), freedom (W4, W7, W8, W10, W12), etc.

### 4.1 Wheelchair Users' Upper Extremity Health Management Practices - A Cycle of Pain

In terms of wheelchair users' current engagement in their UE health management, we found that pain was prominent and often served as the driving force throughout the process. More specifically, we learned that wheelchair users often find themselves in a cycle of pain which usually begins due to excessive UE-dependent activities and proceed with wheelchair users' expectations of living with UE pain and injuries which is correlated with their perception of an "*inescapable*" UE-dependent lifestyle. Within the cycle, wheelchair users will occasionally assess their UE health based on the severity of pain or their functional abilities. Several injury prevention strategies are also developed to preserve their UE function, including regular exercise or strategically offloading the burden on their upper limbs to assistive tools, wheelchairs' built-in functions, etc. Once pain or functional declines escalate beyond their expectation, they would then reach out to therapists for help and further repeat the above process after symptoms get eased due to overall limited health awareness and inadequate self-management. The overall process is illustrated in Fig 1, and detailed findings are reported below.

**4.1.1 Living with Pain and Upper Extremity Issues.** Similar to one recent study [93] investigating shoulder pain experiences in manual wheelchair users, our participants also shared their lived experiences and the resulting attitudes towards UE pain. However, unlike previously reported negative emotions such as fear and anger, we observed a common expectation of living with pain and high tolerance for UE issues among the wheelchair users. For instance, W4 likens chronic shoulder pain to glasses that some people have to wear every day: "*... , it's like you get up in the morning and put your glasses on. I get up in the morning, my shoulder hurts, and it is just my shoulder, it's just gonna happen. I just kind of accept it and deal with it from there, ...*". And W2 described her way of dealing with pain as "*don't really pay attention to it unless the pain is debilitating*". The therapists also echoed on this common attitude as they perceive wheelchair users to have a high tolerance for pain and are willing to live with a certain degree of pain. For instance, T2

detailed their perception of pain expectation and high tolerance within the wheelchair population:

*“My understanding is that most, if not all, wheelchair users live with some degree of pain. And they’re willing to live with a certain amount, . . . , I believe that most of the time, the expectation in their mind is that it is typical and normal to feel pain.”*

As the interviews progressed, we learned that wheelchair users’ expectations of pain and other UE issues are correlated with their perception of a lifestyle that heavily relies on their upper limbs. For instance, W8 mentioned that the frequent gripping action related to wheelchair use is “inescapable” for manual wheelchair users and will often lead to overuse injuries especially in the wrist. Similarly, drawing on her experience of living in a wheelchair for nearly 40 years, W1 commented on the limited choice that wheelchair users have regarding protecting their UEs:

*“Wheelchair users use our arms for more things than non-disabled people which primarily involving movement, . . . , reaching, stretching the muscle more than non-disabled people would. They can reach higher, they can get themselves in a good position, they can stand on a step stool, they can crouch down to reach something, whereas we don’t really have a choice.”*

**4.1.2 Assessment via Pain or Functional Ability Declines.** In terms of self-assessment, 9 out of 12 participants mentioned their practices of evaluating UE health through the existence or variation in the level of pain they experience, as W8 encapsulated: *“it’s sad, but a lot of times it’s the pain that starts talking to you, saying this is what going on now, you need to pay attention.”*

Half of the wheelchair user participants (6 out of 12) also mentioned that they assess their UE health informally through functional abilities. For instance, W12 mentioned that he evaluates his UE strength from his day-to-day performance in wheelchair transfers, including the required effort and degree of fatigue of each transfer. W8 also explained the way he assesses his range of motion through dressing:

*“[I assess] informally, in the sense of when you’re dressing or undressing, you’re either capable of moving your arm to get your garment on, or you’re not. If all of a sudden I can’t get it back as far as I used to. That’s an indication.”*

All therapists echoed wheelchair users’ reliance on pain and functional declines for the awareness of their UE health, as they perceive most wheelchair users tend to communicate their UE issues or therapy goals from the perspective of pain and limited functional activities. For instance, T1 shared her understanding of wheelchair users’ assessment strategies as:

*“I feel like they only become to know their [upper extremity] health when it’s bad. They know when there’s something that they can’t do, but they used to do, and now they’re having problems with pain or strength.”*

Furthermore, in line with the above mentioned expectation and reliance on pain for UE health awareness, 10 out of 12 wheelchair users reported that they mostly seek rehabilitation services when

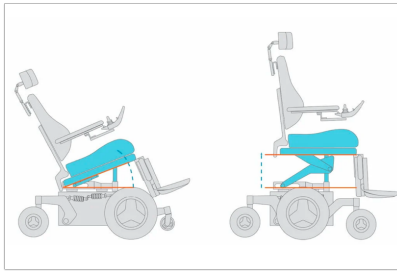
specific UE health issues occur. Therapists echoed on similar problems, as they perceive wheelchair users seek therapy only when they have severe pain or functional decline rather than for preventive health assessments, or they will bring up UE issues when they primarily go for other health issues. For instance, T2 described that wheelchair users generally seek help when *“pain escalates beyond what they expect”*. And T4, who is an occupational therapist and a wheelchair user herself, shared her perceived non-preventive therapy practice among wheelchair users:

*“something that I’ve noticed, just anecdotally, is that people often don’t get help until it’s really bad. You know, they’ll start to get like, a little twinge, and then it’ll be there for years. And then by the time they actually get help is when an injury happens, like if they stopped being able to transfer.”*

**4.1.3 Injury Prevention Strategies.** Other than self-assessment, wheelchair users reported that they employ the following injury prevention strategies to maintain and preserve their UE health:

- **Adopt safe wheelchair techniques.** 5 out of 12 participants mentioned that they will avoid exerting their UE when performing pressure relief by using the specific techniques learned from rehabilitation training, such as leaning forward and to one side. W11 also mentioned that he adopts the efficient propulsion pattern learned from rehabilitation training and tries to maximize his stroke efficiency in his daily life.
- **Utilize built-in power wheelchair functions.** W3 and W6 mentioned that they will use the built-in tilt and recline functions of their wheelchairs to lean backwards and relieve pressure on their lower body. Also, some participants mentioned that they will use their power chairs’ lifting function to minimize the frequency and risk of injury from overhead reaches. For instance, W3 mentioned that she would normally use the seat elevator of her wheelchair to *“raise up to eye level of a standing person”* when reaching for high objects and therefore protects her shoulder. In addition, W7 mentioned that he would adjust the height level of his wheelchair to match the surface to which he transfers, which could help reduce the load on his UEs. For instance, figure 2a demonstrates the tilting and lifting function of Permobil power wheelchair.
- **Utilize external mobility assistance** Wheelchair propulsion is known to be one of the leading causes of overuse injuries in manual wheelchair users. In our study, 3 out of 6 manual wheelchair users (W8, W9, W11) have started using Power Assists in their daily life to reduce the manual propulsion. To illustrate, W8 shared his experience with his Power Assist (as shown in figure 2b) and under what conditions will he use the Power Assist instead of manual pushing: *“ . . . , I only use it [the Power Assist] when I’m pushing a long distance. So for short trips, if I’m going to go to the store, I don’t bother using it. But if I’m going to go to someplace where it might be a mile or so of pushing, then I’ll utilize it just because I don’t need to wear out my arms.”*





(a) Power wheelchair's tilting and lifting functions<sup>1</sup>.



(b) W8's manual wheelchair with a Smart-Drive Power Assist attached on it.



(c) Participant W9's service dog helps her reduce manual pushing by pulling her on flat ground.

Figure 2: Different strategies employed by wheelchair users for UE health maintenance.

Beyond Power Assists, W9 mentioned that she would occasionally ask her service dog to pull her forward on flat ground or slightly inclines which also helps preserve her UE functions, as shown in Figure 2c.

- Strategic Planning.** Several other injury prevention strategies shared among multiple participants were rooted in their day-to-day activities planning. Similar to the reason for adopting Power Assists, W4 shared that he would normally plan the route and activities in advance to avoid over exerting his UEs, such as avoiding uphill and grass. A few participants (W3, W9, W12) also mentioned that they would reduce the load and stress on their UEs by minimizing UE-demanding activities like wheelchair transfers, as W9 mentioned:

*"The transfers I do every day are because I have to do them. I have to transfer from my chair to my bed or from my chair to my shower chair and then I have to transfer back, . . . , I tried to keep my transfers to the essentials."*

In addition, W4 and W8 mentioned their practice of maintaining UE health by making their living environments accessible. More specifically, W8 mentioned that he built an accessible gym at his own house and W4 mentioned that he keeps all kitchen appliances and other essentials low at home for better reachability and therefore reduces the frequency of overhead reach.

## 4.2 Therapists' Clinical Practices

Apart from understanding wheelchair users' self-care engagement, we also investigated therapists' clinical practices of UE health assessment. We learned that in normal assessment sessions, a therapist usually begins by understanding the wheelchair user's daily routines and therapy goal, following some objective measurements including range of motion, certain muscle strength, sensory functions, etc. In addition, another critical part of their assessment is rooted in **body mechanics analysis** of multiple wheelchair-related functional activities, including wheelchair propulsion, transfers, pressure relief techniques, etc. For instance, T2 highlighted the importance of movement analysis in their current practice as it is the basis for iterating diagnosis and home exercise programs:

*"So my goal for day one is movement analysis related to posture analysis, and hopefully trying to connect dysfunctional movement patterns with the provocation of symptoms, . . . , [the treatment will evolve], but it all comes down to movement analysis connected to what-ever hurts."*

In terms of functional activities, all the therapists emphasized the importance of efficient propulsion patterns and transfer techniques for the health of wheelchair users' UEs, especially for manual wheelchair users. T3 further illustrated her practice of evaluating wheelchair propulsion techniques in detail which includes stroke efficiency, push speed, and other body mechanics measurements:

*"... , [the wheelchair propulsion test] it measures not only their speed, but also propulsion effectiveness, like how far they propel with each push. And then it has some observational checkboxes like do they reach back behind on the wheelchair, once they push all the way forward, does their hand come back up, or does their hand drop down below the wheelchair? . . . , do they have a semi-circular type of propulsion pattern, or do they have the half-moon pattern that ends resulting in injury?"*

## 4.3 Challenges of Upper Extremity Health Management

By understanding the above-mentioned UE health management practices, we found that the wheelchair user participants generally face challenges due to a lack of in-depth information about their UE health and complex self-management routines. Here, we highlight the findings regarding wheelchair users' challenges in UE health self-care.

**4.3.1 Limited Wheelchair Skill Training and Health Education Resources.** The limited resources for wheelchair skill training was frequently mentioned by the participants as one huge challenge that hinders their self-care of UE health. Specifically, aligned with the findings from Barbareschi and Holloway [12], most of the participants in our study who have gone through a relatively complete wheelchair training process are spinal cord injury patients. While

<sup>1</sup>Image source: <https://hub.permobil.com/blog/power-tilt-power-recline>



for W2, who are wheelchair-dependent due to Ehlers-Danlos syndrome, she mentioned that most of her learned skills and injury prevention strategies were through “a lot of falling”. Similarly, T3 echoed on the “privilege” of spinal cord injury patients and commented that “for so many other reasons why people end up in a wheelchair, they don’t have the same pipeline and such support from therapy.”

Beyond skill training, several wheelchair users mentioned that it is also hard to find therapists who have sufficient knowledge on treating the wheelchair population and provide relevant UE health education. For instance, W1 mentioned that physical therapists who work with adults with disabilities are hard to find as there are a limited number of knowledgeable therapists, and the demands on their time are significant. W3 also mentioned that she only sees therapists affiliated with rehab hospitals since general physical therapists do not understand her disability and therefore cannot offer helpful therapy and education. W2 further highlighted how her experience with physical therapists varies significantly:

*“my experience with physical therapists [varies significantly], if they’re bad, they’re horrific, and if they’re not, they’re usually good. Like, there’s not a whole lot of middle ground with physical therapy.”*

In terms of UE health education programs for wheelchair users, T2 and T3 mentioned the STOMPS program [74] as the only available exercise program designed for wheelchair users. Further, to our question on the limited availability and impact of UE health guidelines, T2 commented on the challenge of designing broad education and exercise programs for wheelchair users due to the diversity within the population:

*“Even though every human is different, fundamentally I can treat my ambulatory people as pretty similar. But a person who has an L1 complete injury versus a person with the C5 complete, you cannot have broad self-care programs available for those folks, because what works great for one person isn’t going to work at all for another person. So while I have a lot of individuals who are ambulatory do great with self diagnosis, or wellness programs going on YouTube, a lot of that stuff works for them. But you got to be hyper-specific for wheelchair users.”*

**4.3.2 Competing Priorities.** Another challenge we found across multiple wheelchair participants is that they are often struggling with balancing between their UE health and other health issues or between their UE capacity and social engagement. More specifically, due to the limited bandwidth for monitoring multiple issues simultaneously and their varying urgency, most of the time, other health issues and daily activities will be prioritized. For instance, W2 described how her degenerative disease exhausted her mental bandwidth and further led to neglect of her UE health:

*“I do not [pay attention to my upper extremity health], because when you have a disease like I have, you have a zillion things wrong with you all the time, and you deal with the thing that’s causing the most issue. So I pretty much always ignore anything that’s happening*

*above my waist. Because the stuff below my waist, like orthopedically, is always a concern.”*

The therapists also acknowledged the challenge of competing priorities for health monitoring among wheelchair users, as T5 mentioned both bladder issues and pressure ulcers are common among wheelchair users. T1 also illustrated how UE injuries and pain are oftentimes treated as lower priorities than other health issues:

*“other issues are taking priority over their upper extremities, . . . , there are times when people with spinal cord injuries have urinary problems, so it’s like another thing to monitor on top of all these other things [upper extremity health], like you don’t do this, you might end up in the hospital. But if you have a sore arm you may not end up in the hospital, which is not necessarily life-threatening . . . ”*

In addition, W9’s personal experience shined light on how social pressures can also impair wheelchair users’ UE health self-care by forcing them to exert their UEs beyond capacity. More specifically, W9 mentioned that keeping up with able-bodied people can sometimes cause injury as they don’t understand the effort of wheelchair pushing:

*“if I’m dating someone [able-bodied], so a lot of the times I will end up pushing myself for longer than usual sometimes to the point of injury, just a lot of that comes from trying to keep up with a person who can go anywhere, . . . , and a lot of the times they don’t quite understand how much effort that entails.”*

**4.3.3 Limited Body Mechanics Awareness.** Despite that bad body mechanics can be a huge factor to UE injuries, especially overuse injuries, only 1 wheelchair user (W11) reported being consciously aware of his propulsion pattern and trying to maximize his push efficiency in his daily life. Apart from the earlier mentioned challenges of limited education on proper body mechanics and limited mental bandwidth, T2 highlighted another challenge of wheelchair users in being aware of their body mechanics - the proprioceptive difficulty:

*“... , because wheelchair users only have a very specific narrow place to move, so their perception of what an overhead movement or a weight shift might be different than what I think it should be, . . . , I think the hardest part about when they’re on their own is knowing what they’re doing is right and having perceptually and sensory enough feedback to know that they’re in the right place versus continuing to strengthen an impaired position.”*

**4.3.4 External Factors.** There are several external factors, including inaccessible infrastructures, limited adaptive exercise resources, and financial barriers, that spread across multiple contexts also pose challenges in wheelchair users’ UE health self-care. For instance, the participants mentioned that financial barrier prevents them from regularly checking in with therapists as insurance usually does not cover physical therapy services, and inaccessible infrastructure (e.g. transportation, shopping) force them to even further overuse their UEs for essential daily activities.

Beyond those, another external factor, wheelchair fitting, exists and also influences wheelchair users' UE health self-care. More specifically, we learned that wheelchair fitting is highly correlated with wheelchair users' body mechanics, and therefore poorly fitted wheelchairs can cause postural issues or problematic movement patterns of wheelchair users. We found our participants complained about the limited resources of wheelchair fitting and adjustment services. For instance, W11 mentioned that wheelchair fitting can largely affect wheelchair users' range of motion and there is limited recourse, as wheelchair fitting services are difficult to find:

*“some people struggle to get in a chair that is optimally built for them. And if you're not in a chair that is optimally built for your body, you can struggle with the range of motion, ..., and that is an issue for a lot of people.”*

In addition, both T2 and T3 mentioned that female's body structure may introduce additional challenges on wheelchair fitting, as females tend to have wider hips than their shoulders which usually leads to bad arm angles, which can further increase their risk of developing overuse injuries.

#### 4.4 Summary

Within the above three sections, we have so far uncovered wheelchair users' attitudes, practices, and challenges for UE health self-care, as well as the corresponding therapists' clinical practices. Taken together, despite the widely acknowledged significance of UE health among the participants, they often have limited awareness and mostly binary understanding on their UE health. Further, due to challenges like competing priorities, limited health education, and proprioceptive difficulty, they often struggle to perform effective and informed self-care activities. This confirms the unique opportunity for health tracking technologies to enhance wheelchair users' self-awareness and self-management of UE health. Next, we will discuss findings related to desired features and potential benefits of tracking technologies for UE health self-care.

### 5 FINDINGS: NEEDS AND PREFERENCES FOR UPPER EXTREMITY HEALTH TRACKING TECHNOLOGIES

In this section, we present the participants' reported experience with tracking technologies, as well as their desired features of UE health tracking technologies.

#### 5.1 Experience with Tracking Technologies

Unlike other chronic health conditions, there is no existing health tracking solutions for UE health management available on the market. The participants also reported limited experience with fitness tracking devices or applications. Similar to what previous studies have identified [23, 67], many participants expressed their concerns toward the accessibility of commercial fitness tracking devices or applications as they are usually not designed with people with disabilities in mind. Other than that, some participants mentioned that their power chairs or power assists do have some built-in tracking features, as W9 mentioned that her SmartDrive has the travel distance tracking feature and sometimes she will be surprised by

how far she pushed her wheelchair within one day. W3 also mentioned that her Permobil power chair has tracking capabilities for the numbers of tilting back, reclining, etc. Some participants also mentioned that the wheelchair setting of Apple Watch seems to be accessible as it includes roll reminder and pushing workouts, yet W2 commented on her non-inclusive experience of Apple Watch as it does not work well for non-full-time wheelchair users.

#### 5.2 Desired Features

By introducing the concept of health tracking and relevant sensing techniques (e.g. UE motion tracking) to the participants, they further shared their expected benefits of bringing health tracking technologies into UE health management and desired tracking features. Aligned with several general health-related motivations behind self-tracking [30], including making better health decisions, finding balance, and identifying relationships, these findings help illuminate specific design requirements for tracking technologies with regard to wheelchair users' UE health awareness, injury prevention, and self-management during rehabilitation:

**5.2.1 Provide motion awareness.** Corresponding with the importance of wheelchair users' body mechanics and the challenge of motion awareness, 10 out of 12 participants mentioned that tracking and providing feedback on their UE motion may help promote deeper self-awareness of their body mechanics and posture, and further facilitate the learning and adoption of safer mechanics for various UE-dependent activities, including wheelchair propulsion, transfer techniques, exercise, etc. More detailed preferences on relevant tracking metrics are shown in Table 4. Both manual and power wheelchair users indicated similar interests in general biomechanical metrics, such as range of motion and arm usage. However, power wheelchair users indicated less interest in wheelchair transfer-related features compared to manual wheelchair users, which may be correlated with the possession of lift transfer equipment (W3, W5) and sufficient ambulatory ability (W2, W7). Besides, manual wheelchair users indicated higher interests in motion-relevant contextual factors (e.g. terrain and wheelchair condition), which is similar to the finding from Hara et al. [48] that manual wheelchair users tend to be more concerned about environmental barriers, such as reconstructed paths.

**5.2.2 Support capacity understanding.** Understanding wheelchair users' UE capacity is essential for their UE health self-care. All wheelchair user participants mentioned that the tracked UE health data and their trends may help them better understand their UE capacity and further inform activity planning to prevent overuse injuries. 3 participants who are currently doing regular weight training exercises also mentioned that tracked health data can help inform the design and adjustment of their training strategies to avoid overtraining and safely increase UE capacity. Again, many participants believed that novice wheelchair users would benefit greatly from tracking their UE health to achieve a proper self-understanding of their UE capacity with minimal trial and error.

**5.2.3 Facilitate communication with therapists.** Effective communication with the therapists helps to promote patient engagement and confidence, thereby facilitating patients' self-management during rehabilitation [31].

Metrics category	Detailed metrics	Power Wheelchair Users (n = 6)	Manual Wheelchair Users (n = 7)	Therapists (n = 5)
General metrics	Range of motion (active & passive)	W1, W2, W3, W5, W6	W2, W4, W8, W9, W10, W12	T1, T2, T3, T4
	Joint overstretching	W2	W2	None
	Arm usage (e.g. UE joint positions over time)	W2, W5, W7	W2, W8, W12	T1, T2, T4, T5
	Wheelchair skills	None	None	T3
	Muscle strength	W1, W3, W5, W7	W8, W10, W12	T2
Wheelchair transfer	Transfer motion pattern	None	W8, W9, W10, W12	T1, T3, T4, T5
	Transfer frequency	None	W8, W9, W10, W12	T1, T4, T5
Wheelchair Propulsion	Propulsion pattern	N/A	W2, W4, W8, W10, W11	T1, T2, T3, T4, T5
	Push distance	N/A	W4, W8, W9, W10, W11, W12	T2, T3, T5
	Push speed	N/A	W4, W9	T3
	Push duration	N/A	None	T2, T3, T5
	Stroke efficiency	N/A	W4, W9, W10	T3
Contextual factors	Terrain	None	W4, W8, W10	T1, T2, T3, T4, T5
	Wheelchair condition (e.g. tire pressure)	None	W8, W11	None
	Surface texture or level while transfer	None	None	T1, T5

<sup>1</sup> W2 is shown in both the power and manual wheelchair users columns as she uses both types of wheelchairs in her daily life.

**Table 4: Participants’ desired tracking features**

However, similar to the previously identified difficulty of wheelchair users in communicating the pain experience to healthcare professionals [56], W3 and W10 especially mentioned that communicating their UE health conditions and daily usage is often difficult and even stressful, therefore they expect the tracked UE health and motion data to be able to facilitate the communication of clinical visit through objective data and further improve its efficiency.

## 6 DISCUSSION

Our study contributes to an emerging body of work that focuses on the design and development of health tracking systems for wheelchair users. We have provided an empirical account of both wheelchair users’ and therapists’ experiences on UE health management, as well as their perspectives on future UE health tracking technology design. In the discussion below, we reflect on the findings presented above to synthesize the nature of UE health management, derive considerations in designing future UE tracking technologies for UE health self-care, and shine light on future research opportunities.

### 6.1 The Nature of Wheelchair Users’ Upper Extremity Health Management

Reflecting on the uncovered wheelchair users’ attitudes and self-management practices around UE health, we see a clear contrast between their broad consensus on the importance of UE health and their limited UE health awareness. More specifically, despite the negative impacts of UE issues on their quality of life, most wheelchair users reported to rely on pain and ability-level function decline for health evaluation, which often leads to a binary and belated understanding of their UE health. Furthermore, wheelchair users’ expectation of living with UE pain and injury is prominent throughout our data, which is closely tied to their perception of the UE-dependent lifestyle in which they live. These findings further led us to the discovery of a wide range of social, environmental, and intrinsic challenges that lie in wheelchair users’ UE health management. For example, W9 shared how social pressure could force her

to keep up with able-bodied people and therefore overuse her UEs. And many participants complained about the limited resources for wheelchair skill training and the imbalanced distribution even within the wheelchair user population. In terms of environmental factors, many wheelchair users mentioned that inaccessible infrastructures, limited adaptive sports and exercise equipment, and insufficient wheelchair fitting services around their living environment significantly hindered their UE health management. In addition, several intrinsic factors, including the proprioceptive difficulty lying in the nature of human motor cognition and the competing priorities between UE health and other chronic conditions, further complicate wheelchair users’ self-care for their UE health. As a result, wheelchair users will often find themselves in a cycle of pain, which unfortunately serves as the primary perceivable indicator of when and to what extent their UE exertion has exceeded their capacity.

These insights also contribute to a more comprehensive understanding of the practices and challenges lying in wheelchair users’ high-frequency self-care activities, as framed by previous work [73]. The uncovered social and environmental aspects of wheelchair users’ UE health management are aligned with the previously identified complex nature of wheelchair users’ self-care activities. Yet, compared with other high-frequency self-care activities which are often continuum in time, such as pressure relief and bladder management, UE health self-care is arguably intermittent and even more ubiquitous in wheelchair users’ everyday contexts. In addition, the challenge of multimorbidity among the wheelchair user population, which is mostly discussed for older adults [39], has been surfaced through our investigation, as many wheelchair users often face competing priorities across multiple health conditions. These additional factors pose new challenges for relevant technology design. And future investigations on wheelchair users’ self-care activities should recognize those factors when formulating research questions, designing studies, analyzing data, and proposing solutions.

More broadly, inline with the chronic nature of most UE health issues and the prominence of pain, we found similarities between

the identified UE health management practices and people's chronic pain management journey reported by Singh et al. [94, 95]. For instance, acceptance of pain and balancing between being active and overactive is also considered critical for chronic pain management [95]. And the dysfunctional proprioceptive system of people with chronic back pain is identified as a challenge for transferring gains in exercise to everyday life [94]. However, few proactive UE pain management practices were found in the study as the expectation and high tolerance of pain is prevalent among the participants, in contrast to neurological pain management where pain is often more actively managed. Another key difference that distinguishes UE health management from chronic neurological pain management is that while chronic pain is often considered non-curable, UE overuse injuries are theoretically curable and preventable with sufficient effort, as T2 illuminated *"I do believe it (orthopedic pain) can be eliminated in theory. And I've seen miraculous things for the patients who are dedicated. So I see no reason to think that couldn't go away. But it'd be an effort on it."* We acknowledge that wheelchair users may also experience neurological UE pain, but for other types of pain that constitute the majority (e.g. orthopedic pain), there exists a rich design space for technology to scaffold wheelchair users' UE health management and eventually empower them to break the cycle of pain.

Regarding technological influences on wheelchair users' UE health management, we found that many participants adopted Power Assists or power wheelchairs' built-in functions (e.g. elevation and tilt function) as a way to preserve their UE functions in their day-to-day lives. This suggests that technologies have already started playing a role in wheelchair users' UE health management, even though relevant technologies are often designed to improve life convenience in the first place rather than for UE health purposes. In the mean time, we found nearly absent tracking practices for UE health, as most participants reported to be unconfident about the accessibility of commercial fitness trackers and their lack of features dedicated to UE health management.

## 6.2 Key Implications for Designing Upper Extremity Health Tracking Technologies

Informed by the findings obtained through the study, we see a clear opportunity for health tracking technologies to facilitate wheelchair users' UE health self-care and eventually empower them to break the cycle of pain. Specifically, we focus on design implications with regard to augmenting wheelchair users' UE health awareness as well as supporting informed decision-making on balancing UE demand and capacity to achieve better injury prevention and adequate recovery, while with other circumstances (e.g. pain management) in mind. Roughly following the common lifecycle of self-tracking data [76, 104], in which people collect, analyze, and reflect on their health data, below we elaborate each specific implications for tracking technology design.

**6.2.1 Quantify and Qualify the Movement.** As mentioned earlier (Sec. 4.2), wheelchair users' upper body mechanics are directly correlated with the physical demand placed over their UEs, thereby affecting their risk of UE injuries as well as rehabilitation outcomes. While in reality, wheelchair users often fail to consciously stay aware and keep track of this important information due to their

limited mental workload and the proprioceptive difficulty. We see a clear opportunity for UE health tracking technologies to automate such a process by applying appropriate motion tracking techniques. Synthesizing from both the wheelchair users' and therapists' needs, we propose an UE health tracking system should consider including these motion tracking features: 1) passive and active range of motion, 2) arm usage, such as wrist and elbow position over time, 3) frequency and upper body motion pattern during wheelchair transfers, and 4) manual wheelchair specific features (if applicable), including manual propulsion pattern, push speed, push distance, push duration, stroke efficiency, and wheelchair skills.

Here, we see consistency between our work and previous literature regarding tracking metrics. For instance, previous work [24] has identified wheelchair athletes' interest in tracking their push speed and distance for stamina and fatigue management. In addition, existing technical research on wheelchair tracking has also investigated the technical feasibility of quantifying several metrics of interest (e.g. propulsion speed [26, 85, 86, 98] and frequency [17, 80]), which can be adopted for UE health management purposes. Yet, as shown in Table 1, prior tracking research has mostly focused on manual wheelchair users and performance-oriented metrics. In this work, more generalized and quality-oriented motion metrics are further proposed, such as range of motion, transfer and propulsion motion pattern, elbow position over time, etc. We believe that, within the UE health context, the quality of users' movement should be equally important as their quantity, if not more, since inefficient but high quantity movement can significantly increase the risk of overuse injuries. This insight also has a broader implication on the design of inclusive fitness tracking devices. Arguably, current fitness tracking applications are mainly focusing on quantifying users' physical activities and thoughtfully designed to promote users' engagement in physical activities. As wheelchair users' UE health is deeply coupled with their physical activities and more fitness tracking devices are expecting to integrate wheelchair settings, we should be cautious about directly adapting features that were originally designed for the ambulatory population to the wheelchair population. For example, the roll reminder and daily goals for manual wheelchair users might need more deliberation as opposed to a stand reminder for the ambulatory population since inefficient but frequent wheelchair propulsion can potentially lead to overuse injuries.

**6.2.2 Elicit Capacity Understanding.** In overuse injuries, the repetitive demands sustained by wheelchair users' UEs may reduce their tolerance levels to a point where normally acceptable loads can cause failures. The resulting repetitive microtraumas further lead to cascading alterations to UE structural properties and function, which eventually establish a cycle of degeneration and pain [10]. Monitoring wheelchair users' UE mechanics and guiding them to adopt more mechanically efficient patterns is certainly one way to prevent overuse injuries and rehabilitation setbacks. Beyond that, capturing one's UE capacity and arranging related activities accordingly can be equally important. By combining the tracked objective UE usage information with manually logged pain and symptoms, developers may apply appropriate active learning techniques to automatically capture such information and alert users with potential occurrence of overuse injuries. Developers may also

consider further facilitating wheelchair users’ self-exploration on their UE capacity by transforming the collected UE health data to a “prosthetic of feeling” [76]. For example, data analytic tools can be applied here to help wheelchair users better find correlations between UE usage and symptoms. Visualizing the collected motion and UE usage data alongside the occurrence of pain and symptoms could also help wheelchair users better define and manage their UE capacity through long-term practice. However, when designing for self-exploration, developers should also consider balancing the increased mental workload and presented UE health information since many wheelchair users prominently struggle with competing priorities and limited bandwidth. (Sec. 4.3.2).

**6.2.3 Semi-automated Tracking: Promote Engagement and Solidify Experience.** Beyond body mechanics, wheelchair users’ subjective feelings (e.g., UE pain, fatigue, and difficulty in UE-dependent activities) can also reflect their UE health and therefore have great value in day-to-day performance monitoring as well as alerting potential function declines (Sec. 4.1.2). As suggested by previous work [24], it may be possible to infer user fatigue through tracking objective data, such as propulsion speed, heart rate or respiration. Still, information of this nature, especially pain and perceived difficulty, is hard to capture with sensors alone. Semi-automated tracking [29] seeks to support user awareness and engagement in the health tracking process by combining automated data collection with manual input. This framework also applies well here, as developers should consider incorporating manual data logging of wheelchair users’ subjective assessment into UE health tracking applications. For instance, Wheelchair User’s Shoulder Pain Index (WUSPI) [35] has been developed by previous health researchers to measure shoulder pain and related difficulty during basic and instrumental activities of daily living in wheelchair users. The same index can be digitized and prompted to users in a timely manner or whenever relevant activities have been detected by motion sensors. Moreover, manual logging does not have to be limited to the symptoms themselves. The potential triggers or causes to their UE issues as well as things that bring relief to their symptoms can also be integrated into their tracking routine. And we believe this information could further help wheelchair users solidify their epistemic knowledge in UE health management, scaffold self-reflection, and inspire personalized self-care routines.

**6.2.4 Facilitate Wheelchair Skill Learning.** As highlighted by our findings (Sec. 4.2&4.3.1), learning proper wheelchair skills helps ensure that wheelchair users can safely use their wheelchair in the community. Specifically, efficient wheelchair techniques help minimize the demand placed over one’s UEs and therefore reduce the risk of injury. However, relevant training resources are often limited. Acquiring or improving certain skills has always been an integral aspect of any health tracking process [76], developers of UE health tracking technologies may consider embedding certain functions to facilitate such a process. For instance, after detecting inefficient propulsion patterns or unsafe transfer techniques, the system can direct wheelchair users to relevant resources (e.g. online tutorial videos) for education. We also see specific opportunities to combine tracking technologies with motor learning frameworks. The system may provide augmented feedback [90] in visual, auditory, or tactile forms to wheelchair users while they are performing

certain techniques, or visualizations of their movement trajectories after actions are completed to facilitate observational learning [82]. For example, previous studies have explored using 3D animation or motion replay techniques to facilitate dance [59, 97] or sports education [78]. And future work is needed on exploring wheelchair users’ preference for different visualization techniques and their effectiveness.

**6.2.5 Inform Broader Awareness.** We also see a opportunity for UE health tracking technologies to increase wheelchair users’ awareness of the external factors that are relevant to their self-management. For instance, as mentioned in Section 4.3.4, wheelchair fitting and maintenance can significantly affect wheelchair users’ body mechanics. By monitoring wheelchair users’ upper body mechanics (e.g. propulsion pattern, push speed) over time and detecting deviations such as declined push speed or distorted propulsion pattern, the tracking system can alert users to potential needs for wheelchair seating adjustment and maintenance. Similarly, by monitoring the frequency of users’ overhead reach, the tracking system can recommend relevant knowledge on accessible environment modifications. Besides, previous work has explored wheelchair users’ preferences [48] for road accessibility information (e.g. curb ramp, narrow path) and the viability of data collection with crowdworkers [87]. For UE health, we can further combine route information with motion tracking to guide wheelchair users to adopt safer and more efficient body mechanics with respect to different road conditions. However, more fine-grained road accessibility information (e.g. steepness, bumpiness) is not widely available yet. Wheelchair-mounted or body-worn motion sensors may be able to collect such information [57], and more work is needed on further exploring wheelchair users’ preferences for location-based features for UE health management, as well as sustainable ways to collect and integrate those information at scale.

**6.2.6 Recognize Diversity and Support Personalization.** Recalling the findings in Sec. 4.3.1, the diversity within the wheelchair user population poses a great challenge in the design of broad UE health guidelines. In reality, therapists reported that their practices are “client-centered” (Sec. 4.2), as the health assessment and treatment are highly customized to each wheelchair user’s specific conditions and therapy goal. This suggests that, for any UE health tracking system, the diversity within the wheelchair user group should be recognized and carefully considered from the hardware setup, tracking algorithms, health metrics, to the interface design. For instance, the efficient propulsion pattern and safe range of motion may vary between different wheelchair users according to their specific physical impairments, body structure, type of wheelchair, etc. Therefore, any relevant health advice or intervention should be justified on each wheelchair user’s specific conditions. Developers may also consider allowing users to define personalized motion metrics based on their own interests (e.g. the joint overstretching of W2 due to her hypermobility issue), although this may pose higher requirements to the tracking algorithm design, as discussed in later Sec. 6.3.1. Similarly, for wheelchair users who are dealing with multiple chronic health conditions, developers may consider including the data export function or allowing users to integrate other tracking metrics into the system to better support their self-management activities across different conditions. More broadly,

every self-tracking system designed for wheelchair users should recognize the existence of non-full-time wheelchair users and enhance their tracking experience with smooth transitions between different tracking modes. And the need for more fine-grained categorization based on people's purposes or time duration of using a wheelchair remains to be explored in future investigation.

### 6.3 Future Research Opportunities

**6.3.1 Wearable-based Upper Body Motion Capture for Wheelchair Users.** Most existing tracking research for wheelchair users has focused on recognizing and quantifying specific activities with little attention to the quality of movement being performed. Compared to activity recognition, motion capture can bring detailed body mechanics information for qualification, as well as sufficient scalability to support versatility across different activities (e.g. transfer and propulsion) and even personalized motion tracking features. Existing research demonstrated the feasibility of using Microsoft Kinect for transfer motion analysis [105] which however has limited usage scenarios due to the technology form factor. Different from computer vision based approaches, wearable (IMU) based motion capture is insusceptible to occlusion, applicable in both indoor and outdoor spaces, and less privacy-intrusive, which is more suitable for daily tracking purposes. However, existing IMU-based upper body motion capture systems for people with physical impairments rely on dense sensor setup and therefore have poor usability for everyday uses. The state-of-the-art has demonstrated the feasibility of using a single smartwatch to track a user's arm [64, 91] or combining deep learning with sparse inertial sensors for full-body motion tracking [55, 108]. Yet, several technical challenges remain as existing techniques either require users to stay stationary for accurate prediction or a high volume of synthetic IMU sensor readings captured from able-bodied people for model training which doesn't exist for wheelchair users. In addition, existing motion tracking systems usually need sensor calibration before usage. However, the calibration process (e.g. performing N-pose or T-pose [70]) adopted by most existing systems might be inaccessible for wheelchair users who have limited range of motion or muscle strength. Therefore, it remains to be explored in the future on accessible and robust technical solutions for wheelchair users' UE motion capture that suit daily use purposes.

**6.3.2 Collaborative Upper Extremity Health Management through Data Sharing.** Beyond self-care, we also see value in health tracking to support collaborative care on UE health. In line with the potential benefits of facilitating communication between wheelchair users and therapists, all therapists also mentioned that tracked in-field data will be complimentary with in-lab assessment data and can provide unbiased motion and holistic information to inform diagnosis and treatment design. Future work is needed to explore how to efficiently share tracked motion, subjective assessments, and contextual information between wheelchair users and therapists for collaborative UE health management. In addition, even though previous work [68] reported that their participants had no concerns about sharing their health and fitness-related data with therapists, future work is needed to further explore people's privacy preference on sharing automatically-tracked UE motion data, as they are

more fine-grained than psychological or fitness data and inherently contains sensitive information (e.g. typed passwords [102]).

**6.3.3 Reshaping the "Inescapable" Mindset of Pain and Injuries.** Implied by the findings and proposed design considerations, we believe that UE health tracking technologies are inherently persuasive, and future work is needed on running longitudinal studies in real-world contexts to examine the effectiveness of the aforementioned strategies. Besides, apart from continuing investigations on specific ways to encourage and scaffold wheelchair users' UE health management, wheelchair users' mental models on various self-care activities need to be further understood. Previous work defined mindsets as lenses or frames of mind that orient individuals to particular sets of associations and expectations [34]. In our work, the uncovered wheelchair users' expectations of living with UE injuries suggest an underlying mindset correlating wheelchair usage with unhealthy lifestyles which potentially go beyond UE health and extend across other health conditions, such as pressure ulcers, obesity, etc. Existing research suggests that negative mindset reduces people's self-efficacy, self-care engagement, and perceived health [109]. Therefore, better understanding wheelchair users' current mindsets on self-care and related forming factors, as well as defining the optimal mindset to be in, may help inform the technology design and further maximize their effectiveness. In terms of potential solutions for reshaping negative mindsets, prior research has shown that the placebo effect also exists in people's physical health and behavior [33]. Future work may consider incorporating such concepts in technology design (e.g. harnessing the proprioceptive difficulty) to instill positive mindsets.

## 7 LIMITATIONS

In this work, we explored the attitudes, practices, and challenges among wheelchair users and therapists regarding UE health management through semi-structured interviews. Additional findings may be derived from using other qualitative research methods such as observational studies. Also, regarding the participants' demographic distribution, the manual wheelchair user participants are mainly male and spinal cord injury patients. Gender and medical conditions could be correlated with people's attitudes, practices, and perceived challenges, and therefore a more diverse participation population may lead to other novel findings. We also acknowledge that our participants are mostly composed of full-time wheelchair users who have experienced or are currently experiencing UE health issues. Future work could target other more specific populations, such as novice wheelchair users (e.g. acquired wheelchairs less than a year), part-time wheelchair users, or wheelchair users without UE injuries, as they may have different needs and expectations for health tracking technologies. This work also did not consider wheelchair use in different environments such low resource or informal settlements as described in the existing literature [14, 62, 101]. Thus, the perceptions and competing priorities of health management will likely be exacerbated.

## 8 CONCLUSION

In this work, we conducted semi-structured interviews with 12 wheelchair users and 5 therapists to understand their attitudes, practices, and challenges in UE health management. Our findings



highlight the gap between the widely acknowledged importance of UE health and limited practice in UE health management. We further uncover the underlying challenges including limited self-awareness of body mechanics, limited education and wheelchair skill training resources, competing priorities, etc. We discuss the opportunities for integrating tracking technologies with personal informatics into wheelchair users’ UE health self-care to augment the current cycle of pain. We provide design implications for future UE health tracking technologies and illuminate open research questions associated with inclusive wearable-based motion capture, facilitating collaborative UE health management through data sharing, and reshaping wheelchair users’ mindset with longitudinal studies.

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