

# Identifying factors that inhibit self-care behavior among individuals with severe spinal cord injury

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## ABSTRACT

Individuals with spinal cord injury (SCI) need to perform numerous self-care behaviors, some very frequently. Pressure reliefs (PRs), which prevent life-threatening pressure ulcers (PUs), are one such behavior. We conducted a qualitative study with seven individuals with severe SCI—who depend on power wheelchairs—to explore their current PR behavior and the potential for technology to facilitate PR adherence. While our participants were highly motivated to perform PRs because of prior PUs, we found that their understanding of how and when to perform a PR differed by individual, and that while they sometimes forgot to perform PR, in other cases contextual factors made it difficult to perform a PR. Our findings provide insight into the complexity of this design space, identify design considerations for designing technology to facilitate these behaviors, and demonstrate the opportunity for personal informatics to be more inclusive by supporting the needs of this population.

## CCS CONCEPTS

• **Human-centered computing;**

## KEYWORDS

Spinal Cord Injury, Pressure Relief, Self-Care, Assistive Technologies

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## 1 INTRODUCTION

Individuals with severe spinal cord injuries (SCI) may develop a range of impairments and disabilities—such as limited sensation in their hands, arms, elbows, and upper body functions—that necessitate use of power-operated wheelchairs (PWC) [19, 71]. Irrespective of injury level, individuals who have had an SCI need to follow several life-long self-care routines [13], which are complex to perform for PWC users, often requiring assistance from

another individual [22]. Pressure relief (PR) is a crucial and frequent self-care behavior. PUs are necessary to prevent pressure ulcers (PUs) [7, 79]. More than 85% of individuals develop PUs after an SCI, due to life-long wheelchair usage and sitting in the same chair for a prolonged time [7]. PUs often cause hospitalization and result in reduced quality of life [16, 69]. Individuals perform PRs to prevent PU by changing their sitting position manually or with the tilt function of their PWC to redistribute the tissue load. Although PRs are relatively simple to perform, the high frequency with which they should be performed—guidelines call for between two and four per hour [38]—and lack of adequate self-management interventions [7, 83] result in low levels of adherence. Because PRs are important to perform and people find the guidelines difficult to adhere to on their own, developing technology to support adherence to PR guidelines has the potential for important impact.

Unfortunately, current research literature does not provide clear guidance for designing in this challenging context of high-frequency self-care activities for people with a severe SCI. HCI literature has begun to explore self-care behaviors and related assistive technologies for individuals with an SCI and more generally for PWC users [13, 19]. That work shows that, although assistive technologies (e.g., tracking) can support the complex self-care behavior of individuals with an SCI [13], the ability to interact with assistive technologies is limited and challenging, especially for those with severe disabilities [19].

Recent work also shows that HCI research likely excludes participants with a higher level of SCI, particularly those who have multiple disabilities and comorbidities; thus, their perspectives are not represented in research [43]. Therefore, to design assistive technologies to improve PR adherence—a critical self-care behavior for this underrepresented population—research participation from individuals in the target population is essential. Moreover, building an understanding of their current PR practices can provide insights into their perception, motivation, and psycho-social barriers towards improving high-frequency self-care adherence.

The goal of this work is to build insights into how technology can better support high-frequency self-care activities by studying how individuals currently engage in PR behaviors and by exploring their reactions to scenarios that illustrate ways technology might support PR behaviors in the future. We conducted semi-structured interviews and a needs-validation study with seven participants who have had an SCI and currently use a PWC. The interview illuminates current behavior, while the “needs-validation storyboards”—adopted from the *Speed Dating* [88] method—help to understand what latent needs users have that technology might address. We collaborated with SCI experts from our university rehabilitation hospital, including a physician, two engineers, and two occupational

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therapists to develop storyboards for nine imaginary PR-related technology intervention scenarios.

The results of these efforts exposed that, despite high motivation and PR awareness, participants struggle to adhere to PR guidelines for three main reasons: they have varying and sometimes incorrect understandings of how and when to perform PRs, they have difficulty remembering to do PRs in some circumstances, and they encounter situations where performing a PR is difficult either for social or practical reasons. These results also expose important dimensions to consider when designing technology to support PR performance. Our findings highlight the need for dynamic PR reminders to support building PR routines, expose privacy and social concerns of reminder modes, reinforce the importance of chairable interactions for providing convenient control, identify the need to facilitate autonomy, relatedness and competency, and demonstrate an opportunity to apply a personal informatics lens when designing for this and other self-care behaviors.

The primary contribution of this work is a deep understanding of the complex factors that influence how individuals with severe spinal cord injuries perform—or fail to perform—the high-frequency self-care activity of PR and the considerations that designers should make if they intend to build technology to support this behavior. This work also demonstrates an opportunity for personal informatics (PI) tools and approaches to serve individuals who use PWCs, a community that PI research has thus far ignored.

## 2 RELATED WORK

PR is a crucial self-care activity for individuals with an SCI. We explain PR and PU in depth below, review the range of technology designed for SCI self-care routines from an HCI perspective, and summarize the current research on assistive technology for preventing PUs.

### 2.1 Importance of PR adherence to avoid pressure ulcers

PUs are the most frequently acquired secondary complications for individuals with an SCI [23, 27, 75]. PUs are localized damage to the tissue resulting from prolonged interface pressure due to sitting [23, 27]. Around 24% of individuals develop PUs within the first year after an SCI [70], and 85% of individuals who have had an SCI have at least one PU during their lifetime [7, 9, 61, 70]. These life-threatening wounds cause an increased risk of infection [16], complications [69], and negative impact on quality of life [37]. Therefore, learning PU risk factors and following strategies to avoid PUs are crucial for people with SCIs [44].

To avoid PUs, people who use both manual and PWCs need to perform pressure reliefs (PR) by redistributing or repositioning the sitting pressure and tissue load [8, 47, 72]. According to general clinical guidelines, both frequency and duration of PRs are crucial and should be performed regularly: depending on the individual's injury level, typically two to four times per hour for one to two minutes each [38, 64]. Although PUs are one of the most dangerous complications that individuals with an SCI can have [49], PR adherence is typically inadequate [7, 83]. A study on the sitting behavior of full-time wheelchair users found that none of their participants routinely performed PRs [76]. PR performance is typically

self-reported both to researchers and clinicians, leading to uncertainty and unreliability in collected data [9, 48]. Taken together, the literature points to a problematic disconnect: regularly performing PRs is very important but adherence to these guidelines is low. This presents an opportunity to explore human-centered solutions that might facilitate better PR adherence.

### 2.2 Challenges to routinize and improve PR adherence among individuals with an SCI

The low levels of PR adherence described above suggest that people encounter challenges when trying to adhere to PR recommendations. However, research has yet to explore in detail what these challenges are. Although individuals with SCIs develop multiple chronic health problems resulting from their SCI that require routine self-care practices—loss of bladder and bowel control, pressure injuries, respiratory issues, and muscle stiffness—B'uy'ukt'ur et al. [13] found that PR is least routinized among these self-care activities. The primary reason given is that “*completing the activity is bothersome, the consequences are not salient, or the activity is, by nature, one that people easily forget.*” They also reported that individuals with SCIs develop their own routines of self-care activities (e.g., PR) over time depending on personal, emotional, and social contexts. Sprigle et al. [78] further unpacks barriers to self-care, finding that people with an SCI encounter contextual changes after acquiring the injury such as returning home after rehabilitation, changes in equipment or home environment, and changes in functional abilities, health, or job status. These changes can impede the routinization or adherence to PR behaviors.

In addition to these contextual and behavioral factors, wheelchair selection and usage can impede the routinization and improving PR adherence among individuals with an SCI, including selecting the wrong type of wheelchair, adapting to a new wheelchair, wheelchair adjustments, staying in the wheelchair for long periods of time, malfunctioning of wheelchair equipment, and using the wheelchair in unplanned or undesirable situations [30]. The challenges described above capture at a high level the challenges people might encounter when performing PR, and they suggest that the routinization of PR and improving PR adherence are complex, highly individualized, and dependent on contextual factors.

This past work provides a strong basis for understanding how difficult it can be to routinize PR behavior, but misses some of the depth and nuance of individual lived experiences with incorporating PR behavior into everyday life over the long term. We build on this past work by engaging with participants who use PWCs to understand their lived experiences with respect to PR. Further, we use this past literature to motivate nine speculative scenarios for how future assistive technologies could help this population adhere to PR recommendations, which we used with participants to elicit deeper insights into the challenges they face. Here, an HCI lens is critical to ensure that assistive technologies for PR adherence are designed and evaluated with a deep understanding of everyday practices and aim to foster reflection and awareness through health and contextual information [62]. Our findings reveal new insights into how individuals differ from each other in their perceptions of PR timing, the way they perform the PR, and additional contextual factors and considerations they encounter when performing PR. Of

particular note, our participants explained situations where they did remember to perform a PR, but despite remembering to do it, still avoided performing one.

### 2.3 HCI research with wheelchair users

While PR performance has not been deeply explored in the HCI literature, wheelchair users have been studied in other contexts—including physical activity and fitness tracking—that inform our research of performing self-care activities [2–4, 19, 33, 56]. Mason et al. found that manual wheelchair users often abandon physical activity and health behaviors that are highly visible and do not provide immediate benefits due to the complex norms of social pressure and expectations [56]. Similarly, other research has also found that people with upper body impairments, especially those who use PWCs, often discard or choose not to use health and fitness tracking technologies because technology is not always accessible [18, 53] or they feel it will make them stand out or feel abnormal [19]. Gerling et al. [33] found that users' different levels of disabilities impact their level of control over their PWC; that work focused on game design, but the findings suggest that technology designed for this population must consider a variety of individual factors and accommodate a range of users' functional abilities.

Carrington et al. [19] explored the concept of chairable form factors for PWC users to accommodate an individual user's abilities and needs. The main idea of chairable technology is to integrate input and output systems into the body of the wheelchair in a one-off, individualized configuration. The findings illustrate a variety of design considerations for implementing chairable interfaces, and also underscore the role of the wheelchair as a very personal item, which at least one participant described as their "home."

The human-centered work described above reveals important findings that inform the design of technology for power-wheelchair-user populations, but a gap remains between this work and the self-care findings of B'uy'ukt'ur, et. al. described earlier [14]. How might the combined insights from research on how users inhabit and interact with wheelchairs and research on lower-frequency self-care activities come together to better support high-frequency self-care activity of performing 30 to 50 PRs per day? There are likely different considerations to account for in the context of this higher-frequency activity, which is a core focus of this work.

### 2.4 Assistive and Tracking Technologies for improving PR adherence

Despite the lack of deep human-centered insights on barriers to PR performance, clinical researchers have developed and deployed assistive technologies that aim to reduce the risk of developing PUs among individuals with an SCI by providing PR reminders [39] or by employing assistive mechanisms that reposition the wheelchair to perform a PR [77, 79, 82]. Clinical research on PR adherence has also investigated a broad range of prevention tools including educational materials [11, 66], feedback through mobile applications [39, 74], interface pressure mapping (IPM) [84, 87], electrical stimulation for improvements in tissue tolerance [10, 45], and tele-medicine programs [67]. *None of these approaches have independently led to sustained improvement in PR adherence*, which suggests that the barriers to PR adherence are not yet well-enough understood.

Prior research has also shown that assistive technologies often fail to facilitate adherence to health behaviors due to a combination of behavioral and physiological factors [36, 82]. Assistive technologies often act as symbols of stigma and barriers for people with disabilities to interact socially, as they do not meet normative expectations [41, 58]. Thus, to improve PR adherence, there is a need for personalized solutions that address the contextual factors impacting an individual's PR performance including in social contexts [77, 82]. The efforts above to develop assistive technology to support PR adherence do not engage a human-centered perspective. People's own perspectives on their PR behavior are currently missing in the literature, and these human-centered insights can provide invaluable guidance to develop future technology or other interventions to facilitate PR adherence.

### 2.5 Adopting a human-centered perspective for PR adherence

Individuals who have had an SCI and use a PWC are underrepresented in HCI research and in technology-based tools [18, 19, 43]. In particular, we are unaware of any human-centered research to assess user needs for facilitating PRs, which are a crucial self-care behavior. It is essential to understand different personal and contextual factors and barriers such as source of motivation, level of awareness, perception, process, and surroundings [65, 68] that can lead to variations in PR performance. However, due to a higher level of injury, the position and reachability of assistive technology is especially critical for PWC users [19, 31] and must be considered while designing assistive technology [32]. A key objective of this work is to understand the potential for technology to assist this population with adopting and maintaining PR behavior and explore their needs to improve PR adherence. In this study, we aim to address the following research questions:

- RQ1** What are the current PR practices of individuals who sustained an SCI and are dependent on a PWC?
- RQ2** What design considerations are important when designing technology to improving PR adherence?

## 3 STUDY DESIGN

This study combines semi-structured interviews and needs-validation storyboards from the *Speed Dating* method [25, 88] to explore our two research questions. We chose these methods—and adapted them when necessary—to be appropriate for participants who had an SCI and different disabilities and comorbidities, in response to guidance from the literature [43, 50]. In this section, we describe how we designed our storyboards through an iterative process with stakeholders, considerations in our method for this participant population, our data collection, and our analysis process.

### 3.1 Iterative storyboard development

To design a range of possible scenarios to help understand our target users' needs, we adopted the needs-validation storyboard approach from the *Speed Dating* [25, 88] method. In *Speed Dating*, researchers use storyboard scenarios to investigate participants' needs, experiences, interactions and preferences. While designing speculative futures, it is sometimes difficult to find a clear path

**Table 1: Origin of the scenarios based on literature and opinions of expert collaborator team**

Scenario	Concept portrayed in scenario	Literature that motivated the scenario	Collaborator feedback
S1	Vibration in the armrest as reminder	Chairable Form Factors [19]	Social setting - alone
S2	Blinking Light as reminder	Chairable Form Factors [15, 19]	Social setting - with friends
S3	Mobile application, virtual-coaching, push notification, outdoor environment	Virtual-coaching and feedback [39, 74], Reminder notifications [86], accessibility in different places [59]	Outdoor environment
S4	Self-goal-setting, data sharing	Self-goal-setting [14], involving others [56]	Data shared with therapists
S5	Collaborative tracking, mobile application	Collaborative tracking [13, 14], involving others [56]	Collaboration with partner
S6	Headrest- mounted audio notification	Chairable Form Factors [19], audio notification [87]	Reminder while sleeping
S7	Blinking Light	Chairable Form Factors [19]	Other activity - Bottle holder
S8	Reminder based on location in house	Chairable Form Factors [19, 56], accessibility in different places [59]	Indoor environment
S9	Sensing sitting mat on wheelchair	Chairable Form Factors [19]	Data directly transferred to caregivers

towards a possible and preferred design without understanding users' needs: what people might be willing to do and what they desire for the future [88]. We adopt the *Speed Dating* method in our study to elicit users' reactions, not to propose technologies that we should build. *Speed Dating* is an especially good fit for this work as it enables participants to critically reflect on their needs and constraints in the context of the scenarios provided without the burden of real technological implementation [88]. However, for this method to be effective, the choice of scenarios and the way they are portrayed in storyboards are both critical. In this subsection, we describe our iterative storyboard design process.

We started the brainstorming process by identifying two primary sites for interaction: 1. mobile applications, since past work on PR reminders focused on mobile applications [39, 86], and 2. interactions integrated with the wheelchair itself, drawing inspiration from Carrington et al.'s insight on the potential for chairable interfaces [22]. Within each category, we identified different approaches to supporting PR that would be appropriate for that platform, drawing inspiration from past literature (see Table 1. For mobile-application based scenarios, we identified reminder notifications [86], virtual-coaching and feedback [39, 74], self-goal-setting [14], and collaborative tracking [13, 14]. For wheelchair-based scenarios we identified vibration reminders [19, 22], visual reminders using a blinking light [15], head mounted audio notifications [19, 87] and a pressure sensing sitting mat [33]. Using this literature, we worked with our expert collaborators—a physician, two engineers, and two occupational therapists (OTs), all of whom work with individuals with SCIs—to brainstorm 14 PR-related technology-based scenarios.

To increase the empathetic connection between participants and our scenarios, we followed guidance on speed dating [25] and developed fictional stories around the approaches listed above. For each scenario, we discussed the specific literature with our collaborators and decided on the stories. For instance, the scenarios based on a vibration reminder (see Figure 1) in the wheelchair armrest (scenario S1), and blinking light reminders in different parts of the wheelchair body (scenarios S2 and S7) for doing PR were inspired by Carrington et al.'s [19, 22] chairable form factors. One OT collaborator noted the importance of water intake for reducing the risk of PUs. That inspired us to imagine a blinking light in the bottle-holder that is integrated into the PWC (scenario S7). Similarly, in scenario S5, the idea of collaborative tracking came from B'uy'ukt'ur et al. [13, 14] and our physician collaborator suggested that he thought his own patients might be interested in tracking with intimate partner—an idea that we integrated into S5.

We tweaked the stories to accommodate different triggers, notification modalities, interaction mechanisms, purposes (e.g., reminders, feedback, increase motivation), and contexts (see Table 2). We identified different contexts for these stories to take place in, varying factors including: location (in a public place or at home) [59]; social context (alone or around/with other people) [56] and concurrent activities (busy with work or sleeping—suggested by the expert collaborators). We converted these scenarios into storyboards that we illustrated using license-permissive pictures of individuals using PWCs. We used Adobe Photoshop to apply a filter on the images to make them more abstract with the goal of supporting participants to imagine being in those situations themselves.

We received multiple rounds of feedback on our storyboards from our expert collaborators. In particular, the OTs indicated that nuanced details about the type of wheelchair depicted and the blurring of a wheelchair user's face might be negatively interpreted by participants. We adjusted the storyboards in response to be sure we were portraying realistic PWCs and that we were not blurring faces. We also conducted two pilot studies with two researchers who had each worked with an SCI population for more than three years. Our experiences in both pilot sessions led us to reduce the number of scenarios to minimize participation fatigue. We reduced the scenarios from 14 to nine. To do this we identified repetitive concepts—vibration reminder and audio notification in the outdoor environment, blinking light in the wheelchair armrest, sharing PR data with partner through mobile application and mobile notification in different places inside home. We removed those repetitive storyboards to retain a broad range of different scenarios. Table 2 shows the technology dimensions of our final storyboard design, and all nine can be found in the supplemental materials associated with this paper. We also provide detailed tracing of all of the sources of the final scenarios in Table 1.

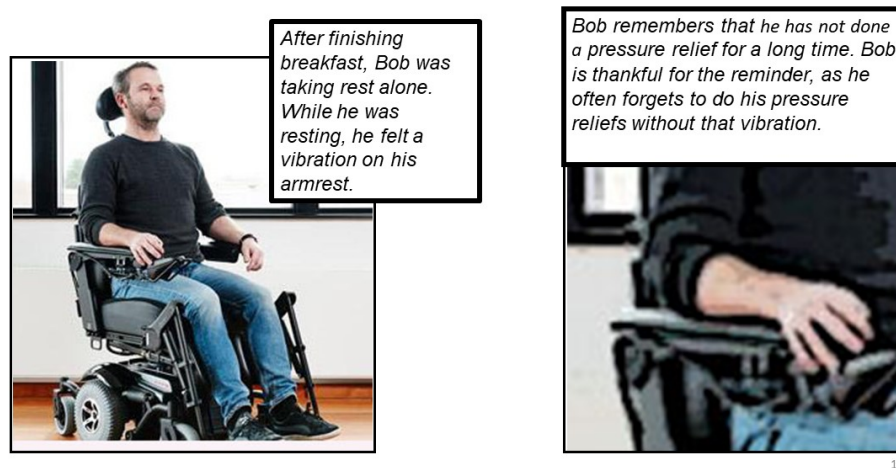
### 3.2 Recruitment

Our recruitment process started in March 2021. We recruited seven participants (six male and one female) who had an SCI and used a PWC. Our collaborators at the rehabilitation hospital helped this effort by posting our recruitment materials on their monthly newsletter (a broad distribution newsletter focused on active living for individuals who have had an SCI) and on their Instagram page to reach out to the potential participants. The inclusion criteria were: (1) 18 years or older, (2) had an SCI in the past, (3) use a PWC, (4) is capable of making informed consent, and (5) not currently an inpatient in an acute care or rehabilitation hospital. Notably, the newsletter recipients and the Instagram page members are geographically distributed across North America.

**Table 2: Overview of dimensions represented in our storyboards. \*CG= Caregiver**

Scenario	Trigger	Modality	Interaction	Purpose	Social setting and context
S1	Auto + no PR for long time	Vibration	Chairable: At armrest	PR reminder	Alone
S2	Auto + no PR for long time	Blinking light	Chairable: Wheelchair body	PR reminder	With friends/public
S3	Auto + performance of last PR	Push notification	Mobile application	Virtual coaching and feedback	Alone
S4	Self-initiated	Self goal-setting	Mobile application	Self-awareness	Alone, shared data with therapist
S5	Self-initiated	Collaborative tracking	Mobile application	Improved motivation	With partner
S6	Self-initiated	Audio notification as alarm	Chairable: Headrest	PR reminder	Alone, during sleeping
S7	Auto + combining with other activity	Blinking light	Chairable: Bottle holder	PR reminder	Alone
S8	Auto + specific location in the house	Beep notification	Chairable: Joystick	PR reminder	Alone
S9	Auto+ no PR for long time	Verbal reminder from CG	Chairable: sensing sitting mat	PR reminder	Shared data with CG

### Scenario 1: Vibration in the wheelchair armrest



**Figure 1: Storyboard for S1, where the user is automatically prompted to do a PR with a vibration in the wheelchair armrest**

We received eleven total recruitment responses between March and June 2021 and identified seven of those respondents as people who entirely depend on PWCs for mobility (the other four use both manual and PWC). PWC usage was important in this context, as PR behaviors differ substantially between PWC and manual wheelchair users. While more participants would have been desirable, literature on doing research with an SCI population cautions that there are many barriers to participation for these participants, and recognizes the importance of every individual’s perspective [43]. Thus, we determined that seven participants was an acceptable number.

We collected participants’ verbal consent to participate in our study as approved by our institution’s IRB. Table 3 shows basic information about our participants, who had a diverse range of injury levels and comorbidities, multiple histories of PUs, different periods of time since their initial SCI, and different experiences with PWC. Each participant was compensated with a \$15 Amazon gift card for participation.

### 3.3 Study Procedure

We conducted all study sessions over Zoom [89] both to comply with university and federal COVID-19 guidelines, and to facilitate reaching our geographically dispersed set of participants. We scheduled the sessions according to participants’ convenience—two were rescheduled due to participants’ medical emergencies. All communication was email-based except for P7, who preferred text messages. We conducted semi-structured interviews first, followed by the needs-validation storyboard session. We shared our storyboard slides with participants using the Zoom screen-share feature. We offered participants a break or the option to schedule another time for the needs-validation study if they felt fatigued; all preferred taking small breaks (2 to 5 minutes) for PR and continued with the study. We did not explicitly collect any clinical information on participants’ injury, ability, or comorbidity during or before our study; we report information that participants voluntarily shared during the session or while demonstrating their PR practices (Table 3). Our study procedure was approved by the University of Utah IRB.

The semi-structured interviews focused on how participants learned about PRs, current PR behaviors, their confidence in those

behaviors, and personal and contextual barriers in performing PR. The full set of questions are in supplemental materials. We started with demographic information including age, gender, occupation (if any), year of SCI, PU history, number of years using PWC, and their estimate of average time spent in the wheelchair per day. We also asked about other self-care or non-health-related behavior tracking and their frequency of smartphone and personal computer usage per day (ranked on a scale of 0 to 5) (see Figure 2). In the needs-validation study, participants shared their reactions to the scenarios and their associated perspectives that they felt informed their reaction, such as: convenience, preferences, thoughts on how variations of the scenario might change their reaction, and barriers that they foresaw for each storyboard scenario.

While collecting demographic information, we identified that P3 and P4 had some speech difficulties. We confirmed this with them and adjusted several questions to accommodate shorter responses, following guidance from the literature [43]. P3 and P4 each sometimes shared their perspectives using only a few words (“vibration best” (P3), “only missed reminder” (P3), “cannot feel armrest” (P4), etc.). We looked out for situations where we inferred additional information based on their short answers, and followed up to confirm our assumptions and interpretations by asking similar questions: “among all the other modes, do you prefer vibration most?” (P3), “do you want reminders for each PR?” (P3); and received “yes” or “no” answers. The average duration of each session was 65 minutes. We recorded all sessions using Zoom’s recording feature with the permission of our participants.

### 3.4 Data Analysis

We transcribed the Zoom recordings using Otter.ai [63] and employed inductive thematic analysis [12] to analyze transcribed data. We started by reading through the seven transcripts (interview and storyboard study) carefully and coding the transcripts in spreadsheets. One researcher coded the transcripts and progressively discussed the codes with each of the other two researchers. We extracted a total of 670 codes from the seven transcripts. Next we transferred all codes into digital sticky notes using the brainwriting function of Miro [57]. Two researchers grouped all the codes in Miro iteratively. We identified 26 themes from the several iterative rounds of analysis, such as “worst scenario for PR”, “reminder should be private”, and “independence is preferred”. After each iteration, we reviewed the grouping as a research team to verify consistency and made adjustments when necessary. By the end of the process, we had consolidated 10 high-level themes to answer our research questions. For RQ1 (current PR practices), we generated six themes on PR-related activities: *motivation and awareness, perception, remembering, performing, barriers, and uncertainty with current practice*. For RQ2 (design guidelines for improved PR adherence), we identified four themes: *purpose, modalities, interaction, and social-setting*.

Additionally, while doing the inductive analysis, we found that the codes under the theme of *social-setting* reflected participants’ need for: *independence and autonomy; connectedness* with their family, friends, caregivers and therapists; and to have and demonstrate *confidence and competence* in their PR behaviors. During this analysis we recognized the similarities of these codes to the core

concepts of Self-Determination Theory (SDT) [73] – concepts of autonomy, relatedness, and competence for “*people’s inherent growth tendencies and innate psychological needs for their self-motivation and personality integration*” [73]. Thus, even though we approached our analysis following an inductive coding process, we report the theme *social-setting* through the lens of the SDT concepts of autonomy, relatedness, and competence to facilitate better connections with the literature. The next section describes the resulting themes of our inductive thematic analysis in detail.

## 4 FINDINGS

Our findings revealed a wide variety of current PR practices, reflections on those practices, and reactions to the scenarios portrayed in the storyboards we presented. Participants communicated a complex set of factors that impact their PR performance, and important considerations for technology that aims to support that performance. We discuss these findings below in more detail. We first discuss RQ1—current PR practices (section 4.1), then RQ2—factors for design implications (section 4.2).

### 4.1 Current PR practices

All of our participants had previously developed PUs on multiple occasions. As a result, all participants stated they are highly motivated to improve their PR adherence, driven by their own prior experience of the pain and misery of a PU and the fear that they would develop another. However, differences in their understanding of how and when to perform PRs, difficulty remembering to perform PRs, and contextual factors that put them in inconvenient and awkward scenarios made participants uncertain about their current PR adherence and the potential to sustain future PUs. We discuss these themes to answer RQ1 in the following subsections.

#### 4.1.1 Fear of PUs motivates PR awareness and lifestyle changes.

For all participants, fear of PU, pain, and suffering are the biggest motivation for improving PR behavior. For instance, the pain and misery of PU drive P1, P2, P3 and P6 to do timely PRs: “*it’s fear that keeps me doing it*” (P1). Likewise, P4, with a current PU, is very concerned about doing PRs correctly to avoid another PU. P5 observed that “*people will not get the importance of PR until they get some pressure ulcers*”. Additionally, P1, P4, and P5 have each endured the miserable experience of having flap surgery<sup>1</sup>, fueling additional fear of PU. P5 had to wait for a year for the surgery schedule, making her skin and bone very fragile in that PU area. Furthermore, P7 has had a PU on his back continuously for the last two years, forcing him to spend long periods of time in bed and significantly diminishing his quality of life. Thus, fear of PUs motivates all participants to be aware and prioritize PR schedules in many situations, for example while in vehicles, out in public, and during meetings at work: “*if I’m in a store with my family, I gotta stop, [and do PR], or if I’m in the car when it’s time to do a pressure release, you know, ... whoever is driving, pull over*” (P1)

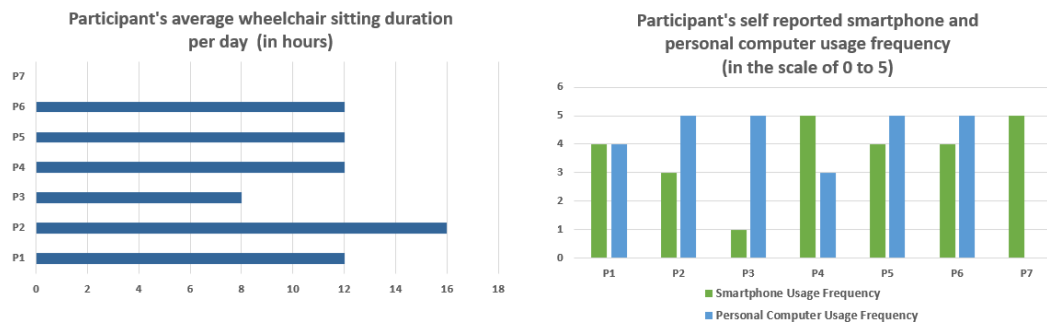
In addition to performing PRs, participants also adopted other changes to avoid further PUs, including: reducing wheelchair sitting duration (P1, P2, P4, P5, P6), obtaining or replacing customized wheelchair cushions and backrests (P1, P3, P5, P6, P7), changing

<sup>1</sup>Flap surgery involves taking a section of skin with an intact blood supply and placing it over the ulcer area [6]



**Table 3: Participant demographic information, year of sustaining an SCI, number of years using a PWC, PU history, current health condition and comorbidities, (\* indicates current PU)**

Index	Age	Gender	Occupation	Year of SCI	Years of PWC usage	History of PUs	Health condition and comorbidities
P1	56	Male	Computer Programmer	1986	13	5 times(1991, 1994, 2001, 2008, 2016)	C4 Quadriplegic, less hand functionality
P2	40	Male	Research Librarian	2009	11	4 times (2009, 2014, 2016, 2019)	Has enough hand functionality to operate the wheelchair joystick
P3	77	Male	Retired	1998	10	2 times (2005, 2020)	Had brain surgery, speech difficulties
P4	36	Male	Part time artists	2017	2.5	2 times(2017, 2021*)	Complete quadriplegic, compressed C3 through C5 and fractured C4, had flap surgery, speech difficulties
P5	52	Female	Retired	1985	10	2 times (1986, 2005)	Complete paraplegic, 2 times flap surgery, can lift her body
P6	63	Male	Retired	1983	18	Once (2016)	Incomplete paraplegic, mild dementia from a head injury, can lift his body
P7	33	Male	Unemployed	2007	13	3 times (2007, 2010, 2021*)	C4, C5 spinal cord injury

**Figure 2: (Left) Participants' self-reported average number of hours per day spent in their wheelchair (P7 was unable to provide data); (Right) Participants' self-reported smartphone and personal computer usage frequency in the scale of 0 to 5, 0 = does not use at all; 1= very infrequent; 2 = infrequent; 3 = moderately frequent; 4 = fairly frequent; 5 = highly frequent**

water and food intake (P1, P2, P6), and having someone regularly check their skin for early indications of a PU (P1, P6). Additionally, P5 takes extra cushions during long drives, and P7 quit smoking to hasten recovery from a PUs. Furthermore, while sleeping, participants (P2, P4, P6) keep themselves reclined in the wheelchair for a more even pressure distribution. Thus, each participant enacts their own set of strategies to make changes in their lifestyles to prevent future PUs.

**4.1.2 Understanding of how and when to perform PR varies dramatically.** Table 4 shows how participants' understanding of PR differed from each other and that they learned about PR from different sources. Participants' understanding of how to perform a PR evolved and varied as well. For instance, P1 and P5 recalled that PRs should be performed once every hour (well below current medical guidelines); P2 and P4 believe they should perform PRs every 15 minutes; P3 and P7 said they should do one every half an hour; P6 responded that once in every four hours would be enough for him. Similarly, participants have diverse perceptions regarding PR duration. Rather than representing participants' real-world behaviors, these represent what participants understand to be the ideal PR behavior. Thus, not having consistent resources and being on their own after being discharged from their rehabilitation hospital made considerable differences in PR their understandings of how and when to perform PR.

**4.1.3 Remembering PR by visual cue or internal sense of time, but mostly by the pain.** No participant reported using any technology or alarm to remember, track, or record their daily PRs. Instead, participants rely on visual cues, their own internal sense of the passage of time, or physical pain and discomfort to remember to perform a PR. For instance, four participants (P1, P3, P4, P7) follow visual cues - P1 keeps a table clock in front of him at his desk, P3 follows the clock on his wheelchair screen, and P4 and P7 use their internal sense of time as a trigger to check a clock: "I keep a mental note of the hours. Sometimes I might be a little late or a little early, but I just try and keep a mental note of the last time I did it like I did at 9:30. Okay, I'm gonna do the other one at 10:30" (P4).

In contrast, P2 relies only on his internal sense of time and does not check a clock; he acknowledged that he ends up forgetting PR frequently. Likewise, P5 and P6 both noted that PR has become more routinized for them because of their long-term experience with their SCI, and thus that they do not think about it explicitly—P6 keeps his PR goal in mind: "it's [PR] in my head, it's becomes ingrained"; and P5 does PR whenever she remembers: "I often don't think about it [PR] and all of a sudden, it's like, oh, yeah".

With some sensation in the back, many participants (P1, P2, P5, P6, P7) primarily remember to do a PR when they feel pain, spasms, or other irritation. For instance, P1 can feel the pain if he does not do PR for a long time. Similarly, P2 can feel the pain and does PR accordingly: "when I kind of in a little bit more pain or a little bit more irritated... That's when I'll go ahead and do a pressure relief".

**Table 4: Participants' perceptions of ideal PR behavior**

Index	Sources of learning about PR	Perceived ideal PR frequency	Perceived ideal PR duration (minutes)	Comments
P1	Rehab hospital and own research	In every hour	5 to 10	NA
P2	Rehab hospital	Once every 15 minutes	NA	Cannot recall any specific duration
P3	Rehab hospital and wheelchair company	Once every half an hour	1	NA
P4	Rehab hospital and own research	Once every 15 minutes	2	NA
P5	Rehab hospital and own research	To lift up every hour	NA	Cannot recall any specific duration
P6	Wheelchair manual, own research and peers	Once every four hours	20 seconds	Learned everything about PR on his own
P7	Rehab hospital and own research	Once every 15 or 30 minutes	1 or 2	NA

Likewise, P5, P6, and P7 remember PR by sore backside (P5), pinches on the backside (P6), and violent spasms (P7). *"I have a sensation. In that sense, when I get some spasms, which also alert me to get up [PR], I really feel different after [doing PR]. It feels better"* (P6).

Thus, participants follow their own intuition or body signals to remember PR without any reminder or tracking technology, leading to irregular PR performance that is below medical guidelines. Participants acknowledged this mismatch and noted that they would like to adhere to the guidelines better, but were unsure of what additional strategies to employ that would increase adherence.

**4.1.4 PWC tilting functionality aids PR, while manual PR processes are burdensome and irregular.** Five participants use the PWC's tilt function for PR with either hand-controlled (P1, P2, P3, P6) or mouth-controlled (P4 Figure 3) joystick (see Table 5). Among them, P1, P2, P3, and P4 depend entirely on the wheelchair tilting functionality to perform PR: *"PR was almost impossible without [a] tilting PWC"* (P1). P2 also uses a reclining bed for performing PRs.

In contrast, P5, P6, and P7 perform PRs manually in different ways, which are burdensome and lead to even more sporadic PR performance. For instance, P7 does not have a tilting function in his PWC due to lack of insurance coverage. He thus repositions himself by tilting his head back or legs out and moving cushions around. That makes doing PR burdensome and demotivating, and this manual approach is likely to lead to improper PRs. P5 and P6 each lift themselves for a few seconds (well below the recommended duration) and change sitting posture and position often by reaching forward to redistribute the pressure. These manual PR methods are burdensome, thus leading to PRs that are being performed incorrectly, and even less frequently: *"even with my experience [of PUs], I don't do it [PR] every hour"* (P5). Whether by necessity because of lack of tilting functionality (P5 and P7) or personal preference (P6), performing manual PRs represents an additional barrier to proper PR performance.

**4.1.5 Loosing track of time or skipping PR for inconvenience or awkwardness.** All participants expressed that they did not meet PR guidelines for a variety of practical reasons, either by accident by loosing track of time or purposefully skipping PRs because of inconvenient times or places or social awkwardness associated with performing a PR (see Table 6).

**Failing to keep track of time.** All participants stated they often forget to perform PRs because they lose track of time. For instance, when away from home, P1 does not have a clock in front of him, P3 cannot easily see the time on the wheelchair screen in the daylight, and P6 loses track of time when focusing on other things outside the home. In contrast, P2 and P7 often forget PR at home

when focused and busy with their work, phone, or computer: *"when I'm playing on my phone, doing my own thing [at home] that's kind of when I forget to do pressure releases"* (P7). P5 forgets about PR both inside and outside the home due to losing track of time, different distractions, and being busy with phones and computers. Notably, P4—who has speech difficulties—also loses track of time both inside and outside the home; however, he did not provide a specific reason on this point and preferred to move to the next question.

**Inconvenient times during other health behavior.** Three participants (P2, P4, P5) deliberately avoid PRs at inconvenient times—during lunch or breakfast time (P4) because of disturbance in eating; while a water cup or bottle is on the wheelchair (P2) as water may spill with the wheelchair tilting, and in the evening time (P5) due to tiredness after being in the wheelchair the whole day. Moreover, while sleeping, participants (P1, P2, P3, P4, P6) avoid PR because they prefer not to wake up.

**Inconvenience due to insufficient space.** P1 and P7 are uncomfortable doing PR in public places because performing a PR takes space and when in public they are unsure of their surroundings. P1 avoids PRs in church, shopping malls, or in transit due to lack of space: *"I always make sure I'm someplace where I'm out of [other people's] way, and it's not gonna be a problem [to tilt]"*. Similarly, doing PRs in vehicles or shopping malls is uncomfortable for P7. *"... I had to go up on a paratransit bus (wheelchair accessible bus). And I needed to tilt [PR], the guy [bus driver] started getting kind of mad ... In any transit, you know, even like [in] my van, there is just no room [for PR]"* (P7).

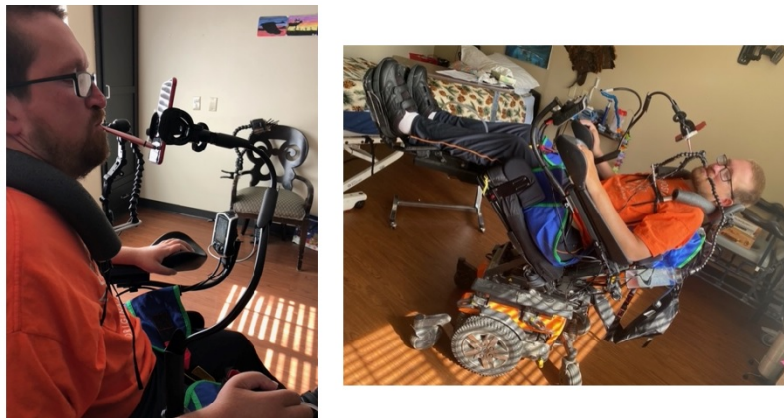
**Doing a PR in public is socially awkward.** Six participants (P1, P2, P3, P5, P6, P7) acknowledged that performing a PR in front of other people is socially awkward (Figure 4), and that they often skip PRs for this reason. P1, P3, and P6 explained they previously felt embarrassed to tilt publicly, but that after many years with an SCI, having had multiple incidents of PUs and associated pain led them to worry less about what other people think: *"... if they [people] ask questions [about PR], that's fine. But I don't really care... First, I worried about what it would look like but then I went, 'No way. It doesn't matter'"* (P6). P5 further explained the awkwardness: *"that's not comfortable for some people to recline like that [in front of people] or for too long."*

With more recent SCIs, P2 and P7 still feel awkward doing PR publicly and purposefully skip PR or avoid certain public places for embarrassment. For instance, P2 avoids doing PRs during meetings or important conversations so as not to distract people around him: *"I would be really unlikely to probably do it [PR], unless, I would be in the back of a room or something like a presentation is going on"*. Likewise, P7 avoids going to stores to buy clothes or other items



**Table 5: Participants’ processes for performing PRs**

Index	PWC tilts?	PWC control	Primary method for performing PR	Secondary method for perform PR
P1	Yes	Hand	PWC tilt function	NA
P2	Yes	Hand	PWC tilt function	Uses reclining bed to change positions
P3	Yes	Hand	PWC tilt function	NA
P4	Yes	Mouth	PWC tilt function	Kicking feet all the way up in the air
P5	No	Hand	Lifting up and manually repositioning	Changing sitting posture, bending, reaching forward
P6	Yes	Hand	PWC tilt function	Lifting up, bending down, doing household work
P7	No	Hand	Manually repositioning, tilting or moving head back and legs out	Moving the seat cushions



**Figure 3: (Left) P4 is operating his smartphone with a stylus he holds in his mouth; (Right) operating the wheelchair tilt function using mouth-joystick**

**Table 6: Barriers to perform PRs for each participant, FnF = Friends and family**

Index	Where lose track of time	Reasons for losing track of time	Inconvenient times	Places with lack of space	Feel socially awkward
P1	Away from home	No visible clock outside	Sleeping times	Vehicles and public places	Yes, but ignore it, comfortable around FnF
P2	Inside home	Busy with work, phone and computer	Sleeping times; drinking liquids	NA	Yes
P3	Away from home	No visual clock outside	Sleeping times	NA	Yes, but ignore it
P4	Inside and away from home	NA	Eating and sleeping times	NA	Comfortable around FnF
P5	Inside and away from home	Distractions, busy with phone and computer	After sitting for a long time	NA	Yes, comfortable around FnF
P6	Away from home	Interaction with other people, distractions	Sleeping times	NA	Yes, overlook due to experience
P7	Inside home	Busy with phone	NA	Vehicles and public places	Yes, comfortable around FnF

and mostly orders online, resulting in bad outcomes: "... [I am] staying away from stores and stuff like that but bad in the fact that positioning and comfort.... a bunch of [sores] in my feet from some shoes... I bought them from the internet" (P7).

Thus, in every situation where an individual is in public, they are forced to weigh their own self-care against feeling as though they are acting in a socially inappropriate way. This calculation inevitably leads to skipped PRs, thus sacrificing self-care to accommodate the comfort of others around them. It even leads P7 to limit his participation in society to avoid these awkward situations. Although some participants (P1, P4, P5, P7) feel less embarrassed to do PR around friends and family who know the importance of PR, the tension between ingrained awkwardness to tilt publicly and the fear of PUs and pain impose a constant mental burden that impedes the PR routine.

4.1.6 *Recurring PUs create uncertainty regarding current PR behavior.* Despite increased motivation, increased awareness, and

lifestyle changes, repeated PUs cause participants (P1, P2, P4, P5, P6, P7) to question their current PR behavior. For example, even though P1 times his PRs using the clock, he has still had multiple PUs. That makes him uncertain about his PR frequency: "sometimes the reality of what you think you're doing and what you're actually doing can be different". Similarly, P5 and P6 stressed that they know they should do PR more frequently. P2's uncertainty makes him believe that he should do something more for proper PR: "I'm uncertain about that [PR frequency and quality]. But also the method [tilting function]... I would say that I am skeptical of how much of a pressure release I'm getting when I fully tilt and recline my wheelchair. I feel like that I should probably be doing something more" (P2). After developing recent PUs, P4 and P7 both became concerned that they do not perform enough PRs. Moreover, after P7 lost insurance and has been unable to obtain a tilting PWC; his complete dependence on manual methods to perform PRs further increases his uncertainty.



**Figure 4: P1 is operating the PWC tilt function to perform a PR which draws attention when in public and requires space.**

Taken together, despite high levels of motivation and PR awareness—and having made lifestyle changes—repeated PUs make participants uncertain about their current PR behavior. Participants struggle to adhere to PR guidelines, and are not confident in how close or far they are to meeting those guidelines. Thus, there is an unmet need for supporting awareness of PR behaviors and adherence to PR guidelines. There is the potential for technology to better support that need, which we explore further in the next section.

## 4.2 Factors to consider when designing technology to support PR adherence

From our analysis, we developed four themes to answer **RQ2**: Factors to consider when designing technology for improved PR adherence. We surfaced that: (1) participants want to receive PR reminders, but only for unaccomplished, incomplete or incorrect PRs; (2) reminder modalities should be private, ability-based, and context-aware; (3) a chairable system is more convenient than a smartphone for most participants; and (4) system should facilitate autonomy, relatedness and competence. See table 7 for an overview of these dimensions. We discuss each theme in the following sub-sections.

**4.2.1 A reminder for every PR is burdensome; prefer reminders only for unaccomplished, incomplete or incorrect PRs.** Instead of receiving

a reminder to do each PR, all participants want reminders to be contextually aware and only delivered for unaccomplished (all), incorrect (P2, P5, P7), or incomplete (P1) PRs — “I wouldn’t want somebody [reminder notification] bugging me every time” (P7). Moreover, P1, P3, P4, P5, and P6 want an immediate reminder for unaccomplished, incomplete, or incorrect PRs: “I think you’re probably better off sending it as soon as [I] did the pressure relief incorrectly. Okay, that’s what I would think better than ... Oh, by the way, it’s three hours later, and you didn’t do it right. Oh, I would like to know that earlier” (P5). However, P2 and P7 would prefer to have a daily summary of PR performance rather than an immediate reminder: “I guess maybe if I get an email, later on, then I might read through it and see how they [PRs] were... this is what you did this is, how you can improve that kind of a thing as opposed to going through each time” (P2). Thus, there is not a one-size-fits-all solution here—participants differ in the functionality and the frequency of interaction that they would want from a system designed to support PR performance.

**4.2.2 Reminder modalities should be private, ability-based and context-aware.** Participants expressed preferences for how they would like reminders to be delivered.

**Private and unobtrusive:** Six participants (P1, P2, P4, P5, P6, P7) prefer PR reminder modalities to be private and unobtrusive so that others around them do not know about the reminder: “I don’t think I would want something that people around me could see that I’m being prompted to do something” (P1). Thus, vibration in the armrest was the top choice as a reminder mode for anyone who would have the sensation to feel it in their arm (P2, P3, P5, P6, P7). P2 stated the vibration mode as “the most effective reminder”; P5 thinks “nobody even knows you kind of have a problem” and P6 mentioned “It’s personal. It’s not intrusive at all to the social setting”. In addition to that, participants do not want the reminder system to be distracting to other people like a loud audio notification (P1, P2) or a highly-visible blinking light in the wheelchair body (P1, P2, P5, P6) that would draw attention to them from other people.

**Ability-based:** Accessibility of reminder modalities is another major concern for participants (P1, P3, P4, P5, P7). For instance, P1 and P4 cannot use vibration in the armrest because they lack upper-body sensation. Instead, they prefer a visual reminder, such as a small blinking light—at the joystick area, that will only be noticeable by them: “That [blinking light] would be a good reminder for somebody like me that cannot feel anything: Visual, something visual—that only I can see” (P4). Additionally, due to complications from brain surgery, P3 will be unable to notice the blinking light outdoor unless the light is bright enough: “...if it’s not very bright. I probably wouldn’t see it”. Similarly, P5 and P6 emphasized the importance of ability-based notifications, including the idea of vibration in the wheelchair headrest (P5) or adjusting the vibration to be stronger (P6) for people with less sensation in their arms.

**Context-aware:** Five Participants (P2, P3, P5, P6, P7) suggested combining reminder modes when outdoors because a single-mode (vibration, blinking light, or audio notification) can go unnoticed in a noisy and distracting outdoor environment. For instance, P2 wants the vibration reminder with a flash of light at the train station or outside his home. Similarly, P5 and P6 prefer combining vibration and a blinking light together: “there’s just so many distractions outdoors.. and unless it was nighttime, you might not even notice

**Table 7: Design recommendations by participants for improved PR adherence**

Aspects	Design Recommendations	Participants
Purpose	Reminders for unaccomplished, incomplete or incorrect PRs only	P1, P2, P3, P4, P5, P6, P7
	Immediate reminder for unaccomplished, incomplete or incorrect PRs	P1, P3, P4, P5, P6
	Daily overall summary of PR performance	P2, P7
Modality	Private and unobtrusive reminder prompt	P1, P2, P4, P5, P6, P7
	Ability-based mode	P1, P3, P4, P5, P7
	Combination of different modes depending on the surrounding context	P2, P3, P5, P6, P7
Interactions	Wheelchair integrated easily reachable and controllable system	P1, P2, P3, P4, P5, P6, P7
	Manual goal setting	P1, P2, P4, P5, P6, P7
	Automated tracking	P1, P3, P5, P6, P7
Social setting	Fostering independence and autonomy	P1, P2, P3, P4, P5, P6, P7
	Facilitating sense of relatedness	P2, P4, P6, P7
	Competency through collaborative tracking	P1, P2, P5, P6, P7

the blinking light” (P5); “There are so many vibrations in the chair itself when it moves, the vibration reminder can get unnoticed” (P6). Likewise, P3 would like audio reminders with the vibration or blinking light outdoors because he might fail to recognize the other reminder modes. Additionally, P7 wants volume control of the audio notification depending on the outdoor surroundings: “If you’re outside, it’s going to be pretty loud. right? If you’re on the street or shopping and stuff, we would have to be a little bit raised. I mean, you could have it’s just a volume key [to control the notification]” (P7).

P6 and P7 described preferred reminder-mode combinations for indoor contexts as well—while playing games or sleeping, blinking light may go unnoticed (P7), or the vibration or audio notifications in the library or during a meeting will disturb others (P2). Thus, the user’s current context influences what the most appropriate notification mechanisms are. While this is true across the general population of smartphone users, the consequences of a disruptive notification can be more significant for someone with a disability who is subject to additional stigmatization.

**4.2.3 A chairable system is more convenient than a smartphone for most participants.** Participants described what kind of technological interaction they would prefer.

**Inconvenience with a mobile-based system.** Four participants (P1, P2, P3, P5) mostly ignore or turn off their mobile notifications, so they would not receive a real-time PR reminder delivered through their mobile phone: “I turn off all my notifications on my phone anyway. I probably wouldn’t see it [mobile notifications] in real-time, it would be something that I wouldn’t see until many hours later” (P2). For these participants, a mobile phone is not an ideal platform for time-sensitive information, such as a timely PR reminder.

However P4, who has less hand functionality, prefers a mobile-based reminder system. His phone is mounted to his wheelchair and he operates it with his mouth (see Figure 3); this transforms the phone into a chairable companion tool [19] which is an ideal platform for a reminder system.

**Convenience in a chairable system.** All participants prefer the reminder system to be incorporated in the wheelchair—either by being built into the chair itself or through a wheelchair-mounted smartphone—because they anticipate it would be less burdensome, convenient, and controllable. For instance, P5 and P6 expressed that there are too many things to remember, so they do not want some additional device or activity for PR reminders that will require extra effort. Thus, a vibration reminder in the wheelchair-armrest (P3, P7)

or the joystick (P7) will be easy and convenient. If a blinking light is used as a PR reminder, P1, P2, P4, and P6 prefer it somewhere around the joystick area to be easily reachable and controllable.

**Integrating reminders with manual goal-setting and automatic tracking.** Participants expressed that chairable reminders with manual goal-setting (P1, P2, P4, P5, P6, P7) and automatic tracking (P1, P3, P5, P6, P7) would be effective in supporting their PR adherence. For instance, a one-time setup for auto-tracking would be more straightforward and helpful for P5 and P6, and they would not need to remember the PR count. Additionally, supporting user-driven goal setting was perceived to increase autonomy (P5 and P6), because auto-tracking will count the accomplished PR, and reminders will notify them when they should take action to ensure they achieve their goal. Similarly, P7 noted that the combination of manual goal setting and auto-tracking would help him to improve PR adherence: “...it would show you how many [PRs] you did that day, How many times you got your goal that week, ... it being an automatic input, You can’t lie. so..yeah, I’ll remember to do my pressure relief”. (P7). Thus, to improve PR adherence, participants are most interested in chairable interactions with manual goal setting and automatic tracking.

**4.2.4 A system should facilitate autonomy, relatedness and competence.** Participants expressed psychological needs that a system should facilitate. During analysis, we recognized that the needs we observed during our inductive coding process were consistent with Self-Determination Theory [26] concepts of autonomy, relatedness, and competence.

**Fostering independence and autonomy.** All participants wanted to be able to control any future system’s modes, timing, and response to missed PRs, and they do not want to depend on others for PR-related activities: “Because I’m a very independent person and like to have control of my own surroundings” (P4). Additionally, no participant wants to involve or rely on others to decide when to do a PR or hold others responsible for their PUs: “...that gives me a little bit of independence. I just don’t want to offload that responsibility to somebody else. Just because then I get a pressure sore. Why don’t you remind me? Yeah, I don’t want to put myself in that situation” (P1). Instead, all participants prefer a reminder system that would facilitate their independence and autonomy: “just a little something [reminder] and then you don’t have to rely on other people” (P5).

**Facilitating relatedness.** Four participants (P2, P4, P6, P7) identified that, while they wanted to maximize their own autonomy in performing PRs, that integrating friends and family members into

the process in some ways could provide a sense of inclusion and relatedness. P6 thinks PR is a routine activity; therefore, having occasional reminders from friends would be a way to include them in his life. Similarly, P2 and P7 would appreciate some friendly reminders from their close friends and family to normalize the PR practice within their social environment. P6 and P7 would like some occasional notes or reminders from their caregiver or therapist for “positive influence” (P6) and “being in touch” (P7). P4 would have liked reminders by a caregiver initially (after having the SCI) to build up the habit until he adopts the practice of PR by himself.

**Demonstrating competence through collaborative tracking.** Five participants (P1, P2, P5, P6, P7) expressed an interest in demonstrating their competence in performing PR—the sense that they are competent in performing the action—by tracking their PR performance collaboratively. For instance, P2 and P7 mentioned that engaging in collaborative tracking will create friendly competition, motivation, and proficiency in PR practice: “*when they have somebody that will hold them accountable and you know, whatever their particular health goal might be ... that little bit of competition or somebody else encouraging you to do something, you’re more likely to do it*” (P2). Likewise, P1 wants to join his family in tracking activities: “*I live with competitive people. And I’ve never been able to be a part of that. I mean, they’re counting their steps and others; I can’t do that. So the idea of somehow equating my doing efficient pressure reliefs with them taking steps. I’d be all over that*” (P1). However, from the perspectives of P2, P5, and P6, tracking PR with non-disabled persons would not be helpful— as the motivation level (P5) and effort level (P6) will not be the same in performing PR in comparison to another activity. Additionally, P5 stressed that collaborative tracking would be more helpful in the early days after an SCI when people are new to this practice. P5, P6, and P7 all think collaborative tracking would have benefited them in the short-term period immediately after sustaining the SCI.

Thus, participants desire autonomy and authority to make decisions and maintain control, relatedness to be socially included and the ability to feel competence in their performance of PRs, and to be able to demonstrate that competence to others. A technological intervention for PR adherence should respect these preferences.

## 5 DISCUSSION

These findings illuminate both the complexity of the challenges and the exciting opportunities to develop better support for PR performance. We found that participants in this study do not currently use any reminder or tracking system to enhance PR practices despite being confident that they are not meeting the recommendations, are afraid of encountering another PU, and are unsure of what action they could take to improve their PR adherence. Instead, we found that different understandings of how and when to perform PRs, forgetfulness, inconvenience, and awkward social scenarios lead them to each follow their own imperfect PR routines [14].

More broadly, the insights from this work can help to facilitate support for other high-frequency self-care behaviors for individuals with a severe SCI. For example **respiratory** self-care can involve: deep breathing exercises every four hours [55] and ventilator weaning every hour when transitioning to independent breathing [35,

80]. Additional high-frequency self-management activities can include: **catheterizing** the bladder every 4–6 hours [5, 35, 52], **bowel management** 30–45 minutes after a meal or hot drinks [5, 35], and frequent activity for **pain management** to avoid spasticity or chronic pain [17, 35]. Although high-frequency is a continuum in this self-care context—some self-care activities need to be done every few hours (e.g., bowel and bladder management) and some must be done multiple times an hour (e.g., PR)—all of these self-care activities are crucial for this population to perform and need to be done multiple times in a day. Thus, similar challenges of inconvenience, and contextual factors might be applicable for these other high frequency self-care behaviors.

Participants would welcome support from technology to help them remember to do PRs when they forget or do them incorrectly in a private, ability-based, and context-aware way, and to facilitate a better overall sense of their PR behavior such that they can be more confident in knowing how far they are away from PR recommendations. Our findings from this human-centric approach provide evidence that previous initiatives to improve PR adherence—constant reminder/feedback [86]; feedback through mobile applications [39, 74]; interface pressure mapping [84]; or electrical stimulation [10, 45] – lack required considerations of context, privacy, or specific user abilities. These findings can also be relevant for technology designed to support other high frequency self-care activities of this population. Such technology must be sensitive to the context and additional constraints these users face—including the specific issues detailed herein of space, social stigmatization, and modality of notifications or interaction.

Aspects of these findings in the context of our severe SCI population are not directly transferable to individuals with less severe SCIs or manual wheelchair users because some of the insights depend on the mechanism for performing a PR (e.g. tilting a PWC) and the need for ability-based chairable interaction. However, even if the specific guidance does not transfer, the general concepts do transfer well to other user contexts and to other types of self-care behaviors. This section consolidates the findings and discusses the takeaways as design implications to improve PR adherence.

### 5.1 Participants wanted to increase their adherence but are in a tough spot

Adhering to PR performance is often framed as an issue of patient motivation—clinical personnel we have spoken to suggest that patients perhaps cannot be bothered to do PRs at the recommended frequency. However, our findings for **RQ1** paint a much more nuanced and complicated picture of the factors that contribute to the (non-)performance of PR and build on existing research for people with SCIs. First, we saw that participants in our study were aware of the need to perform PRs, and that their motivation was high—similar to the awareness of performing physical activity [56]. Here the awareness to perform PR was driven by fear of sustaining another PU [40]. Additionally, participants were using PWCs for different durations (2.5 to 18 years) and most of them had multiple PUs (one to five) during these periods (Table 3 in section 3.2).

Although most participants initially learned about PR from their rehabilitation hospital, multiple instances of PUs made them more cautious and led them to do their own research and learn more about

PR from potentially unreliable sources (Table 4 in section 4.1.2). Thus, they developed their own perception of ideal PR behavior (frequency and duration) over time [13]. Further, the sheer number of PRs that they are expected to perform leave them with a significant burden when integrated with their daily lives. Setting a timer would leave them with constant interruptions, even in situations when they had correctly performed their PR already. Without a timer, they are bound to forget PRs as they focus on the many other activities that fill their lives.

Beyond forgetting—which is the primary reason identified in prior work [13, 39]—our participants’ descriptions of performing PRs both inside and outside of their homes communicate a massive psychological burden that they shoulder, one that inhibits their full participation in society and forces them to choose between taking care of their own bodies and conforming to a societal definition of being socially appropriate. Participants prioritize being mindful of their PRs by constantly checking clocks, mixed with their own internal sense of the passage of time. This approach takes a lot of headspace for 30-50 PRs per day, and it is imperfect as it is too easy to become distracted or lose track of time (Table 6 in section 4.1.5).

Participants also sometimes purposefully skip doing a PR even though they remember that they should do one. One reason for skipping is inconvenient timing. Additionally, most of the participants perform PR using the tilt-function of their PWC (Table 5), which is highly visible and requires additional space to perform. Thus, similar to physical activity [56], participants avoid doing PR—this highly visible self-care activity—due to complex social norms and expectations. Sometimes, they opt for less obtrusive and less effective secondary manual methods of PR—manual maneuvering on their wheelchair seat if they are able—but this is a compromise they make when they are in a difficult situation. In these cases, helpful solutions could consider creative ways of mitigating the barriers they face. While we unfortunately do not have solutions to all of these problems, communicating the perspectives of these users is the essential first step towards better supporting them.

## 5.2 Providing support depends on designing contextually-appropriate interactions

Our participants and the broader target population have a range of multiple disabilities and comorbidities resulting from severe SCIs. Moreover, the lack of accurate tracking and the absence of “quantified past” [28] often make them uncertain about their previous PR performance. Our findings for **RQ2** indicate that technological interactions designed for any high-frequency self-care behavior of this population needs to flexibly accommodate the individuals’ abilities [85], tracking needs, and contextual constraints.

First, smartphone notifications will not be appropriate for many people in this population because their phones are inaccessible, and furthermore too many mobile notifications will be burdensome, easily ignored, and are unlikely to be checked immediately [86]. As a result, while delivery through a mobile device can be a useful approach for some, for others a more convenient, familiar [33], purpose-specific modality—such as the armrest vibration concept—will be a more effective mechanism for delivering a reminder. This echoes some of the thinking described in the “chairable” concept [19].

Second, the contextual factors that combine to create inconvenient circumstances (discussed above and in section 4.1.5) could be recognized by technology. Reminders could be delivered more judiciously in circumstances where a user is likely to be encountering additional external barriers to performing a PR. Finally, for any future designs to be successful, they will need to account for the basic psychological needs of autonomy, relatedness, and competence—consistent with self-determination theory [73]. We found evidence of the importance of these needs to our participants. Our findings also highlight the psychological facts of routinization in self-care activities—improved personal agency, self-efficacy, and social interaction—that are similar to routinization of physical activity among manual wheelchair users reported by Mason et al. [56].

Overall, our participants expressed a desire to continue to engage in PR behaviors and welcome the support of appropriately-designed technology that supports their abilities, facilitates privacy, and considers different contexts to help them do so. One compelling idea is the concept of contextually-aware just-in-time [60] reminders that would be flexible enough to provide users dynamic control to re-routinize self-care behaviors and accommodate the constraints, contexts, and appropriate opportunities to act [1, 46]. We envision that a future system could combine these insights to build a system that addresses the individual needs of PWC users in performing and monitoring PR. Elements of such a system might include:

- **Automatic tracking** to produce an record of self-tracked PR performance (see [81] for an example system)
- The ability to **manually track** PR behaviors to capture relevant PR activity that cannot be easily captured through an automated system—e.g., leaning over, shifting weight, or adjusting cushions are all manual behaviors our participants described performing. Participants may also wish to manually track pain or use semi-automated tracking [24] to capture these manual PR efforts.
- The ability to **specify basic parameters** for the conditions under which they would want to receive a notification from the system, and what kind of notification they would want to receive. As examples, parameters could provide a maximum number of reminders per day, specify the amount of time since the previous PR that should elapse before a reminder is delivered, or specify contexts where reminders should or should not be delivered (e.g. don’t deliver reminders while in transit but do provide a reminder after disembarking from a vehicle). Some users might only want the tracking features and may not want any notifications or reminders at all.
- A **modular chairable interface** that can be customized for the user according to individual functional ability and preference, and can support audio, visual, and/or haptic feedback at the location desired by the user.
- The ability to **review PR behavior data** on a daily, weekly, or monthly basis. This could reveal trends—such as an increase or decrease in PR adherence—as well as help to facilitate self-awareness of current behaviors.
- The ability to **share PR behavior** with friends and family members. For example, perhaps a connection to a service



such as Strava<sup>2</sup> could facilitate social connection on the performance of this important health behavior.

### 5.3 Scope of personal informatics for supporting people with high-level SCIs

Our findings demonstrate the potential for individuals with severe SCIs to benefit from personal informatics (PI) systems. In a recent mapping review, Epstein et al. [29] reviewed 523 papers from the PI literature where only four involved wheelchair users [18, 20, 21, 54]. It is important to note that these studies included only manual wheelchair users except for one participant who used a PWC [18]. Furthermore, none of those papers deployed PI systems to their participants, and only two among all participants from these studies reported using PI tools. All of these observations point to our primary finding that individuals with wheelchairs are interested in the potential of PI (i.e. for tracking, monitoring etc.) to enhance their self-care behavior. However, the PI domain has not been explored adequately through an HCI lens for this population. Although Garmin and Apple have progressed by supporting tracking for manual wheelchair propulsion [42], those efforts still exclude PWC users. As PI aims to broaden its scope to accommodate different non-mainstream scenarios of people's lives through different domain-agnostic theories and models [51], people with severe motor disabilities deserve to benefit from personal informatics.

### 5.4 HCI research methods with individuals with severe SCIs and comorbidities

Among our participants—all of whom had a severe SCI—four had multiple disabilities and comorbidities (P1, P4: with less hand functionality and upper-body impairments; P3, P4: speech difficulties; P3: brain injury; P6: mild dementia). Due to the broader range of disabilities and multiple comorbidities of the target population, participation in research studies is often challenging for them; and thus these participants are often not included in HCI research [34, 43]. According to the recently published study methods guidelines for individuals with an SCI [43], we combined a brief semi-structured interview and “needs-validation storyboard study” from the *Speed Dating* method to collect rich data from participants without the burden of real-time implementation of technological prototypes.

During the semi-structured interviews, we tweaked questions for the participants with speech difficulties to make it easier for them to answer with fewer words. Later, during the storyboard study, when we showed them imaginary scenarios of possible futures, participants expressed their latent needs, perceptions, and current desires and fears [25] that helped us to clarify their brief answers from the interview phase. Notably, we needed to consider the entire transcript from a participant as a whole to infer some answers. We also attempted to email the participants with speech difficulties (P3, P4) during our data analysis phase—three months after the interview session—to confirm our interpretation of their responses. Unfortunately, we did not receive any reply from them.

While this methodological adaptation failed, we believe this approach is an important adaptation in response to the recent call to adapt HCI methods to be more inclusive of participants with

multiple disabilities [43]. In the future, we would take additional steps to increase the likelihood of this strategy succeeding. We would analyze the data immediately after a study session with a participant with speech difficulties. This way we could get back to the participant much sooner if any interpretations need to be confirmed or if there are gaps, increasing the likelihood they would respond. We would also tell them ahead of time that we may follow up, which could improve responsiveness. These continued efforts to be more inclusive in our HCI research methods are essential for producing meaningful and impactful research as a field.

## 6 LIMITATIONS

Our limited number of study participants reflects the common challenge of recruiting participants with disabilities—often resulting in fewer participants than other typical HCI studies with non-disabled participants [43, 50]. Additionally, individuals with a severe SCI need to follow numerous self-care activities, while our study was focused mainly on PR behavior. By conducting similar research for other high-frequency self-care activities, other concerns might be identified that were not captured in this work.

## 7 CONCLUSION

In this paper, we investigated the high-frequency self-care behavior of PR among individuals with a severe SCI. Through a qualitative study, we highlighted current PR practices and provided design guidelines to support adherence. Our research shows that improving self-care adherence is not only about motivation or awareness, but also differences in understanding what to do, remembering to do it at the right time and correctly, and dealing with contexts that can make those behaviors difficult to complete. These considerations point to the possibility that technology could better support these behaviors through a carefully designed and contextually aware self-care reminder system that accounts for the many nuances of high-frequency self-care in a population of individuals with a severe SCI. Finally, we discuss our adaption of methods to accommodate participants with multiple disabilities, so that we could be more inclusive and collect rich data to represent the perspectives of these participants [43]. Although we cannot generalize our findings to all self-care behaviors of individuals with a severe SCI, these design considerations can provide valuable guidance for HCI researchers to design for other complex, high-frequency self-care behaviors.

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